Carers (Scotland) Act 2016 Statutory Guidance



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Updated July 2021 to:

- reflect new legislation on timescales for adult carer support plans and young carer statements for carers of terminally ill people (mainly Part 2, Chapters 1 and 2);
- incorporate guidance on local eligibility criteria for carer support previously published separately (Part 3, Chapter 1);
- incorporate illustrative examples on waiving of charges and replacement care also previously published separately (Part 3, Chapter 3);
- include checklist on content of local carer strategies previously shared by email (Part 5, Chapter 1); and
- update hyperlinks.

Table of Contents

Summary4
Introduction13
Part 1: Key Definitions15
Meaning of 'carer', 'young carer' and 'adult carer'15
Part 2: Adult carer support plans and young carer statements
Chapter 1 – Adult carer support plans21
Chapter 2 – Young carer statements41
Part 3: Provision of support to carers67
Chapter 1 – Local Eligibility Criteria 67
Chapter 2 – Duty to provide support to carers74
Chapter 3 – Waiving of charges and replacement care
Part 4: Carer involvement109
Chapter 1 – Carer Involvement in Services and Service Planning 109
Chapter 2 – Carer involvement in hospital discharge of cared-for persons 114
Part 5: Local Carer Strategies126
Chapter 1 – Local Carer Strategies 126
Part 6: Information and advice for carers, including short breaks services statements
Chapter 1 – Information and advice for carers
Chapter 2 – Short breaks services statements
•
Part 7: Delegation of Functions in the Carers Act
Part 8: Transitional arrangements154
Glossary162
Annex A: Support to carer or cared-for person
Annex B: Carers who are also service users (adults or children with support needs)
Annex C: Short breaks – definition by Shared Care Scotland

Annex D: Carer identification	173
Annex E: Consent and the General Data Protection Regulation (GDPR)	175
Annex F: Local Eligibility Criteria Framework	176
Annex F(a) – Illustrative threshold for carer support	176
Annex F(b) – Determining the impact of the caring role and associated risk	177
Annex F(c) – Table of Indicators	178

Summary

A. Key Messages

This is a summary of the statutory guidance for local authorities, health boards and integration authorities on effective implementation of the provisions of the Carers (Scotland) Act 2016 ('the Act'). It will also be of interest to other organisations working alongside statutory bodies to deliver carer support, as well as the directing authorities of independent or grant aided schools responsible for young carer statements.

The Act gives carers rights to a new adult carer support plan or young carer statement without first requiring them to be providing care on a substantial and regular basis. This reflects a preventative approach to identify each carer's personal outcomes and needs for support through meaningful conversations with individual carers. This preventative approach is also reflected in the requirement to provide information and advice services to carers. The third sector is well placed to help deliver information and advice.

Prevention is pivotal in how carers and the people that they care for are supported. Much of carer support is focused on intervening as early as possible in a carer's journey, including by providing information and support to promote quality of life, independence and engagement with their communities in order to prevent deterioration in their situation. This preventative approach also underpins the integration of health and social care and the embedding of self-directed support as Scotland's mainstream approach to social care and ongoing work on the reform of adult social care. (The preventative approach is discussed further at Part 3, Chapter 2 - Duty to provide support to carers).

The Act also seeks to improve physical and emotional wellbeing and deliver positive outcomes for Scotland's carers by ensuring more personalised and effective delivery of carer support. Personalisation is a social care approach which promotes choice, control and independence for people who use services. This can have a significant impact on the lives of carers and the people they provide care to and can help to sustain good caring relationships. The Act requires local eligibility criteria to be set in each local authority area. These frameworks will help local authorities determine the level of support to provide to carers based on their identified needs.

Carer involvement is a key principle of the Act. It is intended to empower carers with more useful information about the support that may be available to them and to ensure that they can share their caring experiences and knowledge with those responsible for providing support or services. Carers should be involved in setting local eligibility criteria. Carers and carer representatives must also be involved in the preparation of local carer strategies, short breaks services statements and planning of carer services. Carers must also be involved in hospital discharge processes.

B. Local carer strategies

The Act requires local carer strategies to be developed across Scotland. These will set out plans to identifying carers, provide support and services to adult and young carers and provide information about local support. The duty to prepare local carer strategies applies to local authorities and relevant health boards but is delegated to integration joint boards¹.

Local authorities and health boards are strongly recommended to work closely and collaboratively with carers and the third sector in preparing strategies. Part 5 provides guidance on preparing a Local Carer Strategy.

C. Carers Journey- Adult Carers

C.1 Identification of a carer

Under the Act a 'carer' is an individual who provides or intends to provide care for another individual. A carer can be caring for one or more cared-for persons. A caredfor person can have one or more carers. They don't need to live in the same house. See Part 1 of the guidance for further information.

An 'adult carer' is a carer who is at least 18 years old and is not a 'young carer'. Part 1 of the guidance contains more information about definitions.

C.2 Adult carer support plan (ACSP)

Where a person self-identifies as a carer they may request an adult carer support plan (ACSP). If they appear to meet the definition of carer, the responsible local authority must prepare an ACSP.

When carers are identified by practitioners, whether in the community or acute settings, they must be offered an ACSP. If they accept the offer the responsible local authority must prepare an ACSP.

The ACSP provides a framework for identification of personal outcomes and individual needs for support of adult carers. ACSPs are considered in Part 2 of this guidance.

The ACSP links to the duty and power of the responsible local authority to provide substantive support to meet identified needs. Decisions about whether a carer's identified needs meet local eligibility criteria depend on the information obtained through the outcomes focused conversation with the carer whilst preparing their ACSP. The information within the ACSP will include the nature and extent of care; the impact of caring; and the extent to which the carer is able and willing to provide care. Thus decisions about support and the completion of the ACSP (with information on carer support to be provided) are mutually dependent.

¹ Public Bodies (Joint Working) (Prescribed Local Authority Functions Etc.) (Scotland) Amendment (No. 2) Regulations 2017 and the Public Bodies (Joint Working) (Prescribed Health Board Functions) (Scotland) Amendment Regulations 2017.

The ACSP will require to be agreed with the carer before it is completed and the support agreed to be put into place. The carer must be given a copy of the finalised ACSP.

Chapter 1 of Part 2 provides advice on ACSPs, including following a proportionate approach, taking account of the impact of the caring role on the carer.

C.3 Applying local eligibility criteria, decisions about support and charging

There is no national eligibility threshold for support. Instead **local eligibility criteria** are set by each local authority to determine the levels of impact/risk and need which trigger the duty to provide support - acknowledging that there will be circumstances that merit the exercise of the power to provide support to people whose needs fall below the local eligibility threshold.

The Act establishes a process to determine whether a local authority has a duty to provide support to an individual carer to meet their identified needs, as illustrated by the Carer Support Pathway in Figure 1.

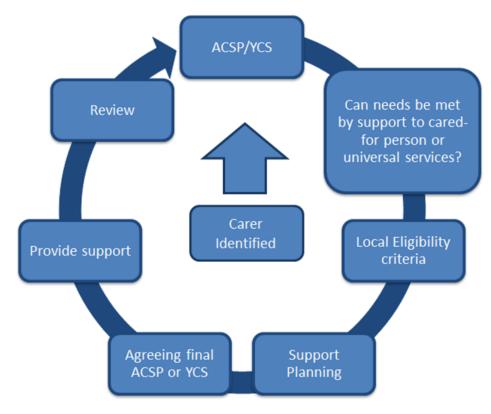


Figure 1: Carer Support Pathway

The duty (as opposed to the power) to provide support to a carer depends on the extent to which a carer's needs for support meets local eligibility criteria. This process is explained in more detail in Part 3 of the guidance. Key steps are outlined in Table 1 below.

Table 1: Key steps in preparation of ACSP/YCS and applying local eligibility criteria

Key Steps	Related sections from the Carers Act
(i) Prepare adult carer support plan or young carer statement setting out carer's identified personal outcomes and identified needs (if any). Accelerated timescales and option of light touch plan/statement apply to carers of people who are terminally ill.	Section 6(1)(a) and (b) and section 12(1)(a) and (b))
(ii) Consider which of the needs can be met through services or assistance to the cared-for person (other than 'replacement care' to provide a break from caring) or provided generally to persons in the area (i.e. by information and advice, universal services and community support).	Section 24(1)(a) and (b)
(iii) If needs are met wholly as per (ii), no further action (but keep under review).	Section 9(1)(I) and section 15(1)(m) re review
(iv) If needs are met only in part by (ii), or not at all, then apply local eligibility criteria to what are the 'outstanding' needs.	Section 24(2) and 3
(v) Decide whether the outstanding needs engage the legal duty to provide support, that is whether the local eligibility criteria are met. Criteria should be applied to each of the areas individually and independently of each other so that if a carer has identified needs in one domain (e.g. health and wellbeing) above the threshold, this would mean that those needs meet the local eligibility criteria and the carer would be eligible for support in that area.	Section 24(4)(a) and section 25(1)
(vi) If the outstanding needs do not meet the local eligibility criteria, decide whether the discretionary power to provide support should be used.	Section 24(4)(b)
NB: Consideration of whether the support to the carer should take the form of or include a break from caring (including replacement care where required) applies in relation to both the duty and power to support carers.	Section 25(1)
(vii) In the case of (v) and (vi), give the carer the opportunity to choose one of the options for self-directed support (unless ineligible to receive direct payments).	Social Care (Self-directed Support) (Scotland) Act 2013

Whilst eligibility criteria enable decision-making regarding support, use of eligibility criteria is not an exact science. Gradations of impact and risk along a five-point scale from 'no impact/no risk' to 'critical impact/critical risk' are not straightforward to describe. It is therefore important that practitioners use their professional judgement in the use of indicators to ensure carers receive the right level of support at the right time. The views of the carer must also be taken into account.

Where the responsible local authority exercises its duty to provide support to the carer to meet the carer's eligible needs or its power to meet the carer's other identified needs (both under section 24 of the Act), the carer must be given the opportunity to choose one of the options for self-directed support (unless the local authority considers that the carer is ineligible to receive direct payments). Any carer support provided for the carer will be provided under section 24 of the Act and cannot be charged for or means tested.

Where support such as general carer training courses, counselling or support groups are openly accessible for carers, e.g. through a local carer centre (without local eligibility criteria being applied), these universal services are not provided under section 24 of the Carers Act. Therefore, the requirement to offer the four options of self-directed support does not apply. A wide range of personal outcomes and identified needs may be met through such preventative carer support.

D. Carers Journey - Young carers

D.1 Identification of a young carer

Under the Act a 'carer' is an individual who provides or intends to provide care for another individual. A carer can be caring for one or more cared-for persons. A caredfor person can have one or more carers. They don't need to live in the same house. See Part 1 of the guidance for further information.

A 'young carer' is a carer who is either under 18 years old or is over 18 but has remained at school since turning 18.

Part 1 of the guidance contains more information about definitions.

D.2 Young carer statement (YCS)

Where a young person self-identifies as a carer they may request a young carer statement (YCS). If they appear to meet the definition of a young carer, the responsible authority must prepare a YCS.

When a young carer is identified by practitioners, whether in the community or acute settings, they must be offered a YCS. If they accept the offer the responsible authority must prepare a YCS.

A YCS provides a framework through which needs for support are assessed and monitored and support is managed. The YCS is intended to ensure that young carers are seen as children and young people first and foremost and are protected from undertaking caring responsibilities and tasks which are inappropriate, having regards to their age and maturity.

The YCS has to set out a young carer's identified personal outcomes, identified needs (if any) and the support (if any) to be provided by the responsible local authority to a young carer to meet those needs. Part 2 of the Guidance considers YCSs in more detail.

The authority responsible for the YCS can be different from that responsible for supporting the young carer. Also, different authorities can be responsible for YCSs compared to ACSPs, as summarised below. In addition, some integration authorities

will have responsibility for children's services while in other cases local authorities will retain that responsibility. Delegation issues are considered further in Part 7.

Decisions about whether identified needs meet local eligibility criteria depend on the information obtained through the outcomes focused conversation with the young carer whilst preparing their YCS. The information within the YCS will include the nature and extent of care; the impact of caring; and the extent to which the carer is able and willing to provide care. Thus, such decisions and the completion of the YCS (with information on carer support to be provided) are mutually dependent.

The YCS will require to be agreed with the young carer before it is completed and the support agreed to be put into place. The young carer must be given a copy of the finalised YCS.

Chapter 2 of Part 2 provides advice on YCSs, including following a proportionate approach, taking account of the impact of the caring role on the young carer.

D.3 Young carers: Applying local eligibility criteria, decisions about support and charging

There is no national eligibility threshold for support. Instead local eligibility criteria are set by each local authority to determine the levels of impact/risk and need which trigger the duty to provide support - acknowledging that there will be circumstances that merit the exercise of the power to provide support to people whose needs fall below the local eligibility threshold. The Act does not preclude the use of different eligibility criteria in relation to young carers. However, it is proposed that very similar local eligibility criteria to those for adult carers are used.

The Act, establishes a process to determine whether a local authority has a duty to provide support to a young carer to meet their identified needs, as illustrated in the Carer Support Pathway in Figure 1, above.

The duty (as opposed to the power) to provide support to a carer depends on the extent to which a carer's needs for support meet the local eligibility criteria. This process is explained in more detail in Part 3 of the guidance. Key steps are outlined in Table 1 above. The distinctive needs of young carers should be considered when assessing eligible need and putting support in place.

Use of eligibility criteria is not an exact science. Gradations of impact and risk along a five-point scale from 'no impact/no risk' to 'critical impact/critical risk' are not straightforward to describe. It is important that practitioners use their professional judgement in the use of the indicators to ensure carers receive the right level of support at the right time. The views of the carer must also be taken into account.

Where the responsible local authority exercises its duty to provide support to the carer to meet the young carer's eligible needs or its power to meet the young carer's other identified needs (both under section 24 of the Act), the carer must be given the opportunity to choose one of the options for self-directed support (unless the local authority considers that the carer is ineligible to receive direct payments).

Any carer support provided for the young carer will be provided under section 24 of the Act and cannot be charged for or means tested.

Where support services such as general young carer forums, counselling or support groups are openly accessible for young carers through a local carer centre (without local eligibility criteria being applied), these universal services are not provided under section 24 of the Carers Act. Therefore the requirement to offer the four options of self-directed support does not apply. A wide range of personal outcomes and identified needs may be met through such preventative carer support services.

E. Responsibilities

Duty	Section	Who is responsible?	See main guidance
Adult carer support plan	6-11	The 'responsible local authority' is responsible for offering and preparing ACSPs. This is the local authority for the area in which the cared-for person resides.	Part 2, Chapter 1
		Local authority functions under sections 6 to 11, must be delegated to the integration authority, so far as they relate to adult social care.	
Young carer statement	12-20	 The 'responsible authority' is responsible for offering and preparing YCSs. This is: for the majority of young carers - the local authority of the area where the young carer resides; for pre-school young carers - the health board for the area where the young carer resides; for young carers who attend a grant aided or independent school - the directing authority of that school. Local authority functions under sections 12 to 20, can be delegated to the integration authority, so 	Part 2, Chapter 2
Local Eligibility Criteria	21 & 22	 far as they relate to children's social care. Each local authority must set local eligibility criteria. Local authority functions under sections 21 and 22, must be delegated to the integration authority, so far as they relate to adult social care. 	Part 3, Chapter 1
Provision of support, waiving of charges and replacement care	24, 25 & 26	The responsible local authority has powers and duties to provide support to carers, including a duty to consider whether support should take the form of or include a break from caring. The responsible local authority is always the local authority for the area in which the cared-for person resides. In relation to young carers, this means that the responsible authority (with the duty to prepare the YCS) may be different from the responsible local authority (with the duty/power to provide support). Local authority functions under sections 24 and 25 must be delegated to the integration authority, so far as they relate to adult social care.	Part 3, Chapters 2, 3

Duty	Section	Who is responsible?	See main guidance
Carer involvement in service planning	27, 29 & 30	Local authorities and health boards must consider appropriate involvement of carers and carer representatives in the planning and evaluation of carer services and support.	Part 4
Carer involvement in hospital discharge	28	Each health board must involve the carer before a cared-for person (the patient) is discharged from hospital.	Part 4
Local Carer Strategy	31-33	Each local authority and relevant health board must prepare a local carer strategy.	Part 5
Information and advice for carers	34	Each local authority must establish and maintain an information and advice service for carers resident in that local authority area or caring for someone in that local authority area. Local authority functions under section 34 must be delegated to the integration authority, so far as they relate to adult social care.	Part 6, Chapter 1
Short breaks services statement	35	Local authorities must prepare and publish a statement which sets out information on short breaks provision available to local carers and cared-for persons. Local authority functions under section 35, must be delegated to the integration authority, so far as they relate to adult social care.	Part 6, Chapter 2
Carers' charter	36	Scottish Ministers must prepare a Carers' charter.	Part 6

Part 2, Chapters 1 and 2 on ACSPs and YCSs and Part 3, Chapter 2 on the duty and power to support carers include advice on situations where carers reside in a different area from the cared-for person.

Introduction

This is statutory guidance for local authorities, health boards and integration authorities. It will also be of interest to other organisations working alongside statutory bodies to deliver carer support, as well as the directing authorities of independent or grant aided schools responsible for young carer statements. It is designed to provide guidance on effective implementation of the provisions of the Carers (Scotland) Act 2016 ('the Act'). Also, it includes links to legislation and policy documents, which are clearly set out in each part of the guidance.

The aims of the Act

It is the intention of the Scottish Government that Scotland's estimated 788,000 carers including 44,000 young carers are better supported on a more consistent basis so that they can continue to care, if they so wish, in good health and wellbeing, allowing them to have a life alongside caring.

The overriding intention for young carers is that they should have a childhood similar to their non-carer peers. We want to ensure that young carers are enabled to be children and young people first and foremost and relieved of any inappropriate caring roles to allow them to have a quality of life.

The Act makes real this ambition by furthering the rights of both adult and young carers.

Provisions and intentions

The Act introduces the right to a new adult carer support plan or young carer statement based on the preventative approach to identify each carer's personal outcomes and needs for support. This will improve access to support for adult and young carers without any requirement that that they are providing, or intend to provide, care on a substantial and regular basis.

The adult carer support plan and young carer statement will encourage meaningful conversations with individual carers to understand personal needs and outcomes. Engaging effectively with carers as equal partners will help empower them with more useful information about the support that may be available to them. This is also reflected in the requirements to involve carers in hospital discharge processes.

The Act introduces a duty to set local eligibility criteria frameworks in each local authority area. These frameworks will help local authorities determine the level of support to provide to carers based on their identified needs

By ensuring more personalised and effective delivery of support to carers, the Act seeks to address the issues that may reduce or impede the wellbeing and positive outcomes for Scotland's carers. Improving the physical and emotional wellbeing of carers also benefits those being cared for and can help to sustain good caring relationships.

Across Scotland, there will be local carer strategies developed which will set out the provision of services to adult and young carers in each integration authority. These carer strategies will also set out plans for how carers are identified and how they receive information about local support in their area.

A cornerstone of the Act is the provision of information and advice services to carers, which must be accessible and proportionate to the needs of carers who use these services. The third sector is well placed in helping to deliver information and advice services to carers.

There is also a requirement for carers and carer representatives to be involved in the preparation of short breaks services statements and planning of carer services, sharing their caring experiences and knowledge with those responsible for providing these services.

A separate Carers' charter will be published setting out the rights of carers as provided for under the Act.

Preparation of guidance

This statutory guidance to accompany the Act is published following collaboration and consultation with a number of key interests, including: adult and young carers; carer organisations; local authorities; health boards; health and social care partnerships; third-sector organisations; COSLA; Social Work Scotland; NES; SSSC and others.

We thank all of our partners in helping to inform this document.

Using this guidance

The Scottish Government encourages those who are responsible for delivering good quality support which benefits carers, and through supporting the needs and personal outcomes of carers, to use this guidance in the spirit of the Act itself, and with the intention of delivering preventative, personalised support which will empower carers through improved choice and control.

It is also important that local authorities, health boards, integration authorities, and others continue to share learning and good practice, helping to ensure successful implementation of new frameworks across the country. Establishing and maintaining good partnerships with third sector organisations will also play an important part in delivering effective local personalised support to carers, which meets their personal outcomes and helps them continue in their caring role.

The guidance includes examples where they are helpful to explain wider points. These examples are illustrative of possible cases and, by their nature, should not be read as providing a full picture of situations or approaches.

Part 1: Key Definitions

Meaning of 'carer', 'young carer' and 'adult carer'

Summary

Section 1(1) and 1(2) defines 'carer'.

Section 1(3) provides a regulation-making power for Scottish Ministers to specify certain exceptions in relation to care provided under a contract or as voluntary work.

Section 2 defines 'young carer'.

Section 3 defines 'adult carer'.

Meaning of 'carer'

1.1.1. Section 1(1) defines a carer as an individual who provides or intends to provide care for another individual ('the cared-for person').

1.1.2. Where the Act refers to 'carers' it means both adult and young carers of the cared-for person.

Intention to provide care

1.1.3. 'Intending to provide' care would encompass situations where, for example, a previously healthy person is about to be discharged from hospital and will require care, which a relative or friend is willing and able to provide. This person will be the carer.

1.1.4. It may also be the case that the cared-for person requires a fluctuating level of care due to their condition, and so the carer would not always be providing care but rather intending to do so should the need arise.

1.1.5. There is a duty on authorities to offer an adult carer support plan (ACSP) or young carer statement (YCS) in respect of an identified carer and to prepare one if that offer is accepted. The duty to prepare an ACSP or YCS also applies in circumstances where a carer has requested one. These duties are considered in Part 2 of this guidance.

Situations involving more than one carer or cared-for person

1.1.6. A carer can be caring for one or more cared-for persons. A cared-for person can have one or more carers. They do not need to live together in the same household.

Removal of 'regular and substantial test'

1.1.7. The definition of carer is not limited to individuals who provide or intend to provide a substantial amount of care on a regular basis. This represents a change from previous legislation on duties to carry out a 'carer's assessment'.

1.1.8. It is expected that people who are being neighbourly to their elderly neighbours (for example, doing the shopping now and again, a spot of gardening, clearing the snow from the path) will not normally be viewed as carers. The expectation is that such people will, for the most part, continue to see themselves as being a helpful neighbour. However, the situation could change if these neighbourly acts become more frequent. In these circumstances, the person might become a carer.

Exclusions – parents of dependent children

1.1.9. Section 1(2)(a) states that a person is not a carer 'in the case of a cared-for person under 18 years old, to the extent that the care is or would be provided by virtue of the person's age'.

1.1.10. This will avoid all parents of dependent children automatically being 'carers' within the Act. But parents of dependent children with additional care and support needs can still be 'carers' to the extent that the care is or would be provided by virtue of something other than the child's age.

1.1.11. This does not mean that a child has to meet the definition of 'disabled child' in section 23(2) of the Children (Scotland) Act 1995² (chronically sick or disabled or having a mental disorder) in order for the parent to be a 'carer'.

1.1.12. A parent would not be viewed as a carer if their child exhibited problematic behaviour which was not due to a condition. The parent might instead be signposted to appropriate parenting support services. It is important to recognise that problematic behaviour may be due to a condition that has not yet been diagnosed. The lack of a formal diagnosis should not prevent parents being recognised as carers and receiving the support they need. This will depend on the relevant multidisciplinary professionals working together with the parent(s) to consider the circumstances of the particular case, to determine whether the parent is in fact a carer and to identify any subsequent support needs.

Exclusions – voluntary work

1.1.13. Under section 1(2)(b)(ii), if the care is or would be provided as voluntary work, then the person undertaking that voluntary work is not seen as a carer.

Exclusions – paid care workers

1.1.14. Paid care workers are excluded from the meaning of carer. This is because under section 1(2)(b)(i), if the care is or would be provided under or by virtue of a contract, then, to the extent that the care is provided under the contract, the person providing the care is not a carer.

Exclusions – foster carers (care under or by virtue of a contract)

1.1.15. The exclusion in section 1(2)(b)(i) also means that foster carers do not fall within the definition of 'carers' under the Act. The vast majority of foster carers are registered as being self-employed and their fostering agreement with a local authority entitles them to a fee or reward element for the care they undertake.

² <u>http://www.legislation.gov.uk/ukpga/1995/36/section/23</u>

Regulation making power – contract and /or voluntary work

1.1.16. Under section 1(3)(b), Scottish Ministers may make regulations to permit a relevant authority to disregard section 1(2)(b) where the authority considers that the relationship between the carer and the cared-for person is such that it would be appropriate to do so. This would enable people who would otherwise be excluded from the definition to be considered carers.

1.1.17. This allows Scottish Ministers to make regulations to allow a local authority to support carers who provide care by way of a contract or through voluntary work to be classed as 'carers'. This is especially relevant in the case of carers who provide care both on a paid and unpaid basis to same family member. As the Social Care (Self-directed Support) (Scotland) Act 2013 ('the 2013 Act') becomes even more widely used, it is likely that direct payments under the 2013 Act will mean that the number of 'mixed carers' who provide both paid care, by way of a contract with the person they care for, and unpaid care are likely to rise. This power allows legislation to take account of the possible rise in the different types of these caring situations.

1.1.18. Scottish Ministers are not using this regulation-making power at the present time. The exclusion under section 1(2)(b) only applies to the extent that care is provided under a contract or as voluntary work. So it would already be possible for a mixed carer to be considered a 'carer' in relation to the unpaid care they provide outwith the contract. On that basis, local authorities will be able to support mixed carers in relation to the unpaid care they provide and will be able to establish how best to do this based on professional judgment and carer involvement without the need for regulations at this stage.

Regulations to place kinship carers³ on the same footing as parents of dependent children

1.1.19. Kinship carers often find themselves undertaking a caring role after a family member has fallen into crisis, with the only alternative being that the child is taken into formal care arrangements. No payment is received for the caring kinship carers undertake but the caring role can be formalised in a written agreement with the local authority.

1.1.20. The Carers (Scotland) Act 2016 (Agreements of a Specified Kind) Regulations 2017⁴ ensure that kinship carers who care for children can be classed as carers for the purpose of the Act, regardless of whether they have a formal written agreement with the local authority or receive a kinship carers allowance. The regulations achieve this by specifying that a written agreement with the local authority⁵ cannot be considered a 'contract' and so would not exclude a kinship carer

³ Kinship carer is a term that is used to define someone who is looking after another individual's child because they are unable to do so. The individual must either be:

⁻ a person who is related to the child; or

⁻ a person who is known to the child and with whom the child has a pre-existing relationship. There are a number of recognised "types" of kinship carer and situations will differ depending on the family's circumstances.

⁴ SSI 2017/257 http://www.legislation.gov.uk/ssi/2017/257/made

⁵Under regulation 12 of the Looked After Children (Scotland) Regulations 2009 (SSI 2009/210) http://www.legislation.gov.uk/ssi/2009/210/part/V/made

from the definition of 'carer' under the Act. This places kinship carers on the same footing as parents of dependent children as considered above.

Meaning of 'young carer'

1.1.21. Section 2 defines young carer as a carer who -

(a) is under 18 years old; or

(b) has attained the age of 18 years while a pupil at a school, and has since attaining that age remained a pupil at that or another school.

1.1.22. Any carer who is under 18 will be a young carer, whether or not they are still at school. Older young carers may continue their studies after leaving school. Post school, until they are aged 18 years old, the young person would still be considered a young carer and may have a young carer statement in place. In addition a carer who turns 18 while a school pupil will remain a young carer until leaving school. There is therefore no absolute cut-off age at which a young carer would cease to be a young carer.

1.1.23. There is no lower age limit for being a 'young carer'. It would be arbitrary to create a lower age limit thus excluding access to the young carer statement and support to younger age groups. In most instances, the expectation would be to remove or lessen the caring responsibilities of the relatively few very young carers and to put in place more services for the cared-for person. The responsible authority⁶ will also be alert to any child protection concerns.

Meaning of 'adult carer'

1.1.24. Section 3 defines 'adult carer'. Adult carers must be at least 18 years old and cannot also be not young carers. So if a carer is aged 18 but still at school, they will remain a young carer until they leave school.

Young adult carers

1.1.25. The only age distinction in the Act is between young and adult carers. The Act does not make any specific provisions for 'young adult carers' (normally understood to mean carers aged 16 to 25); instead the individuals will be either 'young carers' or 'adult carers'.

1.1.26. The 16 to 25 age group is often characterised by transitions that may change the caring role and/or the need for support such as the transition to college, university and work; living away from home; or wanting to reduce the caring role/ not wanting to be a carer at all. These can be reflected in the carer's adult carer support plan or young carer statement. Part 2 of this guidance contains more information on the links and transitions between ACSP and YCS.

⁶ The body responsible for preparing the young carer statement – as defined in section 41 of the Act.

Person caring for someone in residential care

1.1.27. When an adult is in full-time residential care such as a care home, nursing home or secure unit, there is a question as to whether the person who cared for them prior to them being admitted into residential care is still the carer.

1.1.28. The person in residential care is being provided with accommodation, meals, personal and health care. Nevertheless, some people still consider themselves to be a carer. This may be due to continuing with some caring tasks such as shopping, emotional support, personal care, dealing with personal affairs, and taking their loved one on days out. There is also the emotional impact on the carer of the person being in residential care. Other people do not consider themselves to be carers in this situation.

1.1.29. When a cared-for person is first admitted full-time to residential care, the person who was the carer may continue to have caring responsibilities in the initial settling-in period. This then may diminish over time.

1.1.30. In the circumstances of the cared-for person being in full-time residential care, then the responsible local authority⁷ should decide on a case-by-case basis if the person is providing or intending to provide care for the individual. If the responsible local authority recognises that the person is providing or intending to provide care then an adult carer support plan or young carer statement should be offered. Such a person may themselves request an adult carer support plan or young carer statement. Their request should be granted if they are providing or intending to provide care.

Example

Active caring may continue for some time once a person is in full time care and this may be particularly relevant to some communities. For example, carers from a minority ethnic background may continue to provide language support and facilitate participation within the care setting for their family member.

1.1.31. In practice, because there is no definition of 'care' in the Carers Act and because a carer can provide low-level care, then in many cases the person who cared for the cared-for person prior to them moving to residential care may continue to be considered a carer rather than a visitor.

1.1.32. With regard to 'forensic carers' who support people in forensic mental health services, the carers can have significant caring responsibilities, especially at certain times, for example, support required when the cared-for person moves between secure services or is admitted from prison or general psychiatric services.

⁷ Defined in the glossary.

1.1.33. With regard to children, it is clear that the parent of the child in residential settings⁸ or NHS care is a carer, since the care they would be providing goes beyond that which is just because of the child's age as at section 1(2)(a) of the Act⁹.

Meaning of 'cared-for person'

1.1.34. The term 'cared-for person' is not defined in the Act but should be commonly understood. There is no requirement for a cared-for person to be someone receiving social care support. The cared-for person might have health needs only. They might have refused social care support. The care needs of the cared-for person may be permanent or temporary.

1.1.35. A carer therefore might have identified needs which meet the local eligibility criteria whilst the cared-for person is not eligible for support and vice versa.

Meaning of 'care'

1.1.36. The term 'care' in the definition of carer is not defined in the Act and so has its ordinary meaning. It therefore means the provision of what is necessary to the cared-for person in order to support their physical and mental health and wellbeing. This can encompass:

a) medical or nursing care, such as helping someone to take medication or applying dressings;

b) personal care, such as helping to wash, dress or eat;

c) practical support, such as taking a person shopping or to medical appointments, cleaning or accompanying them to social events; and d) emotional support.

1.1.37. The focus is on the impact of care on the carer. As such, the definition of carer does not include any threshold for the level of care provided. In every situation, a proportionate approach to the preparation of the adult carer support plan or young carer statement should be adopted, taking into account the impact of the caring role on the carer. Part 2 of this guidance deals with the preparation of the ACSP and YCS.

⁸ Exceptions would include where the child has been removed from the care of the parent or guardian and placed in a residential setting by the Children's Reporter, it would be unlikely that they would be undertaking the role of an unpaid carer.

⁹ A Supreme Court decision in July 2015 highlighted the care provided by parents to a disabled child during a long-stay in hospital: <u>https://www.supremecourt.uk/cases/docs/uksc-2014-0166-press-summary.pdf</u>.

Part 2: Adult carer support plans and young carer statements

Chapter 1 – Adult carer support plans

Summary

Part 2, Chapter 1 of the Act covers adult carer support plans.

Section 6 sets out the duties to offer and to prepare an adult carer support plan, and carers' right to request a plan.

Section 7 deals with adult carers of terminally ill cared-for persons.

Section 8 deals with the identification of outcomes and needs for support of adult carers.

Section 9 sets out the minimum information that an adult carer support plan must contain.

Section 10 deals with the review of adult carer support plans.

Section 11 addresses the provision of information to the carer about their adult carer support plan.

The duties under section 6 are delegated to integration joint boards under the Public Bodies (Joint Working) (Prescribed Local Authority Functions Etc.) (Scotland) Amendment (No. 2) Regulations 2017¹⁰.

For the purpose of this chapter the terminology 'responsible local authority' will continue to be used in place of integration joint boards or integration authorities.

Purpose of adult carer support plan

2.1.1. The adult carer support plan (ACSP) provides a framework for identification of personal outcomes and individual needs for support of adult carers. This then links to the duty and power of the responsible local authority to provide substantive support to meet those identified needs. These duties and powers are considered in Part 3 of this guidance.

2.1.2. The ACSP is intended to help to increase the numbers of carers identified and having their needs properly considered (when compared to the numbers previously receiving a carers assessment).

¹⁰ SSI 2017/449 <u>http://www.legislation.gov.uk/ssi/2017/449/contents/made</u>

Duty to offer adult carer support plan

2.1.3. Section 6(2) requires a responsible local authority to offer an ACSP in respect of an identified adult carer. This duty applies to all adult carers the responsible local authority has identified, regardless of the intensity of the caring role or whether the carer's identified needs are expected to meet the local eligibility criteria.

Duty to prepare adult carer support plan and right to request one

2.1.4. Section 6(3) requires a responsible local authority to prepare an ACSP if the carer accepts the offer made under section 6(2). Section 6(3) also requires a responsible local authority to prepare an ACSP if an adult carer requests one. This means that anyone who appears to be an adult carer has a right to an ACSP if they want one.

2.1.5. The duties to offer and prepare an ACSP still apply, even if the carer's identified needs do not meet local eligibility criteria. In these circumstances, the ACSP can include signposting and access to any relevant supports, for example, universal or community-based services.

- 2.1.6. Section 6(1)(a) to (c) requires an ACSP to set out:
 - an adult carer's identified personal outcomes;
 - an adult carer's identified needs (if any); and
 - the support (if any) to be provided by the responsible local authority to an adult carer to meet those needs.
- 2.1.7. Further guidance on each of these elements is set out below.

2.1.8. The ACSP is therefore the mechanism through which needs for support are monitored and support is managed.

Responsible Local Authority

2.1.9. As at section 6(6) the 'responsible local authority' in relation to an ACSP, means the local authority for the area in which the cared-for person resides¹¹.

Approach to adult carer support plans

Third sector role

2.1.10. Responsible local authorities are encouraged to work collaboratively with the third sector in developing their models for preparing ACSPs. It is up to the responsible local authority to decide whether it wishes to commission third sector partners to undertake the function of preparing individual ACSPs.

¹¹ This is defined differently to the 'responsible authority' for young carer statements, explained in Chapter 2 of Part 2.

Learning from ACSP pilots

During the pilots for this aspect of implementation of the Act, one Health and Social Care Partnership found that developing their adult carer support plan collaboratively with their local carer centre ensured that an outcomes focused perspective was taken by both partners.

This also allowed both the carer centre and the Health and Social Care Partnership to test out some of the draft adult carer support plans with carers.

Not all carers required a service following on from having an ACSP, but they valued the experience of being involved and having their voices heard on the issues they face including emergency planning.

Information for carers about ACSPs

2.1.11. Carers will need to know what to expect when they request or accept the offer of an ACSP. It is recommended that this information be jargon free, published and provided through carer information and advice services as part of the ACSP offer. This could take the form of a leaflet that is freely available both online and in printed format. Further information about the duties to provide information and advice is set out in Part 6 of this guidance.

Equal opportunity requirements

2.1.12. Section 6(5) requires the responsible local authority to exercise its functions when preparing an ACSP in a manner which encourages equal opportunities, in particular the observance of the equal opportunity requirements (within the meaning of section L2 of Part 2 of schedule 5 of the Scotland Act 1998)¹².

Online approaches

2.1.13. Responsible local authorities covering remote rural areas may wish to consider the option of an ACSP being undertaken through an online platform such as a video call. It is recommended that if this option is pursued, its development would benefit from the involvement of carers and carer representatives from local carer support organisations. It is recommended that responsible local authorities have an option to undertake an ACSP in person for those carers who are uncomfortable with or unable to access the online alternative.

Self-evaluation approaches

2.1.14. Responsible local authorities may also wish to consider providing for a selfevaluation approach through which carers identify their own needs if they are willing and able to do so. Carers can provide certain aspects of the information required for the ACSP. It would still require the responsible local authority to check the completed self-evaluation with the carer; ensure all required information has been considered and recorded; and make decisions about carer support, based on the carer's identified needs and personal outcomes. It is therefore strongly recommended that there is always a conversation, preferably in person with the carer as part of the

¹² See MECOPP's publication, 'Carers (Scotland) Act 2016 and Equalities' for further information on issues to consider for particular groups of carers with protected characteristics. <u>https://www.mecopp.org.uk/mecopp-publications/2018/12/14/briefing-sheet-10-carers-scotland-act-2016-and-equalities</u>

process in order to allow information to be checked and so that it can be determined to what extent the carer's identified needs meet the local eligibility criteria.

2.1.15. It is recommended that the responsible local authority follows the same outcomes focused approach to the preparation and formation of an ACSP using good conversations to aid the process regardless of whether the carer undertakes a self-evaluation or not.

2.1.16. Before offering a self-evaluation, the responsible local authority can take steps to try to determine that a carer has the ability to fully assess and reflect their own needs. Where responsible local authorities have concerns that a carer may experience substantial difficulty in understanding, retaining and using the relevant information in relation to their self-evaluation, they could offer support and advice. It may be worth considering using an independent advocate or another member of the carer's family or support network to assist the carer with their self-evaluation.

Outcomes-focused approach

2.1.17. It is recommended that responsible local authorities take account of the national outcomes for Integration and in particular, National Outcome 6, which states 'People who provide unpaid care are supported to look after their own health and wellbeing, including to reduce any negative impact of their caring role on their own health and wellbeing'.

2.1.18. There are several useful practice approaches for responsible local authorities to make use of when undertaking an ACSP. These include using a conversational approach, an outcomes approach and an assets based approach to assessment. There are several models of assessment but the exchange model is particularly well suited to an outcomes focused approach.

2.1.19. A conversational approach to assessment such as the exchange model¹³ could be considered by responsible local authorities when undertaking an ACSP. In this context, the approach involves practitioners and carers working together to develop outcomes into individual stories and coproduce their collaborative plans.

2.1.20. An outcomes approach supports the exchange model where the carer's strengths and aspirations are fundamental, and it supports a process of negotiation involving the knowledge and skills of each participant. This aligns well with an assets based approach to wellbeing, whereby the focus is on what the carer wants to change in their life and the resources and strengths they bring to realise the intended changes. The Talking Points personal outcomes approach¹⁴ is a valuable evidence-based framework that summarises the outcomes important to adults and carers living in the community who use health and social care services.

Proportionate approach

2.1.21. When preparing the ACSP, the responsible local authority is recommended to take a proportionate approach, taking into account what issues are raised through the conversation with the carer and which issues need to be raised with the carer.

¹³ <u>https://www.scie.org.uk/publications/guides/guide18/teaching/howtaught.asp</u>

¹⁴ https://personaloutcomes.files.wordpress.com/2014/04/talk about outcomes 01.pdf

2.1.22. In carrying out a proportionate approach to an ACSP, authorities will have regard to the carer's wishes, preferences, identified needs and personal outcomes. For example, a carer may be quite specific about the areas of their life where their caring role has an impact. They may not feel the need to discuss other areas, which they feel are not relevant to them, and where their caring role has no impact.

Example

John looks after his adult daughter who has a learning disability. His wife used to be the primary carer, but since her death John's caring role has increased. John is currently in employment and is finding it difficult to balance work with his caring responsibilities.

John's identified needs and personal outcomes are focused on enabling him to continue in employment. John is clear that he is coping well in other areas of his life. He has good health and wellbeing and is able to maintain relationships and have a life alongside caring.

Example

Liliana is 50 and is the carer for her son, who has a long term, degenerative health condition. She has a good support network of family and friends and is coping well across the board. However, she does worry about how she will cope as she grows older and her son's condition worsens.

Liliana's identified needs and personal outcomes are focused on future care planning and this is the main aspect she wants to discuss in her ACSP.

Low and Fluctuating Need

2.1.23. It is recommended that responsible local authorities consider the potential fluctuation of the carer and/or the cared-for person's needs. For example where the responsible local authority is aware that the cared-for person's needs fluctuate over time due to a mental health condition, the ACSP carried out at a particular moment may take into account the cared-for person's history to establish a complete picture of the cared-for person's needs and the impact these fluctuating needs have on the caring situation.

2.1.24. It is recommended that low level needs and the support to meet those needs are considered as part of the ACSP process. This process will be based on the identification of personal outcomes, needs and risks. It would be worth considering whether a carer's identified needs can be met by the local information and advice service or general services in the community.

Signposting to universal support where carer refuses an ACSP

2.1.25. Not all adult carers will want to accept the offer of an ACSP. In these cases the responsible local authority may consider signposting the carer to a carer centre or similar support provider.

Learning from ACSP Pilots

During the pilots for this aspect of implementation of the Act, a Health and Social Care Partnership took a coproduction approach to developing their ACSP. This found that:

- it made sense to allow carers to have access to universal supports without having to undertake an ACSP;
- more information and communication was required to allow carers to know what is available in their area and what choices they can make; and
- any forms used need to be as simple, accessible and as user friendly as possible.

Tensions between carer and cared-for person

2.1.26. There may be tensions between the carer and the cared-for person. Carers can often find their caring role stressful and difficult in a range of different ways. The cared-for person may not be coping well with their condition or a deterioration of their health. This can put tremendous strain on the relationship between the carer and the person that they care for. Responsible local authorities need to take account of this and be sensitive to it when undertaking an ACSP. The authority could consider working with both parties to try and seek a resolution to the situation if possible. In some circumstances, that could involve supporting the carer to end their caring role. In situations where the caring situation has become completely unmanageable or has a harmful impact on the carer's wellbeing or that of the cared-for person, it may be necessary to raise an adult protection¹⁵ concern in line with their local multi-agency adult protection guidelines.

Content of adult carer support plan

2.1.27. Section 9 outlines what information must be contained in an ACSP. However, for the contents of an initial ACSP for an adult carer caring for someone with a terminal illness, known as a 'light touch' plan, please refer to para 2.1.100 to 2.1.102.

Carer's personal circumstances

2.1.28. Section 9(1)(a) requires information about the carer's personal circumstances when the ACSP is being undertaken. This must include information about the nature and extent of care provided or to be provided by the carer and information about the impact of caring on the adult carer's wellbeing and day-to-day life.

2.1.29. In practice, a good conversational approach would be important to determine a picture of the types of care and the intensity of the care being provided by the carer. This might include, for example, emotional support and practical care such as assistance with toileting and bathing.

¹⁵ <u>https://www.gov.scot/policies/social-care/adult-support-and-protection/</u>

2.1.30. The responsible local authority will also need to understand the impact on the carer from undertaking their caring role. This would include the impact on the carer's wellbeing and ability to have a life of their own. Negative impacts could include high levels of emotional distress, regular physical strain and acute social isolation.

2.1.31. When undertaking the ACSP, the responsible local authority must also consider the carer's daily activities and dependents beyond their caring responsibilities, and the impact of caring upon these activities. This includes considering the impact of caring duties on a carer's desire and ability to undertake paid work, to participate in education, training or recreational activities, such as having time to themselves. It is recommended that authorities consider both short-term and longer term cumulative impacts of caring responsibilities.

Able and willing to provide care

2.1.32. Section 9(1)(b) requires information about the extent to which the adult carer is able and willing to provide care for the cared-for person. It is recommended not to make any assumptions about a carer's willingness or ability to care. For example, the carer may indicate that they are willing and able to care in order to facilitate the discharge of the cared-for person from hospital, while in reality they are unable to sustain the caring role in the community without adequate support. This is partly due to the anxiety that many carers have that a statutory involvement may lead to a loss of influence over the care of the cared-for person.

2.1.33. Ability and willingness to care can be closely linked to a carer's opportunities to have some time away from caring and to recover. A break from caring can help the carer to recharge and continue in their caring role. There is therefore a link between this aspect of the ACSP and the support provided to meet the carer's needs (as considered in Part 3 of this guidance). Some carers may not be able to sustain the caring role even with support in the form of breaks from caring. There could be many reasons for this, including mental exhaustion or physical deterioration. In these circumstances, it may be more appropriate to explore home care and other increased support at home or, where required, longer term alternative options for accommodation-based care for the cared-for person. See also the discussion of ability and willingness to care in Chapter 3 of Part 3.

2.1.34. The willingness and ability of the carer to continue to provide care to a cared-for person may be closely linked to the support provided to the cared-for person following other assessments. It is therefore recommended that the responsible local authority takes into account the outcomes of any prior assessment in relation to the cared-for person and consider whether a new assessment is required. This may help to establish whether the carer is able and willing to continue to provide care to the cared-for person. The Act also requires the ACSP to be taken into account when carrying out assessments under other legislation, as considered below.

Link to assessment of cared-for person's needs and outcomes

2.1.35. Section 30 of the Act amends section 12A of the Social Work (Scotland) Act 1968, which sets out the duty of local authorities to assess needs in relation to social care. The effect of the amendments is to require the local authority to take account of the care provided by the carer as set out in the ACSP when making decisions about

the provision of support to meet the cared-for person's needs and outcomes. The local authority is also required to take account of the views of the carer in determining an adult's needs and outcomes for support, so far as it is reasonable and practicable to do so. Normally therefore, the carer's views would be taken into account, unless there are particular circumstances which prevent this from happening.

2.1.36. Section 30 of the Act makes similar amendments to section 23 of the Children (Scotland) Act 1995, which sets out the duty of the local authority to assess the needs of children affected by disability. The effect of the amendments is to require the local authority to take account of the care provided by the carer as set out in the ACSP when making decisions about the provision of support to meet the needs and outcomes of the carer in determining a child's needs and outcomes for support so far as it is reasonable and practicable to do so.

2.1.37. A responsible local authority may consider preparing an ACSP at the same time it undertakes an assessment of needs and outcomes of the supported person/ child.

Emergency care plans for cared-for persons

2.1.38. Section 9(1)(c) requires information about whether the adult carer has arrangements in place for the care of the cared-for person in an emergency.

2.1.39. Emergency planning (sometimes called contingency planning) includes planning for events such as the carer not being able to care due to illness or adverse weather preventing the carer from accompanying the cared-for person to medical appointments.

2.1.40. Some responsible local authorities already offer carers emergency plans or discuss emergency planning with them, whilst other areas offer carers an emergency card which lets the emergency services or social care services know that a person is a carer. Encouraging carers to carry the card at all times can help services to put other support in place in a crisis.

2.1.41. ENABLE Scotland has a suite of resources about emergency planning which applies in all caring situations, including caring for children and adults with learning disabilities¹⁶. Responsible local authorities are encouraged to make use of these resources or direct adult carers to the ENABLE emergency planning resources.

Learning from ACSP pilots

During the pilots for this aspect of implementation of the Act, a Health and Social Care Partnership introduced the ENABLE emergency planning toolkit through a conversation with the carer as part of preparing the ACSP. They found this helped to establish what would be required to be done in an emergency situation. There was very positive feedback from carers about the introduction of emergency planning as part of their ACSP.

¹⁶ <u>http://www.enable.org.uk/families/Pages/Emergency-Planning.aspx</u>

Future care plans for cared-for persons

2.1.42. Section 9(1)(d) requires the ACSP to include information about whether the adult carer has arrangements in place for the future care of the person that they care for. If the carer identifies future care planning through discussion on their personal outcomes or identified needs as part of the ACSP process, they could be provided with support to put such plans in place.

2.1.43. Where carers appear to have a significant need for support with future care planning, this would be considered as part of the ACSP and the identification of needs; and if this identified need meets local eligibility criteria, the responsible local authority will be under the duty to provide support (see separate guidance chapter on duty to provide support to carers).

2.1.44. Information and advice services for carers are covered in Part 6 of this guidance. These services can signpost to or be designed in partnership between a carer centre and specialist, professional, independent services to offer future planning services. Such services could include making wills, trusts and longer term financial planning if appropriate to an adult carer's situation. Responsible local authorities may also consider the provision of carer advocacy services and make reference to the Scottish Government's guidance on carer advocacy in Scotland¹⁷.

Example – Information and advice on future care planning

VOCAL, Edinburgh offers free surgeries to carers to access future planning services. Working in partnership with a solicitor, VOCAL offers carers short consultations, for information and advice about key issues such as wills, trusts and guardianship. They also offer long term care financial advice surgeries via a chartered financial advisor who explores options with carers who are concerned about paying for care home fees and other financial issues.

Link to anticipatory care planning

2.1.45. In terms of future care arrangements, the ACSP is well placed to link to an anticipatory care plan¹⁸ This is a dynamic record that can be developed over time through an evolving conversation, collaborative interactions and shared decision making. It is a summary of the discussions between the cared-for person, their carer and the practitioner. Carers themselves may find it useful to have their own anticipatory care plan which can be kept updated and shared using technology such as the associated app¹⁹.

2.1.46. Anticipatory care planning is more commonly applied to support those living with a long term condition to plan for an expected change in health or social status. It also incorporates health improvement and staying well. Completion of a common document called an anticipatory care plan is suggested for both long term conditions and in palliative care. Future care arrangements will also be relevant when the cared–for person is receiving end of life care. Advance care planning is the term most commonly referred to in end of life care, although it does incorporate the writing of wills or 'Living Wills' now known as advance directives or advance decisions which

¹⁷ <u>http://www.gov.scot/Publications/2016/03/5362</u>

¹⁸ http://ihub.scot/anticipatory-care-planning-toolkit/

¹⁹ http://ihub.scot/anticipatory-care-planning-toolkit/

can be done by the cared-for person early on in life to plan for what may happen at the end of life.

Personal outcomes

2.1.47. It is recognised that caring for another person is likely to impact on a carer physically, emotionally and on the way in which that carer lives his/her day to day life. The policy intention of the Act is to maximise opportunities and minimise negative impacts so as to allow the carer to have a life alongside caring. Consequently, the ACSP seeks to support carers not just in relation to the substantive care that they provide to the cared-for person, but also by putting measures in place that will help a carer to live their own life and to achieve their own goals and aspirations. These day to day goals and longer term aspirations are to be documented within the ACSP as the carer's 'personal outcomes'.

2.1.48. Section 9(1)(e) requires the ACSP to contain information about the identification of the adult carer's personal outcomes and what those outcomes are.

Definition and approach to identifying personal outcomes

2.1.49. The term 'personal outcomes' is defined at section 4 of the Act. It includes outcomes, which if achieved would enable carers to provide or continue to provide care for the cared-for person(s).

2.1.50. Section 4(2) allows Scottish Ministers to make further provision in regulations about personal outcomes. No such regulations have been made.

2.1.51. The Carers (Scotland) Act 2016 (Adult Carers and Young Carers: Identification of Outcomes and Needs for Support) Regulations 2018 require personal outcomes and needs for support to be identified following a conversation with the adult carer. Such conversations can take a variety of forms, for example in the case of carers with communication difficulties. The regulations also state that, like the preparation of ACSPs, identification of personal outcomes and need for support is a function of the responsible local authority. This does not preclude the responsible local authority arranging for another body, such as a local carer support organisation, to do the work on its behalf. The regulations also require an adult carer's personal outcomes and needs for support to be reviewed when his or her ACSP is reviewed.

Evidence on personal outcomes

The review paper *Review of evidence on personal outcomes relevant to the Carers (Scotland) Act 2016*, Emma Miller (2017), University of Strathclyde²⁰ is a valuable source of information on domestic and international practice in the literature to evaluate personal outcomes; their use, efficacy and integration with existing processes and procedures.

2.1.52. In terms of approach to identification of the adult carer's personal outcomes, the discussion can be focused on the adult carer's wellbeing needs, and consider how coordinated services or support can impact on their wellbeing. The outcomes

²⁰ <u>http://www.gov.scot/Topics/Health/Support-Social-Care/Unpaid-Carers/Implementation/UsefulResources</u>

must be specific to the carer and their circumstances and may have a short or longer term focus as required.

Consideration of equalities when identifying outcomes

2.1.53. Section 8(2) requires that in identifying an adult carer's personal outcomes and needs for support, the responsible local authority must take into account any impact that having one or more protected characteristics (within the meaning of section 149(7) of the Equality Act 2010) has on the adult carer²¹.

Equalities Examples

Sensory loss & deafblindness

Where an adult carer has dual sensory loss or is deafblind, responsible local authorities could have an appropriately skilled professional involved in the ACSP or consider a specialist assessment undertaken by a professional with dedicated skills in understanding the impact that deafblindness or dual sensory loss can have on an individual person and their family.

English not a first language

When planning to undertake an ACSP, it is identified that English is not the carer's first language. In this situation, it is recommended that the responsible local authority would offer an interpreting and translation service when undertaking the preparation of the ACSP.

Older carers

Older carers may have to manage their own long-term conditions and frailty which may impact considerably on their ability to provide care. Other factors to consider are whether or not the carer also requires their own social care needs assessment alongside their ACSP and to the level at which they may reach eligibility for support as undertaking a smaller caring role may have a much greater impact on an older carer than other carers.

Carers with a learning disability

In the case of adult carers who have a learning disability, responsible local authorities may consider who is best placed to undertake the ACSP. The carer may have barriers to participate in their ACSP. Consideration of the use of an independent advocate alongside the carer may help the carer to express their views and opinions on what their needs and personal outcomes are.

Identified needs

2.1.54. Section 9(1)(f) requires the ACSP to contain information about the identification of the carer's needs for support, including what these needs are. 'Identified needs' are defined in section 5 of the Act as the needs for support which are identified in order to meet the carer's identified personal outcomes. These support needs could include a broad range including the carer's physical needs, emotional needs, relationship needs, health needs, economic needs and physical environment needs. Identified needs must be recorded in the ACSP. If a carer has no identified needs for support, this must also be recorded.

²¹ See MECOPP's publication, 'Carers (Scotland) Act 2016 and Equalities' for further information on issues to consider for particular groups of carers with protected characteristics. <u>https://www.mecopp.org.uk/mecopp-publications/2018/12/14/briefing-sheet-10-carers-scotland-act-2016-and-equalities</u>

2.1.55. In considering what the carer needs to meet their personal outcomes, responsible local authorities are recommended to consider the carer's strengths and capabilities, and what support might be available from their wider support network or within the community. Suggestions that support could be available from other family and friends could be considered in light of their willingness and ability to provide any additional support and the impact on them of doing so.

Whole family approach

2.1.56. Consideration of what other support may be available through the carer's networks and the wider community, allows for a whole family approach and for the responsible local authority to build a more holistic view of the needs of the carer and the person they care for.

2.1.57. In considering the impact of the cared-for person's needs on those around them, the responsible local authority may consider whether additional information and advice would be beneficial to those people identified. Alongside the main carer there may be others undertaking a caring role. For example where a carer has children, one of whom has additional care needs, there may be other children who are young carers, which allows the offer of a young carer statement to be made.

Support available locally

2.1.58. Section 9(1)(g) requires information about the support available to adult carers and cared-for persons in the responsible local authority's area to be contained in the ACSP. It is recommended that this information is tailored to the specific identified personal outcomes and needs of the adult carer and the person that they care for.

2.1.59. This information may for example, take the format of a leaflet or a carer information pack. We recommend it includes contact details of the information and advice service or carer centre and instructions on relevant online information. It could include information on universal support in the area or more intensive support such as respite which would be outlined in the short break services statement.

Carers living in other areas from the cared-for person

2.1.60. Section 9(1)(h) requires that if an adult carer does not reside in the responsible local authority's area, information must be provided about the support available to them, in the area where they live. The 'responsible local authority' in relation to an adult carer, means the local authority for the area in which the cared-for person resides.

2.1.61. In these circumstances, it is recommended that the responsible local authority, liaises with the local authority where the carer lives so that the responsible local authority can provide appropriate information about the support available locally.

Adult carers caring for people in more than one local authority area

2.1.62. There may be occasions where an adult carer is caring for more than one person across different local authority areas. In these circumstances, both local authorities where the cared-for persons are living have responsibility to offer and if that offer is accepted undertake an ACSP. Following that, they would provide

support to the carer (dependent on the two local authorities' potentially different eligibility criteria) which might involve providing support to the cared-for person.

2.1.63. We encourage each local authority in these circumstances to work together, so that they can jointly:

a) achieve an outcomes focus for the individual carer;

b) minimise the need for the carer to provide the same information twice;c) make decisions on support and eligibility based on a shared

understanding of the total impact of the carer's caring responsibilities; and d) avoid duplication of effort.

2.1.64. Whilst each local authority's eligibility criteria would be relevant in its own decision making about support, we recommend collaboration between each area in that decision making process.

Case Study – Carer caring for two people in different areas

An adult carer is caring for their daughter, a child who has a long term condition, whilst also providing care to their elderly mother, in her seventies with dementia. The carer and her daughter both live in Dundee (the same local authority) but the grandmother (second person being cared-for) lives in Perth and Kinross (another local authority).

The 'responsible local authority' in relation to an adult carer, means the local authority for the area in which the cared-for person resides. The responsible local authority would therefore be Dundee for the first caring situation and Perth and Kinross for the second caring situation.

Therefore the duty to undertake the ACSP and provide support if the carer's identified needs meet the local eligibility criteria for the Dundee caring situation would sit with Dundee as the responsible local authority. For the other caring situation, it would be Perth and Kinross as the responsible local authority.

However, Dundee as the responsible local authority who have identified a carer in their area who also cares for someone who resides in a different local authority area (Perth and Kinross), could liaise with that local authority and make a referral (with consent) to ensure that the carer has access to an ACSP and any requisite support that would benefit them and to which they are entitled.

Carer who resides in Scotland caring for someone outwith Scotland

2.1.65. The Carers (Scotland) Act 2016 does not create a duty to offer an ACSP to a carer in this situation, or provide subsequent support as the cared-for person resides outwith Scotland. However, carers are still able to access local carer support such as: carer centre services; Citizens Advice Bureau; advice shops and local authorities' information and advice services.

2.1.66. A carer living in Scotland who cares for someone outwith Scotland may be eligible for support from the local authority in which the cared-for person resides. In these instances, it would be a matter for the relevant local authority in England or Wales, or the Health and Social Care (HSC) Trust in Northern Ireland to make

decisions as set out under legislation in those countries. (See Part 3, Chapter 2 on duty to provide support).

Carer resides outwith Scotland, caring for someone in Scotland

2.1.67. Instances where a carer outwith Scotland is caring for someone residing in Scotland may also occur. For example, a 'distance caring' relationship where a carer looks after:

a) a frail parent and provides emotional support, liaises with statutory services, and arranges other help from a distance, and visits regularly to provide hands-on assistance; or

b) someone nearby, just over the border.

2.1.68. For adult carers, the Scottish local authority where the cared-for person lives has a duty to offer an adult carer support plan and to support the carer under the Act where their identified needs meet local eligibility criteria.

Support to be provided

2.1.69. Once the responsible local authority is satisfied that the ACSP has accurately captured the carers identified needs, the authority must come to a view on the carer's eligibility for support. This process is detailed in Part 3 of this guidance.

2.1.70. Although the responsible local authority and the carer are working jointly to ascertain needs and eligibility, the final decision regarding eligibility will rest with the responsible local authority. In all cases, the responsible local authority must inform the carer of their eligibility judgement and why it has reached the eligibility determination that it has. Where a carer is identified as having eligible needs for support, it must discuss what these eligible needs are and outline how these might be met including via the four options of self-directed support (Please refer to guidance on local eligibility criteria and duty to support carers).

2.1.71. Section 9(1)(i) requires the ACSP to provide information about the support which the responsible local authority provides or intends to provide to the adult carer to meet their identified needs if those needs meet the local eligibility criteria.

2.1.72. At this support planning stage, if the carer's identified needs meet the threshold of the local eligibility criteria, the responsible local authority must offer the four options (see Table 2 below) of self-directed support²² to the carer based on their indicative budget or relevant amount.

The four options of Self-directed Support are:

Option 1: a Direct Payment (a cash payment);

Option 2: funding allocated to a provider of your choice (sometimes called an individual service fund, where the council holds the budget but the person is in charge of how it is spent);

Option 3: the local authority can arrange a service for you; or

Option 4: you can choose a mix of these options for different types of support.

²² <u>https://www.gov.scot/publications/self-directed-support-framework-standards-including-practice-statements-core-components/</u>

2.1.73. There is no single approach to resource allocation prescribed on the face of the Social Care (Self-directed Support) (Scotland) Act 2013, nor any single method recommended by the Scottish Government. The authority may wish to adopt an equivalence model where they determine the cost of the service to be arranged and then provide the equivalent amount as a budget for the supported person or carer to control. Alternatively, it may wish to adopt a resource allocation system whereby the authority gathers information about the person's outcomes; allocates points to those outcomes; and then allocates a level of funding. In addition, decisions about budgets may be made on a case by case basis. It is recommended to make reference to the statutory guidance to accompany the Social Care (Self-directed Support) (Scotland) Act 2013²³.

2.1.74. If all parties agree, the responsible local authority may decide to offer one holistic budget that extends to meet both the eligible needs and personal outcomes of the adult carer and the eligible needs and personal outcomes of the cared-for person. If budgets are combined, it is important that the focus is not just on the cared-for person but also acknowledges the carer's health and wellbeing. Carers also require choices and their support personalised.

Preventative approach whether or not needs meet eligibility criteria

2.1.75. Section 9(1)(j) requires that where the adult carer's identified needs do not meet the local eligibility criteria, information about any support which the responsible local authority nevertheless agrees to provide must be included in the ACSP. Responsible local authorities can choose to provide individualised support to the carer on a discretionary basis using their powers rather than duties to provide support. This could include making a referral or signposting carers to universal or community based services, for example a local carer centre or a citizens advice service.

2.1.76. If the carer's needs do not meet the local eligibility criteria, then it is recommended that other preventative supports in the community still be considered by the responsible local authority. This for example may include advice and information, emotional support, befriending or a welfare benefits check to maximise family income.

Example

Carer centres can offer a wide range of preventative support to carers including advice and information, emotional support, carer training, short breaks and welfare benefits checks to maximise income. Carer centres are often third sector organisations who specialise in carer support.

Breaks from caring

2.1.77. Section 9(1)(k) requires the ACSP to include information about whether the support should include breaks from caring. Part 3 of this guidance contains more information about breaks from caring.

Review of ACSP

2.1.78. Section (9)(1)(I) requires the ACSP to contain information about the circumstances in which it is to be reviewed. Para 2.1.103 of the guidance below,

²³ <u>http://www.gov.scot/Resource/0044/00446933.pdf</u>

refers specifically to review of ACSPs for adult carers for someone with a terminal illness.

2.1.79. The Carers (Scotland) Act 2016 (Review of Adult Carer Support Plan and Young Carer Statement) Regulations 2018²⁴ specify circumstances in which ACSPs must be reviewed by the responsible local authority. These are:

- a) when the adult carer moves to reside in a different local authority area;
- b) when the cared-for person becomes resident in accommodation provided under:
 - i. Part 2 of the Social Work (Scotland) 1968 Act; or
 - ii. Section 25 of the Mental Health (Care and Treatment) (Scotland) Act 2003; or
 - iii. Part 2 of the Children (Scotland) Act 1995 or
- c) any other change in the adult carer or cared-for person's circumstances which the responsible local authority views as having a material impact on the care provided by the adult carer.

2.1.80. The Regulations highlight that a review of the ACSP may be appropriate where support to the cared-for person has changed. It is for the responsible local authority to decide in each individual situation whether this change in circumstance warrants a review.

2.1.81. Responsible local authorities must also consider what other circumstances will be relevant to trigger a review in individual cases. These may include:

- a) after an agreed period of time, e.g. one year;
- b) deterioration in the health of the adult carer or cared-for person; and
- c) the cared-for person being discharged from hospital.

2.1.82. Responsible local authorities are encouraged to seek the views of the relevant adult carer when identifying whether any other change in circumstance has had a material impact on the care provided by the adult carer.

2.1.83. It would be expected that the review process would be proportionate to the situation. A review will keep the information contained in the ACSP up to date and relevant and would always look at whether the needs for support and personal outcomes of the adult carer have changed. This may result in a change in the adult carer's eligible needs.

Effectiveness of support provided under previous ACSP

2.1.84. After an initial ACSP has been prepared, Section 9(2) requires each subsequent ACSP to contain information about the extent to which any support provided under a previous plan has assisted in the achievement of the adult carer's identified personal outcomes.

Additional information

2.1.85. The responsible local authority can decide what additional content to include in the ACSP, over and above the minimum requirements set out in the legislation. This could be information tailored to individual ACSPs or general information. An

²⁴ SSI 2018/33 <u>http://www.legislation.gov.uk/ssi/2018/33/contents/made</u>

example could be a risk assessment in relation to tasks undertaken by the carer such as bathing the person that they care for or assistance with mobility.

Timescales for offering and preparing an adult carer support plan

2.1.86. There are no timescales set out in the Act for offering, preparing and completing individual adult carer support plans. The Act requires timescales for preparing an ACSP to be set in relation to carers of terminally-ill cared-for persons, as outlined below.

2.1.87. Section 31(2)(h) requires the local carer strategy to set out the intended timescales for preparing ACSPs . Part 5 of this guidance deals with local carer strategies. The intention of section 31(2)(h) is to give carers collectively an indication of how long, on average, they are likely to wait for an adult carer support plan. It is fully expected that some will take less time and some will take longer than those indicated time periods for valid reasons. This means that local carer strategies will need to include the timescales for offering and preparing an ACSP for carers caring for a person with a terminal illness, in line with the guidance below.

2.1.88. It is expected that all carers who want one should be able to benefit from an ACSP in an efficient and timely manner. There may be different timescales for completion of individual ACSPs. ACSPs ought to be offered and prepared within reasonable timescales taking into account the urgency of needs for support and any fluctuation in those needs. Responsible local authorities may have guidance for timescales based on urgency or risk. There may be valid reasons for a plan taking longer to complete than perhaps anticipated, for example, where the carer's needs are complex and require more than one contact to prepare and complete the plan and/or where support required is specialised and not readily available. Responsible local authorities are encouraged to focus on achieving the right outcomes for the carer rather than allowing set timescales to become a *de facto* target or input measure.

2.1.89. Responsible local authorities are advised to inform the individual carer of an indicative timescale over which their assessment will be conducted and keep the carer informed throughout the assessment process. Some responsible local authorities also, as a matter of good practice and courtesy, advise individual carers of any delays and the reasons for the delays.

Timescales for ACSPs for carers of terminally ill cared-for persons

2.1.90. Section 7 of the Act requires Scottish Ministers to make regulations to set timescales for preparing ACSPs for adult carers of people who are terminally ill. A person is terminally ill if they suffer from a progressive disease and death in consequence of that disease can reasonably be expected within six months²⁵. The timescales are set in the Carers (Scotland) Act 2016 (Adult Carers and Young Carers of Terminally III Persons: Timescales for Adult Carer Support Plans and Young Carer Statements etc.) Regulations 2021²⁶ ("Terminal Illness Regulations"), which come into force on 31st July 2021.

²⁵ Carers (Scotland) Act 2016 (legislation.gov.uk)

²⁶ SSI 2021/133 https://www.legislation.gov.uk/ssi/2021/133/made

2.1.91. As responsible local authorities are already required to offer an ACSP to every carer they know about, many carers of people who have a progressive illness are likely to already have had an ACSP, well before the cared-for person meets the above definition of being terminally ill. Therefore, it is anticipated that these timescales will be required for a small number of carers and as local authorities already prioritise these cases, timescales should act as a backstop rather than a target.

2.1.92. The regulations have been designed to ensure timescales do not compromise the quality and personalisation of support for carers; or impact on the prioritisation of other cases. They should not prevent ACSPs being completed quicker, in line with good practice and should help to minimise bureaucracy for both professionals and carers.

2.1.93. Alongside the Terminal Illness Regulations, Scottish Ministers have issued Directions²⁷ ("The Directions") to set timescales for offering ACSPs to carers of people who are terminally ill. These are to support the overall outcome of adult carers receiving an ACSP and associated support in an efficient and timely manner.

2.1.94. The Directions and Terminal Illness Regulations work together. They recognise the urgency of supporting adult carers who are caring for people who are terminally ill. They also recognise that carers may not always wish or be in a position to engage in the preparation of an ACSP within days of being offered one. A diagnosis of terminal illness will have a profound impact on the person diagnosed and on the family and friends who support or intend to support them. People who have recently become aware that the person they support is terminally ill may not have time or be ready to recognise their role or discuss their own needs as carers.

2.1.95. The Directions require all carers of people who are terminally ill to be offered an ACSP within 2 working days of a person being identified as a relevant carer and if this is not possible, as soon as reasonably practical thereafter, as soon as an authority becomes aware that they are caring for someone with a terminal illness. The Terminal Illness Regulations then ensure that as soon as these carers feel ready to participate in the ACSP preparation process, they benefit from accelerated time limits for receiving an ACSP and associated support.

Timescales for offering ACSPs - The Directions

2.1.96. The Directions were issued to responsible local authorities and come into force on 31 July 2021. Once an authority identifies an adult carer of someone who is terminally ill, the authority must offer that carer an ACSP within two working days. If the authority cannot do this within two working days, due to unforeseen circumstances, they must make the offer as soon as reasonably practicable.

Timescales for preparing ACSPs - The Terminal Illness Regulations

2.1.97. Once a carer requests an ACSP or accepts an offer of an ACSP, the authority has a duty to prepare one. The Terminal Illness Regulations²⁸ set timescales within which the authority must prepare an ACSP from the point this duty

²⁷ <u>https://www.gov.scot/publications/carers-scotland-act-2016-terminal-illness-directions-letter-from-minister-for-mental-wellbeing-and-social-care/</u>

²⁸ SSI 2021/133 https://www.legislation.gov.uk/ssi/2021/133/made

arises. There are different timescales for steps in the process, to ensure that it is flexible enough to meet the needs of each carer.

Step 1 - Substantive Conversation

2.1.98. The first step in the process is having a "substantive conversation" with the carer about urgent outcomes and needs for support. Authorities must have this conversation with the carer within five working days of the carer accepting an offer or requesting an ACSP²⁹. At this conversation, the authority must identify immediate or urgent personal outcomes and needs for support³⁰. (See also guidance on the approach to identifying personal outcomes and needs for support, including the requirement for a conversation, at paras 2.1.49 to 2.1.52.)

2.1.99. There may be situations when the carer is unable or does not want to have a substantive conversation within this period of five working days. In that case the carer can request a different date³¹. Where this happens the timescales for the next step (completing a light touch ACSP) are calculated differently (as below).

Step 2 – Light Touch ACSP

2.1.100. The second step in the process is completing a light touch ACSP, based on the substantive conversation. If that conversation takes place within the five working days mentioned above then the authority must complete the ACSP within ten working days³² of the date when the carer originally requested or accepted the offer of an ACSP.

2.1.101. If the first substantive conversation takes place later, then the authority must prepare the ACSP within ten "qualifying working days" from the original request or acceptance of an ACSP³³. The clock is paused so that any working days between the date the carer asks to delay the substantive conversation and the date that conversation takes place are not counted as qualifying working days. This is consistent with a ten working day timescale but also reflects that the information needed to prepare the ACSP is likely to be obtained during the substantive conversation with the carer. So it will not be possible to complete an ACSP until after that conversation has taken place.

2.1.102. The Terminal Illness Regulations also set out what a light touch ACSP prepared within these timescales must contain. A light touch ACSP should focus on immediate or urgent personal outcomes and needs of the carer and include information under section 9 (1)(a),(b), (e), (f), (i) and (j) of the 2016 Act³⁴. (See paras 2.1.28 to 2.1.76 above on (a) carers' personal circumstances; (b) able and willing to provide care, (e) personal outcomes, (f) identified needs, (i) support to be provided, and (j) preventative approach whether or not needs meet eligibility criteria.)

Step 3 – Review date for completion of a full ACSP

²⁹ Regulation 4, SSI 2021/133. <u>https://www.legislation.gov.uk/ssi/2021/133/made</u>

³⁰ Regulation 3, SSI 2021/133. www.legislation.gov.uk/ssi/2021/133/

³¹ Regulation 4(b), SSI 2021/133 <u>https://www.legislation.gov.uk/ssi/2021/133/made</u>

³² Regulation 5(2a), SSI 2021/133 https://www.legislation.gov.uk/ssi/2021/133/made

³³ Regulation 5(2b), SSI 2021/133 <u>https://www.legislation.gov.uk/ssi/2021/133/made</u>

³⁴ Regulation 5(2), SSI 2021/133 https://www.legislation.gov.uk/ssi/2021/133/made

2.1.103. The light touch ACSP is intended to address urgent issues and does not have to cover all the information required under section 9(1) of the 2016 Act. The Terminal Illness Regulations³⁵ therefore require the authority and the carer to agree when the plan should be reviewed to include the rest of the information which should be contained in a plan under section 9 of the 2016 Act. This is to ensure that carers know what to expect from the finalised plan and when those issues will be addressed. In addition, paras 2.1.78 to 2.1.83 above, outline the other circumstances in which an ACSP will need to be reviewed.

Adult carer support plan: provision of information to carer etc.

2.1.104. Section 11 requires the responsible local authority to provide information contained in the ACSP to the carer to whom the ACSP relates and any other person the carer requests, unless the authority does not consider it appropriate to provide the information. For example, it might not be considered appropriate to provide sensitive medical information about the cared-for person to a third party.

2.1.105. When considering information to be shared and who to share it with, the responsible local authority would have to comply with the common law duty of confidentiality and the requirements of data protection and human rights legislation, in particular, the right to private and family life under Article 8 of the European Convention on Human Rights (ECHR).

2.1.106. Section 11(4) states that the information is to be provided as soon as practicable after the plan is prepared or in the case of a revised plan, when the revised plan is prepared. In terms of good practice, this would mean that the carer is provided with a physical copy of their agreed ACSP within a reasonable timescale by the responsible local authority.

Digital Technology

2.1.107. There is an important role for effective IT systems in sharing agreed information between partners and keeping plans up to date. The Scottish Government through the Health and Social Care Delivery Plan has identified digital technology as key to transforming health and social care services. There has been success through previous eHealth and Technology Enabled Care Strategies in the delivery of many core IT systems required to support efficient service delivery at a local level, and in technology assisted home care to support wellbeing, selfmanagement and safer living at home or in community settings. However, there is a need for even better use of digital technology, data and research in order to achieve this transformation agenda. Our new Digital Health and Social Care Strategy will be published in 2018 at www.ehealth.nhs.scot

³⁵ Regulation 5(4), SSI 2021/133 <u>https://www.legislation.gov.uk/ssi/2021/133/made</u>

Chapter 2 – Young carer statements

Summary

Section 12 places a duty on responsible authorities to offer a young carer statement to all identified young carers and prepare a young carer statement for those that take up this offer, as well as for any young carer who requests one.

Section 13 states that Scottish Ministers must, by regulations, prescribe timescales for the preparation of young carer statements for young carers of terminally ill cared-for persons.

Section 14 makes reference to the duty on the responsible authority to take into account any impact that having one or more protected characteristic (within the meaning of section 149(7) of the Equality Act 2010) has on the young carer.

Section 15 details the information that must be contained within a young carer statement.

Section 16 allows Scottish Ministers to make provision about the review of young carer statements through regulations.

Section 17 details under which circumstances and with whom the responsible authority must provide the information contained in the young carer statement with.

Section 18 makes provision for the continuation of a young carer statement.

Section 19 details the meaning of 'responsible authority' in relation to young carers. The responsible authority is based on where the young carer resides or attends school and can be different from the 'responsible local authority' for supporting the young carer (the local authority where the cared-for person resides).

Section 20 details where there may be 'special cases' in relation to the responsible authority and young carers.

The duties at Chapter 2 apply to responsible authorities. Depending on the area, these functions may either sit with children's services or be delegated to the integration joint boards under the Public Bodies (Joint Working) (Scotland) Act 2014. It would be expected that in cases where the functions are not delegated to integration schemes, there would be a level of joint working.

For the purpose of this chapter the terminology 'relevant authority' will be used in place of children's services, local authorities or integration joint boards.

Purpose of young carer statements

2.2.1. The young carer statement (YCS) provides a framework for identification of the personal outcomes and individual needs for support of young carers by the responsible authority and the substantive provision of support by the responsible local authority to meet those identified needs.

2.2.2. The YCS is intended to ensure that young carers are seen as children and young people first and foremost and are protected from undertaking caring responsibilities and tasks which are inappropriate having regard to their age and maturity.

2.2.3. The policy intention is that the YCS will help and empower young carers, provide them with confidence and assist the child or young person recognise their own needs and identify personal outcomes which are important to them. Responsible authorities must offer a young carer statement to an identified young carer and to prepare one if that offer is accepted.

2.2.4. The YCS provides young carers who request or who are offered and accept a young carer statement, a record of their identified needs and personal outcomes. This document becomes a record which they will receive a copy of and can choose to share this information with any other person that the young carer requests to do so.

2.2.5. In order to promote effective planning for transitions, the YCS ensures that even when a young carer has attained the age of 18 years, any young carer statement prepared in relation to that carer continues to have effect until the carer is provided with an adult carer support plan.

Duty to offer and prepare young carer statements

2.2.6. Section 12(2) requires a responsible authority to offer a YCS in respect of an identified young carer. This duty applies to all young carers the responsible authority has identified, regardless of the intensity of the caring role or whether the young carer's identified needs are expected to meet the local eligibility criteria.

2.2.7. Section 12(3) requires a responsible authority to prepare a YCS if the young carer accepts the offer made under section 12(2), or if anyone who appears to be a young carer requests one under section 12(4). Section 12(1)(a) to (c) requires a YCS to set out:

- a young carer's identified personal outcomes;
- a young carer's identified needs (if any); and
- the support (if any) to be provided by the responsible local authority to a young carer to meet those needs.

2.2.8. Each of these elements is considered in more detail below.

2.2.9. The YCS is therefore the mechanism through which needs for support are assessed and monitored and support is managed.

2.2.10. The duty under section 12 to offer and prepare a YCS still applies even if the young carer's identified needs are not or do not seem likely to be deemed eligible for the provision of support (a decision for the responsible local authority according

to local eligibility criteria). In this context, it is also recommended that, as part of the YCS, the responsible authority helps the young carer consider preventative support through the information and advice service which must be provided under the Act (see Part 6 of this guidance) and signposting to any community based support that may be available universally or from a local carer centre.

Responsible authority

2.2.11. The 'responsible authority' for young carer statements can be different from the 'responsible local authority' for supporting the young carer. (The responsible local authority for young carer support is the local authority where the cared-for person resides. For adult carers, the function of preparing an adult carer support plan and providing support both lie with the 'responsible local authority' in which the cared-for person resides).

2.2.12. Section 19 sets out the meaning of a responsible authority for preparing a young carer statement. The responsible authority differs according to the circumstances of the young carer:

- where the young carer is a pre-school child, it is the health board for the area in which the child resides; or
- where the young carer is not a pre-school child, it is the local authority for the area in which the child resides is the responsible authority.

2.2.13. Section 20 outlines special circumstances which need to be followed when determining the responsible authority for a young carer:

- where the young carer is a pupil at a grant-aided school or independent school, the directing authority of the school is the responsible authority. The term 'directing authority' has the same meaning as in section 45 of the Children and Young People (Scotland) Act 2014, that is the managers of a grant-aided school or the proprietor of an independent school; and
- where the young carer is a pre-school child who resides in a different health board area than they would otherwise reside because of a decision of a health board or local authority, the responsible authority is the health board where he or she would otherwise reside.

2.2.14. A responsible local authority may make arrangements for another person to prepare a YCS on its behalf.

2.2.15. The duty to prepare a YCS could come under the delegated responsibilities of integration authorities. Some integration authorities will have responsibility for children's services and others won't. However, under integration duties placed on local authorities, responsibility for young carer support could be a delegated function of the integration authority, unless it is being retained by the local authority as part of children's (social care) services or retained by the health board in terms of children's health services. Part 7 of this guidance provides more information about delegation of functions under the Act.

2.2.16. Section 12(2) requires the responsible authority to offer a YCS to any child or young person they identify as a young carer.

Example – carer identification through awareness raising

Edinburgh Young Carers Project deliver a 'schools awareness raising campaign' in Edinburgh.

This involves carer support workers from the young carer centre speaking at school assemblies, classroom sessions and at continuing professional development sessions to teaching staff on young carer issues.

2.2.17. Section 12(3) requires the responsible authority to prepare a YCS for:

- anyone who accepts an offer under section 12(2); and
- anyone who requests a YCS and appears to the responsible authority to be a young carer.

2.2.18. This duty applies whether or not the young carer also requires a child's plan in accordance with section 33 of the Children and Young People (Scotland) Act 2014 (see section 12(5) of the Act).

2.2.19. Section 12(6) deals with cases where the responsible authority (i.e. the authority responsible for preparing a YCS under section 19 and 20) is different from the responsible local authority (defined in section 12(8) as the authority where the cared-for person resides). In such cases the responsible authority must not provide the YCS to the young carer without the approval of the responsible local authority. In practice, this would involve liaison and agreement between the responsible authority and the responsible local authority on the content of the YCS and on provision of support (if any) to the young carer.

2.2.20. Section 12(7) requires that in preparing the YCS, the responsible authority must exercise its functions under this section in a manner which encourages equal opportunities and in particular the observance of the equal opportunity requirements (within the meaning of section L2 of Part 2 of schedule 5 of the Scotland Act 1998)³⁶.

Approach to YCS

2.2.21. A YCS must combine the identification of a young carer's personal outcomes, and an assessment of their needs for support to help them achieve those identified personal outcomes along with the preparation of a support plan to monitor the needs and the support managed. See Section 5 of the Act and Part 2, Chapter 1 of this guidance for the definition of identified personal outcomes and identified needs.

Outcomes-focused approach

2.2.22. Some responsible authorities may wish to approach the preparation of the YCS in a single event following a face-to-face visit and outcomes-focused conversation with the young carer. Other areas may prefer an approach which requires more than one visit and, particularly for more complex cases, facilitates more time to have an outcomes-focused conversation with the young carer in order to complete the support planning and then finalise the YCS.

³⁶ See MECOPP's publication, 'Carers (Scotland) Act 2016 and Equalities' for further information on issues to consider for particular groups of carers with protected characteristics. <u>https://www.mecopp.org.uk/mecopp-publications/2018/12/14/briefing-sheet-10-carers-scotland-act-2016-and-equalities</u>

2.2.23. At a local level, clear procedures for how a YCS will be undertaken and by whom as well as timescales/prioritisation require to be established and understood by the relevant staff groups. Young carers will need to know what to expect when they request, or accept the offer of a YCS and it is recommended that this information is made freely available.

2.2.24. It is recommended that responsible authorities be mindful that where a young person is preparing for school exams or otherwise focusing on their education, that the preparation and review of the YCS does not interfere with the young carer's studies.

2.2.25. When undertaking the outcomes-focused conversation with the young carer to prepare the YCS the responsible authority is encouraged to be respectful of the young person's wishes, opinions and boundaries. It is suggested that when undertaking the conversation with a young carer, responsible authorities make use of coproduction and child-centred approaches, active listening, use of empathy and any other relevant skills.

2.2.26. The approach to an outcomes focused conversation with a young carer would benefit from a solid understanding of children's rights and for practitioners to promote and respect those rights. The United Nations Convention on the Rights of the Child (UNCRC) is an international law which sets out the rights of children and young people. The UNCRC underpins Getting it right for every child, Scotland's approach to improving outcomes for children and young people. There is useful guidance on the UNCRC and the foundation of Getting it right for every child³⁷.

2.2.27. Responsible authorities would benefit from taking into account the UNCRC when preparing a YCS. All of the rights are of equal importance and all are underpinned by four general principles:

- all the rights must be available to all children without discrimination (Article 2);
- the best interests of the child must be a primary consideration in all actions concerning children (Article 3);
- that every child has the right to life, survival and development (Article 6); and
- that the child's view must be considered and taken into account in all matters affecting them (Article 12).

Who can prepare the young carer statement?

2.2.28. We would expect responsible authorities to give consideration to who is best placed to prepare the YCS, e.g. the local authority, a health professional or someone else who is suitably qualified to do so. This may be someone who has an existing relationship with the young carer and their family.

2.2.29. This function could be undertaken by a third sector organisation such as a young carer support provider or a carer centre, as their staff may have the necessary skills and experience to undertake YCSs. Responsible authorities are encouraged to work collaboratively with the third sector in developing their models for preparing YCSs.

2.2.30. It is for the responsible authority to decide how it carries out the function and whether or not it wishes to commission third sector partners to undertake the

³⁷ <u>https://www.gov.scot/policies/girfec/</u>

function of preparing individual YCSs. There will remain a role for the responsible authority to oversee the delivery and quality of these assessments in practice. Some authorities in Scotland already delegate the assessment function of young carers to the third sector and have contracts in place.

Learning from YCS pilots

During the pilots for implementing this aspect of the Act, it was found that there was potential for further integration of third sector provision when undertaking the YCS. It was found that a strong partnership approach between third sector and statutory services worked best to support young carers. The pilots also found that young carers felt that they ought to be able to choose who helps them prepare a YCS, including teachers, sports coaches or others.

Example – Third sector role in assessment

Quarriers, a third sector organisation are contracted by Moray Council to provide support to young people (aged 18 years and under) who provide care to family members.

They are also contracted by Moray Alcohol and Drug Partnership to specifically identify and support young people caring for family members who misuse alcohol or drugs.

Services offered include undertaking carers assessments; supporting young carers to participate in existing recreational facilities in their community and offering age appropriate information, training and advice.

Potential conflict of interest

2.2.31. There could be a potential conflict of interest where the body carrying out the YCS assessment is also a provider of young carer support. This could happen if the responsible authority commissions the YCS function to an external third sector provider, for example a young carers centre, which also provides support. The conflict could arise because any identified needs of the young carer which meet the local eligibility criteria threshold will trigger the duty to support the young carer and as such could have funding implications for both the responsible authority and the young carer support provider.

2.2.32. This need not prevent delegation of assessment functions to third sector providers. Potential conflicts of interest can be reduced through being careful about offering choice and control to the young carer to meet their eligible needs and personal outcomes. This could be achieved through offering the young carer a range of support options as required under the Social Care (Self-directed Support) (Scotland) Act 2013. Some of those support options may not necessarily be provided by the young carers centre who undertook the YCS.

2.2.33. To mitigate the risks from any potential conflicts of interest, the responsible authority may wish to consider monitoring processes and checks in its contract with a third sector provider, so that it can audit case files against YCSs prepared and see how decisions were reached and budgets allocated.

Links to other plans and strategies for children and young people

Local carer strategy

2.2.34. In preparing a local carer strategy, section 32 of the Act requires the local authority and the relevant health board to have regard to any plans for the provision of services relevant to young carers which are set out in the children's services plan prepared for the area of the local authority under section 8 of the 2014 Act. See Part 5 of this guidance for further information on local carer strategies.

Child's plan

2.2.35. While Part 5 of the Children and Young People (Scotland) Act 2014 has not yet been commenced, a number of authorities may provide an integrated planning framework for children and young people on a policy basis (the child's plan). Where a child's plan is in place for a young carer, it would be good practice to consider and agree with the child and other relevant persons how the YCS sits alongside the child's plan and forms part of it. Where possible it would be of merit to reduce the number of separate meetings for different plans and to coordinate these plans into one meeting. This would help to ensure a coherent approach to planning.

Considerations for children's services and/or education colleagues

2.2.36. The responsible authority will be aware of when a young carer in an educational setting has a co-ordinated support plan (CSP).

2.2.37. Education authorities and other agencies have duties under the Education (Additional Support for Learning) (Scotland) Act 2004 (as amended) ('the 2004 Act') to identify, provide for and review the additional support needs of their pupils. An additional support need can arise for any reason and be of short or long term duration. Additional support may be required to overcome needs arising from learning environment; health or disability; family circumstances or social and emotional factors.

2.2.38. Education authorities can ask other agencies (including social work services, health boards and Skills Development Scotland) for help in carrying out their duties under the 2004 Act. Other agencies must respond to the request within a specific timescale (but there are exceptions to these timescales).

2.2.39. Children and young people's needs are met through planning for their learning and support, usually through an individualised educational programme (this may have another name such as an Additional Support Plan) which sets out targets for learning and the support to be provided (usually termly). For children and young people who have complex or multiple needs which require significant support from education and another agency or agencies a co-ordinated support plan may be required. The purpose of the CSP is to support co-ordinated planning to meet pupils' needs. The plan lasts for up to a year.

2.2.40. A young carer can be eligible for a CSP if the education authority agrees that they have additional support needs which meet the criteria for a co-ordinated support plan. To meet the criteria for a co-ordinated support plan, the support required must be significant and from more than one agency in addition to the education authority and for more than a year. This might include family

circumstances relevant to caring acting as a barrier to the learning outcomes of a young carer

2.2.41. There are a range of dispute resolution mechanisms available; including independent mediation and adjudication, and referral to the Additional Support Needs Tribunals for Scotland. The Tribunals hear references involving children and young people who either have, or are potentially entitled to have, a CSP, certain placing requests and transitional arrangements.

Barriers to learning

2.2.42. The statutory code of practice³⁸ which provides guidance on the 2004 Act makes clear that young carers may experience barriers to their learning and additional support needs should be identified, provided for and reviewed in line with the requirements of the 2004 Act.

2.2.43. Further, the guidance on Attendance in Scottish Schools, 'Included, Engaged and Involved: Part 1^{'39} makes clear that education authorities should recognise the impact that caring responsibilities may have on school attendance. The guidance makes clear the need to follow up on changes in patterns of attendance or increased absence to ensure that appropriate support is provided if necessary.

Signposting, information and advice if young carer refuses offer of YCS

2.2.44. Not all young carers will accept the responsible authority's offer of a YCS. It is a choice for the young carer to decide to accept this offer of a YCS. Where a young carer declines the offer of a YCS, the responsible authority could consider signposting the young carer, if they agree and with consent to a young carer centre or similar support provider. Also some young carers may of their own accord approach a young carer centre or support provider for information, advice and support.

Low and fluctuating needs

2.2.45. It is recommended that responsible authorities consider the potential fluctuation of the young carer and/or the cared-for person's needs. For example where the responsible authority is aware that the cared-for person's needs fluctuate over time due to a mental health condition, the YCS carried out at a particular moment may take into account the cared-for person's history to establish a complete picture of the cared-for person's needs and the impact these fluctuating needs have on the caring situation.

2.2.46. Low level needs and the support to meet those identified needs will be considered as part of the YCS process. This process will be based on the identification of personal outcomes, needs and risks. It is recommended that consideration be given to whether a young carer's identified needs can be met by the local information and advice service or general services in the community.

³⁸ <u>http://www.gov.scot/Publications/2011/04/04090720/0</u>

³⁹ <u>http://www.gov.scot/Publications/2007/12/05100056/0</u>

Tensions between young carer and cared-for person

2.2.47. There can be circumstances where there are tensions between the young carers and the cared-for person. The caring role can be stressful and the cared-for person may not be coping well with their condition. This can put a tremendous strain on the relationship between the young carer and the cared-for person. The responsible authority will need to take this into account when preparing a YCS. Where the caring situation becomes unmanageable or has a detrimental impact on the young carer's wellbeing or that of the cared-for person, it is recommended that the professionals working with the young carer seek advice from the appropriate professionals within the responsible authority.

2.2.48. This could include, if necessary, raising a child protection⁴⁰ concern or an adult protection⁴¹ concern in line with either their local multi-agency child protection guidelines (in accordance with the Children (Scotland) Act 1995 and other relevant legislation) or their local multi-agency adult protection guidelines (in accordance with the Adult Support and Protection (Scotland) Act 2007).

Content of young carer statement

2.2.49. Section 15 outlines what information must be contained in a YCS. However, for the contents of a YCS for a young carer caring for someone with a terminal illness, known as a 'light touch' plan please refer to para 2.2.135.

Young carer's personal circumstances

2.2.50. Section 15(1)(a) requires the YCS to include information about the young carer's personal circumstances at the time when the YCS is being undertaken. This must include information about the nature and extent of care provided or to be provided and information about the impact of caring on the young carer's wellbeing and day-to-day life.

2.2.51. When considering the impact of caring on the young carer's wellbeing and day to day life, section 15(3) requires the responsible authority to assess the wellbeing of a young carer by reference to the extent to which the matters listed in section 96(2) of the Children and Young People (Scotland) Act 2014 are or, as the case may be, would be satisfied in relation to the young carer. In doing so, the responsible authority is to have regard to the guidance issued under section 96(3) of the 2014 Act. This ensures that the eight wellbeing indicators (also known as the SHANARRI indicators) of the national Getting it right for every child approach⁴² must be used when considering the child's personal circumstances.

Able and willing to care

2.2.52. Section 15(1)(b) requires the YCS to contain information about the extent to which the young carer is able and willing to provide care for the cared-for person. When considering whether the young carer is able and willing to provide care, it is recommended to take account of the age and maturity of the young carer along with the nature of the caring role and any associated risks.

⁴⁰ <u>http://www.gov.scot/Publications/2014/05/3052/0</u>

⁴¹ www.gov.scot/policies/social-care/adult-support-and-protection/

⁴² <u>https://www.gov.scot/policies/girfec/</u>

Appropriateness of caring role

2.2.53. Section 15(1)(c) requires information about the extent to which the responsible authority considers that the nature and extent of the care provided by the young carer is appropriate.

2.2.54. It is necessary to ensure that young carers are seen as children and young people first and foremost and that they are protected from undertaking caring responsibilities and tasks which are inappropriate having regard to their age and maturity.

2.2.55. For example, the responsible authority might consider that any personal, intimate care provided by a young carer is not appropriate. They might consider that the young carer is engaged in caring during too many hours per week and have concerns on the impact that this has on their wellbeing. They might consider that the young carer, particularly a very young child, is too young to be carrying out any caring role. In this context, the responsible authority, must consider whether the caring situation of the young carer is appropriate and take any required steps as necessary.

2.2.56. There is a relatively small number of very young carers, where there is a very young child (whether pre-school or in the early years of primary school) caring for a family member, There may be some scope for a young child to make a small contribution to the care of their parents, but this has to be set at the very lowest level, taking account of the child's age and maturity amongst other factors. It is strongly recommended that support provided ought to be directed towards removing them from their caring role through enhanced support for the person that they care for.

Link to assessment of cared-for person's needs and outcomes

2.2.57. The willingness and ability of the young carer to continue to provide care to a cared-for person may be closely linked to the support provided to the cared-for person following other assessments. It is therefore recommended that the responsible local authority takes into account the outcomes of any prior assessment of a cared-for person's needs and outcomes. This may help to establish whether the young carer is able and willing to continue to provide care to the cared-for person. Amendments under section 30 of the Act also require the YCS and the views of the young carer to be taken into account when carrying out assessments under other legislation, as considered below.

2.2.58. Section 30 of the Act amends section 12A of the Social Work (Scotland) Act 1968, which sets out the duty of local authorities to assess needs in relation to social care for adults. The effect of the amendments is to require the local authority to take account of the care provided by the young carer as set out in the YCS when making decisions about the provision of support to meet the cared-for person's needs and outcomes. The local authority is also required to take account of the views of the young carer in so far as it is reasonable and practicable to do so.

2.2.59. Section 30 of the Act makes similar amendments to section 23 of the Children (Scotland) Act 1995, which sets out the duty of the local authority to assess the needs of children affected by disability. The effect of the amendments is to

require the local authority to take account of the care provided by the young carer as set out in the YCS when making decisions about the provision of support to meet the needs and outcomes of the cared-for child. The local authority is also required to take account of the views of the young carer in so far as it is reasonable and practicable to do so.

2.2.60. The responsible authority may consider preparing a YCS at the same time it undertakes an assessment of the cared-for person's needs and outcomes (although not necessarily as a joint exercise where this could lead to a tension).

Emergency plans for the cared-for person

2.2.61. Section 15(1)(d) requires information about whether the young carer has arrangements in place for the care of the cared-for person in an emergency.

2.2.62. Emergency planning (sometimes called contingency planning) includes planning for events such as the young carer not being able to care due to the carer's illness and unable to support the cared-for person taking their daily medication. There may also be adverse weather or transport problems which prevent the young carer from accompanying the person they are caring for to a doctor's appointment or an outpatient clinic. (See guidance in Chapter 2 of Part 4 on carer involvement in hospital discharge).

2.2.63. It is recommended that any discussions on emergency planning with the young carer also be thoroughly discussed with the cared-for person who often will be the parent or guardian of the young carer, to ensure that any agreed emergency plan is appropriate and takes into account the age and maturity of the young carer.

2.2.64. Under section 34(2) local authorities must establish and maintain an information and advice service for relevant carers including emergency care planning and future care planning for carers.

2.2.65. Some areas already offer young carers emergency plans or discuss emergency planning with them whilst other areas offer young carers an emergency card. An emergency card lets the emergency services or social care services know that a person is a carer. Encouraging young carers to carry the card at all times can help services to put other support in place in a crisis.

Example – Young carers card – use in emergency

Perth and Kinross Association of Voluntary Service (PKAVS) in partnership with NHS Tayside and Perth and Kinross Council offer a young carers card.

It has four sections on the reverse of the card showing medication, diagnosis, prognosis and discharge/care planning. As part of the application process, it is agreed with young carers and their parents what sections the young carer card will have information on.

The card also acts as an alert, for example, if the young carer has an accident their young carer card will allow others to know that there is a cared-for person at home and will need to be updated of this situation and possibly require additional care.

2.2.66. ENABLE Scotland has a suite of resources about emergency planning which applies in all caring situations, including caring for adults with health needs or

disabilities⁴³. Responsible authorities are encouraged to make use of these resources or direct young carers depending on their age and circumstances to the ENABLE emergency planning resources.

Future care plans for the cared-for person

2.2.67. Section 15(1)(e) requires the YCS to contain information about whether the young carer has arrangements in place for the future care of the person that they care for. There may be less stress and anxiety on the young carer if appropriate plans are in place for the future care of the cared-for person.

2.2.68. Future care planning could also be identified in relation to a personal outcome or an identified need later in the YCS process. In that case the authority responsible for supporting the young carer is well placed to consider what support can/is to be provided to meet that need. The information and advice services required under Part 6 of the Act must provide information and advice about emergency care planning and future care planning for carers.

2.2.69. When any future care plans are developed, it is recommended that they are part of plans applicable to the cared-for person and not the sole responsibility of the young carer. The young carer may have a role in the implementation of any future care arrangements but wouldn't normally be expected to have a lead role unless it is deemed appropriate to do so and in agreement with the cared-for person.

2.2.70. Where the young carer appears to have a significant need for support with future care planning, this would be considered as part of the YCS and the identification of needs; and if this identified need meets local eligibility criteria, the responsible authority will be under the duty to provide support.

2.2.71. Information and advice services for young carers can signpost to or be designed in partnership between a carer centre and specialist, professional, independent services to offer future care planning services such as including making wills, trusts and longer term financial planning if appropriate to a young carer's situation. Responsible authorities may also consider the provision of carer advocacy services and make reference to the Scottish Government's guidance on carer advocacy in Scotland⁴⁴.

2.2.72. This would be in line with the requirements under section 34(2) around the provision of an information and advice service for relevant carers, particularly on income maximisation for carers, advocacy for carers and emergency care planning and future care planning. Part 6 of this guidance deals with information and advice for carers.

Link to anticipatory care plans

2.2.73. If relevant to the situation of the young carer, information contained in the YCS may aid the preparation of parts of an anticipatory care plan of the cared-for person, if the young carer agrees to share that information. An anticipatory care plan is a dynamic record that can be developed over time through an evolving conversation, collaborative interactions and shared decision making. It is a summary

⁴³ <u>http://www.enable.org.uk/families/Pages/Emergency-Planning.aspx</u>

⁴⁴ http://www.gov.scot/Publications/2016/03/5362

of the discussions between the cared-for person, the young carer (if appropriate) and the practitioner. Chapter 2 of this Part contains more information on anticipatory care planning.

Personal outcomes

2.2.74. It is recognised that caring for another person is likely to impact on a young carer physically, emotionally and on the way in which that carer lives his/her day to day life. The policy intention of the Act is to ensure that young carers are seen as children and young people first and foremost and that they are protected from undertaking caring responsibilities and tasks which are inappropriate having regard to their age and maturity. Consequently, the YCS seeks to support carers by putting measures in place that will help a young carer to live their own life and to achieve their own goals and aspirations. These day to day goals and longer term aspirations are to be documented within the YCS as the carer's 'personal outcomes'.

2.2.75. Section 15(1)(f) requires the YCS to contain information about the identification of the young carer's personal outcomes and what these outcomes are. 'Personal outcomes' is defined at section 4 of the Act to include outcomes which, if achieved, would enable young carers to provide or continue to provide care for the cared-for person(s).

2.2.76. The Carers (Scotland) Act 2016 (Adult Carers and Young Carers: Identification of Outcomes and Needs for Support) Regulations 2018 require personal outcomes and needs for support to be identified following a conversation with the young carer. Such conversations can take a variety of forms, for example in the case of carers with communication difficulties. The regulations also state that, like the preparation of YCSs, identification of personal outcomes and need for support is a function of the responsible authority. This does not preclude the responsible authority arranging for another body, such as a young carer support organisation, to do the work on its behalf. The regulations also require a young carer's personal outcomes and needs for support to be reviewed when his or her YCS is reviewed.

2.2.77. The young carer's identified personal outcomes should link and support the achievement of the child's potential in relation to the eight wellbeing indicators of the national Getting it right for every child approach. The wellbeing indicators are: safe, healthy, achieving, nurtured, active, respected, responsible, and included.

2.2.78. In terms of approach to identification of the young carer's personal outcomes, the responsible authority may wish to consider how coordinated services or support can impact on the young carer's wellbeing. The personal outcomes will be specific to the young carer and their circumstances and may have a short or longer term focus as required.

Evidence – Personal outcomes

The review paper *Review of evidence on personal outcomes relevant to the Carers (Scotland) Act 2016*, Emma Miller (2017), University of Strathclyde⁴⁵ is a valuable source of information on domestic and international practice in the literature to evaluate personal outcomes; their use, efficacy and integration with existing processes and procedures.

Consideration of equalities when identifying personal outcomes

2.2.79. Section 14(2) requires that in identifying a young carer's personal outcomes and needs for support, the responsible authority must take into account any impact that having one or more protected characteristic (within the meaning of section 149(7) of the Equality Act 2010) has on the young carer⁴⁶.

Equalities Example – Race and sexual orientation

During the preparation of a young carer statement, a South Asian teenager discloses to the responsible authority that he is gay and in his culture this can be very difficult for others to accept, including within his own family. He doesn't want his friends or peers at high school to know that he is gay or a young carer, in case he gets bullied.

Therefore, the responsible authority has established through the identification of a young carer's personal outcomes and needs for support, that there is an impact from two protected characteristics, race and sexual orientation on the young carer. This impact must be taken into account when preparing the YCS including the young carer's personal outcomes and eligible needs for support.

Identified needs

2.2.80. Section 15(1)(g) requires the YCS to contain information about the identification of the young carer's identified needs for support and what those needs are if any. 'Identified needs' are defined in section 5 of the Act as the needs for support which are identified in order to meet the young carer's identified personal outcomes. These support needs could include a broad range including the young carer's physical needs, emotional needs, relationship needs, health needs, economic needs and physical environment needs. Identified needs must be recorded in the YCS. If a young carer has no identified needs that must also be recorded. (See also advice above about the requirements of the Carers (Scotland) Act 2016 (Adult Carers and Young Carers: Identification of Outcomes and Needs for Support) Regulations 2018).

2.2.81. All of the matters in section 15(1)(a) to (m) must be considered when preparing a YCS and have an appropriate level of information recorded. A proportionate approach may be considered by the responsible authority when doing

⁴⁵ <u>http://www.gov.scot/Topics/Health/Support-Social-Care/Unpaid-</u>

Carers/Implementation/UsefulResources

⁴⁶ See MECOPP's publication, 'Carers (Scotland) Act 2016 and Equalities' for further information on issues to consider for particular groups of carers with protected characteristics. https://www.mecopp.org.uk/mecopp-publications/2018/12/14/briefing-sheet-10-carers-scotland-act-

²⁰¹⁶⁻and-equalities

this, taking into account what issues are raised through the conversation with the young carer and which issues need to be raised with the cared-for person.

Example

Lucy is 10 years old and lives with her mum, dad and brother. Her brother has cerebral palsy. Lucy had an assembly at school where the local young carers' service spoke about the groups and support they provide, and has since asked her teacher for a young carer statement.

Lucy's parents provide most of the practical care for her brother, but she helps with housework and spends time playing with her brother and making sure he is happy. Her teacher refers her to the young carers' service, who speak to Lucy and her parents and prepare a young carer statement on behalf of the local authority. Lucy attends the young carers group sometimes and is happy with this support.

In Lucy's case, her YCS is focused on making sure she and her parents understand what further support options are available and who to contact if she has any concerns.

Whole family approach

2.2.82. The responsible authority could build a more holistic view of the needs of the young carer and the person they care for by considering what other support may be available through exploring their networks and the wider community, allowing for a whole family approach.

2.2.83. In considering the impact of the cared-for person's needs on those around them, the responsible authority may wish to consider whether additional information and advice would be beneficial to those people identified. Alongside the main young carer there may be others undertaking a caring role in the family. For example where a young carer has siblings, they also may be young carers, which would lead to the offer of a YCS.

Example – Raising awareness of young carers

Action for Children's Young Carers Project in North Lanarkshire which is supported by the Health and Social Care Partnership raises awareness of young carer issues in various locations and professional teams including hospitals, health centres, schools and mental health teams. The carers project is actively promoted in these locations and during carers week, awareness training sessions to GP's and practice staff groups were delivered.

Example – Supporting young carers in school

Stirling Young Carers Service has worked with all secondary schools in their area so that there is a timetabled dedicated young carers class as part of the curriculum. Young carers are referred to the class through pupil support.

The young carers decide what the topics for study will be, and these are often have a home economics focus. The young carers worker from the service drops in on the classes regularly to provide a link between school and the young carers service, but many of the young carers do not attend the young carers groups offered by the service, feeling that they have adequate support at school.

Information provision

2.2.84. Section 15(1)(h) requires information about the support available to young carers and cared-for persons in the responsible local authority's area to be contained in the YCS. It is recommended that this information be tailored to the specific identified personal outcomes and needs of the young carer having regard to the needs of the person that they care for.

Young carers living in different areas from the cared-for person

2.2.85. Section 15(1)(i) requires that if a young carer does not reside in the responsible local authority's area (where the cared-for person resides), information must be provided about the support available to young carers in the area where they reside. (In these cases, the responsible local authority for supporting the young carer will be different from the responsible authority for preparing the YCS).

2.2.86. This information may for example, take the format of a leaflet or a carer information pack. It may also include contact details of the information and advice service of the other local authority area or carer centre and instructions on relevant online information.

2.2.87. The responsible local authority, where the cared-for person resides, has the power and duty to support the young carer. As a matter of best practice, a responsible local authority which has identified a young carer who cares for someone in their area but resides in a different local authority area, is recommended to liaise with the responsible authority (where the young carer resides) to ensure that the young carer has access to a YCS.

YCS for young carer caring for people in more than one local authority area

2.2.88. As the responsible authority is determined by the young carer's circumstances, rare situations such as this would not complicate the decision as to who is responsible for the YCS.

Case study – Young carer to two cared-for people in different areas

A young carer whose parents have separated. Suzie's father has bipolar disorder and her mother has Parkinson's disease. Suzie is aged fifteen and lives with her mother the majority of the time and provides a caring role and also provides a caring role for her father who lives in another local authority area.

The responsible authority where Suzie resides with her mother would be responsible for the preparing the YCS. This is because the responsible authority for a YCS is determined by the young carers' circumstances (rather than those of the cared-for person). In this context, there will only be one responsible authority offering and preparing the YCS.

2.2.89. In these circumstances, the duty (or power if appropriate) to provide support to the young carer, would rest with both local authorities where the cared-for persons are residing.

2.2.90. Similar to adult carers (see Chapter 1 of this Part), each local authority's eligibility criteria would be relevant in its own decision making about support,

however we recommend collaboration between each area in that decision making process.

2.2.91. Decisions about sharing the costs of carer support in these circumstances are a matter for the local authorities involved, however it is recommended that a 50:50 split for carer support is a sensible default position. Any additional support required for the cared-for persons would be a matter for their respective local authorities.

2.2.92. If there is one YCS to cover both caring situations, careful consideration would be required by the responsible authority to ensure that information sharing is well managed.

Young carer who resides in Scotland caring for someone outwith Scotland

2.2.93. There may be a limited amount of these situations for responsible authorities. However, when they do arise there would be a responsibility to offer and prepare a YCS by the responsible authority, if that offer is accepted by the young carer.

2.2.94. Scottish local authorities may still have responsibilities to support young carers by virtue of their wider duties or powers to support them as children under the Children and Young People (Scotland) Act 2014⁴⁷.

2.2.95. A carer living in Scotland who cares for someone outwith Scotland may be eligible for support from the local authority in which the cared-for person resides. In these instances, it would be a matter for the relevant local authority in England or Wales, or the Health and Social Care (HSC) Trust in Northern Ireland to make decisions as set out under legislation in those countries.

2.2.96. Part 3, Chapter 2 of this guidance provides further information about crossborder caring situations.

Case study – 'distance caring' relationship with young carer in Scotland and cared-for person outwith Scotland

Ross is aged seventeen and a young carer, caring for his father who has chronic back pain and lives in England. Ross resides in the Borders with his mother after his parents separated. He visits his father weekly to help provide more practical assistance such as help with a supermarket shop. He also provides his dad with emotional support, liaising with statutory services and arranges other help such as gardening support.

If Ross identifies himself to his responsible authority, Scottish Borders Council, they would then be in a position to offer and undertake a YCS. However, in terms of duty to support that would not sit with the local authority where Ross lives, but they may use their powers to provide some support to him.

Young carer resides outwith Scotland caring for someone in Scotland

2.2.97. There may be a limited number of situations where a young carer who resides outwith Scotland is providing care to someone who resides in Scotland.

⁴⁷ http://www.legislation.gov.uk/asp/2014/8/contents

2.2.98. For young carers that may be in this situation, the Act has not created a duty for the Scottish local authorities of the cared-for person to offer a young carer statement. This is because the 'responsible authority' for a young carer statement, under sections 19 and 20, is determined by the young carer's own circumstances, rather than those of the cared-for person.

2.2.99. As a consequence, because the duty to support young carers under the Act is dependent on the existence of a YCS, there is no duty or power for Scottish local authorities of the cared-for person to support the young carer.

2.2.100. It is recommended that, subject to the normal requirements on consent to sharing of information, the Scottish local authority of the cared-for person makes sure that the local authority where the young carer lives is aware of their circumstances.

2.2.101. Part 3, Chapter 2 of this guidance provides further information about crossborder caring situations.

Case study – 'distance caring' relationship with cared-for person in Scotland and young carer outwith Scotland

Jamal aged fifteen, who lives in Berwick upon Tweed and provides care to his uncle, Saeed who lives in the Scottish Borders. Jamal's uncle has multiple sclerosis and appreciates his regular visits from his nephew who helps him with emotional support and practical tasks in and around his home. Although Jamal is a young carer, he won't have had a YCS undertaken as he resides outwith Scotland.

However, with permission, Scottish Borders local authority, where his uncle lives, has got in touch with Northumberland County Council, to let them know of Jamal's circumstances.

Support to be provided

2.2.102. Section 15(1)(j) requires that if the young carer's identified needs meets the local eligibility criteria, the YCS must contain information about the support which the responsible local authority provides or intends to provide to the young carer to meet these eligible needs. In this section, the responsible local authority, in relation to a carer, means the local authority for the area in which the cared-for person resides.

Example – support provided through young carers card

Dumfries and Galloway Carer Centre offer a young carers card to young carers. This helps the young carer to be involved in information sharing, if consent is given about the treatment and condition of the cared-for person, be better involved with medical procedures and kept up to date by professionals.

Locally if the family of the young carer agrees for the Fire and Rescue Service to be informed that a young carer resides in the household then this information is added to the their system. Then in the event of a fire occurring in the home, the Fire and Rescue Service will be aware of a young carer in the home.

The card also allows peace of mind when away from the cared-for person. It can also be presented to other professionals who are involved in their lives and allows an opening for a conversation about their caring role with professionals including with pupil support teachers, school nurses and class teachers.

2.2.103. Part 3, Chapter 2 of this guidance deals with the power and duty to provide support to carers under section 24.

2.2.104. At this support planning stage, if any of the young carer's identified needs meets the threshold of the local eligibility criteria, the responsible local authority must offer the four options of Self-directed support⁴⁸ to the young carer based on their indicative budget or relevant amount.

2.2.105. There is no single approach to resource allocation prescribed on the face of the Social Care (Self-directed Support) (Scotland) Act 2013, nor any single method recommended by the Scottish Government.

2.2.106. The authority may wish to adopt an equivalence model where they determine the cost of the service to be arranged and then provide the equivalent amount as a budget for the supported person or carer to control. Alternatively, it may wish to adopt a resource allocation system whereby the authority gathers information about the person's outcomes, allocates points to those outcomes and then allocates a level of funding. In addition, decisions about budgets may be made on a case by case basis. Reference can also be made to the statutory guidance to accompany the Social Care (Self-directed Support) (Scotland) Act 2013⁴⁹.

2.2.107. Alternatively, the responsible local authority may decide to offer one holistic budget if all parties agree, that extends to meet both the eligible needs and personal

⁴⁸ <u>https://www.gov.scot/publications/self-directed-support-framework-standards-including-practice-statements-core-components/pages/1/</u>

⁴⁹ http://www.gov.scot/Resource/0044/00446933.pdf

outcomes of the young carer and the eligible needs and personal outcomes of the cared-for person – where it is satisfied this is in the best interests of both parties.

2.2.108. Section 15(1)(k) outlines that if the young carer's identified needs do not meet the local eligibility criteria, information about any support which the responsible local authority nevertheless agrees to provide must be included in the YCS. Responsible local authorities can choose to provide personalised support to the young carer on a discretionary basis using their powers rather than duties to provide support. This could include making a referral or signposting young carers to universal or community based services, for example a young carer service or a local youth centre.

Preventative approach whether or not needs meet eligibility criteria

2.2.109. Regardless of whether the young carer's identified needs meet the local eligibility criteria, it is recommended that other preventative supports in the community are still considered. This for example may include advice and information, emotional support, befriending or a welfare benefits check to maximise family income. Some of these support services may be offered by the local young carer centre or similar resource for children and young people. Some of these identified needs may be met by changes to practices in the school the young carer attends, such as allowing some flexibility in attendance and not penalising the young carer for being late occasionally if this is in relation to caring

Breaks from caring

2.2.110. Section 15(1)(I) requires the YCS to include information about whether support should take the form of or include a break from caring. Part 3, chapter 2 sets out guidance about breaks from caring under section 25 of the Act.

Review of YCS

2.2.111. Section 15(1)(m) requires the YCS to contain information about the circumstances in which it is to be reviewed. Para 2.2.136 of the guidance below, specifically refers to the review of a YCS for young carers of someone with a terminal illness.

2.2.112. The Carers (Scotland) Act 2016 (Review of Adult Carer Support Plan and Young Carer Statement) Regulations 2018⁵⁰ specify circumstances in which YCSs must be reviewed by the responsible authority. These are:

- a) When the cared-for person becomes a resident in a different local authority area;
- b) When the cared-for person becomes resident in accommodation provided under:
 - i. Part 2 of the Social Work (Scotland) Act 1968; or
 - ii. Section 25 of the Mental Health (Care and Treatment) (Scotland) Act 2003; or
 - iii. Part 2 of the Children (Scotland) Act 1995; and
- c) Any other change in the young carer or cared-for person's circumstances which the responsible authority views as having a material impact on the care provided by the young carer.

⁵⁰ SSI 2018/33 <u>http://www.legislation.gov.uk/ssi/2018/33/contents/made</u>

2.2.113. The Regulations highlight that a review of the YCS may be appropriate where support to the cared-for person has changed. It is for the responsible authority to decide in each individual situation where this change of circumstance warrants a review.

2.2.114. Responsible authorities must also consider what other circumstances will be relevant to trigger a review in individual cases. These might include:

- An agreed period of time, e.g. one year;
- deterioration in the health of the young carer or cared-for person; or
- the cared-for person being discharged from hospital.

2.2.115. Responsible authorities are encouraged to seek the views of the relevant young carer when determining whether any other change in circumstance has had a material impact on the care provided by the young carer. It would be expected that the review process would be proportionate to the situation. A review will keep the information contained in the YCS up to date and relevant and would always look at whether the needs for support and personal outcomes of the young carer have changed. This may result in a change in the young carer's eligible needs.

Effectiveness of support under previous YCS

2.2.116. After an initial YCS has been prepared, section 15(2) requires that after each review, the revised YCS must contain information about the extent to which any support provided under a previous statement has assisted in the achievement of the young carer's personal outcomes.

Inclusion of other information in YCS

2.2.117. The responsible authority can decide what additional content to include in the YCS, over and above the minimum requirements set out in the legislation. This could be information tailored to individual YCSs or general information. An example could be a risk assessment in relation to tasks undertaken by the young carer such as the moving and handling of the person that they care for.

2.2.118. Section 15(4) also allows Scottish Ministers to make regulations about other information which a YCS must or must not contain and the form of young carer statements. This power is not currently being used.

Timescales for offering and preparing a young carer statement

2.2.119. There are no timescales set out in the Act for offering, preparing and completing individual YCSs. The Act requires timescales for preparing a YCS to be set in relation to young carers of terminally-ill cared-for persons, as outlined below.

2.2.120. **Section 31(2)(h)** requires the local carer strategy to set out the intended timescales for preparing YCSs . Part 5 of this guidance deals with local carer strategies. The intention of **section 31(2)(h)** is to give young carers collectively an indication of how long, on average, they are likely to wait for a YCS. It is fully expected that some will take less time and some will take longer than those indicated time periods for valid reasons. This means that local carer strategies will need to include the timescales for offering and preparing a YCS for young carers caring for a person with a terminal illness, in line with the guidance below.

2.2.121. It is expected that all young carers who want one should be able to benefit from a YCS in an efficient and timely manner. There may be different timescales for completion of individual YCSs. YCSs ought to be offered and prepared within reasonable timescales taking into account the urgency of needs for support and any fluctuation in those needs. Responsible authorities may have guidance for timescales based on urgency or risk. There may be valid reasons for a plan taking longer to complete than perhaps anticipated, for example, where the young carer's needs are complex and require more than one contact to prepare and complete the plan and/or where support required is specialised and not readily available. Responsible authorities are encouraged to focus on achieving the right outcomes for the young carer rather than allowing set timescales to become a *de facto* target or input measure.

2.2.122. Responsible authorities are advised to inform the individual young carer of an indicative timescale over which their assessment will be conducted and keep the young carer informed throughout the assessment process. Some responsible authorities also, as a matter of good practice and courtesy, advise individual young carers of any delays and the reasons for the delays.

Timescales for YCSs for carers of terminally ill cared-for persons

2.2.123. Section 13 of the Act requires Scottish Ministers to make regulations to set timescales for preparing YCSs for young carers of people who are terminally ill. A person is terminally ill if they suffer from a progressive disease and death in consequence of that disease can reasonably be expected within six months⁵¹. The timescales are set in the Carers (Scotland) Act 2016 (Adult Carers and Young Carers of Terminally III Persons: Timescales for Adult Carer Support Plans and Young Carer Statements etc.) Regulations 2021⁵² ("The Terminal Illness Regulations"), which come into force on 31 July 2021.

2.2.124. As responsible authorities are already required to offer a YCS to every young carer they know about, many young carers of people who have a progressive illness are likely to already have had a YCS, well before the cared-for person meets the above definition of being terminally ill. Therefore, it is anticipated that these timescales will be required for a small number of young carers and as authorities already prioritise these cases, timescales should act as a backstop rather than a target.

2.2.125. The regulations have been designed to ensure timescales do not compromise the quality and personalisation of support for young carers; or impact on the prioritisation of other cases. They should not prevent YCSs being completed quicker, in line with good practice and should help to minimise bureaucracy for both professionals and young carers.

2.2.126. Alongside the Terminal Illness Regulations, Scottish Ministers have issued Directions⁵³ ("The Directions") to set timescales for offering YCSs to young carers of

 ⁵¹ <u>Carers (Scotland) Act 2016 (legislation.gov.uk)</u>
 ⁵² SSI 2021/133 <u>https://www.legislation.gov.uk/ssi/2021/133/made</u>

⁵³ https://www.gov.scot/publications/carers-scotland-act-2016-terminal-illness-directions-letter-fromminister-for-mental-wellbeing-and-social-care/

people who are terminally ill. These are to support the overall outcome of young carers receiving a YCS and associated support in an efficient and timely manner.

2.2.127. The Directions and Terminal Illness Regulations work together. They recognise the urgency of supporting young carers who are caring for people who are terminally ill. They also recognise that young carers may not always wish or be in a position to engage in the preparation of a YCS within days of being offered one. A diagnosis of terminal illness will have a profound impact on the person diagnosed and on the family and friends who support or intend to support them. People who have recently become aware that the person they support is terminally ill may not have time or be ready to recognise their role or discuss their own needs as young carers.

2.2.128. The Directions require all young carers of people who are terminally ill to be offered a YCS within 2 working days of a person being identified as a relevant young carer and if this is not possible, as soon as practical thereafter, as soon as the authority becomes aware that they are caring for someone with terminal illness. The Terminal Illness Regulations then ensure that, as soon as these young carers feel ready to participate in the YCS preparation process, they benefit from accelerated time limits for receiving a YCS and associated support.

Timescales for offering YCS - The Directions

2.2.129. The Directions were issued to responsible authorities and come into force on 31 July 2021. Once an authority identifies a young carer of someone who is terminally ill, the authority must offer that young carer a YCS within two working days. If the authority cannot do this within two working days, due to unforeseen circumstances, they must make the offer as soon as reasonably practicable.

Timescales for preparing YCS - The Terminal Illness Regulations

2.2.130. Once a young carer requests a YCS or accepts an offer of a YCS, the authority has a duty to prepare one. The Terminal Illness Regulations⁵⁴ set timescales within which the authority must prepare a YCS from the point this duty arises. There are different timescales for steps in the process, to ensure that it is flexible enough to meet the needs of each young carer.

Step 1 - Substantive Conversation

2.2.131. The first step in the process is having a "substantive conversation" with the young carer about urgent outcomes and needs for support. Authorities must have this conversation with the young carer within five working days of the young carer accepting an offer or requesting a YCS⁵⁵. At this conversation, the authority must identify immediate or urgent personal outcomes and needs for support.⁵⁶ (See also guidance on the approach to identifying personal outcomes and needs for support, including the requirement for a conversation, at paras 2.2.21 to 2.2.27.)

2.2.132. There may be situations when the young carer is unable or does not want to have a substantive conversation within this period of five working days. In that case

⁵⁴ SSI 2021/133 https://www.legislation.gov.uk/ssi/2021/133/made

⁵⁵ Regulation 7(a) SSI 2021/133 <u>https://www.legislation.gov.uk/ssi/2021/133/made</u>

⁵⁶ Regulation 6, SSI 2021/133 <u>https://www.legislation.gov.uk/ssi/2021/133/made</u>

the young carer can request a different date⁵⁷ Where this happens the timescales for the next step (completing a light touch YCS) are calculated differently (as below).

Step 2 – Light Touch YCS

2.2.133. The second step in the process is completing a light touch YCS, based on the substantive conversation. If that conversation takes place within the five working days mentioned above, then the authority must complete the YCS within ten working days of the date when the carer originally requested or accepted the offer of a YCS⁵⁸.

2.2.134. If the first substantive conversation takes place later then the authority must prepare the YCS within ten "qualifying working days" from the original request or acceptance of a YCS⁵⁹. The clock is paused so that any working days between the date the young carer asks to delay the substantive conversation and the date that conversation takes place are not counted as qualifying working days. This is consistent with a ten working day timescale but also reflects that the information needed to prepare the YCS is likely to be obtained during the substantive conversation with the young carer, so it will not be possible to complete a YCS until after that conversation has taken place.

2.2.135. The Terminal Illness Regulations also set out what a light touch YCS prepared within these timescales must contain. A light touch YCS should focus on immediate or urgent personal outcomes and needs of the young carer and include information under section 15 (1)(a) to (c), (f), (g), (j) and (k) of the 2016 Act⁶⁰ (See paras 2.2.50 to 2.2.108 above on (a) young carers' personal circumstances, (b) able and willing to provide care, (c) appropriateness of caring role, (f) personal outcomes, (g) identified needs, (j) support to be provided, and (k) preventative approach whether or not needs meet eligibility criteria.)

Step 3 – Review date for completion of a full YCS

2.2.136. The light touch YCS is intended to address urgent issues and does not have to cover all the information required under section 15(1) of the 2016 Act. The Terminal Illness Regulations⁶¹ therefore require the authority and the young carer to agree when the plan should be reviewed to include the rest of the information which should be contained in a plan under section 15 of the 2016 Act. This is to ensure that young carers know what to expect from the finalised YCS and when those issues will be addressed. In addition, paras 2.2.111 to 2.2.115 above outline the other circumstances in which a YCS will need to be reviewed.

Young carer statement: provision of information to carer etc.

2.2.137. Section 17 requires the responsible authority to provide information contained in the YCS to the young carer to whom the YCS relates and any other person the young carer requests, unless the authority does not consider it appropriate to provide the information. For example, It might not be considered

⁵⁷ Regulation 7(b), SSI 2021/133 <u>https://www.legislation.gov.uk/ssi/2021/133/made</u>

⁵⁸ Regulation 8(2a), SSI 2021/133 https://www.legislation.gov.uk/ssi/2021/133/made

⁵⁹ Regulation 8(2b), SSI 2021/133 https://www.legislation.gov.uk/ssi/2021/133/made

⁶⁰ Regulation 8, SSI 2021/133 <u>https://www.legislation.gov.uk/ssi/2021/133/made</u>

⁶¹ Regulation 8(4), SSI 2021/133 <u>https://www.legislation.gov.uk/ssi/2021/133/made</u>

appropriate to provide sensitive medical information about the cared-for person to a third party.

2.2.138. The responsible authority is well placed to have a discussion with the young carer about how they might wish to use their YCS and who they wish to share it with. Before the YCS is completed and signed off, it is recommended that the responsible authority records who will receive a copy of it.

Learning from YCS pilots

During the pilots for implementing this aspect of the Act, it was found that when integration authorities involved young carers in the design of the YCS process, this helped to understand their needs better and any relevant support.

Young carers who had been involved also felt that they owned the YCS. They reported that this was aided by including a section in the YCS on who the YCS was to be shared with.

2.2.139. It is paramount that the views of the young carer and any other person, to whom the information relates, for example, the cared-for person, must be sought where it is reasonably practicable to do so and the responsible authority must have regard to these views. If information is to be shared in the absence of agreement of the person to whom the information relates, there must be a clear legal basis for sharing this information. It is good practice to retain a record of the reasons for sharing information in the absence of such agreement.

2.2.140. When considering information to be shared and who to share it with, the responsible authority should comply with the common law duty of confidentiality and the requirements of data protection and human rights legislation, in particular the right to private and family life under Article 8 of the European Convention on Human Rights (ECHR).

Case study – support through communication and information sharing Joe is an isolated young carer in a household caring for both his parents. His father has severe mental health problems and his mother has drug and alcohol issues. He was suffering from anxiety.

The GP and Joe agreed to keep in touch by email. The GP also made a referral to the local young carer centre with Joe's consent. The GP arranged for a room at the medical centre for the worker from the young carer centre to conduct their visits and also kept in email contact with the young carer centre for updates and ways to support. This resulted in a reduction in Joe's anxiety as he now has support to help care for his parents and they are also getting additional support.

2.2.141. Section 17(4) states that the information is to be provided as soon as practicable after the statement is prepared or in the case of a revised statement, when the revised statement is prepared. In terms of good practice, this would mean that the young carer is provided with a physical copy of their agreed YCS within a reasonable timescale by the responsible authority. It is suggested that this information be in a format and language that the young carer can access and readily understand.

Continuation of young carer statement

2.2.142. Section 18 outlines the circumstances in which there would be a continuation of the YCS. It would be good practice for discussions to be taking place between the young carer and the responsible authority as the young carer nears 18 years old. This would include discussion on whether the young carer wishes to remain in their caring role and how they undertake the transition into adult carer services and require an adult carer support plan.

2.2.143. If there is a YCS in place for a young carer that YCS will continue to have effect after the young carer reaches their eighteenth birthday until they are provided with an adult carer support plan.

2.2.144. This should not preclude good planning for the young carer, in particular person-centred transition planning to assist young carers moving to adult carer support from young carer support. Early discussions regarding transition reviews can be undertaken by the responsible authority to ensure the young person is prepared and aware in advance of the support that could be in place for them to support them as an adult carer.

2.2.145. It is recommended that these discussions begin about eighteen months to twenty four months in advance of the transition. If transitions are poorly managed and assessments rushed through at the transition point, this could result in care and support that does not appropriately meet the needs of the young carer. This may in turn result in a greater financial implication to the responsible local authority than it would have been if early discussions and planning took place.

Part 3: Provision of support to carers Chapter 1 – Local Eligibility Criteria

Summary

Section 21 sets out the duty on each local authority to set local eligibility criteria which apply in its area.

Section 21(2) defines local eligibility criteria as follows: *"local eligibility criteria are the criteria by which the local authority must determine whether it is required to provide support to carers to meet carers' identified needs."*

Section 22 sets out the duty on each local authority to publish its local eligibility criteria and duties regarding review of the local eligibility criteria.

Purpose of local eligibility criteria

3.1.1 Eligibility criteria are set locally to enable local authorities to provide support to carers in different caring situations across a whole range of life circumstances. Local eligibility criteria will help local authorities to prioritise support and to target resources as effectively and efficiently as possible. This recognises that demand for support is increasing due to demographic changes, more complex needs and a greater intensity of caring. Demand can vary from council to council. Preventative support to carers also has a role in helping manage future demand where it prevents needs from escalating.

3.1.2 The requirement to publish local eligibility criteria is intended to improve transparency in decisions about eligibility for carer support.

3.1.3 Section 21(4) of the Act provides a power for Scottish Ministers to make regulations specifying matters which local authorities must 'have regard to' in setting their local eligibility criteria. No such regulations have been made at this time. Instead, this statutory guidance promotes the use, on a Scotland-wide basis, of a suite of indicators in order to establish the impact of caring on carers.

Intention

3.1.4 The intention under section 21 is that each local authority must set out all of the information which would enable it to decide whether it is required to provide support in a particular case.

3.1.5 The expectation is that local authorities would do this by deciding on a series of indicators or domains describing levels of impact or risk and a qualitative assessment of how severe the impact on any indicator would be before they would provide support (i.e. a threshold). There are therefore two stages to the decision-making process – describing levels of impact and risk, and then setting an eligibility threshold. After this process local authorities would then establish the <u>services or support</u> that they may provide or arrange under both their duties and powers.

3.1.6 The framework at Annex F sets out best practice for the first two aspects only. It does not attempt to define the type and amount of service or support a carer would be entitled to. That would be neither possible nor desirable since (i) the

service or support must be individualised to the carer's own needs and personal outcomes and (ii) the range and type of services and support available will not necessarily be the same in each local area.

Relationship to adult social care eligibility criteria

3.1.7 National eligibility criteria for adult social care were agreed by the Scottish Government and COSLA in 2009⁶². This guidance proposes that all local authorities use a different and more appropriate set of indicators in relation to carers in their caring role rather than those in the 2009 guidance.

3.1.8 This national set of indicators, attached at Annex F(c) as part of a broader framework, has a much clearer focus on the needs of carers. It is based on work undertaken by the National Carer Organisations (NCOs), involving carers in its design and testing, and is supported by the Scottish Government, COSLA, Social Work Scotland, the National Carer Organisations and other interests⁶³. It has been designed to be capable of adoption across all areas of Scotland.

Outlining the framework

3.1.9 The two diagrams at Annex F(a) and (b) summarise the best practice eligibility framework for carers. This consists of a model of eligibility thresholds where eligibility sits in relation to carer support as a whole. The diagram at Annex F(a) provides an illustrative example of where a local authority may decide to place the eligibility threshold in relation to the levels of impact or need. It also illustrates the role of preventative and universal services in supporting carers who do not meet the eligibility threshold. This includes examples of services to support carers which are not intended to be exhaustive or prescriptive (local circumstances will determine services).

3.1.10 Specific service types should not be categorised as 'eligible' or 'non-eligible' services, with 'eligible' services only being available for those who meet the threshold. For example, different forms of breaks from caring may be provided either side of the eligibility threshold. People whose caring role has a critical impact on one or more areas of their life are likely to require breaks from caring as part of a substantial package of services, and the person they care for is also likely to require replacement care to enable the carer to have a break from caring. People whose caring role has more moderate impacts may well still require a break.

3.1.11 National and local schemes funded from a variety of sources (e.g. micro grants, partnering with local hospitality businesses and respite vouchers⁶⁴) can provide relatively low-cost meaningful breaks for carers by utilising wider community resources. Where services like this are provided 'below' the threshold line they can often prevent or delay the need for more substantial support and therefore carers subsequently requiring more expensive support 'above' the line.

⁶² See <u>http://www.gov.scot/Publications/2014/08/5212/6</u>.

⁶³ A working group in 2017 comprising the Scottish Government, COSLA, Social Work Scotland, two NCOs, Integration Authorities, Care Inspectorate and carers endorsed this approach and took forward this guidance.

⁶⁴ Further information in Part 6, Chapter 2 on short breaks services statements.

3.1.12 The diagram at Annex F(b) on determining the impact of the caring role and associated risk shows the different areas of a person's life where their caring role may have an impact. This includes their health and wellbeing, finances, life balance, relationships, living environment, employment/training and future planning. It sets out the different categories of impact/risk. It is a matter for the local authority to determine where the eligibility threshold is placed on the spectrum of needs, impact and risks.

3.1.13 In circumstances where a carer cares for more than one person, it is necessary to consider the impact of all of the caring situations together as individually they may not meet the local eligibility threshold but the cumulative impact of caring might result in eligible needs.

Indicators – impact and risk

3.1.14 The eligibility framework set out in Annex F(c) is based on the concepts of impact and risk. This builds on the focus on carers' needs and outcomes in the Act and is consistent with previous guidance on support to carers⁶⁵ which stated that:

"local authorities should focus on the impact of the caring role on the individual carer and their family, and should address the following questions:

- is the caring role sustainable?
- how great is the risk of the caring role becoming unsustainable?"

3.1.15 The concept of "identified needs" is also important here, defined in section 5 of the Act as "needs for support (if any) which are identified in order to meet the carer's identified personal outcomes"⁶⁶.

3.1.16 The recommended eligibility framework for support to carers has five categories for impact/risk:

- caring has no impact no risk
- caring has low impact low risk
- caring has moderate impact moderate risk
- caring has substantial impact substantial risk
- caring has critical impact critical risk

3.1.17 In the framework at Annex F(c), these categories are used to measure the impact of caring on seven key aspects of a carer's life:

- health and wellbeing
- relationships
- living environment
- employment and training
- finance
- life balance
- future planning

⁶⁵ Scottish Executive Circular CCD 2/2003 -

http://www.sehd.scot.nhs.uk/publications/cc2003_02full.pdf

⁶⁶ 'Personal outcomes' include outcomes which, if achieved, would enable a carer to provide, or continue to provide, care for the cared for person. They should be outcomes that matter to an individual carer, which could include outcomes around having a life alongside caring, and looking after the carer's own health and wellbeing.

3.1.18 It would be appropriate for the indicator of "future planning" to be considered alongside other indicators rather than on its own. This is because future planning is almost always an aspect of a carer's life which interacts with the other indicators.

3.1.19 Support to the carer to help tackle future planning (for example, supporting a young carer to access independent study opportunities because they are anxious they will not achieve their future ambition to be offered a place in further education) could take the form of self-directed support - option 1 - direct payment, option 2 - choosing own support or option 3 - an arranged service.

3.1.20 Another example would be where a carer is anxious about the future because they are getting older, frailer and sicker, and they worry about who will care for their adult child with learning disabilities when the carer dies. In this case, the support provided - if not a place in supported accommodation for example - might be enabling the wider family and carer to come together to discuss and agree future care arrangements. This type of support, if provided in the form of carer advocacy or family mediation, is again either self-directed support option 2 or option 3.

Eligibility threshold

3.1.21 The indicators in the table at Annex F(c) recognise carers as providers of services to the person or people they care for. They take a broad approach when looking at the different areas of a carer's life where their caring role can have an impact.

3.1.22 There is no national eligibility threshold for support as this is for local decision-making. Each local authority will need to choose the levels of impact/risk and need which are appropriate to trigger the duty to provide support, acknowledging that there will be circumstances that merit the exercise of the power to provide support to people whose needs currently fall below the local eligibility threshold. (The threshold for support shown in Annex F(a) is for illustrative purposes only.)

3.1.23 With the exception of "future planning", eligibility should be applied to each of the areas individually and independently of each other so that if a carer has identified needs in one domain (e.g. health and wellbeing) above the threshold, this would mean that those needs meet the local eligibility criteria and the carer would be eligible for support to meet their needs pertaining to that domain and to help achieve their personal outcomes. Inevitably, there is also a degree of overlap between the indicators as, for example, concerns about financial issues may impact on a carer's health and wellbeing.

3.1.24 Whilst eligibility criteria enable decision-making regarding support, use of eligibility criteria in themselves are not an exact science. Gradations of impact and risk along a five-point scale from *'no impact/no risk'* to *'critical impact/critical risk'* are not straightforward to describe. It is therefore important that practitioners use their professional judgement in the use of the indicators to ensure carers receive the right level of support at the right time. In applying professional judgement, the views of the carer should, of course, be taken into account.

Eligibility – young carers

3.1.25 The Carers Act does not preclude the use of different eligibility criteria in relation to young carers. However, it is proposed that very similar local eligibility criteria to that for adult carers is used.

3.1.26 All of the indicators set out in the eligibility criteria at Annex F(c) apply to young carers although some of the descriptions would change from those provided. The indicators have read-across to the eight wellbeing indicators of Safe, Healthy, Achieving, Nurtured, Active, Respected, Responsible and Included as shown in Table 2.

3.1.27 The use of the local eligibility criteria for young carers is in relation to the impact of the caring role on the young carer. The young carer might have other needs unrelated to the impact of the caring role. In these circumstances, they could be eligible for other services subject to local arrangements.

Carer Indicator (Annex F)	Wellbeing indicator	Comment
Health and wellbeing	Healthy	Applies to young carers as caring can impact on their physical and mental health.
Relationships	Healthy, Safe and Nurtured	The relationships young carers have with their family and friends can be affected by caring and impact on the young carer's health as a result. A young carer might not be safe in the home due to inappropriate caring responsibilities due to their age. A young carer might not be nurtured in the family setting due to caring for a very ill parent.
Living environment	Safe	Relevant to young carers where the living environment poses a risk to the young carer's safety e.g. because young carer is using a hoist for moving and handling. Or the living environment might include lots of medication and drugs lying around. However, in most circumstances the living environment is more an issue for the adult in the house or the whole family.
Employment and training <i>(and education</i>)	Achieving and Responsible	Mostly relevant to young carers aged 16-18 but adapt this to include education which is relevant to all young carers.
		The young carer's achievement might be supported though a skills development course, paid-for tutor support, purchase of laptop. However, mostly, the support should be provided by the school.
Finance	Included	Mostly relevant to young carers aged 16-18 if they are spending money on, for example, utilities. However, also relevant to the younger age group if they are 'out-of-pocket' due to caring. Therefore take age and circumstances of the young carer into account.

Table 2: Local eligibility criteria indicators and comparison with wellbeing indicators

Carer Indicator (Annex F)	Wellbeing indicator	Comment
		Support to help deal with economic inequalities in particular.
Life balance	Active, Achieving and Included	Young carers require a good life balance in order to have time for activities, school and friendships.
Future planning	Achieving	Relevant to planning for college, university, training and work and also for the future care of the cared-for person if the young carer moves away from home.

Prevention

3.1.28 The indicators at Annex F(c) encompass a preventative approach with universal, preventative support being the foundation for helping carers to manage their caring responsibilities. Preventative support is discussed further in Part 3, Chapter 2 of this guidance, on the Duty to Provide Support to Carers.

Consultation on local eligibility criteria

3.1.29 Section 21(3) sets out the consultation requirements before setting local eligibility criteria. Each local authority must consult with persons and bodies representative of carers and take steps to involve carers.

3.1.30 With regard to consultation arrangements, consultation with carers on draft eligibility criteria will take time and will require explanation. It is good practice for local authorities to work together with local carer organisations to develop the consultation approach in an open and transparent manner. It is also necessary to reach out to those such as carers with protected characteristics under equalities legislation who may be more marginalised and not always included in consultation exercises.

3.1.31 For example, in relation to BME carers, evidence suggests that consultation with BME carers should be an integral part of service development.⁶⁷

3.1.32 The same applies with regard to those carers who live in remote and rural areas, including on the islands.⁶⁸

3.1.33 With regard to consultation with young carers, this can often be done via young carer services. In doing so, it is good practice to work with the services to determine whether the young carers want to use their time in this way. There will also be consultation opportunities with young carers in schools.

3.1.34 There are various policies, procedures and guidance documents setting out good practice in consulting with both adult and young carers as carers and as citizens. These are:

⁶⁷ Improving support for black and minority ethnic (BME) carers – Insights, IRISS – 2010 <u>https://www.iriss.org.uk/sites/default/files/iriss-insight-7.pdf</u>

⁶⁸ Guidance on Island Communities Impact Assessments as required under the Islands (Scotland) Act 2018 - Scottish Government – 2020 - <u>https://www.gov.scot/publications/island-communities-impact-assessments-guidance-toolkit/</u>

- Equal and Expert: Three Best Practice Standards for Carer Engagement (Coalition of Carers in Scotland)⁶⁹
- The Easy Consultation Toolkit (Shared Care Scotland)⁷⁰
- The National Standards for Community Engagement (Scottish Community Development Centre)⁷¹
- Co-Production How we Make a Difference Together (Mark McGeachie and Gerry Power)⁷²

Publication and Review of Criteria

3.1.35 Section 22(1) requires each local authority to publish its local eligibility criteria. The Act does not specify the method of publication but it is recommended that the local eligibility criteria (indicators and threshold) are published at least online and be readily available and easily accessible to managers and practitioners in the statutory and third sectors and to carers.

3.1.36 Section 22(2) of the Act, read together with regulation 2 of the Carers (Scotland) Act 2016 (Prescribed Days) Regulations 2017⁷³, required the first local eligibility criteria to be published by 31 March 2018.

3.1.37 Under section 22(3), each local authority must carry out a first review of its local eligibility criteria before the end of the period, prescribed by the Scottish Ministers by regulations, beginning with the day on which the criteria are published. Regulation 3 of the Carers (Scotland) Act 2016 (Prescribed Days) Regulations 2017 prescribes a period of three years within which a first review of local eligibility criteria is to take place. The intention of the timescale for this first review is to ensure that local eligibility criteria are reviewed within a reasonable timeframe. This will enable each local authority to take into account any changes it wants to make to the local eligibility criteria in light of operational practice and the success of the criteria in meeting the needs of carers. The review timescales also allow sufficient time to give local authorities flexibility to align the review with other local service planning.

3.1.38 Under section 22(4), each local authority must thereafter review its local eligibility criteria before the expiry of 3 years but can carry out an earlier review.

3.1.39 Section 22(5) defines the 'relevant period' which is the period of 3 years beginning with whichever is the later of the day on which the local authority last published (a) its local eligibility criteria or (b) a statement under subsection (6)(b).

3.1.40 Under section 22(6), the local authority may set revised local eligibility criteria following a review or must publish a statement to the effect that it has not set revised criteria.

3.1.41 Under section 22(7), any revised local eligibility criteria must be published. See advice on publication above.

⁶⁹ <u>http://www.carersnet.org/policy-legislation/best-practice-standards-for-carer-engagement/</u>

⁷⁰ http://www.sharedcarescotland.org.uk/resources/tools/consultation-toolkit/

⁷¹ http://www.scdc.org.uk/what/national-standards/

⁷² <u>http://www.coproductionscotland.org.uk/resources/co-production-in-scotland-a-policy-overview/</u>

 ⁷³ SSI 2017 No. 207 Social Care - The Carers (Scotland Act 2016 (Prescribed Days) Regulations 2017

http://www.legislation.gov.uk/ssi/2017/207/contents/made

Chapter 2 – Duty to provide support to carers

Summary

Section 24 creates powers and duties to provide support to carers. These fall on the responsible local authority – meaning the local authority for the area in which the cared-for person resides.

Section 25 creates a related duty to consider whether the support provided under section 24(4)(a) (duty to provide support to meet the carer's eligible needs) and under section 24(4)(b) (discretionary power to provide support to meet the carer's other identified needs) should take the form of, or include, a break from caring.

Section 26 makes consequential amendments to the Social Work (Scotland) Act 1968 regarding charging for support provided to carers.

Local authority functions under sections 24 and 25, must be delegated to the integration authority, so far as they relate to adults. This requirement arises under the Public Bodies (Joint Working) (Prescribed Local Authority Functions etc.) (Scotland) Amendment Regulations 2017⁷⁴ and the Public Bodies (Joint Working) (Prescribed Local Authority Functions etc.) (Scotland) Amendment (No.2) Regulations 2017⁷⁵.

Reasons for duty to provide support to carers

3.2.1. The duty to provide support to carers at section 24(4)(a) is intended to ensure support is provided to carers is in a more consistent way across Scotland. The duty is subject to a carer having eligible needs which meet the local eligibility criteria. Guidance on the duty to set local eligibility criteria is covered in Chapter 1 of this Part.

3.2.2. The power at section 24(4)(b) to support carers with identified needs which do not meet the local eligibility criteria provides a mechanism for preventative support to this group⁷⁶.

3.2.3. Each carer's identified needs (if any) will be set out in the adult carer support plan or young carer statement as appropriate.

3.2.4. The 'carer support pathway' at Figure 1 provides a very high level summary of the overall approach set out in more detail in this chapter.

⁷⁴ SSI 2017/190 <u>http://www.legislation.gov.uk/ssi/2017/190/contents/made</u>

⁷⁵ SSI 2017/449 http://www.legislation.gov.uk/ssi/2017/449/contents/made

⁷⁶ The power and duty to support carers at section 24 replace the power to support adult carers under section 3 of the Social Care (Self-directed Support) (Scotland) Act 2013, which is repealed.

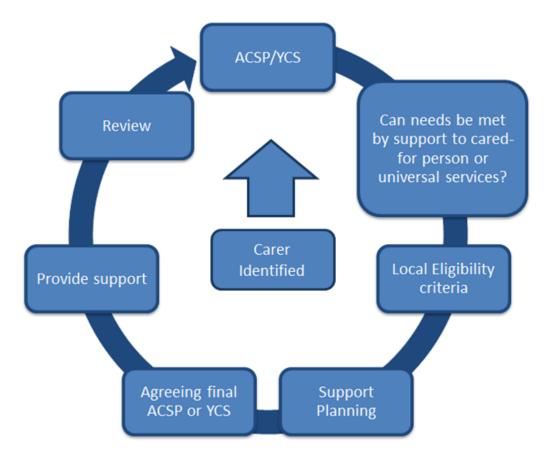


Figure 1: Carer support pathway

Meeting carers' identified needs by provision of support to caredfor person, general services and information and advice

3.2.5. As set out in section 24(1)(a) and (b), the duty and power to provide support to carers only apply where a carer has identified needs which cannot be met by services or assistance:

- provided to the cared-for person; or
- provided generally to persons in the area of the responsible local authority or, where the carer does not reside in the area of that authority, in the area where the carer resides.

3.2.6. Therefore, the local eligibility criteria for carer support are not relevant insofar as the carer's identified needs in an adult carer support plan (ACSP) or young carer statement (YCS) can be met by:

- support to the cared-for person in consequence of an assessment of their needs and outcomes; or
- universal services or support which the local authority provides to the public at large (e.g. leisure and recreation, adult education, or transport services); or
- support that is available to all carers (e.g. universal services).

3.2.7. Relevant examples of services or assistance to the cared-for person include housing adaptations, Technology Enabled Care (TEC), powered wheelchairs, improved medicine management and care at home. It is possible that support

provided to the cared-for person when they are away from the carer might help to achieve the carer's agreed personal outcomes.

3.2.8. Support being provided to the cared-for person will often have an impact on the situation of the carer (and sometimes vice versa). In most cases, the provision of support to the cared-for person will mean that the carer has a reduction in caring responsibilities. This could happen where the responsible local authority arranges for a paid care worker to provide assistance to the cared-for person for a particular period in their own home as part of their support plan. Annex A provides further guidance where there may be interaction between ACSP and YCS and an assessment of the cared-for person's outcomes and needs for support.

3.2.9. In other cases, the caring responsibilities will remain, but they may be less onerous as a result of a service provided to the cared-for person (for example, the provision of a hoist, housing adaptations or TEC).

3.2.10. It is necessary to consider, and take into account, whether the carer has multiple caring responsibilities.

Example – multiple caring responsibilities

A carer of a child with autism may have other caring responsibilities (such as caring for a parent with dementia which are mainly undertaken when the child is at school).

In this situation, the carer may not be able to have time for themselves and might have eligible needs. This would be identified in the adult carer support plan.

3.2.11. It is also possible that the carer's identified needs might be met by universal services available to the public at large, or by accessing support arranged via a local carer centre (e.g. peer-to-peer support, advocacy, or training).

Duty to provide support to meet eligible needs

3.2.12. Sections 24(2) to 24(4) set out the process for determining if carers have identified needs which meet the local eligibility criteria. Where there are eligible needs, the responsible local authority must provide support to meet those needs. For any support under section 24, the carer must be given the opportunity to choose one of the options for self-directed support unless the authority considers that the carer is ineligible to receive direct payments⁷⁷.

3.2.13. In the case of young carers under the age of 16, the support to be provided is to 'an appropriate person' including parent, guardian, etc.⁷⁸.

How do identified needs become eligible needs?

Process

3.2.14. There is a process to be worked through to establish whether a local authority has a duty to provide support to a carer to meet their identified needs. The

⁷⁷ This is set out in section 7 of the Social Care (Self-directed Support) (Scotland) Act 2013 ("the SDS Act"). The consequential amendments to section 7 of the SDS Act made by paragraph 5 of the schedule to the Carers Act have the effect that any support provided under section 24 of the Carers Act must be provided through the option for self-directed support as chosen by the carer.

⁷⁸ As defined in section 7(7) of the SDS Act as inserted by the schedule to the Carers Act.

duty (as opposed to the power) to provide support to a carer depends on the extent to which a carer's need for support meets the local eligibility criteria.

This process is as follows:

(i) Establish carer's identified personal outcomes and identified needs (if any) by preparing ACSP or YCS (section 6(1)(a) and (b) and section 12(1)(a) and (b))⁷⁹

(ii) Consider which of the identified needs can be met through services or assistance either to the cared-for person (other than 'replacement care' to provide a break from caring) or provided generally to persons in the area (i.e. by information and advice, universal services and community support) (section 24(1)(a) and (b))

(iii) If identified needs are met wholly as per (ii), no further action (but keep under review) (section 9(1)(I) and section 15(1)(m) in relation to review))

(iv) If identified needs are met only in part by (ii), or not at all, then apply local eligibility criteria to what are the 'outstanding' needs (section 24(2) and (3))

(v) Establish whether the outstanding needs meet the local eligibility criteria and therefore engage the legal duty to provide support (section 24(4)(a))

(vi) If the outstanding needs do not meet the local eligibility criteria, decide whether the discretionary power to provide support should be used (section 24(4)(b))

(vii) In the case of (v) and (vi), consider whether the support to the carer should include or take the form of a break from caring (including replacement care where required) (section 25(1))

(viii) In the case of (v) and (vi), give the carer the opportunity to choose one of the options for self-directed support (unless ineligible to receive direct payments) (Social Care (Self-directed Support) (Scotland) Act 2013)

Relationship between ACSP/YCS, information and advice, local eligibility criteria and provision of support

3.2.15. Sections 6(1)(c) and 12(1)(c) require the ACSP and YCS to set out the support (if any) to be provided by the responsible (local) authority to an adult or young carer to meet the carer's identified needs.

3.2.16. The process starts from when the local authority begins to collect information about the carer, and will be an integral part of the carer's journey through the care and support system as their needs change. It should not just be seen as a

⁷⁹ Part 2 of the guidance on adult carer support plans and young carer statements includes guidance on personal outcomes and needs for support. The ACSP and YCS seek to support carers in relation to the substantive care that they provide to the cared-for person. They also seek to put in place measures that will help a carer to live their own life and to achieve their own goals and aspirations without compromising their responsibilities as a carer. These day-to-day goals and longer-term aspirations are to be documented within the ACSP and YCS as the carer's 'personal outcomes' (see glossary).

gateway to care and support, but should be a critical intervention in its own right, which can help carers to understand their own situation and the needs they have, to reduce or delay the onset of greater needs, and to access support when they require it. It can also help carers to understand their strengths and capabilities, and the support available to them in the community and through other networks and services.

3.2.17. Regardless of whether, in fact, the carer is identified as having any support needs, they should be able to access preventative information and advice services, facilities or resources provided by the local authority or which might otherwise be available in the community. This is because the responsible local authority must provide appropriate information and advice services for all relevant carers, whether or not those carers have an ACSP or YCS in place or any identified needs. This duty is considered further in Part 6.

3.2.18. The ACSP and YCS are both based on an outcomes focused conversation to determine personal outcomes and identify needs. As part of the assessment process, the local authority considers the capacity of the carer to manage their needs or achieve the outcomes which matter to them, and allows for access to preventative support before a decision is made on whether the carer has eligible needs.

3.2.19. Next, the local authority must apply the local eligibility criteria to decide through a professional judgment which of the identified needs are eligible needs.

3.2.20. The ACSP/YCS and local eligibility criteria provide a framework to identify any level of need for care and support so that responsible local authorities can consider how to provide a proportionate response at the right time, based on the individual's needs and personal outcomes.

3.2.21. Decisions about whether identified needs meet local eligibility criteria depend on the information obtained from the ACSP and YCS (notably information on the nature and extent of care; the impact of caring; and the extent to which the carer is willing and able to provide care). In other words, such decisions, and the completion of the adult carer support plan or young carer statement (with information on carer support to be provided), are mutually dependent.

3.2.22. Where a carer has some needs that are eligible, and also has some other needs that are not deemed to be eligible, the local authority must provide information and advice on services, facilities or resources that would contribute to preventing, reducing or delaying the needs which are not eligible. This should be aligned and be consistent with the ACSP and YCS. Part 6 of this guidance deals with the duty to provide information and advice.

3.2.23. The ACSP/YCS and eligibility framework provide for ongoing engagement with the carer so that, where they have eligible needs, they are involved in the arrangements put in place to deliver the personal outcomes they want to achieve.

3.2.24. The ACSP/YCS should be person-centred, involving the individual carer, the views of the cared-for person, or any other person they might want involved. A carer with their own care needs could, for example, ask for their GP or a district nurse to be contacted to provide information relevant to their needs.

Learning from pilots

One of the areas piloting the adult carer support plan and duty to support provisions, has stated that it is essential that carers are engaged with and involved at every stage as it helps them to take ownership of their ACSP. This will increase the awareness of the caring role, encouraging carers to identify themselves, understand their rights and the supports available for them.

Young carers

3.2.25. The unique needs of young carers should be considered when assessing eligible need and putting support in place. Children and young people should not undertake inappropriate or excessive caring roles that may have an impact on their development. A young carer becomes vulnerable when their caring role risks impacting upon their emotional or physical wellbeing and their prospects in education and life.

3.2.26. A responsible authority may become aware that a child is carrying out a caring role through an assessment or informed through family members or a school. Authorities should consider how supporting the cared-for person can prevent the young carer from undertaking excessive or inappropriate care and support responsibilities. Where a young carer is identified, the responsible authority must undertake a YCS if that offer is accepted.

Prevention

3.2.27. Maintaining and improving support to carers is central to local authority and partnership preventative strategies and is a key priority for health and social care partnerships. Prevention and early intervention are at the heart of the carer support system, and even if a carer has needs that are not eligible at that time, they should still be able to access preventative support including the information and advice services which the local authority is required to provide under the Act. Responsible local authorities are also recommended to consider the carer's own strengths or if any other support might be available in the community to meet their needs.

3.2.28. This means that local authorities need to consider how carers access and benefit from universal services such as education, leisure and transport and the provision of carers' information and advice services, including welfare rights and financial advice. Local authorities also need to consider how community-based support can be further developed to support carers. This includes services provided by carer centres and the wider third sector.

3.2.29. It also means that adult carer support plans and young carer statements need to consider support needs in the round, and not only focus on the more intensive services that may be required by carers where the impact of their caring role and their support needs meet eligibility thresholds.

Non-eligible and eligible needs

3.2.30. Section 24(4)(a) of the Act requires the responsible local authority to provide support to a carer to meet their 'eligible needs'. A carer's 'eligible needs' are those identified needs for support that cannot be met through support to the cared-for person or through accessing services that are available generally, and which meet the threshold for support set by the local eligibility criteria.

3.2.31. Section 24(4)(b) gives the responsible local authority a power to provide support to meet other identified needs which cannot be met through support to the cared-for person, or services available generally, but which do not meet the threshold for support set by the eligibility criteria (i.e. non 'eligible needs').

3.2.32. Table 3 summarises the different ways in which eligible and non-eligible needs can be met, and provides examples of the types of support that can be provided to meet those needs.

Type of support	Illustrative Examples
Services or assistance to the cared-for person	care at home
(other than care provided in order to provide the	 technology enabled care
carer with a break from caring – i.e.	 equipment and adaptations
'replacement care').	 mental health services
	 medicine management
	 support to access activities for disabled children
General services – information and advice.	Information and/or advice on:
	 carers' rights
	education and training (e.g. on
	support at school, advice on
	Further and Higher Education)
	 income maximisation
	carer advocacy
	 health and wellbeing
	 bereavement support
	 emergency care planning and
	future care planning
Other general services – available universally in	leisure centres
the community or in particular neighbourhoods.	libraries
	 art galleries
	 community transport
	Iunch clubs
	 youth clubs
	 education services
	 gardening clubs
	 walking clubs
	 local support groups

Table 3: How to meet a carer's identified needs

Type of support	Illustrative Examples			
A carer's identified needs - both eligible or non-eligible needs – might be met in whole or in part by any combination of services or assistance for the cared-for person or general services above. Where they are not, the following applies.				
LA duty at section 24(4)(a) to provide support to meet a carers eligible needs (explained above). This can be any type of carer support that is not, or cannot be, provided through services for the cared-for person or services that are available generally. LA power at section 24(4)(b) to provide support to meet a carer's non-eligible needs. Again, this can be any type of carer support not covered by services for the cared-for person or general services above.	 course on emotional wellbeing counselling training on moving and handling short break (noting LA duty at section 25 to consider whether support to a carer should include a break from caring) replacement care (care for a cared-for person to allow their carer to take a break) 			
Under both the duty and power to support carers local authority must give the carer the opportunity directed support (unless the local authority consid	to choose one of the options for Self-			

Options for Self-directed support

receive direct payments). These options are explained in Table 4.

3.2.33. As noted earlier in this chapter, where the responsible local authority exercises either its duty to provide support to the carer to meet the carer's eligible needs or its power to meet the carer's other identified needs, the carer must be given the opportunity to choose one of the options for self-directed support (unless the local authority considers that the carer is ineligible to receive direct payments)⁸⁰.

3.2.34. Where support services such as general carer training courses, counselling or support groups are openly accessible for carers through a local carer centre (without local eligibility criteria being applied), these universal services are not provided under section 24 of the Carers Act and therefore the requirement to offer options for self-directed support does not apply. A wide range of personal outcomes and identified needs may be met through such preventative carer support services.

3.2.35. Examples of how carers might address their identified needs under options 1-3 of Self-directed support are provided in the statutory guidance which accompanies the Social Care (Self-directed Support) (Scotland) Act 2013⁸¹. These

⁸⁰ The four options for self-directed support are: Option 1 – the making of a direct payment by the local authority for the provision of support; Option 2 - the selection of support by the carer, the making of arrangements for the provision of it by the local authority on behalf of the carer and, where it is provided by someone other than the authority, the payment by the local authority of the relevant amount in respect of the cost of that provision (directing the available support); Option 3 - the selection of support for the carer by the local authority, the making of arrangements for the provision of it by the local authority, the making of arrangements for the provision of it by the authority and, where it is provided by someone other than the authority, the payment by the authority of the relevant amount in respect of the cost of that provision (directing the available support); Option 3 - the selection of support for the carer by the local authority, the making of arrangements for the provision of it by the authority and, where it is provided by someone other than the authority, the payment by the authority of the relevant amount in respect of the cost of that provision (the local authority arranges support); and Option 4 - the selection by the carer of Option 1, 2 or 3 for each type of support and, where it is provided by someone other than the authority, the payment by the local authority of the relevant amount in respect of the cost of the support.

⁸¹ <u>http://www.gov.scot/Publications/2014/04/5438/8#table9</u>

examples are reproduced (with slight adjustment) in Table 4 below. They show that support to carers can take many forms. **Table 4: Examples of support to carers**

2013 Act option	Example
Option 1 Direct payment	Example 1 An adult carer who lives in a remote rural area is feeling increasingly isolated and depressed. She has no friends or family living nearby and her nearest carer centre is miles away. The carer uses a direct payment to pay for the installation of broadband and for a tablet computer. This means she can keep in touch with her family and friends through video-calls and email, particularly her grandchildren who live overseas. She has also made friends with other carers on an online forum and now feels more connected and supported.
	Example 2 A young carer who cares for his mother expresses that he has not been able to have the same opportunities as his peers. Whilst all his friends are learning to drive, he cannot because his mother cannot afford the cost and because of his caring role he cannot take on a part-time job in order to earn extra money. He thinks that having a driving licence would be useful as the family could get a Motability car, which would help with a lot of the tasks around his caring role such as shopping and taking his mum to places. He also thinks that being able to drive would open up more job opportunities. The young carer uses his direct payment to pay for several driving lessons and the cost of the driving tests.
	Example 3 A carer lives in a rural area with a cared-for person who attends a day centre twice a week. The carer, who can't drive and isn't on a bus route uses her direct payment for a regular taxi to visit her nearest swimming pool, to make the most of her time away from her caring role.
Option 2 Directing the available support	Example 1 A carer has never had a break from caring. He would like to have a break of an afternoon each week to have a rest where he doesn't have to worry about the safety of the person he cares for. The carer receives a carer's short break voucher ⁸² and he uses this to purchase a short break.
	Example 2 The authority arranges for an individual service fund (ISF) to be set up to support the carer. This carer has always been very house-proud, but her husband has had a stroke and the level of care that she has to provide means that she is falling behind with housework and laundry, which is making her feel increasingly tired and depressed. The carer uses the individual service fund to purchase domestic help from an agency so that someone can come in and help with cleaning, ironing and other domestic tasks. The carer also uses the ISF to pay for a fortnightly visit

⁸² See examples later in this chapter on approaches to delivering short breaks as a form of support.

2013 Act option	Example
	from a care worker so that she can meet her daughter for lunch and have a break from caring.
Option 3 Arranged services	Example 1 After the death of his father, a carer is finding caring for his mother, who has dementia, emotionally draining and he is becoming very depressed. He is on a waiting list for NHS counselling services but has been told it may take a long time and his local carer centre does not offer this service. The authority arranges for the carer to attend a private counsellor to help him manage issues of bereavement and caring.
	Example 2 A carer talks about missing out on making new friends as she never has time because of her caring role. She expresses an interest in attending an art class in a local authority community centre. The authority arranges for the carer to attend the class and arranges replacement care for the person she cares for once a week.
	NB: The art class would be categorised under the Carers Act as general services and enabling the carer to attend this class would be providing general services. The provision of replacement care would be either under the power or duty to support the carer (depending on whether her needs met the local eligibility criteria) and would be non-chargeable.

Special cases: Carers of two people and cross border caring

Adult carers, caring for people in more than one local authority area

3.2.36. There may be instances where an adult carer is caring for more than one person across different local authority areas. For example, where a parent caring for a child with a long-term condition is also providing care for their own parent. In such circumstances both local authorities where the cared-for persons are living have responsibility to:

- offer and conduct an adult carer support plan; and
- provide support to the carer (subject to the two local authorities', potentially different, eligibility criteria) which might involve providing support to cared-for person.

3.2.37. Local authorities in these circumstances are recommended to work together in these circumstances so that they can jointly:

- achieve an outcomes focus for the individual carer;
- minimise the need for the carer to give the same information twice;
- make decisions on support and eligibility based on a shared understanding of the total impact of the carer's caring responsibilities; and
- avoid duplication of effort.

3.2.38. Whilst each local authority's eligibility criteria would be relevant in its own decision making about support, collaboration is recommended between each area in that decision making process.

3.2.39. Decisions about sharing the costs of carer support in these circumstances are a matter for the local authorities involved, however it is recommended that a 50:50 split for carer support is a sensible default position. Any additional support for the cared-for persons would be a matter for their respective local authorities.

Young carers, caring for people in more than one local authority area

3.2.40. Situations in which a young carer is caring for more than one person across different local authority areas are not common, however there may be a small number of instances where this occurs. For example, where a child of parents who have separated, and who both have a long term condition or mental health issue.

3.2.41. In such circumstances the duty (or power) to provide support to the young carer falls to each of the local authorities where the cared-for persons reside.

3.2.42. Similar to adult carers, each local authority's eligibility criteria would be relevant in its own decision making about support, however we recommend collaboration between each area in that decision making process.

Carer in Scotland caring for someone outwith Scotland

3.2.43. The Carers (Scotland) Act does not create any duty to support the carer where the cared-for person lives outwith Scotland. Carers are still able to access local carer support such as: carer centre services; Citizens Advice Bureaux; advice shops; council helplines; and local authorities' information and advice services.

3.2.44. Scottish local authorities may still have responsibilities to support young carers by virtue of their wider duties or powers to support them as children under the Children and Young People (Scotland) Act 2014⁸³.

3.2.45. A carer living in Scotland who cares for someone outwith Scotland may be eligible for support from the local authority in which the cared-for person resides. In these instances, it would be a matter for the relevant local authority in England or Wales, or the Health and Social Care (HSC) Trust in Northern Ireland to make decisions under the relevant legislation in those countries.

⁸³ <u>http://www.legislation.gov.uk/asp/2014/8/contents</u>

For information – statutory provision for carers in other UK jurisdictions There is a duty for English local authorities to support an adult carer under section 20 of the Care Act 2014⁸⁴ where the cared-for person lives in England.

Obligations on Welsh local authorities relevant to carers are set out in part 3⁸⁵ and part 4⁸⁶ of the code of practice that underpin the Social Services and Well-being (Wales) Act 2014⁸⁷.

The Carers and Direct Payments Act (Northern Ireland) 2002⁸⁸ imposes a duty on Health and Social Care (HSC) Trusts to inform carers of their right to an assessment of their needs and to carry out the assessment, if they so wish. This only applies to those carers of individuals whom the HSC Trust would ordinarily provide social care services to (i.e. Northern Ireland residents).

Carer outwith Scotland caring for someone in Scotland

3.2.46. Instances where a carer outwith Scotland is caring for someone residing in Scotland may also occur. For example, where:

- a carer looking after a family member or friend provides emotional support, liaises with statutory services, and arranges other help from a distance (who may or may not visit regularly to provide hands-on assistance); or
- a carer looking after a family member or friend nearby, just over the border.

3.2.47. For adult carers, the Scottish local authority where the cared-for person lives has a duty to offer an adult carer support plan and support the carer under the Act, and subject to local eligibility criteria.

3.2.48. For young carers in this situation, the Act has not created a duty for the Scottish local authorities of the cared-for person to offer a young carer statement. This is because the 'responsible authority' for a young carer statement, under sections 19 and 20, is determined by the young carer's own circumstances, rather than those of the cared-for person.

3.2.49. As a consequence, because the duty to support young carers under the Act is dependent on the existence of a young carer statement, there is no duty or power for Scottish local authorities of the cared-for person to support the young carer.

3.2.50. Subject to the normal requirements on consent to sharing of information, the Scottish local authority of the cared-for person must ensure that the local authority where the young carer lives is aware of their circumstances.

⁸⁴ <u>http://www.legislation.gov.uk/ukpga/2014/23/contents</u>

⁸⁵ https://gov.wales/sites/default/files/publications/2019-05/part-3-code-of-practice-assessing-theneeds-of-individuals.pdf

⁸⁶ <u>https://gov.wales/sites</u>/default/files/publications/2019-05/part-4-code-of-practice-meeting-needs.pdf

⁸⁷ http://www.legislation.gov.uk/anaw/2014/4/pdfs/anaw_20140004_en.pdf

⁸⁸ <u>http://www.legislation.gov.uk/nia/2002/6/contents</u>

Carers who are also service users

3.2.51. Annex B provides guidance on carers who are also service users (adults or children with support needs). This issue is also discussed in Part 3, Chapter 3 on waiving of charges and replacement care.

Provision of support to carers: breaks from caring

3.2.52. Section 25(1) requires a local authority, in determining which support to provide to a carer under section 24(4), to consider whether the support should take the form of or include a break from caring. Under sections 9(k) and 15(l), the ACSP and YCS must contain information about whether support should be provided in the form of a break from caring.

3.2.53. The intention of these provisions is to ensure local authorities consider breaks tailored to the needs of individual carers as a mainstream form of support.

3.2.54. This requires local authorities to consider with each individual carer if their personal outcomes and needs for support should be met by a break from caring. It does not create a duty to provide a break from caring in every case.

3.2.55. A 'break from caring' can be any form of support that enables a carer to have time away from their normal caring responsibilities.

3.2.56. The form of support that enables a break from caring will frequently include provision of 'replacement care' for the cared-for person, either on its own or alongside other services that the local authority can provide under section 24 of the Act. Other forms of support can include, for example, assistive technology, or short breaks.

3.2.57. A carer might have identified needs which meet the local eligibility criteria, and may be assessed as requiring a break from caring. If the carer cannot take that break without replacement care being provided by the statutory or voluntary sectors rather than by friends, family or neighbours, then the local authority duty under section 24(4)(a) of the Act would include providing or arranging the replacement care, whether or not the cared-for person has eligible social care needs in their own right.

3.2.58. In other words, replacement care is not restricted to cared-for people who meet local social care eligibility. The duties and powers of local authorities under section 24(4) in respect of breaks from caring may as a consequence require replacement care to be provided or arranged for the cared-for person.

Approaches to delivering short breaks as a form of support

3.2.59. Short breaks are one of many forms of support that can enable a carer to realise their personal outcomes. In establishing and maintaining an appropriate range of short breaks services, local authorities are strongly encouraged to consider the following types of short breaks, some of which are already making a real difference to carers and those that they care for. These include, but are not limited to:

- holiday or leisure breaks (with or without the cared-for person);
- sports and activity breaks (with or without the cared-for person);

- breaks at home during the day or overnight (with support from a care at home service); and
- play-schemes or after school clubs for the cared-for person.

3.2.60. Short breaks can be taken with or without the cared-for person. The consideration of delivering short breaks as a form of support offer local authorities an opportunity to provide more holistic services to carers, cared-for persons, and wider family networks if appropriate.

3.2.61. Whilst there is no definition in the Act of what constitutes a short break, local authorities are encouraged to consider the paper provided by Shared Care Scotland attached at Annex C. This paper may also be useful for local authorities when preparing the short breaks services statement under section 35 of the Act. Guidance for short breaks services statements is set out in Part 6.

3.2.62. Local authorities are encouraged to foster innovative approaches to provide short breaks that seek to maximise the potential of voluntary and third sector contribution. Community-led approaches could be considered in extending the range and providing a good choice of high-quality short breaks to carers to meet their personal outcomes.

3.2.63. Shared Care Scotland produce 'Short Break Stories'⁸⁹ which facilitate good practice sharing and learning by hosting case studies from across Scotland. The Learning Exchange⁹⁰ also curates examples of good practice.

Example – Brokerage Model

Brokerage is a way of working that requires a tailored and flexible approach. Brokerage helps carers plan towards the life they want through the development of long-term, sustainable outcomes. The aim is to help carers to resolve any problems that are preventing them having a more balanced life with access to opportunities outside their caring role.

A brokerage support worker can establish with the carer what outcomes they would like to achieve, work out the resources, make a plan, and then help to arrange any services or support that will help achieve these outcomes.

Example – Voucher Schemes

The use of short break voucher schemes can be a supportive and preventative measure. There is scope to support carers by providing breaks from caring on a preventative basis, even if the carer does not have eligible needs, by using the discretionary power rather than the duty in the Carers Act.

Carers who are registered with Perth and Kinross Council or with PKAVS can be offered free complementary therapy sessions. They receive a voucher pack which includes an approved provider list of therapists and 12 vouchers. These vouchers have a one year expiration from the date of issue.

The control is in the carer's hands, with the flexibility to contact the therapist of their choice and arrange appointments to suit their schedule.

⁸⁹ <u>http://shortbreakstories.org.uk/</u>

⁹⁰ http://lx.iriss.org.uk/sharedcarescotland

Example – Respitality

Respitality⁹¹ brings together carer centres with the Scottish hospitality sector encouraging relationships to be built between carer centres and local hotels, B&Bs, restaurants and local leisure providers (including local authorities) who provide free shorts breaks to carers. This can include overnight stays, meals out, spa days, or beauty treatments – whatever gift the business chooses to offer.

Hospitality and leisure organisations recognise the benefits of being carer aware, helping to promote their business in communities across Scotland, and helping to promote inclusive growth. This community approach to short breaks means a wider choice of short breaks could be provided much closer to the carer.

3.2.64. Section 25(2)(a) allow Scottish Ministers to make regulations about the form of support that may be provided as a break from caring. Scottish Ministers have not used this power for commencement of the Act.

When care for the cared-for person cannot be agreed to enable a break from caring

3.2.65. Section 25(2)(b) allows Scottish Ministers to make regulations about the processes required where there may be a disagreement between the carer and the cared-for person about the provision of care for the cared-for person, which would enable the carer to have a break from caring. Scottish Ministers are not using this power at this time but guidance is provided below.

3.2.66. When determining the support to be provided to a carer under section 24(4) and section 25 practitioners need to consider the relationships between the carer and the cared-for person. There may be stress and tension in the relationship. In some cases, the carer and the cared-for person may be unable to agree on the way in which support is provided.

3.2.67. In such circumstances, it is recommended that local authorities:

- take into consideration the perspectives of both the cared-for person and the carer;
- work closely with the cared-for person, the carer and other family members to seek to resolve situations and provide support where the cared-for person does not want an assessment or re-assessment of their needs, or to accept services suggested by the carer's adult carer support plan;
- consider whether the cared-for person has the legal capacity to make the decision to refuse an assessment or support, and if not consider the implications of the Adults with Incapacity (Scotland) Act 2000 for both the carer and the cared-for person;
- remember that services cannot be imposed on the cared-for person if they have the capacity to refuse them;

⁹¹ https://www.sharedcarescotland.org.uk/respitality/

- consider that the cared-for person's capacity to consent to replacement care being proposed also links with statutory duties to ensure that cared-for persons are supported to be involved in decision making about their own care;
- recognise that tension can arise when either the cared-for person's or carer's ability to communicate is affected by illness, disability or mental health;
- recognise that tension can arise where either the cared-for person's or carer's first language is not English, and one person interprets for the other;
- recognise that the cared-for person must be offered choices in how replacement care is provided via the Self-directed Support legislation;
- provide access to mediation and advocacy services where necessary, which can play and important role in exploring and resolving tensions between the carer and cared-for person; and
- provide access to translation and interpretation services where necessary.

3.2.68. There may be situations when it is necessary to identify who is the legal proxy of the adult cared-for person. Local authorities should seek to clarify the circumstances where the cared-for person has a legal proxy, such as a welfare power of attorney or welfare guardian, in addition to where another family member undertakes the main caring role and views them self as the carer of the cared-for person. In this context, local authorities may wish to consider the Adults with Incapacity (Scotland) Act 2000 Code of Practice for local authorities⁹².

3.2.69. It should be recognised that that any carer who is acting under a power of attorney or a guardianship order under the Adults with Incapacity (Scotland) Act 2000⁹³ is also obliged to act under the principles of this legislation. In essence this means that the least restrictive actions are the ones that should be taken and the carer should be ensuring that, as well as involving the cared-for person in decision making, all decisions should reflect the will and preferences of the cared-for person.

3.2.70. There may be circumstances where another person is the cared-for person's 'named person' under the Mental Health (Care and Treatment) (Scotland) Act 2003⁹⁴ but another family member undertakes the main caring role. 'The New Mental Health Act: A Guide to Named Persons⁹⁵' provides useful information for local authorities on the role and responsibilities of named persons

3.2.71. There may be circumstances where there are tensions between the adult carer and the cared-for person, where the cared-for person is a disabled child. Responsible authorities may wish to consider the 'National Guidance for Child Protection in Scotland' (2014)⁹⁶ where appropriate in addition to following their own child protection procedures.

Planning Breaks from Caring

3.2.72. Section 25(3) sets out that a break from caring can be provided on a regular basis or on a temporary basis, and may be provided for varying periods of time. This

^{92 &}lt;u>http://www.gov.scot/Publications/2008/03/20114619/0</u>

⁹³ http://www.legislation.gov.uk/asp/2000/4/contents

⁹⁴ http://www.legislation.gov.uk/asp/2003/13/contents

⁹⁵ https://www.mwcscot.org.uk/law-and-rights/mental-health-act

⁹⁶ http://www.gov.scot/Resource/0045/00450942.pdf

means that a break from caring can be provided during the day or overnight, and can be a regular or temporary arrangement.

3.2.73. Section 25(4) sets out that a local authority must have regard to the desirability of breaks from caring being provided on a planned basis. This means that the consideration of a break from caring is not only in response to a crisis situation.

3.2.74. Breaks from caring are likely to be more effective in meeting a carer's identified needs if they are planned over a longer-term period in order to give the carer some certainty over what will be provided to them. Several breaks planned in advance rather than one-off breaks are likely to lead to enhanced health and wellbeing for the carer and cared-for person.

Promoting variety in the market

3.2.75. Section 25(5) sets out that section 19(2) of the SDS Act applies in relation to support provided as a break from caring as it applies in relation to any other support.

3.2.76. Section 19(2) of the SDS Act provides for the promotion of options for selfdirected support, i.e., promoting variety in the market. The express reference to breaks from caring makes clear that local authorities should promote a variety of options for these types of service provision (both in terms of support provided by the local authority directly, and other service providers). This can be alongside other preventative support for the carer.

3.2.77. By proactively shaping a relevant and diverse market of provision to support carers, local authorities will be able to more effectively deliver breaks from caring that are appropriate and convenient for the carer's individual circumstances, contributing towards a preventative and personal outcomes approach.

Chapter 3 – Waiving of charges and replacement care

Background to this guidance

3.3.1. This chapter replaces the Statutory guidance to accompany section 3 of the Social Care (Self-directed Support) (Scotland) Act 2013 and the Carers (Waiving of Charges for Support) (Scotland) Regulations 2014. It provides guidance on waiving of charges for support to carers.

3.3.2. This chapter also provides related guidance to assist in determining whether support should be treated as provided to a carer or to the person they care for. Support provided to a carer will often be closely linked to provision of support to the person they care for. The close links between support to carers and support to the people they care for are recognised in and built into the Act as a key element when:

- preparing ACSPs and YCSs;
- assessing whether a carer has eligible needs; and
- considering how to meet the carer's eligible and other identified needs, including through breaks from caring.

3.3.3. As set out below, charges for support to carers must be waived under the Carers (Waiving of Charges for Support) (Scotland) Regulations 2014 whereas support to cared-for people may be charged for. It is therefore necessary to establish whether support is being provided to the carer or cared-for person⁹⁷ in order to establish whether it may be chargeable.

3.3.4. This is particularly relevant in relation to providing 'replacement care', i.e. care provided to the cared-for person, which replaces care normally given by the carer and which is provided as a form of support to the carer so the carer can have a break from caring. The final part of this chapter deals with when care provided to a cared-for person is a form of support to a carer in order to allow that carer to have a break from caring.

Waiving of charges – legislative framework

3.3.5. The Carers (Waiving of Charges for Support) (Scotland) Regulations 2014⁹⁸ (the '2014 Regulations') require local authorities to waive charges⁹⁹ in relation to support provided to carers¹⁰⁰.

⁹⁷ Charging legislation refers to both 'services' and 'support'. This chapter uses 'support' to encompass both.

⁹⁸ SSI 2014/65 <u>http://www.legislation.gov.uk/ssi/2014/65/contents/made</u> as amended by The Carers (Waiving of Charges for Support) (Scotland) Amendment Regulations 2018 (SSI 2018/31) <u>http://www.legislation.gov.uk/ssi/2018/31/contents/made</u>

⁹⁹ Under Section 87 of the Social Work (Scotland) Act 1968.

¹⁰⁰ See COSLA 'Charges Applying to Non-residential Social Care Services' 2017/18 sections 6.17-6.19 for further information.

3.3.6. Similarly, the Self-directed Support (Direct Payments) (Scotland) Regulations 2014 prevent local authorities means testing or requiring a contribution from a carer where carer support is being delivered by way of a direct payment.

3.3.7. This means that charges cannot be made for support provided to carers either directly by local authorities or commissioned by the local authority through other statutory, independent and third sector bodies¹⁰¹.

Waiving of charges and the Act

3.3.8. Part 3, Chapter 2 of this guidance covers local authorities' duty and power to support carers under section 24 of the Act. These replaced powers to support carers under section 3(4) of the Social Care (Self-directed Support) (Scotland) Act 2013 ('the 2013 Act') and section 22 of the Children (Scotland) Act 1995 (the '1995 Act').

3.3.9. The legislation on care charging has been updated¹⁰² to ensure that the requirement for local authorities to waive charges for the support provided to carers remains the same but now refers to the power and duty to support carers under section 24(4) of the Act, rather than the previous powers to support carers under the 2013 Act and the 1995 Act.

Waiving of charges for carer support under the Act¹⁰³

3.3.10. Charges must be waived for all support under section 24 of the Act in order to meet an individual carer's identified needs as set out in their ACSP or YCS. Such support might include, but is not limited, to:

- advocacy;
- emotional support and counselling;
- training for carers;
- translation and interpretation services;
- cost of transport to meet the carer's identified needs;
- breaks from caring that enable the carer to meet their personal outcomes (as set out in their ACSP or YCS), for example the cost of a leisure or other

(<u>http://www.legislation.gov.uk/ukpga/1968/49/section/87</u>). The Carers (Waiving of Charges for Support) (Scotland) Amendment Regulations 2018 (SSI 2018/31

 ¹⁰¹ However, if a carer wishes to supplement and pay for carer support above the agreed level they receive through self-directed support, then this is a matter entirely for the individual carer.
 ¹⁰² Section 26 of the Act updates section 87 of the Social Work (Scotland) Act 1968

http://www.legislation.gov.uk/ssi/2018/31/contents/made) update the 2014 Regulations. The Selfdirected Support (Direct Payments) (Scotland) Amendment Regulations 2018 (SSI 2018/29 http://www.legislation.gov.uk/ssi/2018/29/contents/made) update the Self-directed Support (Direct Payments) (Scotland) Regulations 2014.

¹⁰³ Carer support under the Act - The Act makes provision for planning carer support at a strategic level; for providing information and advice about that support and for putting in place personalised support to individual carers. Part 5 of the Act requires the preparation of local carer strategies, setting out plans to support carers. Part 5 of this guidance contains more information on preparing these strategies. Part 6 of the Act and Part 6 of this guidance deal with the duty on local authorities to provide information and advice services, including, among other things advice on carers' rights, advocacy, income maximisation, education and training, counselling, bereavement support and emergency planning. Parts 2 of the Act and of this guidance deal with the identification of personal outcomes and needs in an ACSP or YCS for individual carers. Part 3 of the Act and Chapter 2 of this Part of the guidance deal with the duty and power to provide support to individual carers and the SDS options in relation to support.

activity. The overall cost of a break from caring may include the cost of providing replacement care to the cared-for person (to replace that routinely provided by the carer) to enable the carer to take a break, recognising that the break would not be possible without replacement care; and

• other personalised support.

3.3.11. There are challenges in deciding how certain forms of support, which arguably meet the needs of both the carer and the cared-for person, should be categorised, in order to determine whether the support may be charged for or whether charges should be waived. These challenges arise where the local authority has to decide whether it will provide:

- support to the cared-for person to meet their assessed needs, the indirect consequence of which is not so much that the carer's identified needs are met, but that the carer no longer has those needs; or
- support to the carer to meet the carer's identified needs, which could be through care or support to the cared-for person.

3.3.12. The difference is subtle but fundamental to the question of whether or not charges are to be waived. Further guidance is provided below on particular circumstances where it may not be straightforward to determine whether the support is for the carer – specifically, where the local authority decides to provide support with household tasks or support to enable breaks from caring.

Support unrelated to the caring role

3.3.13. Individuals who are carers may also receive support or services from local authorities for reasons unrelated to their caring responsibilities because of their own social care needs (e.g. due to a disability or mental health issue). Such support is not provided under section 24 of the Act and the local authority's normal financial assessment and charging policies apply. Annex B provides guidance on carers who are also service users (adults or children with support needs).

Support with household tasks

3.3.14. Where a carer's identified needs are met as a result of support provided to the cared-for person, that is not support under section 24 of the Act, so normal local charging policies apply.

3.3.15. Where the local authority decides to provide support with housework or gardening, determining whether this is support for the cared-for person or support for the carer under section 24 of the Act may not be straightforward. These decisions are particularly difficult where the carer and cared-for person live together.

3.3.16. Cared-for persons can be assessed as needing help with household tasks and might be charged, according to the local authority's normal financial assessment and charging policies.

3.3.17. However, many carers have multiple responsibilities over and above their caring role. Where it is identified in the ACSP or YCS that support with household tasks will enable the carer to maintain their own health and wellbeing and continue to provide care, the local authority may decide to provide such support, as discussed at Part 3, Chapter 2.

3.3.18. It may be possible to meet the carer's needs by providing support to the cared-for person. But where these identified needs 'cannot be met by services ... provided to the cared-for person' then, support must or may be provided to the carer under section 24(4) of the Act. In such circumstances charges for the support would need to be waived. Part 3, Chapter 2 of the guidance deals with 'services to the cared-for person' under section 24 in more detail.

3.3.19. For example, a carer looks after an elderly parent with support needs and is struggling with the volume of household tasks in both the carer's own home and their parent's home. In this case, any support with household tasks at the parent's home would be support for the cared-for person and normal local charging policies would apply. However, any support with household tasks at the carer's home would be support for the carer under section 24 of the Act and therefore free of charge.

Breaks from caring

3.3.20. Section 25 of the Act requires responsible local authorities to consider whether support to meet a carer's identified needs should take the form of or include a break from caring. Part 3, Chapter 2 of the guidance covers local authorities' duty to consider breaks from caring as part of their power and duty to support carers; and explains that a break from caring can be any form of support that enables a carer to have time away from their normal caring responsibilities. This duty to consider breaks from caring applies whether the support is to be provided to meet eligible needs (under the duty to support) or to meet other identified needs which do not meet local eligibility criteria. If personalised support to the carer is to be provided in the form of a break from caring, the local authority must provide that break without making a charge.

3.3.21. The charge to be waived will cover the cost of all of the elements of the break that the local authority has decided to provide to meet the carer's identified needs (having considered its local eligibility criteria).

Replacement care and breaks from caring

3.3.22. The issue of whether support is for the carer or the cared-for person has the potential to arise in the context of 'replacement care', which is provided in order to allow the carer a break from caring.

3.3.23. The Carers Act sets out a structured approach to identifying the nature of the caring role, the personal outcomes of a carer and that carer's need for support in an ACSP/YCS and considering whether those needs for support should be met through a break from caring, which may be facilitated by providing 'replacement care'. An approach is set out below to establish whether care is support to the carer, i.e. replacement care.

3.3.24. The structured approach in the Act, together with this guidance, is intended to make it more straightforward for local authorities to determine whether care provided to the cared-for person should be treated as:

- support provided to a carer under the Act in order to facilitate a break from caring – for which charges must be waived; or as
- support provided to the cared-for person to meet their assessed needs which may be charged for.

3.3.25. Where a carer's needs for support are considered eligible and a break from caring is agreed as an appropriate form of support for the carer to meet those eligible needs, there will be a need to consider the provision of appropriate care for the cared-for person during the carer's absence. In some cases, this may be provided by friends, family or other community supports; however, in other cases there may be a need for more formal 'replacement' care - for example, in circumstances where such alternative resources are not available or the cared-for person has complex care needs and requires specialist care provision.

3.3.26. Part 3, Chapter 2 provides guidance on the cared-for person's agreement to provision of care in order to enable the carer to have a break from caring.

Explaining 'replacement care'

3.3.27. 'Replacement care' is not a term used in the Act. It is used in this guidance as a shorthand to cover care provided to the cared-for person, which replaces care previously given by the carer and which is provided as a form of support to the carer so the carer can have a break from caring.

3.3.28. However, not all care provided, arranged or funded by a public body which a cared-for person receives will necessarily be 'replacement care'. It is recognised that it will not always be straightforward to determine whether care provided to a cared-for person is primarily to benefit them or primarily to benefit the carer. It will be necessary to exercise professional judgment and take the circumstances of the individual case into account in order to determine whether such care falls into the category of replacement care (i.e. support to the carer); or support for the cared-for person.

3.3.29. There may be cases where it appears that support which enables a break from caring is of equal benefit to the carer and the cared-for person. In these circumstances, local authorities may wish to consider whether it would be appropriate to classify half of this as support for the carer and half as support for the cared-for person.

3.3.30. In making an assessment of whether or not care provided to a cared-for person is replacement care, the core question is: Is the care being provided to the cared-for person primarily in order to provide the carer with a break from caring?

3.3.31. This is a complex question but it can be broken down into the following questions, which may be useful prompts. These are considered in more detail below:

Question a: Is the care to be provided to the cared-for person?

Question b: Is the care provided to enable the carer to have a break?

Question b.i: Is the care replacing care previously given by the carer? Question b.ii: Is the purpose of the care primarily in order for the carer to have a break?

Question b.iii: Aside from the need for a break, is the carer willing and able to resume their caring role after their break?

Question b.iv: For young carers, aside from the need for a break is it appropriate for them to continue caring?

Summary

Care provided by the local authority for the cared-for person would be support to the carer under section 24 of the Carers Act and therefore subject to the requirement to waive charges, where it is provided to enable the carer to have a break from caring and all of the following apply:

i) it is replacing care previously given by the carer;

ii) its primary purpose is in order for the carer to have a break from caring which in turn has been deemed a necessary form of support to meet the carer's identified needs;

iii) it is replacing care which the carer is able and willing to provide, i.e. not where the carer is not well enough to continue providing the same level of care or has other commitments; and

iv) for young carers, it is not replacing care which would be inappropriate for the young carer.

Question a: Is care being provided to the cared-for person?

3.3.32. This should be self-evident but if the answer is 'no', it cannot be replacement care.

Question b: Is the care provided to enable the carer to have a break?

3.3.33. The answer to this question is not always straightforward. Various supplementary questions may be helpful in considering the response.

Question b, supplementary question i: Is the care to the cared-for person replacing care usually given by the carer?

3.3.34. In order to answer this question fully it is necessary to understand the caring role. The nature and extent of the care provided or to be provided will be recorded in the ACSP (section 9(1)(a)(i)) or YCS (section 15(1)(a)(i)).

3.3.35. In deciding whether something is 'replacement care' it is relevant to consider whether the care to the cared-for person is replacing care which the carer would otherwise have provided.

3.3.36. Care for the cared-for person may be provided to facilitate a break from caring as a form of support to a carer where it meets the carer's identified needs. In such cases the care will usually replace care normally given by the unpaid carer

3.3.37. It is not necessary for the care provided to the cared-for person to be a likefor-like replacement for the care usually provided by the unpaid carer. There will be circumstances where the unpaid care usually provided by the carer cannot be exactly replicated by paid care.

Example

An example might be if a carer lived next door to the cared-for person and usually provided a range of regular care (e.g. shopping, emotional support, and checking in regularly with the person during the evenings or at night). It may not be possible to replicate this kind of care while the unpaid carer had a break. Instead the 'replacement care' might take another form, such as a short term home care package. The crucial factor is whether the care is provided to facilitate a break for the carer as a form of support provided under section 24 of the Carers Act, as considered below.

Question b, supplementary question ii: Is the purpose of the care primarily in order for the carer to have a break?

3.3.38. Support for the cared-for person provided primarily in order to meet that person's needs may include day care to enable their independence and promote life skills and socialisation, play-schemes and out-of-school care provision for disabled children. This support may often deliver ancillary benefits of providing a break for unpaid carers. But they would not constitute 'replacement care' where they are primarily intended for the purpose of meeting the cared-for person's needs and not the carer's need for a break.

3.3.39. Breaks for cared-for persons can sometimes be identified within their own social care needs assessment and care services can be provided to mainly meet their assessed needs (e.g. to support social opportunities and independent living). Time-off for the carer can be achieved as a welcome consequence of the service. Such breaks for cared-for persons would not constitute 'replacement care'. If, having considered its local eligibility criteria, the local authority decides that to meet the carer's identified needs it will provide support to enable the carer to enjoy activities to make the most of this time off, this would be support under section 24 of the Act and therefore free of charge.

Question b, supplementary question iii: Aside from the need for a break, is the carer willing and able to resume their caring role after their break?

3.3.40. Information about the extent to which the carer is able and willing to provide care for the cared-for person must be included in the ACSP or YCS (under sections 9(1)(b) and 15(1)(b)). (See Chapters 2.1 and 2.2.)

3.3.41. Care to the cared-for person can only be considered to be enabling the carer to have a break if it is replacing care that the carer is otherwise willing and able to provide. In other words, where care to the cared-for person is needed because the carer is unable or unwilling to provide care then the care is not being provided to allow the carer to have a break. So care would *not* be considered replacement care if, for example, a carer was not willing or able to provide care because:

- the carer is ill, in hospital or recovering at home and alternative care therefore needs to be provided for the cared-for person;
- the carer wishes to work full or part-time and will stop or reduce the care they
 provide when they are in employment. Entering employment is not a form of
 break. Care provided in these circumstances would be purely to meet the
 cared-for person's needs, rather than the carer's needs under the ACSP/YCS;
 or
- the carer is no longer able or willing to provide the same level or type of care for health or other reasons, even with support.

Question b, supplementary question iv: For young carers, aside from the need for a break, is it appropriate for them to continue caring?

3.3.42. Young carer statements must include information about the extent to which the responsible authority considers that the nature and extent of the care provided by the young carer is appropriate¹⁰⁴.

3.3.43. Care to the cared-for person would not be 'replacement care' in circumstances where it was provided in order to relieve the young carer of inappropriate caring responsibilities.

3.3.44. This could happen if the care provided by the young carer has been deemed to be inappropriate for reasons such as the age of the young carer, the nature of the care (e.g. personal care in inappropriate circumstances) and the extent of the care (e.g. too many hours of caring impacting adversely on the young carer's health, wellbeing and education).

3.3.45. Although care provided by statutory agencies in these circumstances would be replacing the care which had been provided by the young carer, it would not do so in order to allow the carer to have a break to help sustain that caring situation. Instead it would be provided on a more permanent basis to relieve them of inappropriate caring responsibilities and ensure that the cared-for person's needs are being met. The worked example below illustrates circumstances in which care to the cared-for person is and is not provided for the purposes of giving the carer a break.

Example

The personal outcome agreed in respect of a particular carer might be that she should feel less isolated and more resilient.

The carer will achieve this personal outcome by attending a weekly carer's peer support group on a Saturday afternoon. This form of peer support will enable the carer to continue to provide care for her 20 year-old daughter (the cared-for person). The daughter's needs are such that she requires the constant presence of another person, and the carer usually provides that care except for when the daughter attends a day care centre, which she does from 10am to 4pm every weekday. The daughter's day care placement has been arranged under her social care needs assessment. It provides the ancillary benefit of giving the carer a break but is not provided for that purpose so does not constitute replacement care.

If the carer needs a paid care worker to look after her daughter for a few hours every Saturday in order that she can attend the peer support group, that replacement care would be support which meets the carer's identified needs and so is provided under section 24. Neither the carer nor the daughter would be charged for the replacement care.

On the other hand, if the peer support group meets at lunchtime on a Wednesday, there would be no requirement for replacement care in order for the carer to attend. The daughter's placement at the day care on a Wednesday would not become replacement care just because the carer is now attending the peer support group at that time. Therefore, the local authority will still be able to charge the cared-for person for the provision of the day care placement service according to their own charging policies.

¹⁰⁴ See Part 2, Chapter 2 on young carer statements, in particular, guidance on section 15(1)(c) and explanation of 'responsible authority'.

Breaks with the cared-for person

3.3.46. Where the carer and cared-for person have a break together with extra support for the cared-for person, this would normally be to enable both the carer and the cared-for person to have a break which meets both the cared-for person's assessed needs and the carer's identified needs (subject to local eligibility criteria). In such cases, charges for the cost of the break for the carer will be waived; but charges for the cost of the break for the cared-for person.

3.3.47. The additional support for the cared-for person can be put in place to benefit either party so these costs may require to be waived, depending on the circumstances, as illustrated in example 4 below.

Waiving of charges – illustrative examples

3.3.48. The following seven examples were developed by a task group involving representatives from COSLA, Shared Care Scotland, Social Work Scotland and Integration Authority Chief Finance Officers, plus social care practitioners from Integration Authorities/Local Authorities.

Example 1 – Distinguishing between need to reduce caring role permanently and need for breaks from caring

This example illustrates how the waiving of charges rules interact with the (sometimes marginal) distinction between situations where support¹⁰⁵ is:

a) to permanently reduce the caring role due to the carer's willingness or ability to provide care; or

b) to provide a regular break from caring.

Situation

Karen lives with and cares for her mother, Alison, who is 70. Alison cannot be left alone overnight due to night terrors and other mental health symptoms and has not left her home for 20 years other than to go to hospital. Alison is unable to leave her home to go to a residential care setting. Alison has had her support needs assessed and Karen has accepted the offer of an adult carer support plan.

Scenario 1(a) - Caring role needs to be permanently reduced

It is clear from Karen's adult carer support plan that she is not coping with the disturbed nights which are having a significant impact on her own health and wellbeing. She needs a lot more uninterrupted sleep to be able to continue caring and stay well. She is willing and able to provide some care at night but no longer able to provide 24/7 care without significant risks to her health and wellbeing. Having considered the circumstances of this case in light of its local policies, this local authority decides to provide three nights per week of overnight home based care and support.

<u>Analysis:</u> This is support which Alison needs because Karen is no longer available to provide it and needs to permanently reduce her caring role¹⁰⁶. It would therefore be part of Alison's care package and subject to the local

¹⁰⁵ Charging legislation refers to both 'services' and 'support'. These examples use 'support' to encompass both.

¹⁰⁶ See Carers (Scotland) Act 2016 Statutory Guidance, paragraphs 3.3.31 (summary point iii), 3.3.40 and 3.3.41.

authority's normal charging policies (including the requirements for free personal care). (It also meets Karen's identified need to reduce her overnight caring role in order to get more sleep.)

Scenario 1(b) - Carer needs a break

Alternatively, in terms of Karen's adult carer support plan, it is clear that she is willing and able to provide 24/7 care, but needs a break from overnight caring from time to time. The local authority decides to provide 20 nights per year of overnight home based care and support for Karen to take when she needs them.

<u>Analysis:</u> This meets Karen's identified need for a periodic break from overnight caring and is for Karen's benefit. It would therefore be carer support provided to Karen and the requirement to waive charges would apply.

In terms of the legislation

Scenario 1(a) would fall under section 24(1)(a) of the Carers (Scotland) Act 2016 ('the 2016 Act') That envisages cases where the carer's identified needs, for something other than a break, can be met by support for the cared for person¹⁰⁷. In those cases, even though the support to the cared for person may meet the carer's needs, it is not provided under the duty or power under section 24(4) of the 2016 Act so it is not covered by the requirement to waive charges. Instead it is support for the cared-for person provided under section 12 of the Social Work (Scotland) Act 1968.

Scenario 1(b) would be covered under section 24(4) and section 25 of the 2016 Act¹⁰⁸. The support is provided under the 2016 Act for the purposes of a break from caring and would therefore be covered by the requirement to waive charges.

Example 2 – Carer unavailable

This example illustrates decisions about the waiving of charges rules in cases where the carer is temporarily unavailable to provide care – in this case due to medical appointments and recovery. Other examples could include longer term unavailability due to work or childcare commitments, higher education, etc.

The example also illustrates local authorities' discretion to waive charges for social care support which is not carer support.

Situation

Tomáš cares for, and lives with his 45 year old son, Manuel, who has to be cared for in bed. Manuel has previously had his social care needs assessed and Tomáš has had an adult carer support plan. Tomáš receives a budget to enable him to take breaks from his intense caring role as and when he needs them. Because this budget is for carer support, the local authority has previously concluded that the rules on waiving of charges apply and Tomáš's budget is not means-tested¹⁰⁹.

¹⁰⁷ See Carers (Scotland) Act 2016 Statutory Guidance, paragraphs 3.2.5 and 3.2.14 (especially point ii).

¹⁰⁸ See Carers (Scotland) Act 2016 Statutory Guidance, paragraph 3.2.14 (especially points v, vi and vii) and summary following paragraph 3.3.31 (points i, ii, and iii).

¹⁰⁹ See Carers (Scotland) Act 2016 Statutory Guidance, paragraphs 3.3.5-7, 3.3.20 and summary following paragraph 3.3.31 (points i, ii, and iii).

Tomáš is subsequently diagnosed with a health problem which requires him to undertake a number of outpatient appointments followed by a short hospital stay and recuperation during which time he will be unable to continue in his caring role.

Following a joint home visit to update Tomáš's adult carer support plan and the assessment of Manuel's support needs it is agreed to put in place:

- additional care and support at home for Manuel to enable Tomáš to attend his outpatient appointments;
- short term residential care for Manuel while Tomáš is in hospital and while he starts his recuperation;
- further care and support at home for Manuel while Tomáš continues to recover at home and becomes able to re-establish some less strenuous aspects of his caring role.

<u>Analysis:</u> These additional supports are provided for Manuel while Tomáš is unable to provide care¹¹⁰. On that basis, this is not carer support so the rules on waiving of charges do not apply and the local authority's normal charging policies apply (including the requirements for free personal care from April 2019).

Tomáš's budget for breaks from caring is not affected by this additional support.

Scenario 2(a): Local authority decides to charge for the additional support for caredfor person

It is open to the local authority to charge Manuel for this support, as explained above, subject to its normal approach to means testing.

<u>Scenario 2(b): Local authority decides not to charge for the additional support</u> Alternatively, because of the individual circumstances of the case and in line with its local policy, the local authority decides to use its discretion not to charge a contribution towards this short-term additional support, while Tomáš is unavailable to provide care¹¹¹.

In terms of the legislation

The short term additional support provided in this example is support for the caredfor person provided under section 12 of the Social Work (Scotland) Act 1968 ('the 1968 Act').

In terms of the Carers (Scotland) Act 2016 ('the 2016 Act'), the support provided to Manuel will also meet Tomáš's need for time to undertake treatment and recovery. These needs will be identified in his updated ACSP but they are for something other than a break so would fall under section 24(1)(a) of the 2016 Act. This means the support to Manuel is not provided under the duty or power under

¹¹⁰ See Carers (Scotland) Act 2016 Statutory Guidance, paragraphs 3.3.31 (summary point iii), 3.3.40 and 3.3.41.

¹¹¹ COSLA's non-residential social care charging guidance 2018/9: "It is unlikely that charging policies will be able to make provision for the full range of personal circumstances. This means that councils should exercise local discretionary powers to apply flexibility in cases deemed appropriate." See www.cosla.gov.uk/social-care-charging-information

section 24(4) of the 2016 Act so it is not covered by the requirement to waive charges.

The local authority may, in line with its power under section 87 of the 1968 Act, 'recover such charge (if any) for it as they consider reasonable'. Scenarios 2(a) and 2(b) demonstrate that the local authority's power to charge includes the option for it to decide not to charge.

Example 3 – Varying degrees of benefit to carer and cared-for person

This example illustrates how the waiving of charges rules apply in cases where care and support is primarily to benefit either the carer or the cared-for person. It also illustrates how these rules can be applied in circumstances where care and support are of equal benefit to the carer and cared-for person.

Situation

Declan and Carol are both in their late 60s and live together in a rural community. Carol helps Declan with a lot of tasks, including toileting, washing, preparing food and eating, although Declan always does as much as he can for himself. Carol is able to help him around the home but cannot manage to take him out without additional help. There is no suitable club or day-care centre for Declan in the area.

Following an adult carer support plan for Carol and an assessment of Declan's support needs, it is agreed they would benefit from a weekly 2½ hour visit from a local agency who can match Declan and Carol with a regular care worker to chat with Declan and provide the care and support he needs while Carol has time to herself.

The following scenarios illustrate three alternative interpretations of how the waiving of charges rules might apply, depending on the circumstances.

Scenario 3(a): Support for the carer to have a break

Declan already has friends who visit regularly but Carol needs to stay during their visits to provide the personal care he needs. She is restricted due to her intense caring role and is unable to leave the house. She needs the support to provide a regular break from caring so that she can enjoy some time to herself, walking or going out with a friend.

<u>Analysis:</u> In this case, the support provided is primarily to allow Carol to have a break from caring. It is therefore carer support and the waiving of charges rules apply¹¹².

Scenario 3(b): Support for the cared-for person, to reduce isolation

Declan rarely sees anyone apart from Carol and his isolation is leading to depression. She is able to leave him for a couple of hours at a time and often goes out to the shops or to spend time with friends. In this case, the support provided is primarily to benefit Declan¹¹³. It is to help him feel less isolated and he looks forward to discussing issues which do not really interest Carol.

¹¹² See Carers (Scotland) Act 2016 Statutory Guidance, paragraphs 3.3.5-7, 3.3.20 and summary following paragraph 3.3.31 (points i, ii, and iii).

¹¹³ See Carers (Scotland) Act 2016 Statutory Guidance, paragraph 3.3.31 (question b.ii), 3.3.38 and 3.3.39.

<u>Analysis:</u> Because this is support for Declan, the waiving of charges rules do not apply and the local authority's normal charging policies apply (including the requirements for free personal care).

Scenario 3(c): Support for the wellbeing of both the carer and the cared-for person Both Declan and Carol are struggling emotionally because both are confined to the house with limited opportunities to spend time with other people.

<u>Analysis:</u> In this case, the support is provided to give them both a break from their normal routine and a chance to socialise with someone else. The local authority may therefore decide to apportion the costs of the support equally. That could mean treating 1¼ hours per week as support for Declan and 1¼ hours as carer support for Carol¹¹⁴. Alternatively it could mean treating 2 sessions per month as support for Declan and 2 as support for Carol. The waiving of charges rules would only apply to the support treated as carer support.

In terms of the legislation

Scenario 3(a) falls under section 24(4) and section 25 of the Carers (Scotland) Act 2016 ('the 2016 Act'). The support is provided under the 2016 Act for the purposes of giving Carol a break from caring. It would therefore be covered by the requirement to waive charges.

Scenario 3(b) would not be support provided under section 24 of the 2016 Act in order to give Carol a break. It may provide incidental benefits to Carol but it is intended to meet Declan's needs. It would therefore be support for the cared-for person under section 12 of the Social Work (Scotland) Act 1968 ('the 1968 Act'). It is therefore not covered by the requirement to waive charges.

Scenario 3(c) envisages a mixture of carer support under the 2016 Act and support for the cared-for person under the 1968 Act. The statutory guidance on the 2016 Act suggests at paragraph 3.3.29 that 'local authorities may wish to consider whether it would be appropriate to classify half of this as support for the carer and half as support for the cared-for person'. This could mean treating 1¼ hours a week or 2 sessions a month as support for the carer under the 1968 Act and 1¼ hours a week or 2 sessions a month as support to the carer under the 2016 Act.

Example 4 – Holiday break for carer and cared-for person together

This example shows how the waiving of charges rules can apply where a carer and a cared-for person take a holiday break together.

Situation

Tina and Bobby are a couple in their 50s. Bobby cares for Tina because of her mobility problems - she uses a wheelchair to get about but needs help transferring, toileting, washing and food preparation. Bobby works part time and is providing most of the support for Tina. Tina has already had her support needs assessed and care workers come in twice a day when Bobby is at work to help with her lunch and to

¹¹⁴ See Carers (Scotland) Act 2016 Statutory Guidance, paragraph 3.3.29.

ensure she gets to the toilet. (This is support for Tina while Bobby is unavailable and so not carer support, meaning that the waiving of charges rules do not apply.)

During discussions as part of preparing his adult carer support plan, Bobby explains that the pressure of juggling work and his caring role is getting to him. He feels that this pressure is having a negative impact on his relationship with Tina and that they could both benefit from a break. He has an identified need for a break from caring. As a consequence, the assessment of Tina's support needs is reviewed and confirms that Tina would also benefit from a break.

Tina and Bobby want to strengthen and support their relationship by taking a break together but in a way which also enables Bobby to have a break from caring. Funding is agreed to support them to have a break at a hotel they have stayed at before Tina's mobility deteriorated. Having an accessible room in this familiar setting helps Tina and Bobby to be confident that their stay will go well. As part of the break, it is agreed to provide:

a) equipment to assist Tina to use the shower and toilet in their bathroom;

b) a local care agency to provide two daytime visits per day to assist Tina, similar to her normal package of support at home; and

c) two additional visits from the local care agency in the morning and the evening to help Bobby with Tina's care to give him a rest.

<u>Analysis:</u> This break meets both their identified needs and delivers a mixture of both carer support and support for the cared for person. The local authority therefore treats 50% of the funding provided towards shared costs of the hotel accommodation as carer support for Bobby and 50% as support for Tina. The waiving of charges rules would therefore apply to Bobby's 50% share of those shared costs.¹¹⁵

Of the additional support, (a) and (b) are support for Tina and subject to the local authority's normal charging policies (including the requirements for free personal care from April 2019). The equipment hire (a) is to meet Tina's needs to enjoy the break and the two daytime visits per day (b) are equivalent to those she already receives as part of her normal care package.

The two additional morning and evening visits (c) from the local agency are intended to give Bobby a break from his normal caring role. They are therefore provided as carer support and the waiving of charges rules would apply.

In terms of the legislation

The holiday break is delivering a mixture of carer support under section 24(4) and section 25 of the Carers (Scotland) Act 2016 ('the 2016 Act') and support for the cared-for person under section 12 of the Social Work (Scotland) Act 1968 ('the 1968 Act').

The statutory guidance on the 2016 Act advises at paragraph 3.3.46 that the carer's share of the costs should be seen as support under the 2016 Act and therefore subject to the waiving of charges rules, while the cared for person's

¹¹⁵ See Carers Act Statutory Guidance, paragraphs 3.3 29 and 3.3.46.

share of the costs would not be carer support and the waiving of charges rules would not apply.

The equipment to assist Tina to use the shower and toilet in their bathroom (a) is needed to enable her to stay in the hotel. The two daytime visits from the local care agency (b) to assist Tina are effectively a continuation of her normal package of support at home. Both (a) and (b) are therefore support for the cared-for person provided under section 12 of the 1968 Act.

The additional morning and evening visits from the local care agency (c) are not to enable Tina to stay in the hotel because, in theory, Bobby could provide this care as part of his normal caring role. Instead this additional support is provided under section 24(4) and section 25 of the 2016 Act for the purposes of giving Bobby a break from caring during their stay at the hotel. It would therefore be covered by the requirement to waive charges.

Example 5 – Break for a carer with needs that do not meet local eligibility criteria

This example shows how the waiving of charges rules can apply in cases where a local authority decides to provide breaks for a carer even though his identified needs do not meet local eligibility criteria.

Situation

Mark is a widower and is the main carer for his daughter, Jordan (24), who has a learning disability. Jordan is physically fit, can do most things for herself and can safely be left at home on her own for a few hours, but she can be quite demanding of Mark's time. When her mother was alive this was manageable but now that Mark is trying to cope on his own he is finding it harder. Jordan's brother provides support but this is limited because he has a young family. Jordan has already been assessed as needing support and attends a day support service five days a week. However, this is while Mark is at work so it doesn't give him a break.

In the review of his adult carer support plan, it emerges that Mark's mood is quite low because he feels he has to respond to Jordan's demands whenever he is at home. He would like to play golf one Saturday a month with friends but it is 3 months since he has managed this because Jordan makes it difficult for him to go. This leads to an identified need for a monthly short break for Mark to ensure he can join his friends to play golf.

This identified need does not meet the threshold for funded carer support in this local authority's local eligibility criteria. Nevertheless, the local authority decides to use its power to provide a regular short break to prevent potential deterioration in Mark's health and wellbeing. It provides additional social support for Jordan to go out with a support worker some Saturdays, to ensure Mark can go to play golf.

<u>Analysis:</u> This extra support is primarily to allow Mark to have a break from caring. Even though it is for an identified need which does not meet the local

eligibility criteria, the waiving of charges rules apply since it is carer support.¹¹⁶

In terms of the legislation

The extra support provided for the carer in this example is provided under the power at section 24(4)(b) of the Carers (Scotland) Act 2016 ('the 2016 Act'). This power allows local authorities to provide support to a carer to meet identified needs which fall short of the local eligibility criteria.

The requirement to waive charges applies to all support provided under section 24 of the 2016 Act – regardless of whether it is under the duty at section 24(4)(a) or the power at section 24(4)(b).

Example 6 – Support already in place for the cared-for person

Example 6 illustrates how the cost of support already in place for the cared-for person can interact with the waiving of charges for replacement care. It also illustrates how these rules apply to the other costs of a residential break for a cared-for person organised specifically to benefit a carer, including the costs of board and lodging (sometimes known as 'hotel costs').

Situation

Gillian and Craig are in their 80s and live at home. Gillian is Craig's main carer providing a variety of personal and other care, 7 days a week. Craig is fine on his own for a couple of hours but Gillian still has an intense caring role.

Craig already receives 10 hours per week of social care support for care which Gillian is no longer strong enough to provide. He already pays a means-tested contribution towards this according to the local authority's normal charging policies (including the requirements for free personal care).

When her adult carer support plan is reviewed, Gillian explains that she is starting to struggle. As a consequence, she has an identified need for a complete break from time to time, so that she can totally switch off. After discussion with Gillian and Craig, the local authority decides to organise an occasional residential stay for Craig at a short break unit in a nearby care home, to allow Gillian to have a short break.

<u>Analysis:</u> Craig's existing social care package provides support for him which Gillian is not able to provide. His needs for that support will have to be met while he is staying in the short break unit, although the support may be provided in a different way and in a different setting. Accordingly, the local authority continues to charge exactly the same for providing this support (in line with the requirements for free personal care).

The stay at the short break unit is provided to allow Gillian to have a break from caring. Aside from the ongoing social care support Craig will continue to receive, the costs of that stay are carer support so the waiving of charges

¹¹⁶ See Carers (Scotland) Act 2016 Statutory Guidance, paragraphs 3.3.5-7, 3.3.20 and summary following paragraph 3.3.31 (points i, ii, and iii).

rules apply.¹¹⁷ The local authority therefore makes no other charge for the short break.

In terms of the legislation

Craig's existing social care support package is provided under section 12 of the Social Work (Scotland) Act 1968 ('the 1968 Act'). He will continue to require such support under the 1968 Act while he is staying in the short break unit, although that support will be provided in a different setting. Accordingly, the local authority can continue to charge for that support, subject to the requirements for free personal care.

Craig's stay at the short break unit falls under section 24(4) and section 25 of the Carers (Scotland) Act 2016 because it is support provided to allow Gillian to have a break from caring. Aside from the ongoing social care support Craig will continue to receive as outlined above, the costs of his stay at the short break unit are carer support so the waiving of charges rules apply.

Example 7 – Support for Young Carer

This example shows how the waiving of charges rules can apply where a young carer needs support to alleviate their caring role.

Situation

Ben is thirteen and cares for his mother Jane who has a progressive neurological disease. Her symptoms fluctuate and the caring role can become more intensive at times. The condition affects her mobility and co-ordination and ability to undertake daily living tasks. The situation is sensitive in that Ben and Jane are coming to terms with the recent diagnosis and its effect on them both.

Discussions as part of preparing Ben's young carer statement identified that he would want to have more time with his friends (an identified personal outcome). However, he is reluctant to spend time way from his home as he feels guilty about leaving Jane on her own. It is also apparent that during the school summer break, Ben is likely to take on a more extensive caring role. This would prevent him from socialising and therefore would have a negative impact on his wellbeing.

As a consequence, he has an identified need for support during the summer holidays. The local authority decides to provide a summer programme of activities over seven weeks. This includes one to one support, as well as joining his peers at a series of sports and outdoor activities.

During a family meeting as part of preparing the young carer statement, it was also felt that Ben's summer activities would allow Jane time to come to terms with the impact of her diagnosis and start to consider longer term support options to meet her increasing care needs. Jane was referred for assessment of her own support needs to ensure that Ben's caring role could be alleviated in the longer term.

<u>Analysis:</u> The summer activity programme is support for Ben to ensure he maintains a social life beyond caring, similar to that of his non carer peers. It

¹¹⁷ See Carers (Scotland) Act 2016 Statutory Guidance, paragraphs 3.3.5-7, 3.3.20 and summary following paragraph 3.3.31 (points i, ii, and iii).

is provided at a time when he would otherwise be at risk of taking on an inappropriately intensive and isolating caring role, which could have a negative impact on his health and wellbeing. The waiving of charges rules would therefore apply to the cost of the summer activities.¹¹⁸

In terms of the legislation

The summer programme falls under section 24(4) of the Carers (Scotland) Act 2016 because it is support provided to protect Ben's health and wellbeing by ensuring that he maintains contact with his peers and that the extent of his caring role does not become inappropriately intensive during the holidays.

¹¹⁸ See Carers (Scotland) Act 2016 Statutory Guidance, paragraphs 3.3.5-7 and 3.3.10.

Part 4: Carer involvement

Chapter 1 – Carer Involvement in Services and Service Planning

Summary

Section 27 requires local authorities and health boards to involve carers and persons representative of carers in the carer services they provide. 'Carer services' are defined to include both services to carers and services to cared-for persons. 'Involvement' is defined to include involvement in considering what needs might call for services, what services might be provided to meet those needs, and how those services might be provided and evaluated. This ensures the involvement of carers at a strategic level in the design and delivery of services.

Sections 29 and 30 amend other legislation so as to require local authorities to involve individual carers in decision making at an individual level.

Section 29 amends section 1 of the Social Care (Self-directed Support) (Scotland) Act 2013. The amendments provide that carers must have as much involvement as they wish in the assessment of their needs and the provision of support under the Carers (Scotland) Act 2016.

Section 30 amends section 12A of the Social Work (Scotland) Act 1968 and section 23 of the Children (Scotland) Act 1995. The amendments require local authorities to take carers' views into account in assessing the needs of the cared-for person and in deciding whether and how to provide services to the cared-for person.

Section 28 deals with carer involvement in hospital discharge of cared-for persons. This is covered in the next chapter of this guidance.

The duty under section 27 applies to local authorities and health boards but is not required to be delegated to integration joint boards as integration joint boards already have responsibilities to ensure carer involvement under the Public Bodies (Joint Working) (Scotland) Act 2014.

For the purpose of this chapter the terminology 'local authorities' and 'health boards' will continue to be used in place of integration joint boards or integration authorities.

Purpose of carer involvement

4.1.1. The Act strengthens the existing commitment to the principle of carer involvement in the development and delivery of services supporting both carers and cared-for persons at both strategic and individual levels. It does this through a combination of free standing duties in the Act and amendment to other relevant legislation.

4.1.2. At an individual level, the expertise and knowledge of carers can be seen as a vital resource to help inform the design and delivery of relevant care and support

services. As such, the principle of carers as equal and expert partners is important. This is especially pertinent in the case of carer groups with particular needs or sensitivities; for example, specific considerations relevant to carers from minority ethnic communities.

4.1.3. The National Carers Strategy 2010-2015¹¹⁹ articulated Scottish Government policy of carers being viewed as equal partners in care. The established Equal Partners in Care (EPiC) framework states: 'Carers have a unique role in the life of the person they care for. When we are planning and delivering care for that person, it's important that we involve their carer. They have valuable knowledge to contribute and any decision will have an impact on their caring role. Carers, the person they care for and workers from health and social services should work together as partners to achieve better outcomes for all involved.'

Form of Involvement

4.1.4. Carer involvement can take many forms, including informing carers and carer representatives of relevant information relating to the range and types of carer services available to them. It can also empower carers and carer representatives to make informed decisions, as with the shaping and delivery of any personalised support using the four options of Self-directed Support.

4.1.5. Shared Care Scotland has published a toolkit¹²⁰ for consulting and engaging with stakeholders on short breaks that contains a range of different tools with which to seek involvement from carers and people who use services.

4.1.6. Authorities may wish to consider appropriate forums for sharing learning and experiences both between carers and between authorities, including information hubs, Carer Leads meetings and where appropriate, social media.

Duties to involve in carer services

4.1.7. Section 27 requires local authorities and health boards to take such steps as they consider appropriate to involve carers and such persons and bodies representative of carers in the planning and evaluation of carer services.

4.1.8. 'Persons and bodies representative of carers' may include third or voluntary sector organisations. Authorities are strongly recommended to work closely with such organisations in developing services.

4.1.9. Under section 27(4) 'carer services' are defined as services provided or to be provided by the relevant authority to carers (in relation to the care they provide, or intend to provide), or to cared-for persons (in relation to the care they receive).

4.1.10. Certain services are excluded from the duty to involve carers by virtue of section 27(5), to avoid duplicating existing requirements to involve carers in these cases. These are:

• services which are contained in a children's services plan (within the meaning of section 8 of the Children and Young People (Scotland) Act 2014 if the

¹¹⁹ <u>http://www.gov.scot/Publications/2010/07/23153304/0</u>

¹²⁰ https://www.sharedcarescotland.org.uk/resources/tools/consultation-toolkit/

persons mentioned in section 27(3) of the Carers Act have been consulted in relation to the preparation of that plan; and

services provided by virtue of functions which have been delegated under an integration scheme (within the meaning of section 1(3) of the Public Bodies (Joint Working) (Scotland) Act 2014) or which are to be carried out in conjunction with those functions – as integration authorities already have similar responsibilities to involve carers under the 2014 Act.

4.1.11. 'Involvement' is defined in section 27(6)(a) to (d) to include involvement in considering what needs might call for services, what services might be provided to meet those needs, and how those services might be provided and evaluated. This ensures the involvement of carers at a strategic level in the design and delivery of services.

4.1.12. This includes involvement in the decision making process for the setting of local eligibility criteria.

4.1.13. In looking at what services might be provided, carers would be involved in considering:

- what services or assistance could be provided to cared-for persons other than care for the cared-for person (e.g. equipment and adaptations or mental health services);
- what general services might be provided such as information and advice (under section 34); and
- what other general services available universally in the community (e.g. youth clubs or leisure centres).

4.1.14. In looking at how services might be provided, carers would be involved in considering:

- provision through the commissioning process of support services; and
- provision at an individual level in design and delivery of support to the carer and/ or the cared-for person.

4.1.15. Looking at evaluation of services might include carers being involved in considering how evaluation of carer services may form part of a relevant authority or service provider's practice of continuous improvement.

Timing and level of involvement – individual cases

Carer involvement in assessments and support to carers

4.1.16. Section 1 of the Social Care (Self-directed Support) (Scotland) Act 2013 (as amended by section 29 of the Act) requires authorities to have regard to the principles in section 1¹²¹ of that Act when carrying out functions relating to adult carer support plans, young carer statements, eligibility criteria and the duty to provide support to carers. These principles are:

a) a person must have as much involvement as they wish with regard to their needs assessment and support provision;

b) a person must be provided with any reasonable assistance to enable them to express views the person may have about the self-directed support options or make an informed choice about the options; and

¹²¹ <u>http://www.gov.scot/Publications/2014/04/5438/4</u>

c) a local authority must collaborate with a person regarding a person's needs assessment and support provision.

4.1.17. Statutory guidance¹²² produced to support the Social Care (Self-directed Support) (Scotland) Act 2013 elaborates on the core values and principles of care and support in section 1.

4.1.18. This requirement for carer involvement applies to all stages of a carer providing, or intending to provide, care and to all local authorities and health boards.

Carer involvement in assessment and provision of support to cared-for person

4.1.19. Section 30 of the Act amends both section 12A of the Social Work (Scotland) Act 1968 and section 23 of the Children (Scotland) Act 1995. The amendments require local authorities to take carers' views into account so far as it is reasonable and practicable to do so in assessing the needs of the cared-for person and in deciding whether and how to provide services to the cared-for person.

4.1.20. The amendments at section 30(2) to (4) incorporate the principles of carer involvement into section 12A of the Social Work (Scotland) Act 1968¹²³. Section 12A(1B) of the 1968 Act (as amended) requires that as far as it is reasonable and practical to do so, a local authority must take account of the views of the carer when:

- a) assessing the needs of the cared-for person;
- b) deciding the need for support; and
- c) deciding how any support services are provided.

4.1.21. The amendments at section 30(5) to (7) incorporate the principles of carer involvement into section 23 of the Children (Scotland) Act 1995¹²⁴. Section 23 of the 1995 Act (as amended) requires that as far as it is reasonable and practical to do so, a local authority must take account of the views of the carer when:

- a) assessing the needs of the child being cared-for;
- b) deciding the need for support; and
- c) deciding how any support services are provided to that child.

4.1.22. The level and means of carer involvement in these decisions about the cared-for person can be determined on a case-by-case basis and may require professional judgement from those involved. There may be conflicts between the wishes of the carer and the cared-for person. Sometimes the cared-for person will not accept services to support them, which may in turn place an additional burden back onto the carer.

Involving young carers

4.1.23. The duties to involve carers apply equally for young carers. They apply to strategic planning, particularly for the design and provision of young carer specific services, and to individual assessment and decision making.

4.1.24. Different considerations and approaches will be relevant for the involvement of young carers. In this context, the aim of authorities would be to minimise the impact of their caring role on the young carer's life, and to provide alternative support

¹²² http://www.gov.scot/Publications/2014/04/5438/0

¹²³ http://www.legislation.gov.uk/ukpga/1968/49

¹²⁴ http://www.gov.scot/Publications/2004/10/20066/44708

to the cared-for person that minimises the need for the young carer to act as a carer, taking into account their age and maturity.

4.1.25. There is a risk that, in supporting young carers in their caring role, authorities could inadvertently perpetuate inappropriate levels of caring by the young person. Young carer input and involvement will be a particular consideration in ensuring this does not happen.

4.1.26. Authorities should recognise that in some situations, young carers may wish to continue to care for someone, but require to be supported sensitively with the aim of minimising the impact of their caring on their wellbeing indicators in line with the Getting it right for every child approach¹²⁵.

¹²⁵ <u>https://www.gov.scot/policies/girfec/</u>

Chapter 2 – Carer involvement in hospital discharge of cared-for persons

The terminology 'patient' is used throughout this chapter of the guidance in place of 'cared-for person'. This is to place it in the context of the hospital setting. 'Cared-for person' will be used only when quoting and paraphrasing the legislation.

This chapter is not intended to provide guidance on all aspects of hospital discharge and other associated processes. Instead, it provides statutory guidance on the key aspects of the duty placed on health boards at section 28 of the Act along with some suggestions and recommendations on how to meet the duty.

There are many other local and national guidance and best practice documents that comprehensively cover many different aspects of hospital discharge planning, many of which are referenced in this chapter.

Summary

Section 28(1) and (2) requires each health board to involve the carer before a cared-for person is discharged from hospital. It must do so by

(a) taking steps as it considers appropriate to: inform the carer as soon as reasonably practicable of the intention to discharge the cared-for person; and invite the views of carers about the discharge; and

(b) taking account, 'so far as it is reasonable and practicable to do so', of any views given by the carer in making decisions relating to discharge of the cared-for person.

Section 28(3) provides that this duty only applies where:

- the carer of the cared-for person can be identified 'without delay'; and
- where it appears to the health board that the cared-for person is likely to require care following discharge.

The duty under section 28 is subsidiary to any hospital functions delegated to integration joint boards. That means that where hospital functions are delegated to joint boards, the subsidiary duty to involve carers under section 28 will automatically be delegated. In these cases, although the duty applies to health boards and the State Hospital Board for Scotland, in practice it will be implemented by health boards, the State Hospital Board and local authorities working together under the direction of the integration joint boards. This approach will ensure that the functions are exercised in an appropriately integrated way, joining up support for professionals, patients and carers. Where hospital functions are not delegated to joint boards, the subsidiary duty to involve carers under section 28 will not be delegated either.

For the purpose of this chapter, the terminology 'health boards' will continue to be used in place of integration joint boards or integration authorities.

Definition of hospital

4.2.1. A hospital in the context of this duty is a 'health service hospital' as defined in section 108 of the National Health Service (Scotland) Act 1978 (as amended)¹²⁶. The duty is also placed on State Hospital Board for the state hospital in Scotland as defined in section 102 of the 1978 Act¹²⁷.

4.2.2. Community hospitals are included within this definition.

4.2.3. This duty does not apply to private hospitals in Scotland unless they are providing NHS treatment to the patient, in which case it is the health board responsible for the patient that has responsibility to ensure the duty is complied with.

Definition of discharge

4.2.4. There is no legal definition of a hospital discharge. Health boards are encouraged by the Scottish Government to prepare an Admission, Transfer and Discharge protocol (ATD). This will be an agreed protocol for use in NHS facilities. The Scottish Government has published a Framework for the Production of Joint Hospital Discharge Protocols¹²⁸.

4.2.5. It is recommended to consult the local ATD protocol or seek advice from the relevant health board if unclear about the discharge process in an individual setting or locality.

4.2.6. It is generally understood that when a patient has finished their course of treatment or medication and a doctor has assessed they are fit to leave hospital, they will be clinically ready for discharge.

When this duty applies

- 4.2.7. The duty applies in situations where:
 - either:
 - The identified carer is an adult carer or a young carer (as defined at section 1 of the Act); or
 - an individual is identified who intends to provide care to a patient postdischarge; or
 - the individual is providing or intends to provide care but does not selfidentify as a carer; and
 - professionals consider it likely that the patient will require care from a carer following discharge; and
 - a formal discharge process takes place.

4.2.8. There are settings, such as Assessment Units, in which it can be more ambiguous whether patients require a formal discharge. In such cases no absolute rule should be applied and each case dealt with on an individual basis.

¹²⁶ http://www.legislation.gov.uk/ukpga/1978/29/section/108

¹²⁷ http://www.legislation.gov.uk/ukpga/1978/29/section/102

¹²⁸ http://www.sehd.scot.nhs.uk/publications/CC2003 09.pdf

4.2.9. Neither the nature nor amount of the care estimated to be required following discharge of the patient from hospital should affect whether the hospital involves the carer in the discharge process.

4.2.10. The health board discharging the patient may not be the board for the area where the patient resides. Where this is the case, the health board discharging the patient must still apply this duty.

4.2.11. The duty applies regardless of the patient's discharge destination. It may be the case that a patient is to be discharged to a different place from where they were living before they were admitted to hospital. For example, an individual who had previously been living at home might be discharged to a care home, another NHS facility for further treatment, or to a lower security hospital.

Exceptions – Outpatients and A&E

4.2.12. The duty does not apply if the patient is an outpatient or is attending A&E.

Mental Health

4.2.13. In relation to mental health, the duty does not apply if the patient has a suspension of detention or has received conditional discharge under the Mental Health (Care and Treatment) Act 2003 (the '2003 Act').

4.2.14. It is not necessary for the section 28 duty to apply here because there is already a separate duty to have regard to carers views under section 1 of the 2003 Act. This requires any person undertaking a function under the 2003 Act, to have regard to relevant views of any carer about that function. For discharge, this includes suspension of detention or conditional discharge. The Code of Practice Volume 1 for the 2003 Act goes into further detail on the requirement to take consideration of the carers' situation and needs, 'so far as is practical and reasonable'¹²⁹.

For information

Suspension of detention can apply to individuals who are detained in hospital under the Mental Health (Care and Treatment) Act 2003. It enables the Responsible Medical Officer (RMO) to suspend a person's detention, to allow greater freedom and a better quality of life, while still providing the care and treatment he or she needs. Generally, suspension of detention must be authorised by the RMO for any time a detained patient spends outside the hospital grounds.

Conditional discharge allows a period of formal supervision of a patient in the community by closely monitoring his/her mental health and behaviour for any indicators of increased risk to others so that steps can be taken to assist him/her and protect the public. It also allows a period of assessment of the patient in the community before a final decision is taken on whether to remove the safeguards and control imposed by the restriction order by means of an absolute discharge.

¹²⁹ <u>https://www.legislation.gov.uk/asp/2003/13/contents</u>

Why involve carers?

4.2.15. There is evidence to suggest that there has been a significant increase in recent years of post-discharge care being provided by unpaid carers¹³⁰. It is believed that if the hospital discharge is handled in a positive way and involves the carer, this can help with patient recovery and improved outcomes as well as preparing the carer for the care provision to be transitioned back into the community¹³¹.

4.2.16. Professionals involved in discharge planning may not be aware of all aspects of a patient's requirements and wishes. Carers often have detailed knowledge of the patient's medical and social care history as well as an understanding of other relevant issues and personal beliefs. This knowledge can aid professionals who are making decisions around discharge and appropriate after-care and support arrangements.

4.2.17. Evidence shows that the involvement of carers in hospital discharge planning can reduce the risk of delayed discharge and readmission¹³². There is a large cost attached to the provision of additional, perhaps unnecessary, support to someone who has been readmitted to hospital or whose discharge has been delayed.

4.2.18. It is important that the carer feels prepared for the hospital discharge of the patient. Being informed and involved in the process can reduce the risk of negative impacts on the carer's health and wellbeing and produce better outcomes for the carer overall.

4.2.19. Through the involvement of the carer in the hospital discharge process, carers are likely to be better supported through signposting to and awareness of appropriate support and services available to both themselves and the patient.

Workforce readiness

4.2.20. Health boards are encouraged to ensure their local guidance is up to date in relation to the new duty. It will be the responsibility of the health board to ensure that professionals are aware of the duty and have the required training to allow them to meet it.

4.2.21. The Equal Partners in Care¹³³ (EPiC) national framework contains an online learning resource which can be used by all professionals to develop their skills and knowledge to enable them to actively involve carers in the care of the cared-for person at all stages of the planning and decision making process.

¹³² <u>https://www.nice.org.uk/guidance/qs136/chapter/Quality-statement-5-Involving-carers-in-discharge-planning</u>

¹³⁰ Dellasega C & Nolan M (1997) Admission to care: facilitating role transition amongst family carers, *Journal of Clinical Nursing 6*, 443–451; Shepperd S, Parkes J, McClaran J & Phillips C (2004) Discharge planning from hospital to home, *Cochrane Database of Systematic Reviews* 1, 1–38; Goodwin V & Happell B (2006) Conflicting agendas between consumers and carers: the perspectives of carers and nurses, *International Journal of Mental Health Nursing* 15, 135–143.

¹³¹ The Princess Royal Trust for Carers, *Out of Hospital' Project – Learning from the Pilot Projects Final Report*, May 2010

¹³³ https://learn.nes.nhs.scot/22660/person-centred-care-zone/carers/equal-partners-in-care

4.2.22. Although the duty is placed on health boards, it would be expected that health, social care and third sector professionals would work together to ensure that patients and carers are supported.

Involving the carer

4.2.23. The health board must take 'such steps as it considers appropriate' to meet the duty at section 28. As such, professionals will be required to exercise judgement in certain cases, including where concerns in relation to the carer about child or adult protection have been raised.

4.2.24. In order to involve the carer, it would be expected that a discussion would take place between professionals, the patient and the carer if possible. Professionals may wish to provide information to the carer on what they might reasonably expect to happen during the hospital discharge process and how they should be involved.

Example

The Triangle of Care¹³⁴ model of carer involvement has been developed by Carers Trust Scotland, particularly for use in mental health settings, but is a transferable tool. Its aim is to encourage improved engagement and collaboration between service user, carer and professional. The Triangle of Care details six key standards that are required to achieve better collaboration and partnership with carers in planning for the patient's care. These are:

1) carers and the essential role they play are identified at first contact or as soon as possible thereafter;

2) staff are 'carer aware' and trained in carer engagement strategies;

3) policy and practice protocols relating to confidentiality and information sharing are in place;

4) defined posts responsible for carers are in place;

5) a carer introduction to the service and staff is available, with relevant range of information across the care pathway; and

6) a range of carer support services is available.

Planned and unplanned admissions

4.2.25. In cases where hospital admission is planned, such as pre-planned operations, the involvement of the carer in hospital discharge may have begun before the patient is admitted to hospital. Discussions with GPs and other professionals in order to plan for the admission may include the carer where appropriate. This is likely to include an element of anticipatory care planning¹³⁵. It may be useful for professionals in the hospital setting to identify if any such plans have been produced when they begin to involve the carer in the discharge planning process.

 ¹³⁴ Carers Trust Scotland, *The Triangle of Care: Carers Included: A Guide to Best Practice in Mental Health Care in Scotland*, 2013: <u>https://carers.org/resources/all-resources/78-triangle-of-care-a-guide-to-best-practice-in-mental-health-care-in-scotland-</u>.
 ¹³⁵ http://ihub.scot/anticipatory-care-planning-toolkit/

4.2.26. It would be helpful for professionals to identify whether an emergency plan is in place where the patient's hospital admission is not planned. This may have been produced in conjunction with the carer and detail useful information.

Who is the carer?

4.2.27. If a patient has more than one carer all identified carers must be involved in the discharge process. If for whatever reason it has not been possible to identify all carers of a patient where it is known that a patient has more than one, then the duty is intended only to apply in respect of the carer(s) identified 'without delay'.

4.2.28. Professionals must not assume that the most frequent visitor, the next of kin or a patient's welfare guardian have a caring role for the patient. It would be expected that introductory conversations with family and friends would seek to identify whether or not there are any caring responsibilities without making any prior assumptions.

Specific Considerations

4.2.29. There will be specific considerations for the health board to take into account in certain situations in order to meet the duty. In rural and remote areas this might include consideration of whether carers may be unable to travel to the hospital to visit the patient. In this situation it may be appropriate to call the carer at home instead of assuming they will be able to travel to the hospital. Where the carer is a young carer they may not be available during school hours.

Identifying the carer 'without delay'

4.2.30. Section 28 of the Act only applies when:

- the carer can be identified 'without delay' ; and
- where the patient is likely to require care following discharge. This applies in circumstances including where the care need has increased, decreased or stayed the same or if the nature of care required has changed.

4.2.31. It is expected that professionals would take steps as early as possible after a patient's admission to identify whether they have a carer if this is not already known. In doing so, professionals may wish to consider the most appropriate approach.

Example

Professionals may wish to ask the patient if they have a carer or when speaking to patient visitors, ask whether they or someone they know undertakes caring responsibilities.

4.2.32. A family member or friend may have been providing care for a period of time prior to the patient's hospitalisation however does not self-identify as a carer. This could be for a number of reasons¹³⁶, including because they do not recognise the term as being relevant to their situation or they are unsure of its meaning. In this

¹³⁶ Carers UK, *Missing Out: The Identification Challenge* November 2016 provides an overview of some of the reasons for and challenges of carer identification.

case, the individual may not respond positively to professionals using certain terminology and language.

4.2.33. Professionals should be aware that using alternative language may help with identifying whether or not they have a caring role. For example: 'do you look after...' or 'do you provide any support to...'.

4.2.34. Professionals should not place pressure on the individual to self-identify as a carer however professionals may wish to signpost them to further information and support.

4.2.35. There may be situations where it is not possible to identify a carer. For example, where communication between health professionals and the patient is difficult, or where the patient has been living independently prior to admission and does not therefore have a carer.

Informing the carer

Timing

4.2.36. The carer must be informed 'as soon as reasonably practicable' of the intention to discharge the patient. This means the carer should be informed of the intention to discharge the patient as soon as possible when they are considered clinically ready to be discharged. That might be soon after the patient's admission or it might be later during the hospital stay but will vary depending on the individual situation.

Method

4.2.37. Appropriate methods of informing carers about the discharge of the patient will be a decision for the health board however the method of doing so is likely to depend on the individual situation. It is good practice to give consideration to the carer's circumstances when identifying the most appropriate way to inform the carer.

Example

If a carer is often present on the ward, the most appropriate method may be for professionals to approach them to make them aware of the intention to discharge, or alternatively scheduling a phone call to inform the carer if they are at home.

Inviting the carer to give views about the discharge of the cared-for person

4.2.38. Identified carers must be invited by professionals to give their views about the discharge of the patient. Professionals may prompt the carer to provide these views at an appropriate time. This is likely to take place before the patient is declared medically fit for discharge.

4.2.39. Professionals are encouraged to be mindful of how a carer may be feeling as a result of the patient being admitted to hospital and be sensitive in their approach to seeking views.

4.2.40. The method for obtaining the views of the carer will be dependent on the individual situation.

Example

The carer may be invited to the hospital to give their views, however a discussion over the telephone may suffice.

4.2.41. Professionals should be aware that carers will have different levels of understanding of the medical treatment (medicines, special diets, aides and adaptations etc.) the patient is receiving. Treatment may have changed during the patient's stay in hospital. It is important that carers are fully informed of the patient's updated medical situation before taking their views as this may impact on a number of things, including suitability of the discharge destination and their willingness and ability to care.

4.2.42. It may be that a carer has been identified at an earlier stage and views about the hospital discharge have already been provided prior to the patient being clinically ready for discharge. In this case, it would be good practice to revisit any views given at an earlier stage prior to the discharge, especially if the patient or carer situation has altered.

Example

Health boards may wish to consider using the exchange model, an approach to conversation often used by social workers that recognises people are 'an expert in themselves'. If the carer is unsure about the sort of views or information that might be appropriate to share in relation to hospital discharge, professionals may wish to prompt them with questions.

Taking account of any views given by the carer

4.2.43. The health board must take account of the carer's views 'so far as it is reasonable and practicable to do so'. There will be circumstances where it may not be reasonable and practical to take account of their views. This might happen if the carer is out of the country and staff are unable to get in contact with them by the time the patient is clinically ready for discharge.

4.2.44. Where there is more than one identified carer invited to give views and these views are contradictory, it would be expected that professionals will work together, having taken both sets of views into account, so far as it is reasonable and practicable to do so, to identify the most appropriate course of action for the patient.

4.2.45. Professionals are expected to work towards meeting the target of discharging the patient within 72 hours of being clinically ready.

4.2.46. As is current practice, the health and safety of the patient will be the primary consideration when taking account of the views of the carer. Health and social care professionals will be expected to use their professional judgement by asking the primary eligibility question for discharge: 'can this individual's care needs be properly met in any other setting than hospital?'

4.2.47. If a carer is unhappy about a decision made regarding the patient's discharge after having given their views, it may be considered appropriate to have a

conversation with the carer to explain the reasoning behind the decision. It might be helpful to provide information to the carer on any additional support for themselves or the patient to enable them to care for the patient post discharge.

Young carers

4.2.48. The intention of the Act is that young carers are able to be children and young people first and foremost and are protected from undertaking inappropriate caring responsibilities.

For Information

Professionals may wish to consider the following when the carer is a child:

- whether the young carer understands what hospital discharge means and the process which will follow;
- whether the patient understands that the child has a caring role at home, and what it is;
- there may be differences in accounts given by the young carer and the patient about the level of caring already being undertaken at home;
- whether the young carer may need an advocate to confidently present their case during the discharge process; and
- what impact the condition of the patient at time of discharge is likely to have on any children in the family and arrange for appropriate referral for support.

Patient is an adult with incapacity

4.2.49. The involvement of carers in situations where the patient is an adult with incapacity¹³⁷ is likely to require sensitive handling by professionals. Professionals may wish to refer to the tool 'Adults who lack capacity - discharge process: key actions ¹³⁸' for guidance on the matter.

4.2.50. The final decision as to whether or not to involve the carer will be that of the professional, using their professional judgement, having sought the views of the welfare attorney or guardian where possible.

Patient is a child

4.2.51. Standard codes of practice apply when providing consent for information to be shared when the patient is a child (under the age of 18). These are issued by the Information Commissioners Office¹³⁹. Further information about consent and the General Data Protection Regulation (GDPR) is provided at Annex E.

¹³⁷As defined in section 1(6) of the Adults with Incapacity (Scotland) Act 2000 <u>http://www.legislation.gov.uk/asp/2000/4/section/1</u>

¹³⁸<u>https://www.gov.scot/publications/key-actions-managing-end-end-discharge-process-adults-lack-capacity-including-legal-measures/;</u> For a learning resource that captures wider issues around patient incapacity, please see the learning resource "Think Capacity, Think Consent",

https://www.nes.scot.nhs.uk/media/fqca5enl/capacity_and_consent-interactive.pdf

¹³⁹ https://ico.org.uk/for-organisations/data-sharing-a-code-of-practice/data-sharing-and-children/

Recording of information

4.2.52. A multi-disciplinary approach is often required to treat patients in hospital, sharing information between professionals regarding carer involvement will be necessary.

4.2.53. It is recommended that health boards establish a method of recording actions taken by professionals under section 28. This might include information on attempts made to identify the carer as well as a record of how and when the carer was informed of the intention to discharge and any views that may be given regarding the discharge of the cared-for person.

4.2.54. Recording this information may help to avoid any communication duplication and ensure a joined-up approach, allowing information to be easily shared and could be used as a reference point in the future. This might be recorded as part of the patient's notes or separately.

Carer information and consent to share

4.2.55. Under section 11(2)(b) of the Act the responsible local authority must share information contained in an adult carer support plan with any other person the adult carer requests. Section 17(2)(b) applies to responsible authorities in regard to young carers and the young carer statement.

4.2.56. One of the intentions of provisions under section 28 of the Act is that carers are involved and invited to provide views about the discharge of the cared-for person, and so to ensure that appropriate support is provided and that the health and wellbeing of the carer and the cared-for person are considered.

4.2.57. There may be situations where the carer does not want the cared-for person to have access to the information they have shared with practitioners about the hospital discharge.

4.2.58. Health boards should respect the wishes of the carer as far as it is reasonable and practicable to do so as part of the hospital discharge process. Further guidance about consent and the General Data Protection Regulation (GDPR) is provided at Annex E.

4.2.59. In such circumstances, health boards are encouraged to:

- take into consideration the perspectives of both the carer and the cared-for person;
- consider whether the cared-for person has the legal capacity to be involved in the hospital discharge decision making process, and if not consider the implications of the Adults with Incapacity (Scotland) Act 2000 for both the carer and the cared-for person;
- recognise that tension can arise when either the cared-for person's or carer's ability to communicate is affected by illness, disability or mental health;
- recognise that tension can arise where either the cared-for person's or carer's first language is not English, and one person interprets for the other;

- provide access to mediation and advocacy services where necessary, which can play and important role in exploring and resolving tensions between the carer and cared-for person; and
- provide access to translation and interpretation services where necessary.

Patient information and consent to share

4.2.60. Professionals will be aware of the various legal requirements around confidentiality and the sharing of patient information in cases where the patient declines to have a carer informed of the intention to discharge. Patient rights, including the right to privacy and confidentiality, are also enshrined in the Patient Rights (Scotland) Act 2011¹⁴⁰ and information on confidentiality in relation to patient information can be found in the General Medical Council's explanatory guidance 'Confidentiality: Good Practice in Handling Patient Information¹⁴¹'. Each health board will have a Data Protection Officer who will be able to provide advice on data protection and confidentiality in their locality. Some health boards will have their own information and guidance on what patient confidentiality means for carers.

4.2.61. There may be a number of reasons for a patient to withhold consent for the sharing of their personal information with the carer. A patient may also withhold consent for the sharing of patient identifiable information with a carer and may not want the carer to know they have been admitted to hospital. In these situations, it would be expected that each case would be looked at individually and normal codes and standards of practice regarding information sharing would be applied by professionals¹⁴².

4.2.62. Where consent has been withheld and professionals believe it to be appropriate, it is encouraged that an attempt be made to negotiate with the patient around the sharing of information. This might be achieved by laying out the benefits of doing so for the carer or the patient. Pressure should not be placed on the patient to change their mind if they are not comfortable. It may be that the patient is content for the carer to be informed of the discharge but does not want any further information shared.

4.2.63. If the situation allows, good practice would see professionals supporting and signposting the carer to relevant support.

Signposting and support for the carer

4.2.64. Through the process of involving the carer in the hospital discharge of the patient, it would be good practice for professionals to ascertain whether the carer has an adult carer support plan or young carer statement. If not, with the carer's consent, professionals may wish to notify the relevant authority which must offer one (as at sections 6(1) and (2) and 12(1) and (2) of the Act).

¹⁴⁰ <u>http://www.legislation.gov.uk/asp/2011/5/contents</u>

¹⁴¹ http://www.gmc-uk.org/guidance/ethical_guidance/30605.asp

¹⁴² http://www.wdhscp.org.uk/media/1256/revised-code-of-confidentiality-final.pdf

4.2.65. If this is not appropriate, professionals may advise the carer of their right to request an adult carer support plan or young carer statement (as at section 6(4) and 12(4) of the Act).

4.2.66. It may be the case that professionals within the hospital have responsibility for the preparation of an adult carer support plan or young carer statement, in which case the offer should be made to each identified carer.

4.2.67. Professionals are encouraged to make themselves aware of local and national carer support services. Many health boards will already have relationships with local carer centres, general community support services and provide resources on support available to carers.

4.2.68. Professionals are recommended to make carers aware of the local information and advice service for carers under section 34 of the Act. See Chapter 6 on information and advice for carers.

4.2.69. If considered necessary, a professional might make a referral to a social work team or carer support worker in the hospital.

Part 5: Local Carer Strategies

Chapter 1 – Local Carer Strategies

Summary

Section 31 requires each local authority and relevant health board to prepare a local carer strategy and provides for what that strategy must set out.

Section 32 requires the local authority and relevant health board to have regard to a non-exhaustive list of factors when preparing their local carer strategy.

Section 33 deals with the publication and review of the local carer strategy.

The duty under section 31 applies to local authorities and relevant health boards but is delegated to integration joint boards under the Public Bodies (Joint Working) (Prescribed Local Authority Functions Etc.) (Scotland) Amendment (No. 2) Regulations 2017¹⁴³ and the Public Bodies (Joint Working) (Prescribed Health Board Functions) (Scotland) Amendment Regulations 2017¹⁴⁴. As sections 32 and 33 are subsidiary functions of section 31, these will also fall under the delegation of integration joint boards.

For the purpose of this chapter the terminology 'local authorities' and 'relevant health boards' will continue to be used in place of integration joint boards or integration authorities.

Statutory local carer strategy

5.1.1. A local carer strategy which deals specifically with the exercise of all functions relating to carers will allow matters to be dealt with more comprehensively than can be the case in the integration strategic plan or children's services plan. It will also allow issues relating to the needs of both adult and young carers to be planned in one exercise. This in itself will support planning for the transition of individuals from being young carers to adult carers.

5.1.3. The requirement to prepare a local carer strategy is intended to help deliver consistency of approach. Each local authority and relevant health board must prepare and have regard to the same factors when preparing a strategy (section 32) and each strategy must contain information about the same things (section 31). This will ensure a consistent approach while allowing the content and presentation of local carer strategies to reflect different local circumstances in the planning and delivery of support to carers.

5.1.4. It is a matter for each local authority and relevant health board to consider whether they wish to include further information in the local carer strategy over and above that required by section 31.

¹⁴³ SSI 2017/449 http://www.legislation.gov.uk/ssi/2017/449/contents/made

¹⁴⁴ SSI 2017/381 http://www.legislation.gov.uk/ssi/2017/381/contents/made

5.1.5. The duty under section 27 to involve carers and persons and bodies representative of carers in carer services applies to the preparation of a local carer strategy. Authorities and health boards are strongly recommended to work closely and collaboratively with carers and with the third sector in preparing strategies.

Duty to prepare local carer strategy

Local authority and relevant health board

5.1.6. Section 31(1) provides that each local authority and relevant health board must jointly prepare a local carer strategy.

5.1.7. Section 31(5) defines 'relevant carers', who should be covered by the local carer strategy. Relevant carers include both (a) carers who reside in the area of the local authority (whether or not they provide or intend to provide care for cared-for persons in that area) and (b) carers who do not reside in the authority's area but who provide or intend to provide care to cared-for persons in that area.

5.1.8. This means that the local carer strategy must cover carers:

- living and caring in the local authority area;
- living in the local authority area and caring for people living elsewhere; and
- not living in the local authority area but caring for a person or people who live in the local authority area.

5.1.9. Section 31(6) sets out the meaning of 'relevant health board'. It means a health board with a coterminous boundary with the local authority or the health board within whose area the area of the local authority falls.

5.1.10. Where functions have not been delegated, in particular children's services in some areas, the requirement for health boards and local authorities to work closely together to prepare the local carer strategy still applies.

5.1.11. Section 31(2) sets out what the local carer strategy is and what information it must contain.

Joint working – two or more local authorities and health boards

5.1.12. There may be some local authorities and health boards which will work together to prepare a joint local carer strategy covering two or more local authority areas. Given that the duty is on each local authority and relevant health board to ensure that it has prepared a local carer strategy applicable to its area, the duty will equally be discharged by working together with another authority to have one local carer strategy which applies to each area.

Content of strategy

Local carer strategy checklist

A local carer strategy must cover all of the things listed at section 31 of the Act. A document which doesn't include all of these would not meet the statutory definition of a local carer strategy. The nine things which must be included are:

- ✓ plans for identifying relevant carers and obtaining information about the care they provide (or intend to provide) to cared-for persons in the local authority's area,
- ✓ an assessment of the demand for support to relevant carers,
- ✓ support available to relevant carers in the authority's area from -
 - \circ the authority,
 - the relevant health board,
 - any other organisations that the authority and health board consider appropriate,
- ✓ an assessment of the extent to which demand for support to relevant carers is currently not being met,
- ✓ plans for supporting relevant carers,
- plans for helping relevant carers put arrangements in place for the provision of care to cared-for persons in emergencies,
- ✓ an assessment of the extent to which plans for supporting relevant carers may reduce any impact of caring on relevant carers' health and wellbeing,
- ✓ the intended timescales for preparing adult carer support plans and young carer statements.
- ✓ information relating to the particular needs and circumstances of young carers.

Carer Identification

5.1.13. Section 31(2)(a) requires the local carer strategy to set out plans for identifying relevant carers and obtaining information about the care they provide or intend to provide to cared-for persons in the local authority and relevant health board area.

5.1.14. It will only be possible for the local authority and relevant health board to plan for the delivery of the Act's functions by taking steps to identify carers and determine the extent of caring responsibilities. Local authorities and health boards may already know the number of existing identified carers in their areas. They may also use Scottish Government statistical data obtained through surveys such as the Scottish Health Survey¹⁴⁵ and the Census¹⁴⁶ to obtain carer number data.

5.1.15. The plans for identifying relevant carers will be particular to each area but might include identification by different parts of the statutory workforce as well as by the third sector in a number of different ways set out in Annex D.

¹⁴⁵ <u>https://www.gov.scot/collections/scottish-health-survey/</u>

¹⁴⁶ http://www.scotlandscensus.gov.uk/

Assessment of demand for support

5.1.16. Section 31(2)(b) states that the local carer strategy must include an assessment of the demand for support to relevant carers¹⁴⁷.

5.1.17. It is recognised that assessing current and future demand is not an exact science. The caring population is fluid and carers are constantly moving in and out of the caring role. Many factors will determine demand including:

- the extent to which carers are identified;
- the changing national demographics with the growth in the older population, more adults with complex and multiple care needs and more children with complex needs surviving into adulthood;
- local demographics age profile and socio-economic make-up of the local population;
- the impact of local publicity and communications regarding support for carers; and
- the extent to which carers are supported by family, friends and neighbours rather than by statutory services.

5.1.18. It should be noted that factors such as complex caring situations and intensive caring in areas of deprivation can exacerbate ill-health and result in increased demand.

Evidence

47% of carers in the most deprived areas care for 35 hours a week or more which is almost double the level in the least deprived areas where 24% of carers care for 35 hours a week or more¹⁴⁸.

5.1.19. There is evidence of lessening demand from the Community Led Support (CLS) Programme in selected areas of Scotland, England and Wales where CLS assists organisations to work collaboratively with their communities and their staff teams to redesign a service that works for everyone¹⁴⁹.

5.1.20. An assessment of the demand for both preventative support and support for those with eligible needs will help local authorities with the relevant health board to plan for meeting current and future needs, including unmet need.

Support available to carers

5.1.21. Section 31(2)(c) requires the local carer strategy to set out the support available to relevant carers in the authority's area from: (i) the authority, (ii) the relevant health board, (iii) such other persons and bodies as the authority and relevant health board consider appropriate.

5.1.22. The purpose of this section is for the local carer strategy to set out the support available at the time when the local carer strategy is being prepared.

¹⁴⁷ Professor John Bolton, Predicting and Managing Demand in Social Care, Discussion Paper, Institute of Public Care, Oxford Brookes University, 2016 -

https://ipc.brookes.ac.uk/docs/John Bolton Predicting and managing demand in social care-IPC_discussion_paper_April_2016.pdf ¹⁴⁸ http://www.gov.scot/Publications/2015/03/1081

¹⁴⁹ https://www.ndti.org.uk/our-work/our-projects/community-led-support

5.1.23. 'Such other persons and bodies' as at section 31(2)(c)(iii) may include support from the third and independent sectors. The support available across all sectors could include community-based assets such as leisure and recreational facilities, gardening clubs, libraries etc. and people assets and expertise. It may also include support from educational bodies.

Unmet demand

5.1.24. Section 31(2)(d) requires the local carer strategy to set out an assessment of the extent to which demand at a macro level for support to relevant carers is currently not being met. This means that having set out the support available to relevant carers; the next step is to set out an assessment of whether this is sufficient to meet the need.

Plans for supporting relevant carers

5.1.25. Section 31(2)(e) requires the local carer strategy to set out plans for supporting relevant carers. Having assessed demand, considered the existing support available and then assessed the extent to which demand for support is not being met, the final step in this process is to set out the plans for supporting carers.

Emergency planning

5.1.26. Section 31(2)(f) requires the local carer strategy to set out plans for helping relevant carers put arrangements in place for the provision of care to cared-for persons in emergencies.

5.1.27. There is separate provision in sections 9(1)(c) and 15(1)(d) of the Act about emergency planning at an individual level. These sections require adult carer support plans (ACSPs) and young carer statements (YCSs) to contain information about whether the adult or young carer themselves have arrangements in place for the care of the cared-for person in an emergency.

5.1.28. Section 31(2)(f) is intended to be more strategic, reflecting the importance of emergency planning to provide carers with an agreed plan and peace of mind. Emergency planning (sometimes called contingency planning) includes planning for unplanned emergencies. For example a carer not being able to care due to:

- ill health;
- a family emergency; or
- the impact of adverse weather conditions (heavy snow, flooding, etc.)

5.1.29. Some areas already use resources¹⁵⁰ to offer carers emergency plans or discuss emergency planning with them whilst other areas offer carers an emergency card.

5.1.30. An emergency card lets the emergency services or social care services know that a person is a carer. Carrying the card at all times can help services to put other support in place in a crisis.

¹⁵⁰ <u>https://www.enable.org.uk/get-support-information/families-carers/future-planning/</u>

Reduce impact of caring on health and wellbeing

5.1.31. Section 31(2)(g) requires the local carer strategy to set out an assessment of the extent to which plans for supporting relevant carers may reduce any impact of caring on relevant carers' health and wellbeing.

5.1.32. This reinforces the preventative approach underpinning the Act. This requires the local authority and the relevant health board to assess how effective their plans for supporting carers are on a preventative basis.

5.1.33. This provision means that the local authority and the relevant health board will assess the extent to which support may meet carers identified needs in order to achieve their personal outcomes. It also means authorities and health boards will assess the extent to which preventative support may prevent, delay or reduce carers' needs, or potential needs, for support.

5.1.34. There are Audit Scotland reports which focus on the need for transformation in health and social care to take forward preventative approaches to supporting people, including carers, in order to reduce costs and promote health and wellbeing¹⁵¹.

Examples of preventative support to carers:

- proactive and comprehensive use of the information and advice service for carers, ensuring that carers are provided with the right information and advice at the right time and in the right way;
- providing early support such as a short break to carers who have moderate needs but whose needs might become substantial without such support;
- promoting carers' resilience; and
- carers' health checks.

Intended timescales for preparing adult carer support plans and young carer statements

5.1.35. Section 31(2)(h) requires the local carer strategy to set out the intended timescales for preparing ACSPs and YCSs.

5.1.36. There are no set timescales in the Act for preparing these except for carers of terminally-ill persons. Part 2 of this guidance provides more information on the timescales for preparing individual ACSPs and YCSs, including specific timescales for carers of terminally-ill persons.

5.1.37. The intention of section 31(2)(h) is to give carers an indication of the maximum time for preparation of the ACSP or YCS.

5.1.38. There may be different timescales for completion of ACSPs and YCSs. Local authorities may have their own guidance for timescales based on urgency or risk. There may also be factors in individual cases which can result in ACSPs and YCSs taking longer to complete. For example where the carer's needs are complex

¹⁵¹ Social Work in Scotland, December 2016 (<u>www.audit-scotland.gov.uk/report/social-work-in-scotland</u>); Changing Models of Health and Social Care, March 2016 (<u>www.audit-scotland.gov.uk/report/changing-models-of-health-and-social-care</u>); Health and Social Care Integration, December 2015 (<u>www.audit-scotland.gov.uk/report/health-and-social-care-integration</u>)

and require more than one contact to prepare and complete the ACSP or YCS or where support required is specialised and not readily available.

5.1.39. Local authorities are recommended to prepare each ACSP or YCS as quickly as possible and without delay but to focus on achieving the right outcomes for the carer rather than allowing set timescales to become a *de facto* target.

Other information

5.1.40. Section 31(2)(i) also allows a local carer strategy to include such other information as each local authority and relevant health board consider appropriate. This enables each local carer strategy to reflect and take into account local circumstances.

5.1.41. This would enable a local authority and health board to include information about, for example:

- achievements and successes from previous non-statutory local carer strategies; and
- an overview of caring situations in relation to different types of conditions of cared-for persons.

Financial Information

5.1.42. Section 31(2)(i) would also allow the strategy to include relevant financial information about how money will be spent in the area on supporting adult and young carers. It will be a matter for the local authority and relevant health board to decide if they wish to include financial information.

5.1.43. It is recognised that carers can be supported indirectly by support put in place for cared-for persons. For various reasons, it may be challenging to identify the total resource supporting carers indirectly¹⁵². Self-directed support has also made it more difficult to disaggregate individual budgets.

5.1.44. The performance management framework for integration authorities under the Public Bodies (Joint Working) (Scotland) Act 2014 requires integration authorities to publish certain financial information on an annual basis. The detail of this is set out in The Public Bodies (Joint Working) (Content of Performance Reports) (Scotland) Regulations 2014¹⁵³. Regulation 4(1), read with regulation 4(2)(d) of those regulations requires an integration authority to publish, in an Annual Financial Statement, the total amount and proportion of funds which have been spent in each reporting year on 'social care services provided in pursuance of integration functions to support unpaid carers in relation to needs arising from their caring role'.

5.1.45. The figure in the integration performance report may well be different from that which might be included in the local carer strategy at the discretion of the local authority and relevant health board for the following reasons:

• it will be a retrospective account of sums actually spent rather than potentially a projection of sums to be spent;

¹⁵² Indirect support is services put in place for the cared-for person which are of benefit to the carer and include technology enabled care, day care, support for disabled children, medicine management and social care services.

¹⁵³ SSI 2014/326 <u>http://www.legislation.gov.uk/ssi/2014/326/contents/made</u>

- it may not cover exactly the same services in particular if the local authority has chosen not to include the function of supporting young carers in the integration scheme; and
- the performance management obligation relates specifically to money that the integration authority has spent, and so would not cover funding from charitable or other sources.

Young carers

5.1.46. Section 31(3) requires a local carer strategy to contain information relating to the particular needs and circumstances of young carers as defined at section 2 of the Act. This information must include in relation to young carers all the issues covered by section 31(2)(a) to 31(2)(i) of the Act.

5.1.47. The Act does not specify how this information is to be included in the local carer strategy. There is therefore local discretion on whether such information is contained in a single local carer strategy document covering both adult carers and young carers or whether a the local carer strategy consists of two documents, one in relation to adult carers and a separate document covering young carers.

Consultation before preparing strategy

5.1.48. Before preparing a local carer strategy, section 31(4) requires the local authority and the relevant health board to jointly (a) consult such persons and bodies representative of carers as they consider appropriate and (b) take such steps as they consider appropriate to involve relevant carers.

5.1.49. Persons and bodies representative of carers may include, for example:

- local adult and young carer organisations;
- condition-specific organisations which work with carers;
- disability or age-focused organisations which do not support carers directly but who have an interest in issues such as short breaks; and
- education bodies.

5.1.50. In order to involve relevant carers, it will be important to consult with carers in different caring situations and with those carers with whom agencies cannot easily interact. Carer centres, young carer projects and other local carer services may be able to help support this engagement with carers.

Links between local carer strategy and other plans and strategies

5.1.51. In preparing a local carer strategy, section 32 requires local authorities and relevant health boards to take account of a range of statutory criteria and planning obligations, including under integration and children's services planning.

Children's Services Plans

5.1.52. Section 32(a) requires the local authority and the relevant health board to have regard to any plans for the provision of services relevant to young carers which are set out in the children's services plan prepared for area of the local authority under section 8 of the Children and Young People (Scotland) Act 2014. Section 32(b) also requires the local authority and relevant health board to have regard to the aims of children's services plans under section 9 of the 2014 Act.

5.1.53. Statutory guidance on Part 3 (Children's Services Planning) of the Children and Young People (Scotland) Act 2014 was published in December 2016¹⁵⁴. Paragraphs 205 to 208 of that guidance refer to the local carer strategy and to supporting young carers.

Wellbeing of children

5.1.54. Section 32(c) requires the local authority and the relevant health board to have regard to the criteria for assessing the wellbeing of children and young people set out in section 96 of the Children and Young People (Scotland) Act 2014.

5.1.55. This means that the wellbeing indicators set out in section 96¹⁵⁵ of the 2014 Act must be used in considering the particular circumstances of young carers in the area.

For InformationThe wellbeing indicators are:Safe, Healthy, Achieving, Nurtured, Active, Respected, Responsible and Included.

National Health and Wellbeing Outcomes

5.1.56. Section 32(d) requires the local authority and the relevant health board to have regard to any national health and wellbeing outcomes prescribed under section 5 of the Public Bodies (Joint Working) (Scotland) Act 2014¹⁵⁶.

5.1.57. These prescribed outcomes include the following as outcome 6: 'People who provide unpaid care are supported to look after their own health and wellbeing, including reducing any negative impact of their caring role on their own health and wellbeing'.

5.1.58. There are a number of questions in the Scottish Health and Care Experience Survey¹⁵⁷ which provide evidence in support of this outcome. This survey is run every two years and the results are published by individual Health and Social Care Partnerships as well as for Scotland as a whole. It would be useful to consider these results when preparing the local carer strategy, alongside any local data collections, such as local indicators, and to consider the change every two years.

Integration functions in Strategic Plan

5.1.59. Section 32(e) requires the local authority and the relevant health board to have regard to any arrangements for the carrying out of integration functions relevant to carers which are set out in the strategic plan prepared for the area of the local authority under section 29 of the Public Bodies (Joint Working) (Scotland) Act 2014.

Other local or national plans

5.1.60. Section 32(f) requires the local authority and the relevant health board to have regard to any other local or national plans relating to the provision of social

¹⁵⁴ <u>https://www.gov.scot/publications/statutory-guidance-part-3-childrens-services-planning-children-young-people/</u>

¹⁵⁵ http://www.legislation.gov.uk/asp/2014/8/section/96/enacted

¹⁵⁶ SSI 2014/343 http://www.legislation.gov.uk/ssi/2014/343/contents/made

¹⁵⁷ <u>https://www.gov.scot/collections/health-and-care-experience-survey/</u>

work services and health services as the authority and relevant health board consider appropriate.

5.1.61. The local authority and relevant health board may consider it appropriate to take into account the National Health and Social Care Standards: 'My support, my life¹⁵⁸'. These aim to ensure that people across Scotland receive the same high standard of care and support, delivered in a way which reflects their own personal needs and circumstances. The Standards sit beneath five overarching principles (dignity and respect; compassion; included; responsive care and support; and wellbeing). They set out what people should experience every time they use health and/or social care services.

5.1.62. In terms of local plans there are likely to be other, non-statutory, planning processes in the area which may be relevant to assessing the needs of carers and the support to be provided to them. An integration authority may, for example, have detailed planning processes in relation to dementia, mental health, learning disabilities, autism, sensory impairment, augmentative and alternative communication and/or substance misuse. Where such planning processes exist, they may be taken into account when preparing the local carer strategy.

Publication and Review of Local Carer Strategy

5.1.63. Sections 33 sets requirements for publication and review of the local carer strategy.

Publication

5.1.64. Section 33(1) requires each local authority and relevant health board to jointly publish their local carer strategy. There is no statutory provision for the form or method of publication. This could however be on websites and/or made public in other ways. The Scottish Government would however find it useful to have notification of publication and a link to any web based local carer strategy.

Timescales

5.1.65. Section 33(2) means that the first local carer strategy must be published by the next date after 1 April 2018 when the corresponding integration authority is required to review its strategic plan under section 37 of the Public Bodies (Joint Working) (Scotland) Act 2014. Such reviews are required three years after:

- the integration start date;
- the date a replacement strategic plan takes effect after a strategic plan has been reviewed; or
- the date the integration authority has decided not to prepare a replacement strategic plan following such a review.

5.1.66. Before preparing a local carer strategy, the local authority and the relevant health board must carry out consultation under section 31(4), as outlined above. Because of these statutory consultation requirements, it is not expected that the first statutory local carer strategy would be in place in April 2018.

¹⁵⁸ *Health and Social Care Standards: My support, my life.* (2017). Produced by the Scottish Government. <u>https://www.gov.scot/publications/health-social-care-standards-support-life/</u>

5.1.67. The timing of local carer strategies and integration strategic plans may not synchronise with that of children's services plans under Part 3 of the Children and Young People (Scotland) Act 2014. Under section 8 of that Act, the local authority and health board must prepare a children's services plan in respect of each three year period. The first three year period will start on 1 April 2017 and subsequent periods will start on each 3 year anniversary of that date. Secondary legislation on Part 3 came into force on 7 October 2016 and requires that a children's services plan, prepared in accordance with the provisions of Part 3 of that Act, should be in place by 1 April 2017. This date will apply consistently to all local authorities and health boards across Scotland.

5.1.68. Section 32(a) and (b) of the Act is intended to ensure that, although timescales may not synchronise, the local carer strategy is prepared in a way which takes proper account of children's services plans. Likewise the guidance in relation to children's services planning takes account of local carer strategies as highlighted above.

Review

5.1.69. Section 33(3) and (4) requires the local authority and relevant health board jointly to review their statutory local carer strategy at least every three years. This should enable local authorities and relevant health boards to keep the review of their statutory local carer strategy in line with the integration strategic plans if they wish to do so, or to allow the statutory local carer strategy to run for a full three years even if the integration strategic plan is reviewed sooner if they feel that is more appropriate.

5.1.70. In conducting the review, section 33(5) requires the local authority and relevant health board to comply with the consultation requirements in section 31(4) Guidance on these requirements is set out above.

5.1.71. Following the review, section 33(6) and (7) requires the local authority and relevant health board to revise and publish the revised strategy or to publish a statement that they have not revised it. Section 33(7) also requires the local authority to comply with section 32 (duty to have regard to other statutory plans, aims, criteria and outcomes) into account in preparing a revised strategy. Guidance on section 32 is set out above.

Part 6: Information and advice for carers, including short breaks services statements

Chapter 1 – Information and advice for carers

Summary

Section 34 requires each local authority to establish and maintain an information and advice service, covering a range of mandatory areas for carers either resident in that local authority area, or caring for someone in that local authority area.

Section 36 requires Scottish Ministers to prepare a carers' charter, setting out the rights of carers as provided for in or under the Carers (Scotland) Act.

The duties under sections 34 and 35 are delegated to integration joint bodies under the Public Bodies (Joint Working) (Prescribed Local Authority Functions etc.) (Scotland) Amendment Regulations 2017¹⁵⁹ and the Public Bodies (Joint Working) (Prescribed Local Authority Functions etc.) (Scotland) Amendment (No.2) Regulations 2017¹⁶⁰.

For the purpose of this chapter the terminology 'local authorities' will continue to be used in place of integration joint boards or integration authorities.

Reasons for information and advice for carers

6.1.1. Providing good quality, appropriate, and timely information and advice to carers has dual benefits of improving the health and wellbeing of carers, and the cared-for person, reducing the potential need for, and costs of, crisis management.

6.1.2. The aim of information and advice services for carers is to enable them to access independent and comprehensive information and advice, to assist them with decision making in relation to their caring role and to have a life alongside caring.

6.1.3. Signposting to services alone is often ineffective at providing people with the support they need¹⁶¹. A proactive approach following early identification of the carer that goes beyond signposting and starts the conversation between carers and identified services is therefore recommended as good practice. Initially this may include arranging introductions to services/ direct referrals, rather than solely signposting to services to help reduce barriers that exist between information and advice provision to carers and support uptake.

6.1.4. This helps mitigate risks around carers not accessing appropriate advice or services, and the long-term wellbeing benefits and cost savings this may have. This research also recommends that carers are meaningfully involved in the design of support systems to ensure their effectiveness.

¹⁶¹ Creating a stronger information, advice and advocacy system for older people. (2009) John Rowntree Foundation. <u>https://www.jrf.org.uk/report/creating-stronger-information-advice-and-advocacy-system-older-people</u>

¹⁵⁹ SSI 2017/190 <u>http://www.legislation.gov.uk/ssi/2017/190/contents/made</u>

¹⁶⁰ SSI 2017/449 http://www.legislation.gov.uk/ssi/2017/449/contents/made

6.1.5. As part of information and advice to carers, short breaks services statements are expected to set out the range of different short breaks services and support that is available to carers in a local authority area and nationally.

6.1.6. It is well recognised that short breaks can be of great benefit to a carer's wellbeing, and drawing relevant information together in one place will help carers to make decisions on the support they receive.

6.1.7. A major barrier for carers' access to short breaks is the lack of information and advice surrounding local provision, with 43% of carers citing a lack of knowledge of how to access services¹⁶².

Duty to provide information and advice services

6.1.8. Section 34(1) requires local authorities to ensure that relevant carers have access to quality, comprehensive and consistent information and advice services to allow carers to be aware of support available. Relevant carers are defined in section 31(5) of the Act to include both: a) carers who reside in that local authority area, and b) carers who provide or intend to provide care for someone in that local area.

Timing and targeting of information and advice according to need

6.1.9. The intention is that information and advice services should be provided in an appropriately timely manner. Information and advice will be most effective where it takes account of individual carer's needs and is provided at an appropriate time. For instance, a raft of information and advice received at the onset of a caring role may be overwhelming and may not be the best way to fulfil the carer's needs. A carer may require time to come to terms with the pressures of the caring role.

6.1.10. There are differing information and advice needs associated with different caring roles. It is recommended that, in providing information and advice services, local authorities are mindful of the potentially changing nature of the caring role. Caring roles broadly differ across each of three main axes:

- the specific stage of a carers' journey (e.g. new to caring, caring long term, ending a caring role);
- the specific condition(s) of the cared-for person (e.g. physical disability, mental illness, dementia); and
- the specific circumstances of the carer (e.g. young carer, older carer, rural carer, minority ethnic carer).

6.1.11. Where a carer already has an ACSP or YCS, it is recommended that their identified needs and personal outcomes should be considered when providing appropriate information and advice. However, information and advice provision can also play an important preventative role and need not wait until an initial ACSP or YCS has been prepared.

¹⁶² Rest Assured? A Study of Unpaid Carers Experiences of Short Breaks. (2012). Produced by the Institute for Research and Innovation in Social Services (Iriss), in partnership Shared Care Scotland, the Coalition of Carers in Scotland & MECOPP <u>https://www.iriss.org.uk/sites/default/files/2016-03/iriss-rest-assured-full-report-2012-07.pdf</u>

Reviewing and building on existing provision

6.1.12. Local authorities may provide information and advice services as appropriate in their area in line with existing services, local demand and other considerations.

6.1.13. It is recommended that information and advice services should build on the existing networks of carer centres and other local information and advice providers. This approach will ensure that local knowledge and experience is retained and embedded in any system that is developed.

6.1.14. Carer Information Strategies (CIS) have been an important lever to drive forward improved outcomes for adult carers and young carers. It is recommended that local authorities use existing CIS health and social care networks to ensure that local knowledge and experience is retained and embedded in any information and advice service that is developed. This may include, e.g. carer centres, young carer projects, and appropriate training to meet the needs of carers in their area.

6.1.15. Mapping existing provision may assist local authorities and their partners to determine whether services are robust enough to cover a range of carer needs; whether any new services are required; and where additional resources can be best targeted and a co-ordinated approach developed.

6.1.16. Local authorities may wish to approach this from a carer journey perspective using the carer voice as a guide, which would also consider the linkages between parts of a service and equity of services across that authority area.

6.1.17. Consideration of workforce capability and capacity would form an important part of this process, as would the system-wide outcome measures to be able to evaluate the efficacy of the services provided.

6.1.18. In addition to specific information and advice services for carers (for instance those provided by local carer centres), other sources of information and advice may be relevant, such as:- Citizens Advice Scotland; local authority run Advice Shops; Jobcentre Plus; Royal National Institute of Blind People; Macmillan Cancer Information and Support Centres.

6.1.19. Particularly for universal services it will be important to consider resource allocations, and therefore capacity, alongside the sources of information and advice themselves.

Collaboration and partnership working

6.1.20. Local partnership working is strongly encouraged when developing information and advice services, including by working closely with health boards and third sector organisations (including carer centres) to design and deliver these information and advice services to ensure effective integration and minimise duplication.

6.1.21. A local authority's duty to provide information and advice services may be discharged through these partners at the discretion of the local authority.

General principles for quality advice provision

6.1.22. As part of its review of its support to existing advice services, the Scottish Government has developed a set of principles for advice services in order to address inequalities across Scotland, treat people with dignity and respect, and deliver

services in a holistic way focusing on the individual. Local authorities may wish to draw on these principles during the design and delivery of local information and advice services as required by the Act. The principles are:

- **Responsiveness:** that people are able to access information and advice at a time and place that fits their needs;
- Integration: that providers of information and advice services work in partnership with other local and national organisations to ensure holistic service provision;
- **Professionalism:** that people receive high quality information and advice services; and
- **Inclusivity:** that additional access needs are supported and steps are taken to ensure vulnerable and socially isolated people are reached with the services and support.

6.1.23. Scottish Government supported services are expected to achieve the relevant quality framework accreditation (e.g. Scottish National Standards for Advice and Information Providers). This may be an approach that local authorities wish to replicate to ensure they support high quality service provision.

Scope of information and advice provision

6.1.24. The scope of information and advice provided is at the discretion of the responsible local authority or integration authority (where these functions have been delegated). As a minimum, it must cover the areas set out in Section 34(2):

- carers' rights, including those set out in the carers' charter;
- income maximisation for carers;
- education and training for carers;
- advocacy for carers;
- health and wellbeing (including counselling) for carers;
- bereavement support services for carers following the death of a cared-for person; and
- emergency care planning and future care planning for carers.

Carers' Rights

6.1.25. Section 34(2)(a) requires services to cover carers' rights, including those in the carers' charter. It is important carers are made aware of the carers' charter. This will be prepared and published separately by Scottish Ministers, as required under section 36 of the Act.

Income Maximisation

6.1.26. Section 34(2)(b) requires local authorities to provide information and advice on income maximisation for carers.

Evidence

Research shows that around one third of carers report financial difficulties¹⁶³. According to the Scottish Index of Multiple Deprivation (which includes income and employment factors) in the 2011 census, 47% of carers in the most deprived areas provide on average 35+ hours a week, compared to just 24% is the least deprived areas¹⁶⁴. This indicates a positive correlation between financial security and the amount of care that a carer provides.

6.1.27. Information and advice services may aid the reduction of this inequality and financial stress by facilitating carers to maximise their available income and sustain employment.

6.1.28. Local authorities are encouraged to consider relevant information and advice which helps to prevent or mitigate financial hardship through early financial planning, including assessing the balance between work and care, residential care costs, guardianship for funds.

6.1.29. Providing the appropriate information and advice to carers to support them to sustain employment alongside their caring role, should they wish, is also important in income maximisation.

Example

The **Carer Positive**¹⁶⁵ scheme encourages organisations to establish and maintain flexible and carer friendly practices for their employees. This includes employers in the public, private, and third sectors. We would encourage local authorities to consider Carer Positive when developing their information and advice service (and local carer strategy if appropriate).

6.1.30. The devolution of social security powers to Scotland is expected to bring some changes to the benefits carers may be eligible for. The new Scottish social security agency, being created to administer devolved benefits, will provide information to people on their entitlements. This will be accessible through a number of channels including an enhanced digital and phone service and locally, where possible, in places where people already visit, to provide one-to-one claims advice and support when required.

¹⁶³Carers, Employment and Services in Scotland: focus on East Ayrshire, Falkirk and Highland (2007) Yeandle, S. Bennett, C., Buckner, L., Fry, G. and Price, C., Leeds: Carers UK and University of Leeds <u>http://circle.group.shef.ac.uk/wp-content/uploads/2018/04/carers-uk-report-7-scotland.pdf</u>

¹⁶⁴ Scotland's Carers: An Official Statistics Publication for Scotland. (2015) Scottish Government. https://www.gov.scot/publications/scotlands-carers/

¹⁶⁵ <u>http://www.carerpositive.org/</u>

Example

Carers Trust Scotland provides an **online benefits calculator**¹⁶⁶ that may be an appropriate first step for carers. Local information and advice sources, including carer centres, other third sector organisations and local authorities will form an important part of provision alongside national sources, such as the **Citizen Advice Bureaus and Citizens Advice Direct**¹⁶⁷ of **Citizens Advice Scotland**¹⁶⁸.

6.1.31. Local authorities may wish to raise carer awareness of the relevance of total household income to benefits or charges calculations relating to the carer and/or cared-for person, particularly if both the carer and the cared-for person are in the same household.

Education and training for carers

6.1.32. Sections 34(2)(c) requires information and advice on training and education available to carers. This can include both universal opportunities and those that specifically for carers. Consideration of carers' personal outcomes as agreed in their ACSP/YCS will be important to provide appropriate information and advice.

Advocacy for carers

6.1.33. Section 34(2)(d) requires information and advice on advocacy services available to carers. This covers provision of information and advice about available advocacy services. Unlike section 259 of Mental Health (Care and Treatment)(Scotland) Act 2003¹⁶⁹, this does not require the provision of independent advocacy services themselves.

Evidence

Research by the Joseph Rowntree Foundation states, 'information is what you need or want to know; advice is being guided as to how to go about things; advocacy is a way of acting on that information and advice to get your due¹⁷⁰' This connects information, advice and advocacy in a continuum in terms of the services and support a carer might receive.

6.1.34. It is recommended that local authorities and integration authorities consider Scottish Government guidance on carer advocacy¹⁷¹. The Scottish Independent Advocacy Alliance website¹⁷² provides information on independent advocacy services nationally. Local authorities may wish to consider what local sources of advocacy currently exist and if there are potential gaps in relation to advocacy services for carers.

6.1.35. Local authorities have an separate duty under the Social Care (Self-directed Support) (Scotland) Act 2013 ('SDS Act') to provide assistance on Self-directed

¹⁷¹ <u>https://www.gov.scot/publications/guidance-unpaid-carer-advocacy-scotland/</u>

¹⁶⁶ <u>https://carers.org/benefits-calculator</u>

¹⁶⁷ 0808 800 9060 between 9am - 8pm Monday to Friday and 10am - 2pm on Saturday

¹⁶⁸ https://www.citizensadvice.org.uk/scotland/benefits/

¹⁶⁹ http://www.legislation.gov.uk/asp/2003/13/pdfs/asp_20030013_en.pdf

¹⁷⁰ Information, advice and advocacy for older people: Defining and developing services. John Rowntree Foundation <u>https://www.jrf.org.uk/report/information-advice-and-advocacy-older-people-</u> <u>defining-and-developing-services</u>

¹⁷²The Scottish Independent Advocacy Alliance: <u>http://www.siaa.org.uk/ https://www.siaa.org.uk/find-advocate/</u>

Support services to those who would benefit, which could include carers, young carers or cared-for persons where they have an eligible need. There is separate guidance for assistance relating to the SDS Act¹⁷³.

Health and wellbeing

6.1.36. Section 34(2)(e) requires information and advice for carers about their own health and wellbeing. This may take the form of counselling, peer mentoring or other peer support groups, all of which may be of value to a carer and help empower them to manage the emotional impact of a caring role¹⁷⁴. Maintaining good physical health can also help a carer build good emotional resilience. The content of an ACSP/YCS may include details of personal outcomes related to the health and wellbeing of the carer which can best be met through this type of support.

Bereavement support

6.1.37. Section 34(2)(f) requires information and advice on bereavement support services for carers in the event of the death of a cared-for person.

6.1.38. If a carer anticipates a need for bereavement support, in advance of the death of a cared-for person, this can be considered as part of the ACSP/YCS process. This may allow for the carer to prepare for that eventuality, and be in a better position to provide care prior to that point.

For Information

There is existing information available about bereavement support services, including but not limited to:

Carers Scotland; which has comprehensive information and advice about coping with bereavement¹⁷⁵;

Bereavement Zone (NHS Inform, which offers practical advice after a death; **Breathing Space**; a free, confidential phone and web based service for people in Scotland;

Cruse Bereavement Care Scotland; a charity providing face-to-face and remote bereavement services nationally;

When someone has died information pack, which is widely used across NHS Scotland to help people through the first few days of a bereavement¹⁷⁶; and *What to do after a death in Scotland*, the Scottish Government publication which includes the steps that have to be taken following a death¹⁷⁷.

6.1.39. Some of these services offer specific advice for children or young people, which young carers may find particularly helpful.

¹⁷³ <u>http://www.gov.scot/Publications/2014/04/5438/6</u>

¹⁷⁴ https://www.nhsinform.scot/healthy-living/mental-wellbeing/therapy-and-counselling/benefits-oftalking-therapy

¹⁷⁵ http://www.carersuk.org/help-and-advice/practical-support/when-caring-ends/bereavement

¹⁷⁶When someone has died. (2016) NHS Scotland. <u>https://www.nhsinform.scot/publications/when-someone-has-died-information-for-you</u>

¹⁷⁷ What to do after a death in Scotland. (2017) One Scotland, Scottish Government. <u>https://www.gov.scot/publications/death-scotland-practical-advice-times-bereavement-revised-11th-edition-2016-9781786522726/</u>

6.1.40. A carer may be eligible for a Funeral Payment¹⁷⁸ or Bereavement Support Payment¹⁷⁹ following the death of the cared-for person. Local authorities may wish to provide this specific information and support to carers in this position.

Emergency care planning and future care planning

6.1.41. Section 34(2)(g) requires information and advice on emergency care planning and future care planning for carers. This links to the requirements elsewhere in the Act for individual ACSPs and YCSs to contain information about emergency care planning and future care planning (see Part 2 of this guidance) and for local carer strategies to set out plans to help carers put emergency care plans in place (see Part 5 of this guidance).

6.1.42. It would therefore be good practice for services to include information and advice about how and when local authorities will ensure care for the cared-for person during an emergency situation. This may go on to form a part of an emergency care plan that a carer can themselves be supported to create.

6.1.43. Information and advice about future care planning may also be required when a carer wishes to enter employment or education. It would be relevant where a carer is no longer willing or able to carry out a caring role in the same capacity. It may also be relevant where the cared-for person may require an increased amount of care. It may be appropriate for carers to be provided with information and advice about the different legal status' they may have, e.g. power of attorney or guardianship.

Other information and advice – transitions from young carer to adult carer

6.1.44. Specific information and advice may be necessary when a carer transitions from being a young carer to being an adult carer. This transition may involve a change in circumstance and eligibility for support (e.g. children's services) relating to, for example: leaving school; starting further or higher education; starting work; any potential relocation; and other situations. Guidance on the transition from a YCS to an ACSP can be found in Part 2.

Accessibility, proportionality and equalities

6.1.45. Section 34(3) requires information and advice to be accessible to carers. This will include, among other factors, consideration of their:

- digital competence and equipment;
- mobility;
- rurality;
- level of understanding (including any cultural or language barriers); and
- opportunities to access services in light on their caring role.

6.1.46. Section 34(3) also requires information and advice to be proportionate to the needs of the carer. At an individual level, these needs will be stated in the ACSP or YCS and when conducting the conversation, responsible authorities should be flexible when determining any bespoke support needs the individual carer may have.

6.1.47. Section 34(4) requires information and advice services to identify information which is likely to be particularly relevant to people with one or more

¹⁷⁸ <u>https://www.gov.uk/funeral-payments</u>

¹⁷⁹ https://www.gov.uk/bereavement-support-payment

protected characteristic as set out in section 149(7) of the Equality Act 2010¹⁸⁰. These protected characteristics are:

- age;
- disability;
- gender reassignment;
- marriage and civil partnership;
- pregnancy and maternity;
- race;
- religion and belief; and
- sex; and sexual orientation.

6.1.48. A person with one or more protected characteristics may also have specific accessibility needs for information and advice services which deserve consideration. Local authorities may wish to consider the impact of rurality and isolation in particular when designing or procuring their information and advice services.

¹⁸⁰ See MECOPP's publication, 'Carers (Scotland) Act 2016 and Equalities' for further information on issues to consider for particular groups of carers with protected characteristics. <u>https://www.mecopp.org.uk/mecopp-publications/2018/12/14/briefing-sheet-10-carers-scotland-act-2016-and-equalities</u>

Chapter 2 – Short breaks services statements

Summary

Section 35 requires each local authority to prepare, publish, and review a short breaks services statement.

The duties under section 35 are delegated to integration joint bodies under the Public Bodies (Joint Working) (Prescribed Local Authority Functions etc.) (Scotland) Amendment Regulations 2017¹⁸¹ and the Public Bodies (Joint Working) (Prescribed Local Authority Functions etc.) (Scotland) Amendment (No.2) Regulations 2017¹⁸².

For the purpose of this chapter the terminology 'local authorities' will continue to be used in place of integration joint boards or integration authorities.

Duty to prepare short breaks services statement

6.2.1. Section 35 requires local authorities to prepare and publish a statement setting out information about short breaks services available for local carers and cared-for persons. To provide this information local authorities will need to consider how a break from caring fits within the context of the duty to provide support (set out in Part 3, Chapter 2) and how this information can help empower carers' choices, including the use of Self-directed Support.

Evidence

Research shows that carers can lack the information to access short breaks services, can feel that they receive insufficient provision to cope with the pressures of caring¹⁸³ or feel that shorts breaks are increasingly being used to respond to crisis situations rather than in a preventative or planned capacity¹⁸⁴.

Content of statement

6.2.2. Section 35(2) defines a short break services statement as a statement of information about the short breaks services available in Scotland to carers and cared-for persons. This will cover both short breaks services which may be provided as a form of support where a carer's identified needs in an ACSP or YCS meet the local eligibility criteria and also short break services that are available to all (universal services).

6.2.3. Whilst there is no definition of what constitutes a short break, local authorities are encouraged to take a broad view and to consider the paper provided by Shared Care Scotland at Annex C.

¹⁸¹ SSI 2017/190 <u>http://www.legislation.gov.uk/ssi/2017/190/contents/made</u>

¹⁸² SSI 2017/449 http://www.legislation.gov.uk/ssi/2017/449/contents/made

¹⁸³ <u>http://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-report-2017</u>

¹⁸⁴ *It always comes down to the money.* (2013). Kirsten Stalker (University of Strathclyde) et al. for Scotland's Commissioner for Children & Young People.

http://lx.iriss.org.uk/sites/default/files/resources/it-always-comes-down-to-money.pdf

6.2.4. Section 35(3) requires information in the statement to be proportionate to the needs of local carers. This is the same requirement as for section 34(3), which is considered in Chapter 1 of this Part.

Preparation, publication and review

6.2.5. Section 35(4) allows Scottish Ministers to make regulations about the preparation, publication and review of short break services statements by local authorities. The Carers (Scotland) Act 2016 (Short Breaks Services Statements) Regulations 2018¹⁸⁵ have been made under this power.

6.2.6. Local authorities are required to consider the views of relevant carers and carer representatives in the preparation and review of the statement. This is intended to ensure that the statement remains fit for purpose and appropriate to the needs of local carers. It will also help to inform local authorities with future planning and market shaping of short breaks services. Local authorities may also wish to involve short break service providers when preparing the statement.

6.2.7. Each local authority must provide contact details of the department or organisation responsible for the short breaks services statement. This will help ensure carers understand who to approach with enquiries about the short breaks provision available.

6.2.8. Each local authority is to publish their first short breaks services statement by 31 December 2018. This is to allow time to fully consider how best to source and present the information to be contained in their short breaks services statements. This will help ensure good quality statements are produced, providing carers with accurate and up-to-date information they require to build an appropriate package of support in light of changes resulting from the commencement of the Act.

6.2.9. It is the responsibility of each local authority to review and update its short breaks services statement as and when required, whilst giving regard to changes such as new short breaks services becoming available locally or nationally; or short breaks services that are no longer available.

6.2.10. It is recommended that short breaks services statements have an emphasis on local provision, as well as including relevant information about provision which may be available outwith the local authority area. Local authorities can provide support towards, and signpost carers to appropriate services from a variety of sources (universal, specialist, local authority operated, third sector etc.) This could include, for example, community cafes offering the carer an opportunity to socialise and relax on a regular basis, or a national residential service supporting people with long-term conditions or complex needs and their carers.

6.2.11. Local authorities are encouraged to include relevant statistics on local provision as part of the statement. This could include, for example, total local provision of short breaks broken down into different categories of service provision, or the number of carers supported by a particular service. This will help carers better understand the local short breaks landscape, and enable local authorities to consider

¹⁸⁵ SSI 2018/32 <u>http://www.legislation.gov.uk/ssi/2018/32/made</u>

any gaps in service provision, and in planning for future local demand of short breaks.

6.2.12. Some carers have made it clear that it would be useful for short breaks services statements to contain information about any criteria that needs to be met in order to access short breaks services. This would enable carers to have exercise more choice and control. Local authorities are encouraged to consider this as part of their preparation and content.

6.2.13. Local authorities are encouraged to use the statement as a way of sharing information and good practice in order to meet the needs of local carers and to plan for future demand. This is important where, for example, short breaks provision in a neighbouring local authority would meet the eligible needs of the carer.

For Information

There are also several national directories for information relating to short break services provided, which may be useful for identifying the sufficiency of local markets as well as for signposting purposes, including:

Short Break Services Directory¹⁸⁶ – a national directory of short break providers catering for different care needs and conditions (Shared Care Scotland);

Short Breaks Funding Directory¹⁸⁷ – a directory of national and local sources of funds that individuals can apply to help with a short break (Shared Care Scotland); **Euan's Guide**¹⁸⁸ – a national disabled access guide;

ALISS (A Local Information Service for Scotland)¹⁸⁹ – links to a range of local community supports that can support health and wellbeing;

Short Break Stories¹⁹⁰ – examples of voluntary sector Short Break provision in Scotland (Shared Care Scotland);

Autism Society Directory¹⁹¹;

Care Inspectorate¹⁹² – a directory of care services that are registered with and inspected by the Care Inspectorate; and

OSCR¹⁹³ – the Scottish Charity regulator who can provide a list of all charities registered in Scotland.

6.2.14. The principles of Self-directed Support (choice, control, flexibility, outcomes) apply to the provision of short breaks. Implications of the Social Care (Self-directed Support) (Scotland) Act 2013 for carers are set out in the Self-directed Support: a guide for carers guidance¹⁹⁴ and in Part 3 of this guidance.

¹⁸⁶ <u>https://www.sharedcarescotland.org.uk/directory/?action=search</u>

¹⁸⁷ https://www.sharedcarescotland.org.uk/fundingbreaks/funddirectory/

¹⁸⁸ https://www.euansguide.com/

¹⁸⁹ https://www.aliss.org/

¹⁹⁰ http://shortbreakstories.org.uk/

¹⁹¹ http://www.autism.org.uk/directory.aspx

¹⁹² <u>http://www.careinspectorate.com/index.php/care-services</u>

¹⁹³ https://www.oscr.org.uk/

¹⁹⁴ <u>https://www.gov.scot/publications/guidance-unpaid-carer-advocacy-scotland/</u> Note: this guidance was written before the passing of the Carers (Scotland) Act 2016.

Approaches to preparation

6.2.15. There are a number of different approaches used across the UK to disseminate information on short breaks that local authorities may wish to consider when preparing their own short breaks statements, some are described below.

6.2.16. Some Scottish local authorities have produced similar documents alongside referencing short break services in usual reporting documents. As an example, Midlothian Council produced a short breaks services statement that stated the context and approach of the council to short breaks¹⁹⁵.

6.2.17. The different legal requirements and circumstances in England require English local authorities to meet certain criteria for their statements in order to meet the needs of families with disabled children¹⁹⁶.

6.2.18. Shared Care Scotland has established a time-limited action learning project in 2017-18, involving local authority and integration authority representatives to help develop good quality short breaks services statements. Local authorities are encouraged to consider the outcomes from this project as they emerge.

For Information

Enfield Council publishes a good example of a short breaks statement for families with disabled children¹⁹⁷. Supporting documents from Enfield council, rather than the statement itself, provide the specific detail of local short break options that would be expected of Scottish local authorities.

Kent County Council also publishes a good short breaks statement for parents and carers of disabled children and young people¹⁹⁸. It includes useful case studies of the different forms short breaks can take to meet individual needs, and whether these are universal, targeted, or specialist support services.

Format

6.2.19. It is for local authorities to determine who prepares the short break statement. The format and exact content of the statement will be for local authorities to decide, as long as it meets the requirements set out in regulations. The short breaks services statement is to be a useable product for carers forming part of the information and advice service provided to them, and empowering them to take their own decisions regarding the support they need.

6.2.20. Local authorities may want to consider whether their short breaks services statement is prepared as a single piece that is relevant to both adult carers and

 ¹⁹⁵ <u>https://www.midlothian.gov.uk/downloads/file/3254/midlothian_short_breaks_services_statement_</u>
 ¹⁹⁶ <u>https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/245580/Short_Break_s_for_Carers_of_Disabled_Children.pdf</u>

¹⁹⁷ Short Breaks Statement. Enfield Joint Service for Disabled Children, Enfield Council <u>https://new.enfield.gov.uk/services/children-and-education/local-offer/short-breaks-statement-local-offer.pdf</u>

¹⁹⁸ Short Breaks Statement for Parents and Carers of Disabled Children and Young People in Kent. Kent County Council <u>https://www.kent.gov.uk/about-the-council/strategies-and-policies/childrens-social-work-and-families-policies/short-breaks-statement/short-breaks-statement-overview</u>

young carers, or if separate and distinct publications are produced to meet local needs.

6.2.21. Section 35(3) requires the statement to be in a readily accessible format. A recommended approach for the short breaks services statement is to publish the statement online in an easily searchable location alongside supplementary locations (e.g. physical copies in GP surgeries, carer centres, community centres, youth projects, schools and colleges).

Part 7: Delegation of Functions in the Carers Act

Summary

Each chapter of this guidance describes the different Carers Act functions of 'local authorities' and 'health boards' using those terms, as they appear in the Act.

References in the Carers Act guidance to 'local authorities' and 'health boards' will be understood to refer to the integration authorities of health and social care partnerships for all adult services and children's services where these have been delegated.

Purpose of this chapter

7.1.1. This chapter provides guidance on the health and social care integration context for the Act as a whole, taking account of the variation in approaches to integration for adults and children across different localities.

7.1.2. There was an overlap in the passage of the Public Bodies (Joint Working) (Scotland) Act 2014 (the '2014 Act') with the preparation of the Carers Act. This created uncertainty regarding final provisions of the 2014 Act so the Carers Act does not refer to the terminology of integration. This chapter therefore explains how bodies given responsibilities and powers under the Carers Act operate within health and social care integration.

7.1.3. The 2014 Act sets out the legal framework for the integration of health and social care. Regulations under that Act set out those functions which must be delegated to integration authorities (such as adult social care) and those which may be delegated to integration authorities (such as children's social care)¹⁹⁹.

Integration models

7.1.4. There are two distinct models of integration in operation across Scotland. Within these two forms there is further flexibility and variation between local authority areas as to the detail of what these integration models entail. Therefore the exact implications of integration will vary between local authority areas.

7.1.5. The 'Corporate Body Model' has been adopted widely across Scotland. In this model the pattern for delegation is for:

- all adult social care to be delegated to integration authorities, as part of the minimum delegated functions²⁰⁰; and
- Children's social care can also be delegated to integration authorities.

¹⁹⁹ <u>http://www.gov.scot/Topics/Health/Policy/Health-Social-Care-Integration/Statutory-Guidance-Advice/HSCFuncNote</u>

²⁰⁰ Pg. 3 for minimum delegation requirements <u>http://www.gov.scot/Topics/Health/Policy/Health-Social-Care-Integration/Statutory-Guidance-Advice/HSCFuncNote</u>

7.1.6. In integration models where children's social care is not delegated, the local authority retains responsibility for those relevant children's services.

7.1.7. The 'Lead Agency Model' is in operation in Highland. This is an alternative integration model in which all health and social care functions relating to adults and children are transferred to particular authorities separately. In the case of Highland this means:

- NHS Highland is responsible for all adult health and social care; and
- Highland Council responsible for all children's health and social care.

7.1.8. It is worth noting that a young carer, as defined in section 2 of the Carers Act, is a carer who is under the age of 18 or a carer over the age of 18 if they remain in school. The transition between children and adult social care services typically occurs from age 16 to 18. There will, therefore, be some instances where a young carer can be over 18.

Carers Act functions

7.1.9. Each chapter of this guidance describes the different Carers Act functions of 'local authorities' and 'health boards' using those terms, as they appear in the Act. (The terms 'responsible authority' and 'responsible local authority' are also used and defined).

7.1.10. Local authority functions which must be delegated to the integration authority are identified in the Public Bodies (Joint Working) (Prescribed Local Authority Functions etc.) (Scotland) Amendment Regulations 2017²⁰¹ and the Public Bodies (Joint Working) (Prescribed Local Authority Functions etc.) (Scotland) Amendment (No. 2) Regulations 2017²⁰²:

- Section 6 Duty to prepare adult carer support plan (and associated responsibilities to review and provide information);
- Section 21 Duty to set local eligibility criteria (and associated responsibilities to publish and review);
- Section 24 Duty to provide support;
- Section 25 Provision of support to carers: breaks from caring;
- Section 31 Duty to prepare local carer strategy (and associated responsibilities to publish and review);
- Section 34 Information and advice service for carers; and
- Section 35 Short breaks services statements

7.1.11. In line with the approach noted above, the requirement to delegate the above functions only extends to adult social care. Delegation of these functions with respect to children's social care remains a matter for local decision.

7.1.12. Local authority functions under section 12 – duty to prepare young carer statement (and associated responsibilities to publish and review) may also be delegated.

²⁰¹ SSI 2017/190 http://www.legislation.gov.uk/ssi/2017/190/contents/made

²⁰² SSI 2017/449 http://www.legislation.gov.uk/ssi/2017/449/contents/made

7.1.13. Health board functions which may be delegated to the integration authority are identified in The Public Bodies (Joint Working) (Prescribed Health Board Functions) (Scotland) Amendment Regulations 2017²⁰³:

- Section 12 Duty to prepare young carer statement (and associated responsibilities to publish and review); and
- Section 31 Duty to prepare local carer strategy (and associated responsibilities to publish and review).

7.1.14. Health board functions under section 28 of the Carers Act (Carer involvement in hospital discharge of cared-for persons) are subsidiary to any hospital functions delegated to integration authorities and will therefore automatically be delegated with those functions. (See expanded explanation of this point in Part 4, Chapter 2 – carer involvement in hospital discharge of cared-for persons.)

7.1.15. Local authority and health board functions under section 27 (Duty to involve carers in carer services) are not required to be delegated as integration authorities already have responsibilities to ensure carer involvement under the Public Bodies (Joint Working) (Scotland) Act 2014.

²⁰³ SSI 2017/381 <u>http://www.legislation.gov.uk/ssi/2017/381/contents/made</u>

Part 8: Transitional arrangements

Summary

Before the Act came into force on 1 April 2018, assessments for carers were carried out under section 12AA of the Social Work (Scotland) Act 1968 and section 24 of the Children (Scotland) Act 1995. Support for carers could then be provided under section 3(4) of the Social Care (Self Directed Support) (Scotland) Act 2013 or as 'services' under section 22 of the Children (Scotland) Act 1995. The Act replaces this old system.

The Carers (Scotland) Act 2016 (Transitional Provisions) Regulations 2018 provide for existing carers who receive support or services under the old system to move to the new system under the Act. In summary, local authorities must:

- continue providing support or services to existing carers and continue to waive charges, until they move to the new system or cease to need carer support; and
- keep this support or services under review until the carers move to the new system.

For any existing adult carer who, on 1 April 2018, is already receiving support under section 3(4) of the Social Care (Self Directed Support) (Scotland) Act 2013, the responsible local authority must offer an adult carer support plan where a change in circumstances has had (or could have) a material impact on the care provided by the carer and in any case by 31 March 2021. And they must carry out an adult carer support plan if requested.

For any existing carer who, on 1 April 2018, is already receiving services under the Children (Scotland) Act 1995, the responsible authority must offer a young carer statement (or if the carer has become an adult carer, the responsible local authority must offer an adult carer support plan) where a change in circumstances has had (or could have) a material impact on the care provided by the carer and in any case by 31 March 2019. The responsible authority or responsible local authority (as appropriate) must also carry out a young carer statement or adult carer support plan if requested.

What are transitional arrangements for?

8.1.1. From 1 April 2018, assessments for carers under the Social Work (Scotland) Act 1968 and the Children (Scotland) Act 1995 are superseded by the more comprehensive and outcomes-focused adult carer support plans (ACSPs) and young carer statements (YCSs) under the Act and support for adult carers and young carers will be provided under section 24 of the Act.

8.1.2. Transitional arrangements are needed to regulate the way existing carers move from the old system of carer assessments and support to the new system under the Act. The Carers (Scotland) Act 2016 (Transitional Provisions) Regulations 2018²⁰⁴ ('the Regulations') have therefore been made under section 43 of the Act.

²⁰⁴ SSI 2018/34 http://www.legislation.gov.uk/ssi/2018/34/made

They work by providing for when existing carers must be offered ACSPs or YCSs, so that they can move to the new system.

Principles

8.1.3. The transitional arrangements were developed with three principles in mind.

Continuity of support

8.1.4. The transitional arrangements are intended to provide continuity of support and services for existing carers during the transition process. Carers who currently receive support or services under the old system should continue to do so until they move to the new system under the Act. Authorities should continue to provide that support or services until these carers have an adult carer support plan or young carer statement (as appropriate) and until decisions about future support under the Act are in place.

Managed transition to new system

8.1.5. The transitional arrangements are also intended to ensure that existing carers move onto the new system on a phased basis and over a reasonable timescale. This approach is designed to avoid creating bottlenecks and to allow authorities to manage the process of existing carers moving to the new system alongside providing ACSPs, YCSs and support to 'new' carers.

Responsive to individual circumstances

8.1.6. The transitional arrangements are intended to be responsive to the circumstances of individual carers. Existing carers should be able to request an ACSP or YCS under the Act at any time. Existing carers must also be offered an ACSP or YCS when their caring circumstances change significantly. These provisions will work alongside longstop dates to ensure that all existing carers benefit from the person-centred approach of an adult carer support plan or young carer statement within a reasonable timescale.

Transitional Provisions Regulations

8.1.7. The Regulations themselves are quite technical and complex to read. Some of that technical complexity arises from differences in concepts and terminology between the old and new systems for supporting carers. In some cases responsibility for supporting an individual carer will also move from one local authority to another when the carer moves from the old system to the new one.

8.1.8. There is added complexity in relation to young carers because some existing carers will be transitioning to become adult carers during the same period as they move between the old and new systems. The regulations are drafted to allow for that possibility.

8.1.9. The regulations are summarised above. Their effect for adult carers and young carers is considered in more detail below.

Adult Carers

Carer's assessments in progress under the old system on 31 March 2018

8.1.10. Where a carer's assessment has been or is being carried out under the old system but no support has yet been provided to the carer, the carer should be treated as having been identified for the purpose of the Act and the responsible local authority must offer the carer an ACSP under section 6(2) of the Act. The regulations do not make any specific provision for these cases so the normal requirement to offer an ACSP applies.

8.1.11. It is recommended that authorities consider prioritising these cases which are already in progress. Authorities may wish to draw on information from the carers assessment under the old system when preparing ACSPs under the new system.

Duty to continue support under the old system.

8.1.12. Where a local authority is providing support to a carer under section 3(4) of the Social Care (Self Directed Support) (Scotland) Act 2013 immediately before 1 April 2018, regulation 3 requires the local authority to continue to provide that support. That duty applies until the carer is provided with an ACSP, rejects the offer of an ACSP or no longer has needs for support.

Review of support under the old system

8.1.13. A local authority who is continuing to provide support to a carer (under Regulation 3) must make arrangements to keep that support under review (Regulation 5). This is intended to ensure that the local authority becomes aware of changes in circumstances which could have a material impact on the caring situation and could therefore trigger the duties to offer the carer an ACSP under Regulation 11. This will also ensure the local authority becomes aware of changes which mean the carer no longer has any needs for support.

8.1.14. The Regulations do not dictate what the arrangements to keep support under review should be. It could involve light touch arrangements to keep in regular contact with the carer and cared-for person. Local authorities can put in place arrangements which work in their local context and which are proportionate to the individual caring situation. For example, a carer in good health who cares for someone whose condition is stable may require less frequent contact from an authority than a carer in poor health who cares for someone with a deteriorating condition.

8.1.15. Local authorities may wish to ensure that their review arrangements are responsive and flexible enough to take account of changes which are brought to their attention by the carer. Less responsive review arrangements could result in more individual requests for ACSPs from existing carers, which the authority would have to respond to on a reactive basis.

8.1.16. If as a result of light touch review a local authority considers that a more in depth assessment is required to understand how the caring situation has changed, it may often be more appropriate to offer an ACSP at that stage, rather than carrying out a more in-depth review of existing support.

Moving to the new system

8.1.17. The trigger for an existing carer to move to the new system under the Act can be a request for an ACSP from the carer or an offer of an ACSP from the responsible local authority.

Request from carer for ACSP

8.1.18. An adult carer who is receiving support under the old system can move to the new one by requesting an ACSP from the responsible local authority under section 6(4) of the Act. The carer's existing support must continue under regulation 3 until they are provided with an ACSP under section 6 of the Act.

Material change triggering duty to offer ACSP

8.1.19. Regulation 11 requires the responsible local authority to offer a carer an ACSP where it appears to the local authority a change in circumstances has had a material impact on the care provided by the carer.

8.1.20. In some cases the local authority providing support to the carer under the old system will not be the responsible local authority under the new system. In such cases, where the local authority under the old system identifies that there has been a material impact on the care provided they must inform the responsible local authority. The responsible local authority must then offer an ACSP to the carer.

Proactive offer of ACSP by responsible local authority

8.1.21. Regulations 6 and 8 require all adult carers who receive support under the old system to be offered an ACSP by 31 March 2021 (three years after the Act comes into force). This three year transition period provides a longstop date rather than a target. It is intended to allow local authorities to manage a smooth, gradual transition, alongside supporting new carers under the Act.

8.1.22. Local authorities can offer an ACSP to a carer at any time after the Act is in force. It is not recommended that authorities wait until the end of the transition period before offering ACSPs to the majority of existing carers.

8.1.23. It is expected that all existing carers will move to the new system on a gradual basis over the course of the three years. Some carers will request ACSPs under the Act, other carers will move to the new system when their circumstances change (as outlined above) and the remaining carers should be offered ACSPs on a proactive basis by their responsible local authority.

8.1.24. It is recommended that local authorities put arrangements in place to manage the process of offering ACSPs to existing carers. These could be scheduled in different ways, tailored to local circumstances, needs and priorities, for example, prioritising carers with particular levels or types of need.

8.1.25. This approach will mean that some groups may move to the new system later than others. This could be achieved without disadvantaging individual carers because (as highlighted above) any carer can still request an ACSP and must be offered one if they have a material change in circumstances.

What to do when responsibility is moving from one authority to another

8.1.26. There will be cases where the local authority providing support to a carer under the old system is not the 'responsible local authority', which has the duty to prepare an ACSP and provide support under the Act. That arises because the local authority supporting a carer under the old system may be the authority where the carer lives, whereas under the Act, the responsible local authority is the authority where the cared-for person lives.

8.1.27. Where a local authority is supporting a carer under the old system but will not be the responsible local authority under the new system, regulation 8 requires the (old) local authority to inform the (new) responsible local authority. This is intended to ensure that responsible local authorities will become aware of all adult carers who are receiving support under the old system so that they are identified as carers for the purpose of the duties in the Act.

8.1.28. Where local authorities share a boundary, it is recommended that they work together, firstly to identify whether responsibility for supporting a number of carers is likely to transfer between them in this way and secondly to use their powers to offer ACSPs to manage and co-ordinate their cross-border transitions from the old system to the Act. This proactive approach may help to manage the number of individual requests for ACSPs.

From offer to ACSP

8.1.29. Once an ACSP has been offered the carer's existing support must still continue under regulation 3 until they are provided with an ACSP, reject the offer of an ACSP or they no longer have needs for support.

8.1.30. Once an offer has been made, regulation 13 ensures that it is treated as an offer under the Act. This means that all the other provisions in the Act will apply as normal to the preparation of the ACSP.

Young Carers

Assessments in progress under the old system on 31 March 2018

8.1.31. Where an assessment has been or is being carried out under the old system but no support or services has yet been provided to the carer, the carer should be treated as having been identified for the purposes of the Act. The regulations do not make any specific provision for these cases so the normal requirement to offer a YCS (or ACSP) applies. If the carer is a young carer under the Act, the responsible authority must offer the carer a YCS under section 12(2) of the Act. (If the carer is an adult carer under the Act, the responsible local authority must offer the carer an ACSP under section 6(2) of the Act).

8.1.32. It is recommended that authorities consider prioritising cases which are already in progress under the old system. Authorities may wish to draw on information from the assessment under the old system in order to provide the YCS (or ACSP) under the new system.

Duty to continue support under the old system

8.1.33. Support to young carers under the old system will take the form of services under section 22 of the Children (Scotland) Act 1995. Where a local authority is providing such services to a carer immediately before 1 April 2018, Regulation 4 requires them to continue to provide those services. That duty applies until the carer is provided with a YCS or an ACSP, rejects the offer of a YCS or an ACSP or no longer has needs for support.

8.1.34. The regulations make provision for a carer to be provided with either a YCS or an ACSP. There are two reasons for this. Firstly, there may be carers receiving services under section 22 of the Children (Scotland) Act 1995 who are over 18 and not at school, so would not be 'young carers' under the Act. Secondly, if a carer is under the age of 18 on 1 April 2018, they may become an adult carer during the course of the transition period so would need to be offered an ACSP and not a YCS under the Act.

Review of support under the old system

8.1.35. A local authority who is continuing to provide services to a carer (under Regulation 4) must make arrangements to keep those services under review (see Regulation 5). This is intended to ensure that the authority is aware of changes in circumstances which could have a material impact on the caring situation and could therefore trigger the duties to offer the carer a YCS or an ACSP under Regulation 12.

8.1.36. The Regulations do not dictate what the arrangements to keep services under review should be. It could involve light touch arrangements to keep in regular contact with the carer and cared-for person. Authorities can put in place arrangements which work in their local context and which are proportionate to the age of the carer and the individual caring situation. For example, an older young carer who cares for someone whose condition is stable may require less frequent contact from an authority than a younger carer who cares for someone with a deteriorating condition.

8.1.37. Authorities may wish to ensure that their review arrangements are responsive and flexible enough to take account of changes which are brought to their attention by the carer. Less responsive review arrangements could result in more individual requests for YCSs and ACSPs from existing carers, which the authority would have to respond to on a reactive basis.

8.1.38. If as a result of light touch review a local authority considers that a more in depth assessment is required to understand how the caring situation has changed, it may be more appropriate to offer a YCS or ACSP at that stage, instead of carrying out a more in-depth review of existing services.

Moving to the new system

8.1.39. The trigger for an existing carer to move to the new system under the Act can be either:

- a request for a YCS or an ACSP from the carer;
- an offer of a YCS from the responsible authority; or
- an offer of an ACSP from the responsible local authority.

Request from carer for YCS

8.1.40. A carer who is receiving services under the old system can move to the new one by requesting a YCS from the responsible authority (under section 12(4) of the Act) or an ACSP from the responsible local authority (under section 6(4) of the Act). The carer's existing services must continue under regulation 4 until they are provided with a YCS or ACSP under the Act.

Material change triggering duty to offer YCS or ACSP

8.1.41. Regulation 12 requires responsible local authorities to offer carers a YCS or an ACSP (as appropriate) where it appears to the local authority that a change in circumstances has had a material impact on the care provided by the carer.

8.1.42. In some cases the local authority providing support to the carer under the old system will not be the responsible authority or the responsible local authority under the new system. In such cases, where the local authority under the old system identifies that there has been a material impact on the care provided they must inform the responsible authority and responsible local authority. Then, depending on whether the carer is a young carer or an adult carer for the purposes of the Act, either the responsible authority must offer a YCS or the responsible local authority must offer an ACSP to the carer.

Proactive offer of YCS or ACSP by responsible authority and responsible local authority

8.1.43. Regulations 7, 9 and 10 require all young carers who receive services under the old system to be offered a YCS or an ACSP by 31 March 2019 (one year after the Act comes into force). The shorter transition period for young carers (one year as opposed to three) reflects the need for more frequent reviews in this vulnerable group. The reference to ACSPs is to allow for the possibility that carers may move from receiving services under section 22 of the Children (Scotland) Act 1995 to being adult carers under the Act.

8.1.44. The one year transition period provides a longstop date rather than a target. It is intended to allow local authorities to manage a smooth, gradual transition, alongside supporting new carers under the Act.

8.1.45. Responsible authorities can offer a YCS to a young carer and responsible local authorities can offer an ACSP to an adult carer at any time after the Act is in force. It is not recommended that authorities wait until the end of the transition period before offering YCSs or ACSPs to the majority of existing carers.

8.1.46. It is expected that all existing carers who receive services under the old system will move to the new system on a gradual basis over the course of the year. Some carers will request YCSs under the Act, other carers will move to the new system when their circumstances change (as outlined above) and the remaining carers should be offered YCSs or ACSPs (according to whether they are young carers or adult carers under the Act) on a proactive basis by their responsible authority or responsible local authority.

8.1.47. It is recommended that local authorities put arrangements in place to manage the process of offering YCSs and ACSPs to existing carers. These could

work in different ways and could be tailored to local circumstances, for example, prioritising carers with particular levels or types of need.

8.1.48. This approach could mean that some groups would move to the new system later than others but this could be achieved without disadvantaging individual carers because (as highlighted above) any carer can still request a YCS or an ACSP under the Act and must be offered one if they experience a material change in circumstances.

What to do when responsibility is moving from one authority to another

8.1.49. There will be cases where the local authority providing services to a carer under the old system is not the 'responsible authority', which has the duty to prepare a YCS or is not the 'responsible local authority', which has the duty to prepare an ACSP and to provide support to young carers and adult carers under the Act.

8.1.50. Regulations 9 and 10 deal with circumstances where a local authority is providing services to a carer under the old system but will not be the responsible authority or the responsible local authority under the new system. The regulations require the (old) authority to inform the (new) responsible authority and (new) responsible local authority that it is providing services to the carer. This is intended to ensure that responsible authorities and responsible local authorities will be made aware of all carers who are receiving services under the old system.

8.1.51. Where local authorities share a boundary, it is recommended that they work together, firstly to identify whether responsibility for supporting a number of carers is likely to transfer between them in this way and secondly to use their powers to offer ACSPs to manage and co-ordinate their cross-border transitions from the old system to the Act. This proactive approach may help to manage the number of individual requests for YCSs and ACSPs from carers receiving services under the old system.

From offer to YCS or ACSP

8.1.52. Once a YCS or an ACSP has been offered, the local authority must continue to provide the carer's existing services under regulation 4 until the carer is provided with a YCS or ACSP, rejects the offer of the YCS or ACSP or no longer has needs for support.

8.1.53. Once an offer has been made, regulation 14 ensures that it is treated as an offer under the Act. This means that all the other provisions in the Act will apply as normal to the preparation of the YCS or ACSP.

Information about transitional arrangements

8.1.54. It is recommended that local authorities consider including information on their local transition arrangements in their first local carer strategies under Part 5 of the Act. This information is unlikely to be relevant to subsequent strategies as all existing carers should have moved to the new system by the time the strategies fall to be reviewed under section 33 of the Act.

8.1.55. It is also recommended that local authorities ensure that the information and advice services they provide under Part 6 of the Act can provide information and advice about the transition arrangements for existing carers.

Glossary

the Act

• The Carers (Scotland) Act 2016

ACSP

• Adult carer support plan

adult carer (defined in section 3 of the Act)

• A carer who is at least 18 years old and not a young carer.

adult carer support plan (defined in section 6)

• Replaces the 'Carer's Assessment' for adult carers and sets out a carer's identified personal outcomes, identified needs for support (if any), and any other support that the responsible local authority is to provide to the carer.

break from caring

• Any form of support that enables a carer to have time away from their caring responsibilities. Support can include, for example, a short break or care for the cared-for person that enables the carer to have a break.

care for the cared-for person

• This is care provided to the cared-for person, which replaces care previously given by the carer, and which is provided as a form of support to the carer so the carer can have a break from caring. This may include 'replacement care'.

carer (defined in section 1)

- Someone who provides (or intends to provide) care for a cared-for person, but not:
 - $\circ~$ only by virtue of the cared-for person's age if they are under 18 years old;
 - o if the care provided is under contract; or
 - if the care provided is voluntary work.

eligible needs (defined in section 24(3))

- These are the needs for support identified in the adult carer support plan or young carer statement, to enable a carer to achieve their personal outcomes which:
 - cannot be met through services available to the cared-for person, or through services generally available to people in the area of the responsible local authority or where the carer lives; and
 - o also meet the local eligibility criteria.

identified needs (defined in section 5)

 These are the needs for support identified in the adult carer support plan or young carer statement, to enable a carer to achieve their personal outcomes. Carers whose identified needs do not meet local eligibility criteria may still have access to other forms of support including, for example, information and advice services. Responsible local authorities have a power to provide support to meet carers' identified needs which do not meet local eligibility criteria.

information and advice service (required under section 34)

 A service in each local authority area, providing information and advice on a range of mandatory topics relevant to carers. It should be accessible to carers who are resident in that local authority area, or caring for someone in that local authority area.

integration authority

 Established between the local authority and health board, an integration authority is responsible for directing the execution of various local authority and health board functions that have been delegated to it. These arrangements are detailed in a local Integration Scheme and must include adult social care, adult primary health care and unscheduled adult hospital care. They may also include children's care and criminal justice social work.

kinship carer

• A relative or close friend looking after a child in place of the child's parents. In some cases they will have a kinship carer agreement with the local authority.

local eligibility criteria (defined in section 21(2))

• The criteria to be set and published by each local authority, which are to be used to determine whether the local authority is required to provide support to meet an individual carer's identified needs.

personal outcomes (defined in section 4)

• These include outcomes which, if achieved, would enable a carer to provide, or continue to provide, care for the cared-for person. They should be outcomes that matter to an individual carer, which could include outcomes around having a life alongside caring and looking after the carer's own health and wellbeing.

responsible authority (defined in section 41)

• The body responsible for preparing a young carer statement. This can be either a health board, local authority, or the directing authority of a grant-aided or independent school.

responsible local authority (defined in section 41)

• The local authority for the area in which the cared-for person lives. Many of the duties under the Carers (Scotland) Act 2016 are for local authorities to exercise.

short break

• A short break is a form of support that can enable a break from caring. They can be taken with or without the cared-for person, and normally involve a leisure pursuit, holiday break, or other type of informal activity.

short breaks services statement (defined in section 35(3))

• A publication in each local authority area setting out information about short breaks services available in Scotland for carers and cared-for persons.

young carer (defined in section 2)

• A carer who is under 18 years old, or is 18 or over and still attending school.

young carer statement (defined in section 12)

• A new document for young carers, prepared by the responsible authority which sets out a young carer's identified personal outcomes, identified needs for support (if any) and any other support that the responsible local authority is to provide to the young carer.

YCS

• Young carer statement

Annex A: Support to carer or cared-for person

1. There are various reasons why it is important to be clear about whether a decision to provide a particular service is being taken in relation to the cared-for person or the carer:

- if support is provided as a result of an assessment of the cared-for person's social care needs and outcomes under section 12A, then it is clear from sections 5, 6 and 11(2) of the SDS Act that it is for that person to decide whether the support should be provided and how it should be delivered;
- the cared-for person might not wish to receive particular support and so they may not be delivered in practice even though the local authority has decided they have an eligible need through assessment of their social care needs;
- as set out above, different eligibility criteria might apply in assessing whether the needs of the cared-for person call for the provision of social care support or carer support; and
- the rules in relation to whether a charge can be made in respect of the support or services will be different if it is provided for the carer or the cared-for person.

2. Section 12A of the Social Work (Scotland) Act 1968 and section 8 of the Disabled Persons (Services, Consultation and Representation) Act 1986 make provision for social care assessments to take into account the care provided by a carer and the carer's ability to continue to provide that care. These provisions are intended to ensure that the local authority is fully informed about the level of care that a carer is willing and able to provide.

3. Section 12A(1)(b)(ii) of the 1968 Act also expressly requires the local authority to take into account any views which the carer wishes and is able to express, so far as it is reasonable and practicable to do so.

4. As such, the two assessments should dovetail. For example, if a cared-for person requires 24/7 care and the carer is willing and able to provide that care for 8 hours a day, the social care needs assessment should cover the cared-for person's needs for the remaining 16 hours a day.

5. If there is already a social care needs assessment in place at the point where an adult carer support plan (ACSP) or young carer statement (YCS) is being prepared, and if support is being delivered in accordance with that assessment, then the support provided by the local authority to the cared-for person should be reflected in the part of the ACSP or YCS which sets out the nature and extent of the caring role.

6. The local authority would be required to consider the extent to which the carer's needs are not already being met by the provision of support to the cared-for person, and apply its eligibility criteria to those remaining needs.

7. Additional support that might be suitable or needed for the cared-for person could be identified in the context of the ACSP or YCS and not the social care needs assessment. This might happen where the carer does not agree with the support provided to the cared-for person, either because the situation has changed since the last social care needs assessment; because the cared-for person wants more support from the carer than the carer wishes; or because the carer feels that the

decisions already made are not good decisions and make too many assumptions about the carer's willingness to care. This sort of concern may well be raised during the ACSP or YCS process and the Scottish Government would expect them to be taken seriously. If it was agreed that the concerns were valid, there might be agreement to revisit the social care needs assessment to see what could be done to resolve matters.

8. Guidance on the Community Care and Health (Scotland) Act 2002²⁰⁵ makes clear that carers and cared-for persons should have the opportunity to discuss their needs individually without the other person being present.

9. As and when the social care needs assessment is reviewed, that might result in additional support being put in place for the cared-for person which would in turn change the needs which are identified under the ACSP or YCS. However, until any change to the social care needs assessment had been made, the local authority would still be under a duty to meet those needs identified in the ACSP which meet the eligibility criteria. This could not be through a change in support for the cared-for person without their social care needs assessment having been reviewed and so the local authority would have to consider other options available which would provide support to the carer.

10. As a matter of good practice, a revision to the social care needs assessment done quickly would enable a final decision on how to meet the carer's needs could be met once changes to the cared-for person's support had taken effect. However, there may well be cases where it takes time for any new support to be available and put in place, so completion of the ACSP or YCS should not be conditional on the social care needs assessment having been reviewed.

11. Therefore, each of the social care needs assessment and ACSP or YCS processes include a requirement on the person conducting the process to have regard to what is decided from time to time under the other process. If the duty to provide tailored support to the carer then operates by reference to the needs which are still existing when both general services and indirect services provided to the cared-for person are taken into account, this will give the correct result.

12. A similar analysis applies in relation to the interaction between ACSP/YCS and an assessment under section 23(3) of the Children (Scotland) Act 1995 where the carer cares for a disabled child. The assessments may be easier to bring together in practice where the carer is a parent of a disabled child, since the carer will often be responsible for agreeing to the support to be provided to the child in their capacity as parent. This means that there is a smaller risk of conflict about what is required to be provided to the child than in the case of a cared-for adult. However, the general principles about the interaction between the two processes should apply equally to considering how far support provided to a disabled child in accordance with a section 23(3) assessment impacts on the needs of their carer.

13. In situations where the cared-for person does not have a social care needs assessment, the carer may still have identified needs which meet the local eligibility criteria. In such circumstances, the carer may have identified needs which might be met by services or assistance provided to the cared-for person but which are not

²⁰⁵ Scottish Executive Circular CCD 2/2003 http://www.sehd.scot.nhs.uk/publications/cc2003_02full.pdf

provided via a social care needs assessment, for example, the provision of additional health services to the cared-for person. This should be recorded in the ACSP or YCS.

Annex B: Carers who are also service users (adults or children with support needs)

1. Carers might also have support needs themselves due to their own illness or disability. Section 24(5)(a) and (b) of the Carers Act (application of duty to support carer to meet the carer's eligible needs) applies where a carer's eligible needs might also be met through social care support provided to the carer and assessed under section 12A of the Social Work (Scotland) Act 1968 or support for children and their families provided to the carer under section 22 of the Children (Scotland) Act 1995. If the carer's needs meet the eligibility criteria for carer support, then the duty to provide support to the carer in subsection (4)(a) applies even if those eligible needs for support also in themselves call for the provision of social care support under the 1968 or 1995 Acts.

2. This means a carer can have needs themselves as a disabled or ill person and have those needs met by social care support delivered to them. If they have eligible needs as a carer in their caring role, then the duty to provide support applies.

3. Where carers have support needs themselves, for example, each member of an elderly couple in a mutually dependent relationship, the responsible local authority will have to make decisions about whether the need arises because of the caring (e.g. depression due to challenges of caring) or because of other factors (e.g. depression due to isolation or which pre-existed the beginning of caring). This may result in artificial distinctions having to be drawn but the responsible local authority will need to exercise their judgment in determining whether the needs relate to the person's caring role. The distinction should however be clear enough.

4. If it is impossible for a local authority to isolate a person's needs as a carer from that same person's needs as a user of services, the local authority may be in a position where there are potentially two sets of eligibility criteria which are relevant. (There is no statutory obligation to have eligibility criteria in respect of the decision about whether needs identified in social care needs assessments 'call for' the provision of services in terms of section 12A of the Social Work (Scotland) Act 1968, but the Scottish Ministers issued guidance in 2009 suggesting that local authorities should do so for older people (with relevance to adults with support needs too). In such a case, the duty to provide the support to the person as a carer takes precedence when the local eligibility criteria are met, regardless of whether the local authority also decides (or would have decided) that the needs call for the provision of services under section 12A of the 1968 Act.

- 5. In summary, and to offer pragmatic examples, a carer could have:
 - support needs as a carer, some or all of which might be eligible needs and could receive, for example, emotional support at the carer centre (because the caring situation is causing the carer stress and anxiety) and a short break; and
 - concurrent support needs with regard to their own social care needs, some or all of which might be eligible needs and could receive, for example, telehealth, (a health monitoring kit) because they have diabetes and this kit helps them to monitor and self-manage their condition at home.

6. In other instances, as noted above, the distinction between a carer having eligible needs as a carer and as an adult with needs for social care support could be less clear. For example, it may be difficult to distinguish if the mental ill health of the carer is due to their caring role or not, but it is apparent that a certain type of support will help the carer's mental health. In this circumstance, the local authority must decide for itself which eligibility criteria framework to use and do so quickly so that timely support is provided.

Annex C: Short breaks – definition by Shared Care Scotland

Definition

1. A short break is any form of service or assistance which enables the carer(s) to have periods away from their caring routines or responsibilities.

Purpose

2. The purpose is to support the caring relationship and promote the health and well-being of the carer, the supported person, and other family members affected by the caring situation.

Description

- 3. Breaks from caring may:
 - be for short or extended periods;
 - take place during the day or overnight;
 - involve the person with support needs having a break away from home allowing the carer time for themselves;
 - allow the carer a break away with replacement care, if required, in place; and
 - take the form of the carer and the person they care for having a break together, with assistance if necessary, providing a break from the demands of their daily caring routines.

Rationale

4. Due to the intensity of their caring role, carers are often only able to get the rest and relaxation which are essential to their health, well-being and continuing capacity to care with the help of a short break, including replacement care if appropriate.

Provisos

- 5. Services or assistance enabling carers to be in employment are not a 'respite' break because the right to work is a universal human right. Such services or assistance are vital to many carers, but in addition carers, like any employed person, have a right to time for themselves for rest, leisure and to pursue wider interests. Equally however, such services or assistance are a form of replacement care to enable the carer to work rather than to have a short break.
- 6. Cover for carers when they are unwell should be deemed as an emergency break. Again, this cover or services and assistance is a form of replacement care but not to enable the carer to have a short break.

Choice and Flexibility

7. Whichever form the break takes, choice, flexibility and personalisation are key to achieving successful outcomes all round with the needs of everyone in the caring relationship carefully considered and balanced.

Planning

8. Carers and those they care for should be offered assistance to weigh up the different options and to plan ahead for their breaks. This will help them feel more confident about the service or support being provided, to make necessary arrangements and have time to plan what they want to do to make the most of their break.

Examples

- 9. In order to meet these different needs a diverse range of short break opportunities should be available locally. These could include:
 - a choice of specialist services such as:
 - o hospice care
 - o residential accommodation with nursing or personal care support
 - generic or condition specific short break services;
 - community flats with care support;
 - building-based day centre provision;
 - services which offer breaks in the home of another individual or family;
 - breaks at home through the day or overnight provided through a care at home service;
 - a range of accessible and inclusive community-based activities and groups;
 - holiday breaks using mainstream or specialist holiday providers, with or without the carer;
 - specialist play schemes and after school clubs;
 - befriending schemes where volunteers help facilitate the short breaks; and
 - peer support groups.

Self-directed support

- 10. The further expansion of self-directed support will allow carers and supported people to explore a range of different short break options tailored to their personal outcomes and to purchase equipment to enable a short break to take place. For example, they may use their agreed budget to:
 - employ a personal assistant to accompany the supported person on leisure breaks, with or without the carer;
 - hire or purchase equipment that helps facilitate breaks for the carer, the supported person or both;
 - receive time flexible vouchers that can be exchanged for assistance from registered care providers/agencies; and
 - purchase membership of leisure facilities.

Emergency Breaks

- 11. It is also important for people to have access to emergency support if they need replacement care at short notice, due to the unexpected ill health of the carer; deterioration in the health of the person they are looking after; or in response to a crisis such as bereavement.
- 12. Emergency services may need to be available at short notice, with the duration unknown, but limited.

13. To minimise the levels of stress that can be generated by these events, an emergency plan should be prepared in advance that includes any options for emergency respite cover. This will be particularly important for any carers that are at increased risk due to their own health or caring circumstances.

Annex D: Carer identification

- 1. Carer identification can be carried out by, amongst others:
 - health and social care and children's services professionals when carrying out assessments with cared-for persons;
 - health and social care professionals during anticipatory care planning;
 - health and social care professionals in hospital settings;
 - district nurse teams;
 - occupational therapists;
 - social care assistants;
 - GP Link Workers;
 - guidance and teaching staff in schools and staff in colleges and universities;
 - providers of care and support services;
 - housing staff;
 - third sector and independent organisations;
 - employers (including those who are Carer Positive²⁰⁶);
 - multilingual groups; and
 - outreach with gypsy traveller communities and by those working with Black and Minority Ethnic (BME) communities.
- 2. The potential barriers to carer identification include:
 - identifying with the term 'carer' both because of confusion with care workers being referred to as carers and because they see themselves primarily as a 'mother', 'daughter' etc.;
 - the view that caring is a legitimate domain of family responsibility;
 - resisting access to support in order to protect a person's identity;
 - pride in self-sufficiency and a sense of shame in asking for, or being offered, support;
 - lack of family contact with social work departments;
 - fear of societal stigma if caring for someone with substance misuse or mental ill health;
 - self-management by people with long-term conditions but the caring role becomes more intense over time as people's health deteriorates;
 - with respect to young carers, fear of family break-up or being treated differently to friends who are not carers since young people like a group identity;
 - language barriers and lack of translation services, for example, there is no word for 'carer' in Punjabi and Urdu;
 - lack of training with some GPs and other healthcare professionals;
 - a need to fully consider the personal outcomes of the carer in the family dynamic; and
 - the visibility of services to support carers in some 'hard-to-reach' communities, such as in rural and remote areas and in BME communities.
- 3. Examples of good practice in identifying carers include:

²⁰⁶ Carer Positive is the Scottish Government's accreditation scheme which recognises employers who support carers in the workplace. It is operated by Carers Scotland on behalf of the Scottish Government. <u>http://www.carerpositive.org/</u>

- link workers in GP and hospital settings;
- employers with carer registers and websites on carers in employment;
- sensitive young carer identification in schools via awareness raising, small group exercises and teacher training and continuous professional development with links to Getting it right for every child;
- carer awareness raising in colleges and universities via carer campaigns and carer policies;
- local publicity and communications; and
- training of health and social care professionals.

Annex E: Consent and the General Data Protection Regulation (GDPR)

1. The requirement to have a lawful basis in order to process personal data exists under the Data Protection Act 1998 (DPA). The GDPR places more emphasis on being accountable and transparent about an organisation's lawful basis for processing.

2. To process personal data 'fairly and lawfully' an organisation needs to identify one condition under Schedule 2^{207} of the DPA, and also Schedule 3^{208} if the data is sensitive (for example health data). From 25 May 2018, Article 6^{209} and Article 9^{210} of the GDPR apply accordingly.

3. Under the GDPR, it is mandatory for all public authorities and bodies to designate a Data Protection Officer responsible for ensuring compliance with the data protection law. Consideration should be given to the role and responsibilities of any third sector organisation commissioned to undertake duties under the Carers Act. For example, where they are the data processor acting on behalf of local authorities or the data controller. This is likely to be the case where a local carer centre completes the adult carer support plan and young carer statement.

4. Under the GDPR an organisation can process personal data without consent if it's necessary for:

- a contract with the individual: for example, to supply goods or services they have requested, or to fulfil obligations under an employment contract. This also includes steps taken at their request before entering into a contract;
- **compliance with a legal obligation**: if the organisation is required by UK or EU law to process the data for a particular purpose, then they can;
- vital interests: organisations can process personal data if it's necessary to protect someone's life. This could be the life of the data subject or someone else;
- a public task: if the organisation needs to process personal data to carry out
 official functions or a task in the public interest and have a legal basis for the
 processing under UK law then they can. If the organisation is a UK public
 authority, the ICO view is that this is likely to give them a lawful basis for many
 if not all of their activities; and
- **legitimate interests**: for a private-sector organisation, they can process personal data without consent if they have a genuine and legitimate reason (including commercial benefit), unless this is outweighed by harm to the individual's rights and interests.

5. A Privacy Impact Assessment has been completed to accompany the Act and published on the Scottish Government website.

²⁰⁷ https://www.legislation.gov.uk/ukpga/1998/29/schedule/2

²⁰⁸ https://www.legislation.gov.uk/ukpga/1998/29/schedule/3

²⁰⁹ https://www.privacy-regulation.eu/en/6.htm

²¹⁰ https://www.privacy-regulation.eu/en/9.htm

Annex F: Local Eligibility Criteria Framework

Annex F(a) – Illustrative threshold for carer support

Critical or Substantial Impact

Local Authority *duty* to support eligible carers

Local Authority provides for eligible need

Moderate Impact

Local Authority *power* to support carers

Cocal Authority commissions community supports and carer services which are provided on a preventative basis

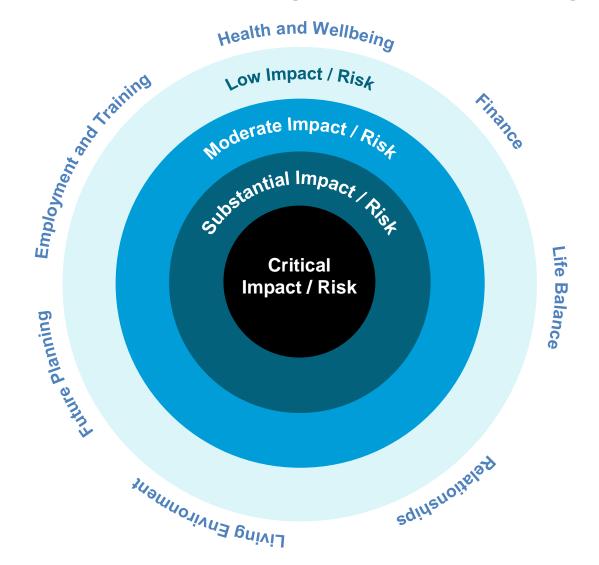
Services are developed according to local need. This may include some form of short breaks and services such as peer support, advocacy and counselling

Low or No Impact

Local Authority power to support carers

Local Authority supports information and advice services for carers and other universal, community supports. This may include access to a local carer centre, peer support, training and access to universal services and community support

Illustrative eligibility threshold



Annex F(b) – Determining the impact of the caring role and associated risk

Annex F(c) – Table of Indicators

	Caring has no impact NO RISK	Caring has low impact LOW RISK	Caring has moderate impact MODERATE RISK	Caring has substantial impact SUBSTANTIAL RISK	Caring has critical impact CRITICAL RISK
Health & Wellbeing	Carer in good health.	Carer's health beginning to be affected.	Carer's health at risk without intervention.	Carer has health need that requires attention.	Carer's health is breaking/has broken down.
	Carer has good emotional wellbeing.	Caring role beginning to have an impact on emotional wellbeing.	Some impact on carer's emotional wellbeing.	Significant impact on carer's emotional wellbeing.	Carer's emotional wellbeing is breaking/ has broken down.
Relationships	Carer has a good relationship with the person they care for and is able to maintain relationships with other key people in their life.	Carer has some concerns about their relationship with the person they care for and/or their ability to maintain relationships with other key people in their life.	Carer has identified issues with their relationship with the person they care for that need to be addressed and/or they find it difficult to maintain relationships with other key people in their life.	The carer's relationship with the person they care for is in danger of breaking down and/or they no longer are able to maintain relationships with other key people in their life.	The carer's relationship with the person they care for has broken down and their caring role is no longer sustainable and/or they have lost touch with other key people in their life.
Living Environment	Carer's living environment is suitable posing no risk to the physical health and safety of the carer and cared for person.	Carer's living environment is mostly suitable but could pose a risk to the health and safety of the carer and cared for person in the longer term.	Carer's living environment is unsuitable but poses no immediate risk.	Carer's living environment is unsuitable and poses an immediate risk to the health and safety of the carer and/or cared for person.	Carer's living environment is unsuitable and there are immediate and critical risks to the health and safety of the carer and/or cared for person.

	Caring has no impact NO RISK	Caring has low impact LOW RISK	Caring has moderate impact MODERATE RISK	Caring has substantial impact SUBSTANTIAL RISK	Caring has critical impact CRITICAL RISK
Employment & Training	Carer has no difficulty in managing caring and employment and/or education.	Carer has some difficulty managing caring and employment and there is a risk to sustaining employment and/or education in the long term.	Carer has difficulty managing caring and employment and there is a risk to sustaining employment and/or education in the medium term.	Carer has significantly difficulty managing caring and employment and there is a risk to sustaining employment and/or education in the short term.	Carer has significant difficulty managing caring and employment and/or education and there is an imminent risk of giving up work or education.
	Carer does not want to be in paid work or education.	Carer is not in paid work or education but would like to be in the long term.	Carer is not in paid work or education but would like to be in the medium term.	Carer is not in paid work or education but would like to be soon.	Carer is not in paid work or education but would like to be now.
Finance	Caring is not causing financial hardship e.g. carer can afford housing cost and utilities.	Caring is causing a risk of financial hardship e.g. some difficulty meeting housing costs and utilities.	Caring is causing some detrimental impact on finances e.g. difficulty meeting either housing costs OR utilities.	Caring is having a significant impact on finances e.g. difficulty meeting housing costs AND utilities.	Caring is causing severe financial hardship e.g. carer cannot afford household essential sand utilities, not meeting housing payments.
Life balance	Carer has regular opportunities to achieve the balance they want in their life.	Carer has some opportunities to achieve the balance they want in their life.	Due to their caring role, the carer has limited opportunities to achieve the balance they want in their life.	Due to their caring role, the carer has few and irregular opportunities to achieve the balance they want in their life.	Due to their caring role, the carer has no opportunities to achieve the balance they want in their life.

	Caring has no impact NO RISK	Caring has low impact LOW RISK	Caring has moderate impact MODERATE RISK	Caring has substantial impact SUBSTANTIAL RISK	Caring has critical impact CRITICAL RISK
Life balance (continued)	They have a broad choice of breaks and activities which promote physical, mental, emotional wellbeing.	They have access to a choice of breaks and activities which promote physical, mental, emotional wellbeing.	They have access to a few breaks and activities which promote physical, mental, emotional wellbeing.	They have little access to breaks and activities which promote physical, mental, emotional wellbeing.	They have no access to breaks and activities which promote physical, mental, emotional wellbeing.
Future Planning	Carer is confident about planning for the future and has no concerns about managing caring.	Carer is largely confident about planning for the future but has minor concerns about managing caring.	Carer is not confident about planning for the future and has some concerns about managing caring.	Carer is anxious about planning for the future and has significant concerns about managing caring.	Carer is very anxious about planning for the future and has severe concerns about managing caring.

NB: In determining a carer's eligibility for funded services, it is important to recognise that indicators will not always exist in isolation from one another. It is appropriate and desirable that indicators should be explored in relation to one another, as there may be a 'multiplier' effect when two or more indicators overlap or interact. For example, it would be appropriate to discuss the impact of insufficient household income in relation to the effect financial hardship can have on the emotional health and wellbeing of a carer. Similarly, some indicators may be overarching, such as the ability to have a life alongside caring, which may be affected by the cumulative impact of the caring role in several areas of a carer's life.



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