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# Welcome

**to the Equal Partners in Care (EPiC) learning resource for health and social care staff.**

In your job it's highly likely that you come into direct contact with carers.

By carers we mean people who provide unpaid support and care to another person. They are the family, friends, partners, neighbours, and colleagues of the people you offer services to...and the role they play is vital. If you don't encounter carers yourself then you probably support other staff who do.

This resource will help you (and the staff or students you support) to have better conversations and interactions with carers.

The aim is to make a positive difference and improve outcomes for carers...and the people they care for.

## Video clips



### Coming soon

A short animation about  
Carers in Scotland.

## How to use this resource



Either on your own, or with a  
group or team to get the best  
out of this resource.

## EPiC Principles



Learn more about the  
background to EPiC and  
the EPiC principles

## Audiences & outcomes



Find out more about who  
this resource is for and  
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# How to use this resource



## Individually

You can use the resource by yourself by reading, reviewing and reflecting on the material provided. You can easily dip in and out of the sections or work through them sequentially depending on your learning preferences and what suits your role.



## In a group

There are also short exercises and discussion prompts to support group or team learning which can be used in team meetings or staff development sessions.

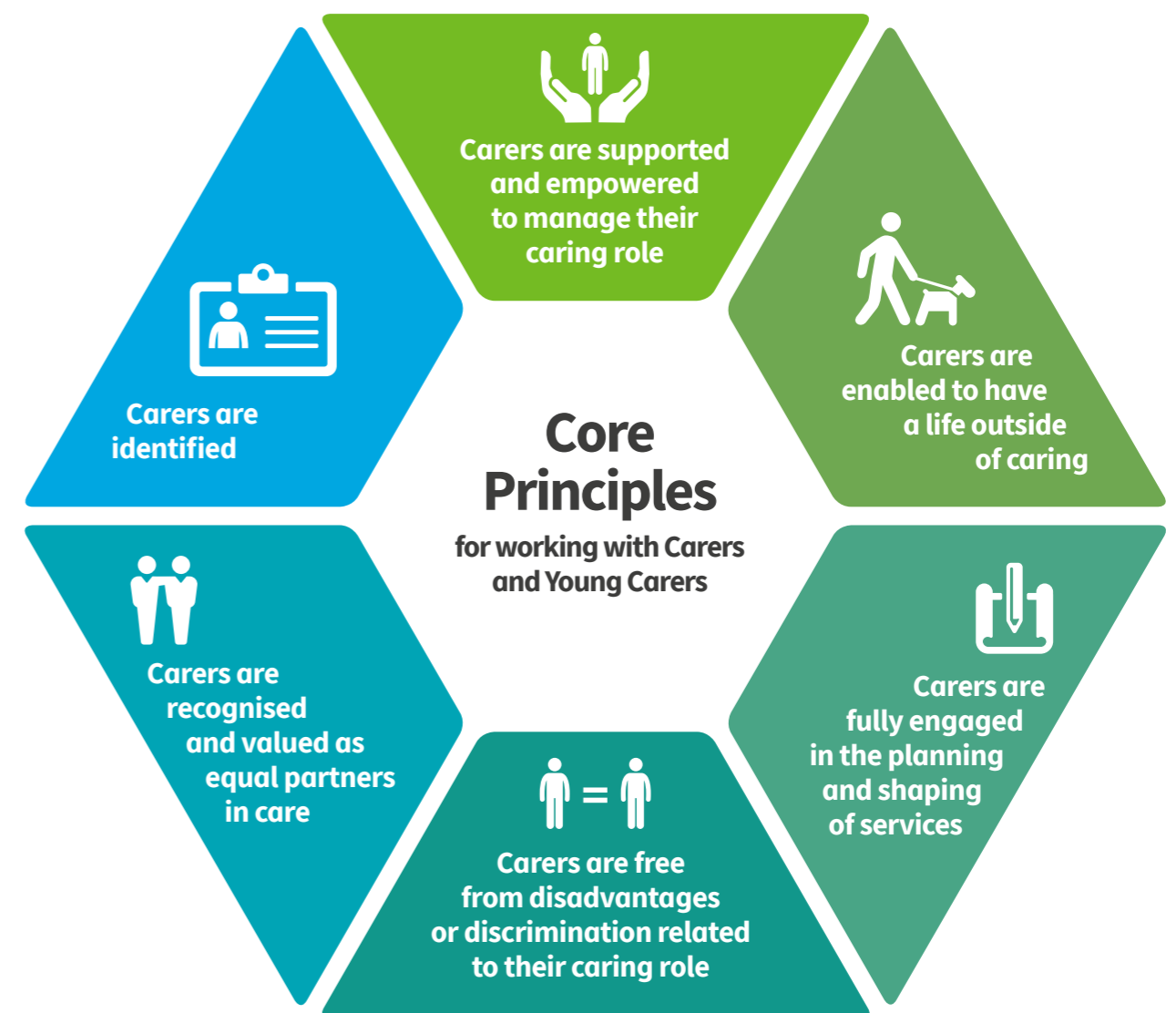
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# EpiC Principles

**The EpiC core principles** are based on six key outcomes for carers and young carers. They were developed in partnership with a wide range of stakeholders including carers and young carers. The principles support workforce education and learning and promote consistent understanding of how to work effectively with carers. Whatever your role, there will always be opportunities to identify carers and to work in ways which;

- recognise, acknowledge and value the role of carers as partners in care
- involve carers in planning for the person they care for
- support carers to manage their caring role
- avoid discrimination and disadvantage related to the caring role, and
- support the carer to have a life outside caring

Working in partnership with carers results in better outcomes for everyone involved - for the cared for person, for the carers and, ultimately, for the service.



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# Who is this resource for?

EpiC is intended for all staff who come into direct contact with carers in their day to day jobs. It is also intended for anyone with a workforce education and learning role, and/or managers who support the workforce to improve outcomes for carers and the people they care for.

This resource has been designed with the understanding that different professionals will have varying levels of opportunity to engage with carers in their roles.

At a minimum, the intention is that any member of staff will:

- understand what a carer is and be able to identify carers and young carers
- understand that every conversation with a carer can make a difference to them
- know that carer support is available and be able to make links for the carer.

In addition, the resource will support staff in diverse roles who may have significant opportunities to engage with carers to:

- work in a person-centred way to achieve better outcomes
- successfully manage tension or possible conflict in the caring relationship, such as around areas of confidentiality and different views about whether to accept outside support
- improve health, wellbeing and quality of life for carers and the people they support.



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- The Carers  
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## What to expect from this section


- ✓ The central idea, repeated throughout the resource, is that **there is value in engaging with carers** and there are always ways to do that, even for staff whose roles involve limited interactions with people.
- ✓ **Information about who carers are**, including relevant facts and figures, and the rationale for carer support.
- ✓ **Brief background to the Carers (Scotland) Act 2016** and other relevant policy.
- ✓ An introduction to **Equal Partners in Care** and the associated principles.





  
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## Who are carers?

A carer is someone who provides unpaid support to a family member, friend or colleague.

They may care for an older person, someone who is disabled, has a long-term illness, mental health problems or is affected by alcohol or drug misuse, or any combination of these. Unpaid carers also provide support to people at the end of their lives.

Carers can be any age, from children to older people, from all cultures and all parts of our society.

Some carers may be disabled or have health and social care needs themselves. Few caring relationships are entirely one way in terms of care giving and care receiving. Many people are involved in mutual caring relationships.

They may be parents, spouses, grandparents, daughters, brothers, same sex partners, friends or neighbours.

**YOU** might be a carer now or you might be a carer in the future. Like other carers, many health and care staff are juggling caring roles with work. We will include examples of carers working in health and social care in this resource.



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## Who are young carers?

A young carer is a child or young person with a significant role in looking after someone in their family. Any carer under 18 is viewed as a young carer, whether or not they are at school.

Young adult carers are usually understood as carers aged 16 to 25. There is recognition in the Guidance to the Carers (Scotland) Act 2016 and in many carer services that the 16 to 25 age group is characterised by transitions that may change the caring role and/or the need for support such as transition to further education or work; living away from home; or reducing the caring role/not wanting to be a carer at all.





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## Carers in Scotland Some facts and figures<sup>1</sup>



1 in 6 adults have unpaid caring responsibilities for someone with a longstanding illness or disability.



While there can be valued and positive aspects of caring roles, caring responsibilities affect many carers' physical and mental health.

Nearly half of carers have long-term conditions themselves.

Many carers are looking after people with complex needs.



There are more older carers.



Increasing number of carers are looking after more than one person.



The time individuals spend caring is increasing.



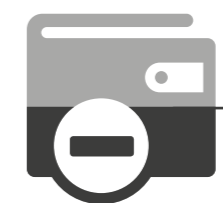
The estimated cost of replacing the care provided by carers is the same as the budget for the whole of the NHS in Scotland.



### Percentage caring for 35 hours a week or more

Most deprived

Least deprived



almost 50%



24%

Almost 50% of carers in the most deprived areas care for 35 hours a week or more. This is almost double the level in the least deprived areas where 24% of carers care for 35 hours a week or more.



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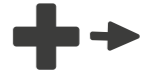
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### The Carers (Scotland) Act 2016



*We want the Carers Act to make a difference to real people, and that's about what matters to people. It's about having meaningful and satisfying lives alongside caring. Getting that right is fundamental to building a sustainable health and social care system.*

**Lindsey Henderson**

Lead for Carers, Scottish Government speaking at the Personal Outcomes Network, Oct 2018



The Carers (Scotland) Act 2016 came into force on 1 April 2018, introducing new legal duties and a range of provisions to help better identify, assess and support carers.

The Act extends and enhances the rights of carers. The aim is to **better support carers on a more consistent basis so that they can continue to care, if they so wish, in good health and to have a life alongside caring.** For young carers, the intention is similar to that for adult carers but also that **young carers should have a childhood similar to their non-carer peers.**

The Act gives all carers rights to an adult carer support plan or young carer statement to identify each carer's personal outcomes and needs for support. This reflects a general preventative approach, which also underpins the duty on local authorities to provide information and advice services to carers.

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## Wider policy context

The focus on increased recognition and more effective support for carers fits with the global agenda of **person centred and integrated care**, as promoted by the WHO (2016), which makes frequent references to carers.<sup>2</sup>

In Scotland, **Realistic Medicine** is intended to put people at the centre of decisions about care and support. It encourages staff to find out what matters most to people to make sure that responses are appropriate. Realistic medicine is intended to include all health and social care staff, as set out by Chief Medical Officer, Catherine Calderwood (2017).<sup>3</sup>

There are also **national health and care standards** in Scotland which are based on human rights and outcomes focused approaches. They are **Dignity, Privacy, Choice, Safety, Realising Potential** and **Equality and Diversity** and they explain what people can expect from any care service they use, and can be found in the resources section.



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## Rationale for carer support

The impact of being a carer varies. It is unlikely to be ‘all good’ or ‘all bad’ but will depend on the individual, their unique set of circumstances and will vary from month to month, day to day or even hour to hour depending on their role. Factors including gender, culture, age, income, life roles, family history and relationships and work status can all impact on the individuals experience of being a carer.

Prevention is pivotal in supporting carers and the people that they care for. Intervention and support (including by providing information) at an early stage in a carer’s journey can promote quality of life, independence and engagement with their community. Early intervention can prevent deterioration in the caring situation – and sustain relationships.<sup>4</sup> Fundamentally, supporting carers can result in better outcomes for them and for the people they care for and can support more effective use of health and care services.

Caring for my Mum has changed our relationship, we are so much closer now because of all the things we have had to go through together.

It’s huge...sometimes it’s fine but then something will happen, even something that seems really small to other people, and I end up feeling frantic and like I don’t know what I’m doing.

Since being a carer for my partner I’ve learned I have a lot of skills that I didn’t realise I had. I’ve also learned a lot from being a carer that I use in other bits of my life.

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### Rationale for carer support

I had to give up my job so I could care for my daughter, that was hard because I loved my work and it means we are financially struggling more than we ever have.

Caring for my sister when I was growing up was hard sometimes, but it helped me to know that I wanted to be a physiotherapist when I left school. I'm working as a physio now and I think my experiences with my sister help me in my work everyday.

There's just no break...it's constant, it's having a really bad effect on all our family relationships. We keep falling out over little things and we never did that before.

“

*Remember today's carers could be tomorrow's service users or patients if we don't support them in their caring role*  
quote from Local Carers Lead, Feb 2019

”

Stop for a second and think about how working well with carers could support both outcomes for them **and** more effective use of services.





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### Why equal partners in care?

Carers have a unique role in the life of the person they care for. They have valuable knowledge to contribute to the care and support of the person they care for, and any decision will have an impact on them and on their caring role.

Carers have the right to play an equal and active role in care planning and decisions. This does not mean that all carers are the same or that the caring is shared equally. Every carer does however have the same right to have the support and information they need and to be as involved as they choose to be.

It's important that workers also feel valued as equal partners. This will help create a culture of mutual respect and partnership.

If carers, the person they care for, and workers from health and social services work together as partners they increase the chances of achieving better outcomes for all involved.

There are always opportunities to identify who the carer is and in many cases there will be opportunities to:

- recognise, acknowledge and value the role of carers as partners in care
- involve carers in planning for the person they care for
- support carers to manage their caring role
- avoid discrimination and disadvantage related to the caring role
- support the carer to have a life outside caring.

These are explained further in the core principles for working with carers and young carers.

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## Why equal partners in care?

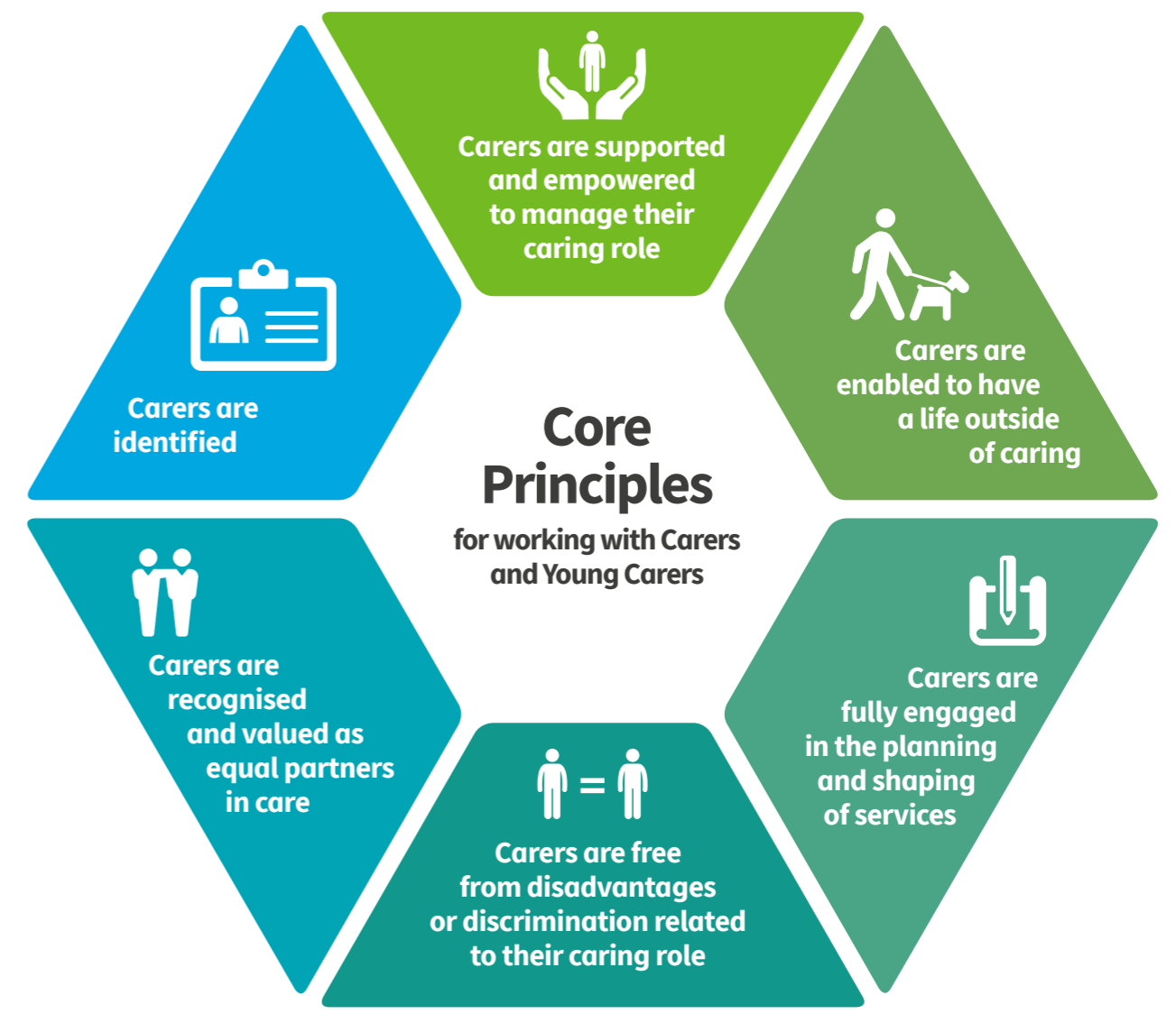


Working in pairs, pick one of the principles that strikes you as important.

Can you think of three reasons why this principle matters?

In your team or service, what are you already doing that supports this principle. What difference does it make and how do you know?

What else could you do?



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## What to expect from this section

- ✓ Bearing in mind the central idea of this resource, that there **is value in engaging with carers and there are always ways to do that**, this section starts with the challenges of carer identification, as a first step towards engaging with carers.
- ✓ **Information and questions to ask** to help with carer identification, including young carer identification.
- ✓ Brief section on avoiding unintentional discrimination with links.
- ✓ **Key concerns** held by staff about engaging with carers, with responses.





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## Challenges of carer identification

Most people will have at least some experience of caring in their life. However, many people in a caring role do not recognise themselves as a carer. Often carers will see themselves as acting in the role defined by their relationship with the person they are caring for “I’m just looking after my mum because I’m her daughter.” This was highlighted in research by Carers UK as follows:

*For many people, looking after an ill, older or disabled loved one doesn’t have a name, it is ‘just something you do’. However, not recognising you are carrying out a caring role can be a real barrier to accessing vital support.<sup>5</sup>*

There are many positive aspects of caring. Not every carer needs or wants support. However, the caring role can change over time, depending on the cared for person’s condition. Increased demands may result in the carer requiring support at different stages. Intense caring roles can take a toll on the health and wellbeing of carers, particularly considering that half of carers have a long-term condition themselves. It can be a lifeline for a carer to know that support is available, should they come to need it. Often, a major concern of carers is what will happen to the person they care for if they become too unwell to continue caring. This has to be a key concern of health, social care services too.

Even if a carer does not see themselves this way, and does not want to be called a carer, they should still be able to access vital help, advice and information.

“

*One of the staff suggested that I contact [specialist service] for information on my relative’s condition. It was extremely useful but I wish I had this earlier as I would have asked a lot more questions if I had known what I know now*

Carer quoted in Greater Glasgow and Clyde  
Carer Awareness Training

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# Carer identification

## Supporting carer identification

Once you start paying attention and put carers at the forefront of your mind you will find that you notice carers more often. However, although it might seem obvious who the carer is, our own assumptions might lead to missed opportunities for identification. For example;

- the 13 year old child visiting his/her parent on the ward may also be the main carer
- the older woman with early stage dementia you are assessing may also be the main support for her daughter who has a mental illness
- the older sibling who you 'never see' may also be the person who ensures that the cared for person gets out of bed, makes it to appointments with you and takes his/her medication.

In the following example, Kevin, who is a nurse himself, talks about how he wished he had seen himself as a carer when he was looking after his partner at the end of her life:

“

*When my partner was at the end of her life, I wish I had been able to recognise that I was her carer, and that support might have been available to make things a bit less traumatic. I was worried sick about becoming a single dad, about how to manage the loss we were all facing and even about keeping a roof over our head. We got through it and I'd know better now, but I'd advise anyone in a difficult caring situation to get in touch with their nearest carer centre*

Kevin, psychiatric nurse,  
following the loss of his partner from melanoma

”

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Kevin describes a particularly challenging caring situation. Even though a health professional himself, Kevin did not recognise himself as a carer.



Can you think of a time now or in the past when you have looked after someone close to you who faced illness or disabilities?

Do/did you think of yourself as a carer? Or do you think of yourself primarily in terms of the relationship you have with the person?

You can be a professional and a carer, and we will consider further examples of this in this resource.

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# Carer identification

## Asking questions to identify carers

As we've seen, identifying who the carer is, even if they would not describe themselves as such, is an important step towards being able to access information, advice and support. But for reasons already described asking "are you the carer?" won't work for everyone. Greater Glasgow and Clyde NHS have pulled together some questions which can help staff to find out who the carer is in a given situation:



Who picks up their prescriptions?



Who is making the tea while you do your assessment?



Who do they always mention?



Who helps get them to their appointments?



Who is by their hospital bed?

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# Carer identification

## Identifying young carers

Young carers face particular challenges with regards to identification. Young carers who have grown up with caring responsibilities might not think of their situation as anything unusual. But, where they do, they may have concerns about problems arising for the family if they say that they are struggling with their caring role. They may also be concerned about negative reactions from their peers.

Schools and colleges have a critical role in identifying and supporting young carers. There are materials to support schools to develop strategies to identify and support young carers, with links in the resources section. The following comment is from a school liaison officer who works with young carers. She describes how significant the impact of the caring roles has on young carers at school.

“

*When I go into schools to talk to pupils about young carers, my presentation touches on social, emotional and health impacts. The biggest one though is difficulties in school, which include worries about missing school, managing homework and how teachers and other pupils might react. I ask the classes ‘what do you think the biggest challenge for young carers is’ and show the slide with all the options. They almost all pick school!*

**Amy Alexander**

Action for Children, Lanarkshire

”

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# Carer identification

## Identifying young carers

There are also efforts being invested in some sections of higher education to support young adult carers at college or university. The following example again highlights the importance of carers having the information so that they know where to go should they need support:

“

*Many colleges and universities in Scotland are now asking if students have unpaid caring responsibilities through admission procedures. If a student responds yes, this information is often passed to student support or the carer support lead and they then contact the student carer to introduce themselves and provide information about available support. Staff have told us that sometimes they don't hear back from students for months, but students often get in touch when circumstances get difficult or they are approaching a crisis point. From the initial communication, student carers know that support is there, which can be the difference between the student carer successfully completing their course and dropping out.*

**Paul Traynor**  
Carers Trust Scotland

”



**Discuss with your colleagues  
your experiences of noticing carers  
in your work context.**

What questions could you ask the person that would help them to talk about their caring role?

How might you let them know that information, advice and support can be available to them should they need it?

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## Avoiding unintentional discrimination

One of the EpiC principles is that carers are free from discrimination and disadvantage. Carers may experience disadvantage as a result of their caring role, which can have an impact on health, finances, work and education. Some carers may have more difficulty accessing support from services than others due to age, disability, sexuality, ethnicity or other issues.

Carers from minority ethnic communities may face barriers relating to language, communication and culture. People don't fit neatly into categories, so an older person may also be an LGBT carer and have health needs themselves. We should always be aware of equality and diversity issues, referred to as cultural competence. In any case, identifying and engaging with carers, regardless of their background is an important first step in avoiding further disadvantage.

Regarding young carers specifically, they can be prone to stigma if their caring situation and its impacts are not well understood. This can be amplified if the condition of the cared for person is prone to stigma too, such as alcohol and substance misuse and/or mental health problems. The following young carer support worker describes this stigma from her perspective and the benefits she sees of peer support.

“

*I think there definitely is still stigma – young carers can be seen as different – amongst staff and other young people. There is still a lot of work to do with young carers, professionals and peers – there will always be room for improvement. But in here, in our young carer support groups, it's completely different for the young carers, which I get excited to see.*

**Amy Alexander**

Action for Children, Lanarkshire

”

The next section on **key concerns held by staff** includes a concern about speaking to carers from minority groups, and suggested way of responding. There is also a link to further relevant information on the Minority Ethnic Carers of People Project (MECOPP) in the resources section.



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## Key concerns of staff

Even when health, social care and education staff do identify carers, there is a range of concerns which can inhibit staff from engaging with carers. **Click on a concern to see the corresponding response.**

I don't have time to ask people about their caring role

I'm afraid of raising expectations with carers when the service doesn't have any resources to support them

I'm not sure I am the right person to have a conversation with a carer

I feel awkward asking people about their caring role if they haven't approached me...I feel like I am intruding especially if someone is from a cultural group I don't know much about. I might cause offense

What if the person gets upset if I ask them about their caring role?

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**What if the person gets upset if I ask them about their caring role?**

**I don't know what questions to ask**

## Response

Even taking a few minutes to acknowledge a carer and ask how they are can make a significant difference to how they feel; it can mean everyone feels more satisfied with the situation and it can prevent avoidable delays and future problems.

If you only have 5 mins then be honest about that. Let the carer know that and arrange for a better time to talk ...or offer to find time with someone else who can offer the support they need. Supporting carers and involving them in decisions are not nice to have add-ons....they are duties under the Carers (Scotland) Act 2016. Taking a few moments to talk to the carer today can save a huge amount of time later on.

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## Response

Often just recognising that someone is in a caring role, acknowledging that and giving them a chance to talk can make a huge difference. More often than not carers are not expecting you to fix situations. Being heard, treated with respect and compassion can have a positive impact. Feeling connected can help carers feel a little bit more able to cope, and knowing that further information and advice can follow, can leave a bit of hope.

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## Response

There is no right or wrong person to have a conversation with a carer. Regardless of the situation, you can ask a carer how they are doing and acknowledge the situation they are in. If the carer needs more time or different information or support than you can provide then you are still able to facilitate this happening.

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## Response

If you don't ask then you run the risk that the carer will remain 'hidden'. There is no harm in asking someone who appears to be in a caring role if there is anything you need to know about them that could help you/your colleagues to support them better. Asking a simple question like this can help to overcome perceived cultural barriers and allows the person to voice any particular concerns they might have concerning ethnicity or gender for example, as well as any concerns about caring. Don't assume that you know their needs.

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## Response

It is not unusual for a carer to be upset, particularly if they are anxious and concerned about the person they care for, or if they are struggling to manage with the responsibilities. Simply being alongside a carer and providing a listening ear can make a difference, and can help the carer to cope with the emotions involved. The question of time can again be a concern, because you don't want to leave the carer in a state of distress. However, even if time is limited, a compassionate response and, as above, an offer of a follow on or link to further support can be invaluable.

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## Response

Don't overcomplicate it...start with a simple 'how are you doing?' The important thing is that you listen and show interest in the answer. Although it is tempting to do so when under pressure, try to avoid making assumptions.

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## Key concerns of staff

Think of a situation where you can see that a carer is showing signs of distress. You are in a busy work situation and only have a few minutes before your next meeting starts.

How might you approach the person in a way that acknowledges their distress and offers some support to them within the limited time available?



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### What to expect from this section

- ✓ Understand that **every conversation** with a carer can make a difference to them, even if on a 'checking in' basis.  
Be familiar with the **core skills** that underpin good conversations with carers.
- ✓ Consider **different techniques** which can support good conversations with carers.
- ✓ Know that carer support is available and be able to **make links** for the carer.





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### Checking in with carers

Checking in with a person can help to prevent a caring situation from deteriorating and can make a significant positive difference to the carer.

Acknowledging a carer's role can be beneficial in itself by providing recognition and validation.



If you ask a carer about how they are it could be the first time someone has asked about them rather than the person they are caring for. A deceptively simple "...and how are you?" or "how are things going for you" may be a step towards getting the vital support they need. It can be surprising how many carers get so locked into their caring role that they forget about self-care or feel guilty if they do things that were previously ordinary parts of life, like going to a movie or meeting friends. Frontline staff including those in health, social care and education play a critical role in helping people to recognise that they have caring roles, even if they don't want to be identified as carers.

However, given that most people don't think of themselves as carers, asking someone outright if they are a carer may not be the place to start. It might be more helpful for example to ask someone if they 'look after someone' instead of asking if they are 'a carer.' In the section on [identifying carers](#), we suggest ways of working out who has a caring role.

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## Knowing that information and advice is available

Even if you have limited time within your role to engage with carers, providing acknowledgement, asking how the carer is and being able to identify sources of support can be invaluable. Having the right information at the right time can make a significant difference to the quality of life and wellbeing of both the carer and the cared for person.

Ideally, teams within services should be sharing information with each other about community-based resources that can support carers, and indeed people who are being cared for, with their wellbeing and quality of life. At a minimum, with regard to carers, knowing where the nearest carers centre is can be a good starting point and the carers centre will usually know what resources are available locally for young carers too. Links are available in the resources section for carers centres and wider community resources.

Where a carer is having difficulties coping with their caring role, they may require more than provision of a phone number or weblink. Where possible, in such situations, offering to make a call or locate a specific resource can make the difference between the carer continuing to struggle or being able to get essential support.

### A point to note

As we've said above sharing information, signposting to advice etc. is a vital role you can play. But as with all situations the information has to be meaningful to the person and they have to see its relevance and value for them to then act on it.

So, for example a person may;

- not think of themselves as a carer
- feel totally overwhelmed and unable to act on information given
- think everything is fine
- feel anxious about the information being shared
- believe the implication is that they are not coping.

Think yourself how often you have been given information that you didn't act on for various reasons, even though you know the intention was good. So, sharing information in ways that are meaningful and acted on requires a range of communication skills. One technique is described on the following page.

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## Knowing that information and advice is available

The ***elicit/provide/elicit*** way of sharing information described below has been adapted from the Thistle Foundation’s Good Conversations training. **Click on a box to see some example of questions you could ask.**

### Elicit - check persons knowledge and understanding of a topic.

It makes sense to find out what the person already knows first before you share your information/advice. That way you can find about any gaps or misconceptions or previous experience that have an impact on the person’s willingness to act on the information you provide eg ‘Well, I’ve heard about carers centres but they are for people who care 24 hours a day aren’t they’?

### Provide information with permission.

Only offer advice and information once you’ve asked permission to do so.

### Elicit again to check understanding and self-efficacy (understanding on its own is ok but it doesn’t necessarily lead to action).

You are checking and supporting a person’s confidence in their ability to act.



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#### For example

What do you understand about the support that is available to people who are looking after their mum/dad/child/sibling etc?

What do you know about your local carers centre?

What do you know about the local information services and people who can offer advice?



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### For example

Would it help if I told you more about what carers centres do?

Would it be useful if I gave you some information?



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**For example**  
Can I check I have explained that?  
  
How likely are you to contact eg the carers centre?  
  
What would make it more likely/ what would help?



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## Knowing that information and advice is available

Thinking about the people you work with, what kind of information needs or challenges do they identify that do require support but are outwith the direct remit of your service?

What resources and services do you know of, including those based in the community, that might be relevant for people facing such challenges?



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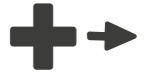
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## Establishing trust and rapport

Effective engagement between staff and carers requires the establishment of trust and rapport. Trust is built by genuine listening, an empathic approach and a willingness to respond, even if the response is limited by the time available. Although it can be tempting to offer to go out of your way to help a carer, it is important not to make promises you won't be able to keep. However, if you are able to offer a follow-on conversation at a less busy time, that can be very reassuring to the carer.

Carers often value being asked about their perspective on the cared for person. Seeking out the information and intelligence they have about what does and does not work can contribute to effective care of the person (they often hold unique information on this).

Think of a time when you looked after or supported someone who was unwell, had care needs or was in hospital. Now think of a member of staff who was involved and who you felt you could trust.

What did that staff member do that helped to build the trust? What did you notice about the way they were, what they did, how they engaged with you?

How has that experience influenced your own practice?



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### Understanding and listening as an intervention

Asking about and listening to the carer's experience, how things are going for them and how they are coping can really make a difference. It sounds simple but acknowledging when things are difficult, or when they are going well for the carer can be important. And indeed, acknowledging the role that the carer is playing can be helpful to them, as they may not feel valued in or confident about their caring role. Where they identify challenges in balancing the caring role with their life outside caring, a listening ear can help the carer to clarify their own thinking about this. A chance to talk and be heard can in itself be beneficial, even where further help and support is also required.

The ability to be a good listener is an under-rated skill. It requires concentration and effort, particularly to avoid distorting what the other person is saying. The goal is to listen with an open mind, and resist a natural tendency to jump to conclusions. Gerry Egan and Andrew Bailey<sup>6</sup> highlight the need to avoid partial listening, or listening that skims the surface.

An example of partial listening would be when a carer tells a practitioner that they are devastated by their mother's diagnosis of dementia. The worker stops listening at that point and starts thinking about how the person could fit into the dementia carer peer support group. She is so busy thinking about this that she misses the person saying that they find it very difficult to talk to others about their situation because privacy is a key concern. When the worker then suggests the peer support group, the person feels discouraged because the point about privacy hasn't been heard.



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## Conversations 1 Core skills

### Showing you have listened

Some core skills support active listening.  
Although well known, they are worth repeating:

#### Paraphrasing or giving a concise statement of what the person has said

‘You believe that your father needs more help  
now with staying safe at home.’

#### Reflecting feeling, where the listener concentrates on the feeling words

‘You feel anxious because you think your brother  
might not manage in his new tenancy’

#### Summarising or revisiting the main ideas and feelings to shows and clarify understanding

‘You were angry and disappointed because you felt  
you were being passed from pillar to post. Now you’ve  
talked it through you want to get back in touch with  
the volunteer who really seemed to understand how  
you felt and had some good ideas about coping.’

In the following example, Kevin, who is a qualified nurse,  
and who cared for his partner Ella who died as a result of  
melanoma, talks about the importance of engaging with carers.  
While he has direct experience of the challenges for practitioners,  
he emphasises the importance of remaining compassionate,  
having been on the receiving end himself:

“

*I have worked in the care system my whole life and I know how  
difficult it can be to maintain your values and your compassion.  
There are so many competing pressures. But being on the other  
side of it, as a carer, has been a powerful reminder to me about  
how important it is that you show that you care and understand  
and that you leave a bit of hope.*

”

**Kevin,**  
qualified nurse and former carer, Glasgow

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## A listening game for team development

This game is adapted from a website called the [Training Zone](#).

### Raise your hand

Group split into pairs, A & B

Take B's out of the room and ask to wait outside

Inform the A's that whilst they listen to their partner, every time their partner says something that evokes their 'inner voice' i.e. they want to ask a question, they think about something etc... they put their hand up for five seconds then put it back down.

Ask them to do this for the entire conversation – A's are not allowed to interact with B's, ask questions, affirm understanding etc. A's remain silent, just raising their hand every time their inner voice kicks in.

Next inform the B's outside they they are going to talk to their partner A about something for two minutes. It can be something they feel strongly about, a passion, an interest, an experience, their last holiday, anything positive that has happened recently.

Now take B's back into the room and ask them to talk to their partners for 2 mins, and to keep talking no matter what their partner does.

Stop at the end of two minutes. Invite the B's to share how it felt whilst they were talking eg what emotions it evoked, what impact it had etc.

Now ask the A's to share how it felt to not be able to interact, to not ask questions, share own stories etc.

There is no right or wrong responses to this exercise. Each person will have a different response to it...the purpose is to notice that response and reflect on it. Use prompt questions to help with this eg For B's...was it hard to stop yourself from jumping in with your own story or question? how often were you tempted to interrupt? What was it like to listen without interrupting in anyway? For A's What was it like to just talk and not be interrupted? Did that make you feel more listened to, or maybe less. What impact did it have?



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### Solutions or strength-based approach; facilitating rather than fixing

The urge to fix people can be quite overwhelming for many practitioners. This can at times be counter-productive, especially where practitioners avoid having conversations which they fear might lead to difficulties being identified that are outwith their scope to 'fix.' It is not possible to fix everything for everyone and most people understand that. In fact, many people just want to be heard and to have an opportunity to talk about their concerns. Sometimes the high expectations that staff fear from carers are rooted more in the high expectations that staff have of themselves.

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## Asking questions

A useful online resource is Asking Questions to Aid Recovery (Hawkes and Hingley<sup>7</sup>). The authors offer a list of 42 questions to ask people to promote hope and wellbeing. We include brief descriptions of the question types they identify and examples of each here.

### Exception and Existing strength

Questions are asked to identify how people's earlier attempts to get help led to successful change. People can be asked to recall what they have learned or done themselves since the last meeting that have been helpful to them or that they deem to be successful. Success in these terms can mean behaving consistently rather than changing.

For example, if practitioners can identify a single day in which a person felt a little different, or during which problems or symptoms did not occur, they can ask exception questions to explore what happened on that day or how the person's behaviour had changed.

### Future-focused and Goal-setting

This requires consideration of the changes needed for a better future. Using the 'miracle' question can help to prompt the conversation i.e. if you woke up tomorrow and everything was as it should be what would look different. Follow-up 'questions

can include: What would you or your family do differently if this change happened? Who else would notice these changes have happened? By asking such questions, practitioners can work with people to understand their goals.

### Partitioning

These questions break down problems into smaller, more easily assimilated parts that can be dealt with separately. A question could be 'Which of the things that need to be changed do you want to tackle first?'

### Relationship-focused

These questions are asked to help people to see themselves from other people's perspectives. This challenges existing frames of reference or beliefs and helps people form connections with others in their lives.

'Suppose you go out of here and your best friend sees you, what would they see differently about you that would tell them it was a good idea to attend that appointment, that it has helped?'

The section on support planning includes further ideas to supporting the carer to think about their own resources as well as community-based resources and local supports.

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### Understanding that carers sometimes minimise challenges ...the 'I'm fine' conundrum

Often the response “I’m fine” means exactly that...someone asks how you are and you reply that you are doing OK because you are. But how often do you say ‘I’m fine thanks’ when that’s not really the case? In the section on Carer Identification we identified concerns that practitioners hold about having conversations with carers. Equally, carers can have real concerns about opening up to practitioners.

Some examples include:

- **Trust** – if I say I’m not fine you might do something I don’t want you to do
- **Perception of role** – it’s my responsibility as a daughter/son to care for my mum so I have to be fine
- **Perception of self** – I’m a coper, I always cope with whatever is thrown at me. I’m a strong person
- **Emotions** – I might break down and cry, then I’ll never stop. Or I might get angry
- **Time** – I haven’t got time to think about how I am, I’m too busy and have too many other things on my mind
- **Need for rapport** – how could I even begin to explain to you how I feel, it’s too complicated and I doubt you would understand anyway

Even when trust is established, and a carer does feel they have been listened to, some carers might not acknowledge that they are struggling.



## Conversations 1 Core skills

### Understanding that carers sometimes minimise challenges... the 'I'm fine' conundrum

Lanarkshire Carers Centre have adapted a resource called Emotional Touchpoints to help to change the conversations they have with carers. Staff and carers worked together to develop and test a set of additional prompt cards. The cards are used to support conversations about the effect the caring role is having on the carer.

“  
Before thinking about the plan, I try and find out ‘how are you feeling?’ and ‘what effect is caring having on you?’ Some people are very good at putting on a front and will insist everything is fine. And using normal questions, that can put people’s defences up – you can actually see people withdrawing away from the conversation. We adapted emotional touchpoints and I thought what about using some prompt cards that have just words on them. And allow carers to take their time and choose the cards that most reflect how their caring role affects them.”

**Support Worker,**  
Lanarkshire Carers Centre



Patience



Anxiety



Compassion



Worthless



Listener



Frustration

The boxes above are sample word cards from many used by the carers centre to encourage carers to explore their feelings about the role. When staff and carers developed the resource they deliberately put in positives to support people to identify their skills and strengths.

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### Understanding that carers sometimes minimise challenges... the 'I'm fine' conundrum

The following comment is from two carer support workers who describe how using emotional touchpoints allowed them to find out new information about how a carer really felt after knowing her for years.



*Thinking back to that carer we mentioned to you before – that was a lightbulb moment for us. She seemed bubbly, she was outgoing. Our jaws hit the ground when we heard how she really felt. She said she would never have told us about how she really felt if she hadn't been asked to talk about her feelings in this way. She would have put a face on it, saying everything is fine. She picked up the card saying worthless. It gave us a new insight.*

**Carer Support Workers,**  
Lanarkshire Carers Centre



We are not suggesting that it is always necessary or possible to access how each person is really feeling. It is just worth bearing in mind that some carers will not want to admit that they are struggling. A further consideration is that the carer might not want to sound critical of the person they cared for, due to loyalty for example. In any case, it is still ok to point to sources of information and support should they wish to access them in the future.



*Seeing the cards was an eye opener. I don't like asking for help, but this made it easier to do*

**Carer,**  
Lanarkshire Carers Centre





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### Understanding that carers might find it difficult to let others in to help them

Sometimes carers can become lost inside their caring role. They may not remember what life was like before the caring role took over.

“

*Some people – especially but not exclusively women – have given up themselves, their identity, sense of self and what they want. They are a carer. They have disappeared. They are lonely because they don't exist.*

**Carer Support Worker,**  
Lanarkshire Carers Centre

”

Even where someone realises that their caring role might be getting too much for them, it might be difficult to admit this for fear of feeling like a failure. The following extract from the supercarer website, which provides advice for carers, suggests this is not uncommon:

When you're caring for a family member or partner, it's easy to feel like you need to handle everything on your own. The truth is, caring doesn't have to be a one-person, all-or-nothing role and getting help is not failing – sometimes it's the most sensible thing to do.

[supercarers.com/blog/being-a-family-caregiver](https://supercarers.com/blog/being-a-family-caregiver) (accessed May 2019)

Again, it is possible to let carers know that help is available for people in their situation without any suggestion that they are not coping.



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Thinking about some of the information here, and your own experience, can you identify different reasons why carers might be reluctant to talk openly about challenges they might be facing?

Can you also identify different ways of enabling them to talk about the challenges?

Can you identify ways of letting them know support is available, even if they don’t feel they need it at this stage?



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### What to expect from this section

- ✓ Explore the **exchange model** as a way of thinking about negotiating different perspectives.
- ✓ Consider how different approaches to conversation can help to **navigate through conflicting points of view**.
- ✓ Understand **different ways people respond to conflict situations** or growing tension and reflect on your own way of responding to conflict.
- ✓ Consider carer related issues around **confidentiality, capacity and mental health** and how the Triangle of Care and guidance from the Mental Welfare Commission can help with these.





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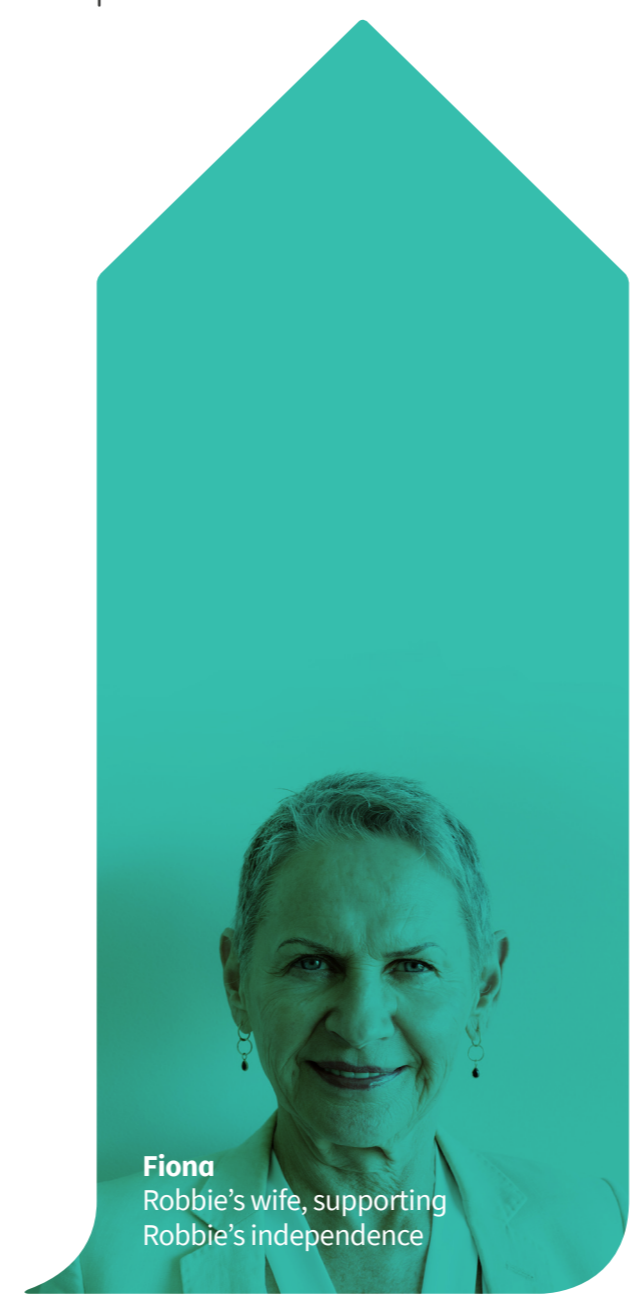
Scenario 3

### Scenario 1 Fiona and Robbie

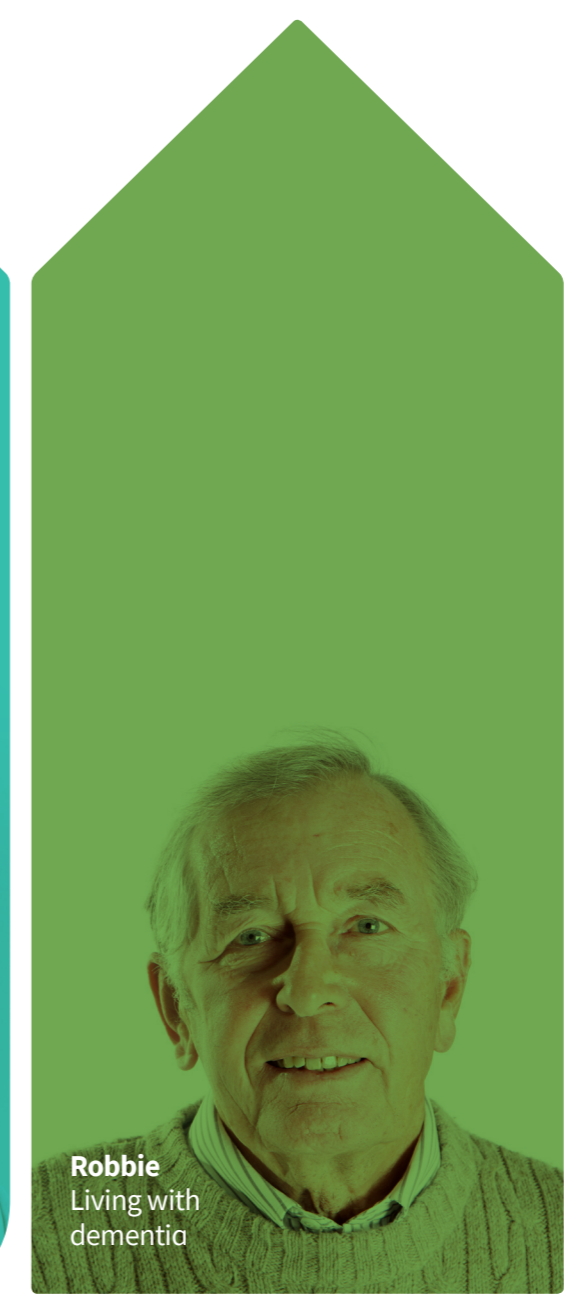
Have been married for 40 years. They have a daughter (Ruth), who lives a distance away. Robbie was diagnosed with dementia three years ago. Fiona has supported Robbie to keep his independence, however his condition is deteriorating. Fiona finds herself making all of the decisions and doing more and more for Robbie. She is not always in the best of health herself and has noticed recently that she is having more asthma attacks than usual.

Click on each person to discover what's important for them.

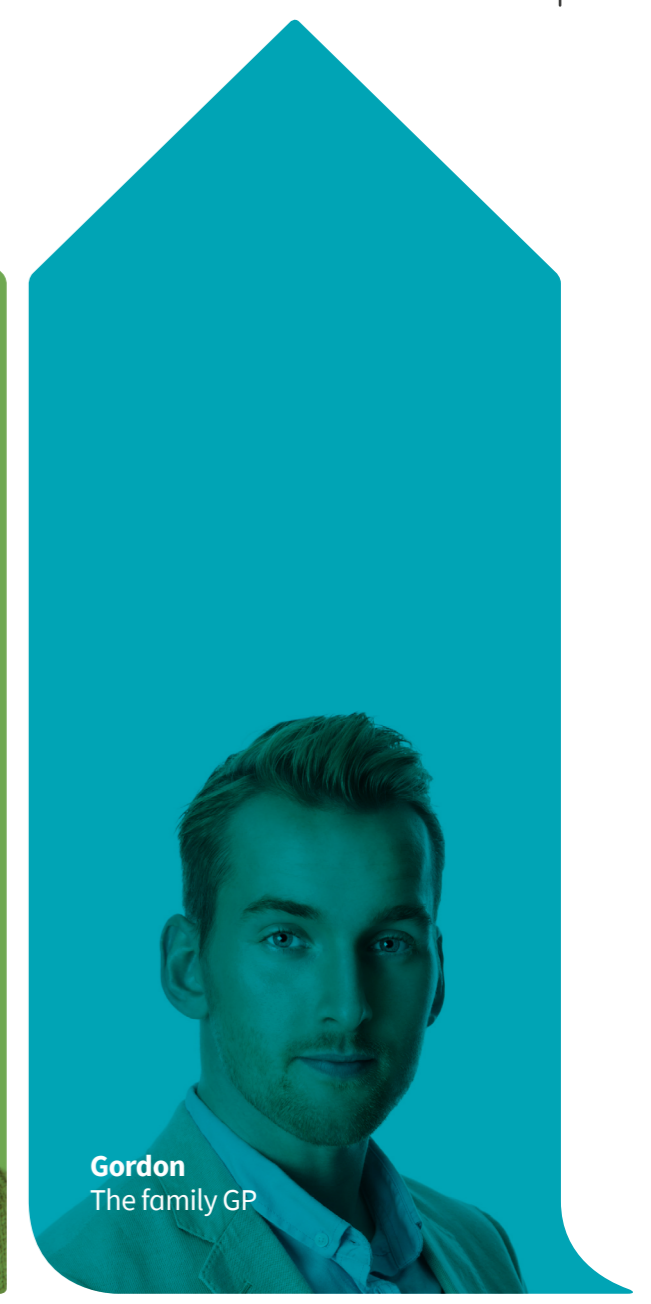
Working towards  
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**Fiona**  
Robbie's wife, supporting  
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**Robbie**  
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**Gordon**  
The family GP

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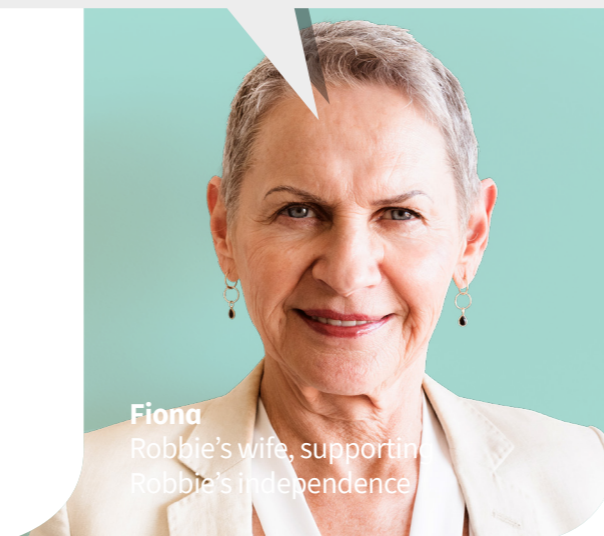
### Scenario 1 Fiona and Robbie

Have been married for 40 years. They have a daughter (Ruth), who lives a distance away. Robbie was diagnosed with dementia three years ago. Fiona has supported Robbie to keep his independence, however his condition is deteriorating. Fiona finds herself making all of the decisions and doing more and more for Robbie. She is not always in the best of health herself and has noticed recently that she is having more asthma attacks than usual.

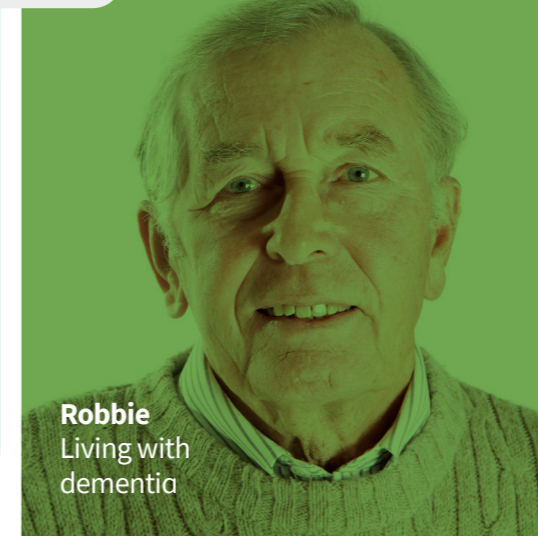
Click on each person to discover  
what's important for them.

Working towards  
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I want to be able to stay as fit and healthy as possible because it helps me keep well... But right now I am exhausted. It's great that Robbie phones Ruth so much because they were always close. But she only sees his side of things when he complains that I'm not letting him go out on his own or take his medication by himself. I don't want her to worry or think I'm taking away her dad's independence but we keep bickering because she really doesn't understand what it's like.



**Fiona**  
Robbie's wife, supporting  
Robbie's independence



**Robbie**  
Living with  
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**Gordon**  
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Click on each person to discover what's important for them.

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**Fiona**  
Robbie's wife, supporting Robbie's independence



**Robbie**  
Living with dementia



**Gordon**  
The family GP

Our home is private and just for me and Fiona. I don't want or need strangers coming in and out all the time like it's Picadilly Circus. I'd love to play a round of golf again. I know my memory is getting worse but I can still do things for myself. I wish Fiona would stop fussing about me... I know Ruth agrees with me too.

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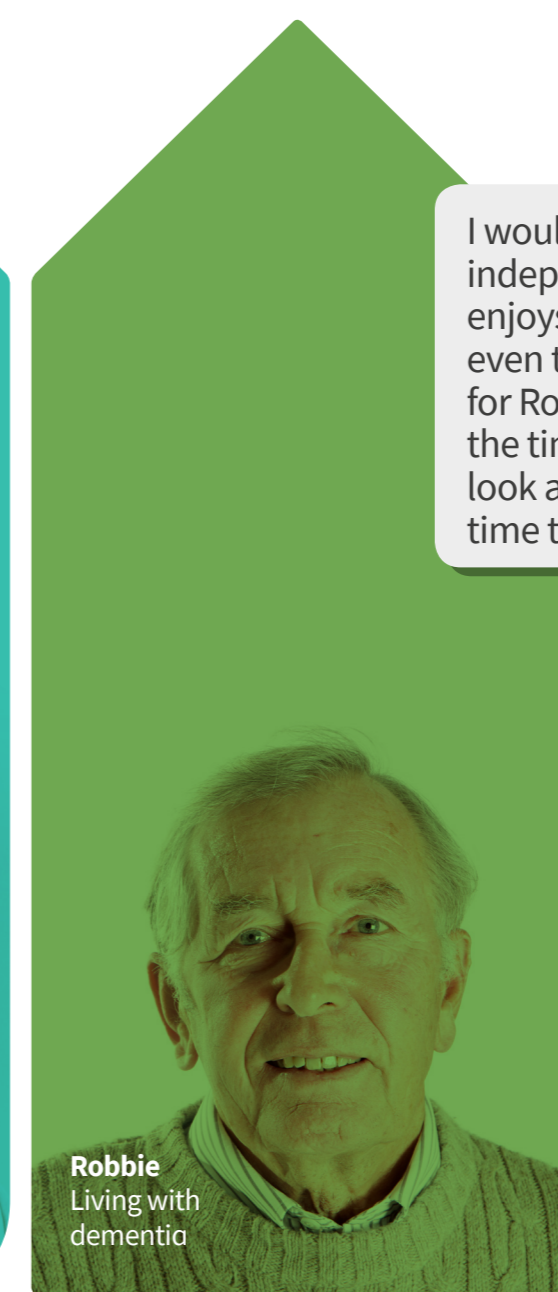
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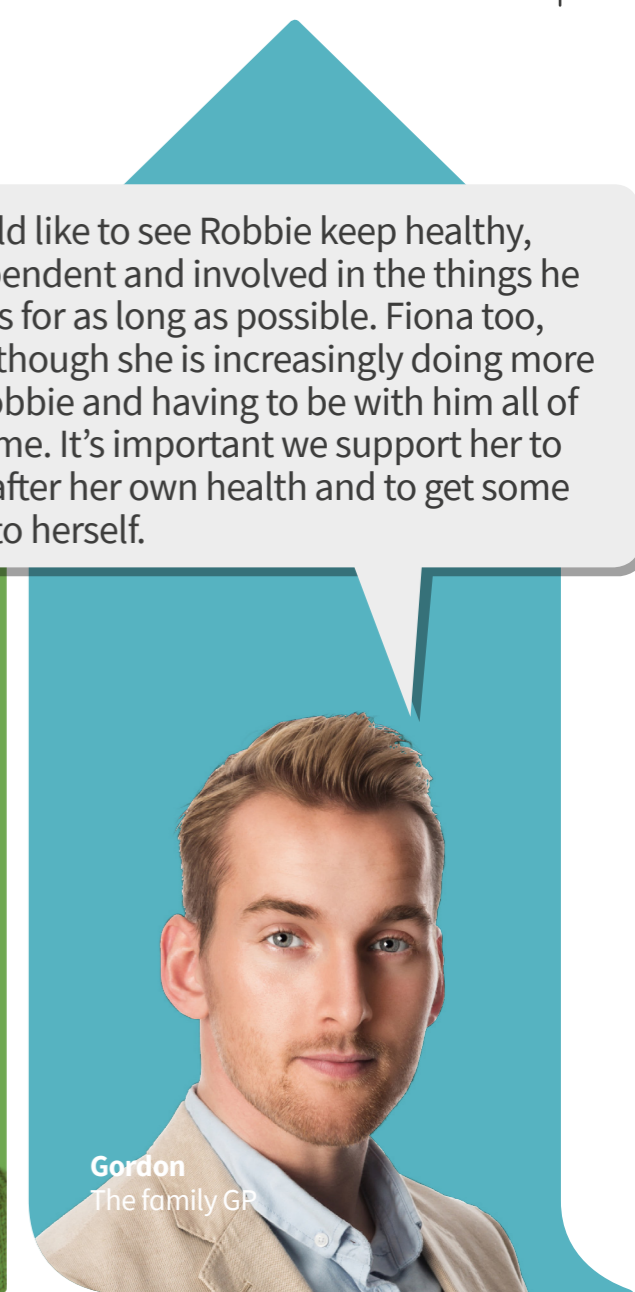
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**Fiona**  
Robbie's wife, supporting  
Robbie's independence



**Robbie**  
Living with  
dementia



**Gordon**  
The family GP

I would like to see Robbie keep healthy, independent and involved in the things he enjoys for as long as possible. Fiona too, even though she is increasingly doing more for Robbie and having to be with him all of the time. It's important we support her to look after her own health and to get some time to herself.

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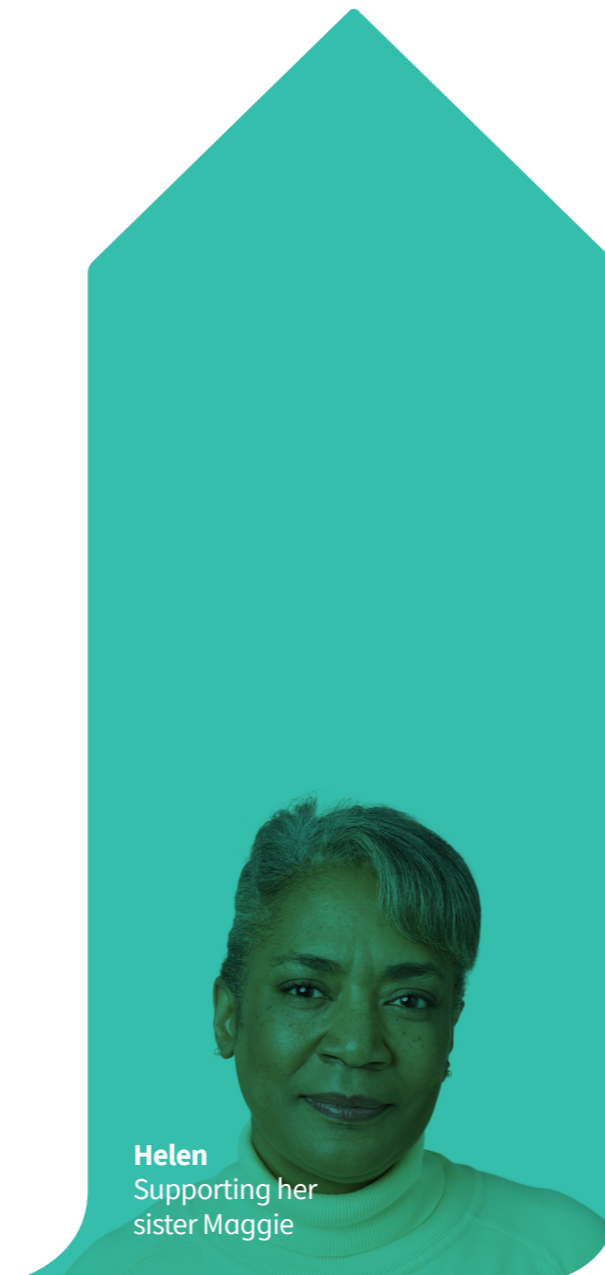
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### Scenario 2 Helen and Maggie

Helen supports her sister Maggie to live by herself in her own flat. Helen has a young family and says she sometimes feels that she has to split herself between them and Maggie. Maggie loves her flat and is proud that she is maintaining a tenancy and staying out of hospital. But she does feel lonely and isolated which she knows is bad for her mood and thinking. She is working really hard to look after herself, be more involved in things and make new friends. In Helen's eyes some of these new friends are taking advantage of her sister, just looking for a place to sleep and someone to 'borrow' money from.

Click on each person to discover  
what's important for them.

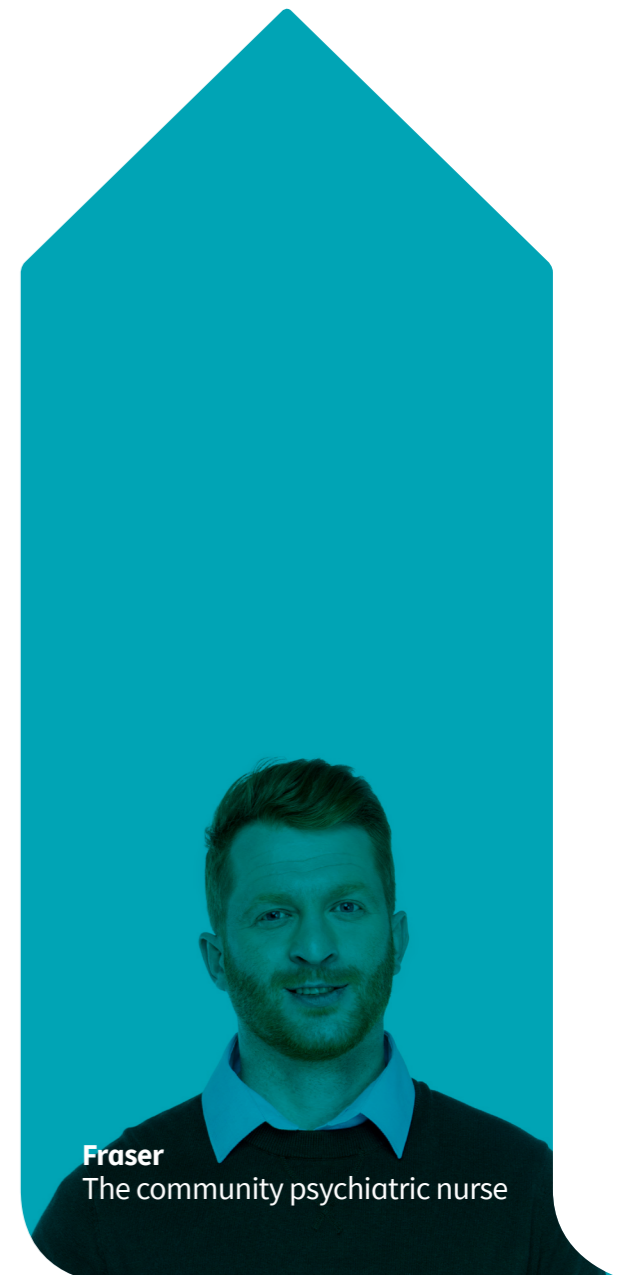
Working towards  
a positive outcome



**Helen**  
Supporting her  
sister Maggie



**Maggie**  
Staying independent  
in her own home



**Fraser**  
The community psychiatric nurse



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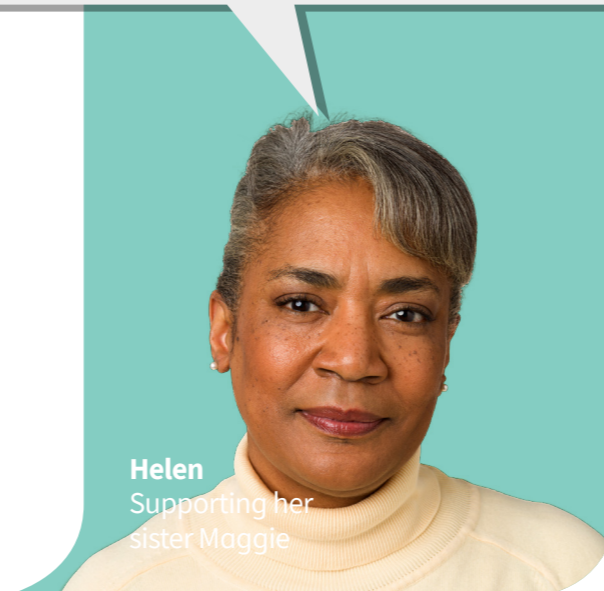
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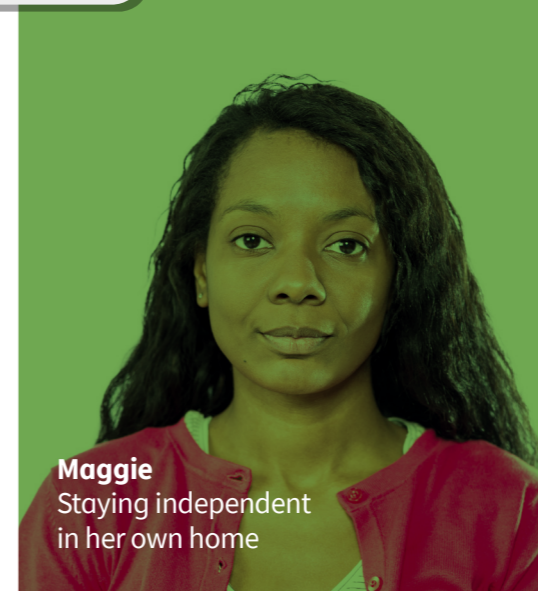
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I'd like to know more about my sister's condition and treatment. I do understand some things are private but I'm also the one who steps in when things get difficult. I get really frustrated with Fraser because I feel he keeps me at arms length. She's my sister...I just want to make sure she is safe. Sometimes I feel like I need a break from always being the supportive one... it gets exhausting.



Helen  
Supporting her  
sister Maggie



Maggie  
Staying independent  
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### Scenario 2 Helen and Maggie

Helen supports her sister Maggie to live by herself in her own flat. Helen has a young family and says she sometimes feels that she has to split herself between them and Maggie. Maggie loves her flat and is proud that she is maintaining a tenancy and staying out of hospital. But she does feel lonely and isolated which she knows is bad for her mood and thinking. She is working really hard to look after herself, be more involved in things and make new friends. In Helen's eyes some of these new friends are taking advantage of her sister, just looking for a place to sleep and someone to 'borrow' money from.

Click on each person to discover  
what's important for them.

Working towards  
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Click on each person to discover what's important for them.


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Supporting her sister Maggie



**Maggie**  
Staying independent in her own home



**Fraser**  
The community psychiatric nurse

I want to respect and support Maggie's right to choose her own friends but I don't want her to put her tenancy at risk. I want to maintain the trust of both Maggie and Helen even when they get frustrated with each other, and with me. I want to support Maggie to stay well.

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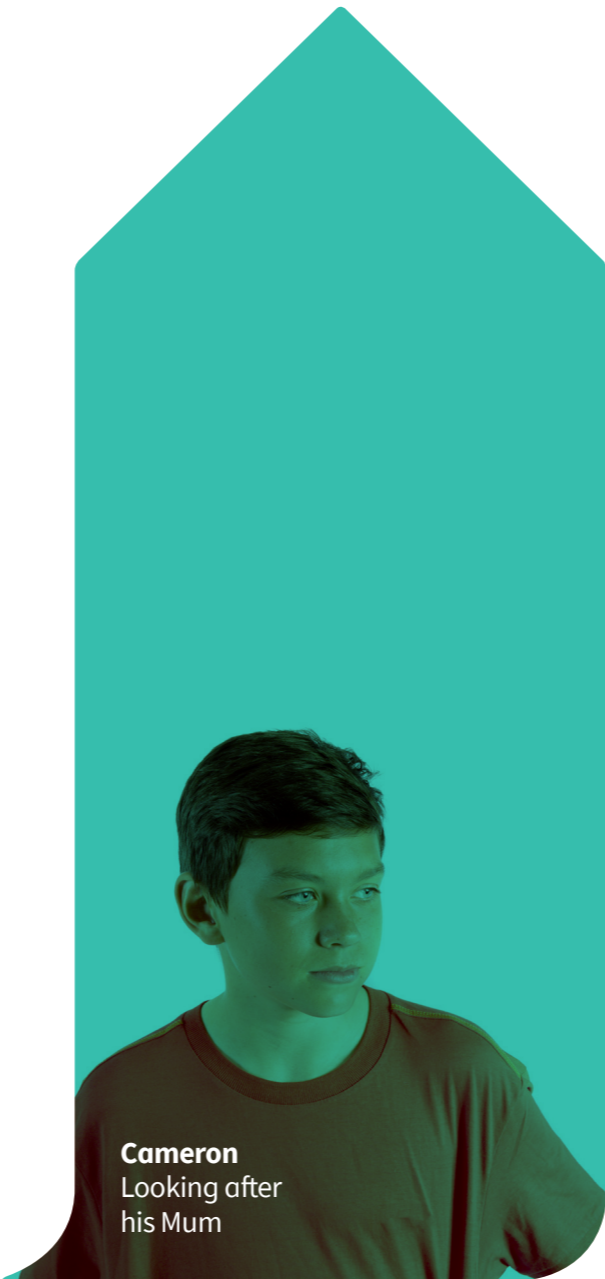
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### Scenario 3 Cameron and Nancy

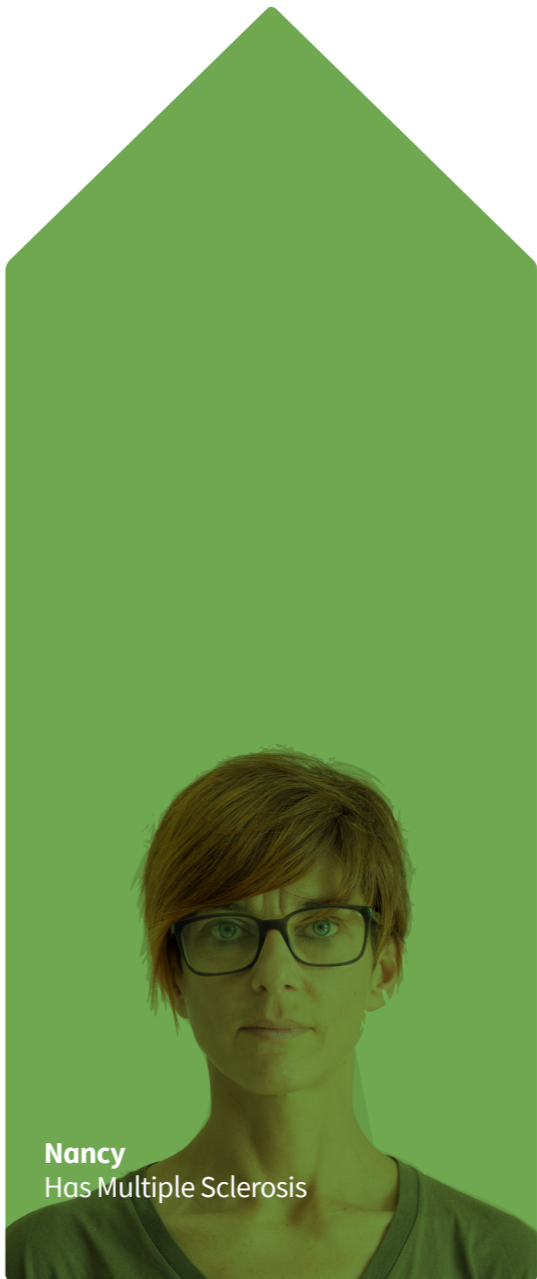
Cameron is 15 and looks after his mum, Nancy, who has multiple sclerosis. He does most of the household chores and gets his little sister off to school in the morning. He sometimes misses school himself. Nancy does as much as she can herself and feels worried and guilty about the amount that Cameron does. It crept up on her... And now she is scared that if she says how hard things are becoming then the family won't cope and that will be worse.

Click on each person to discover  
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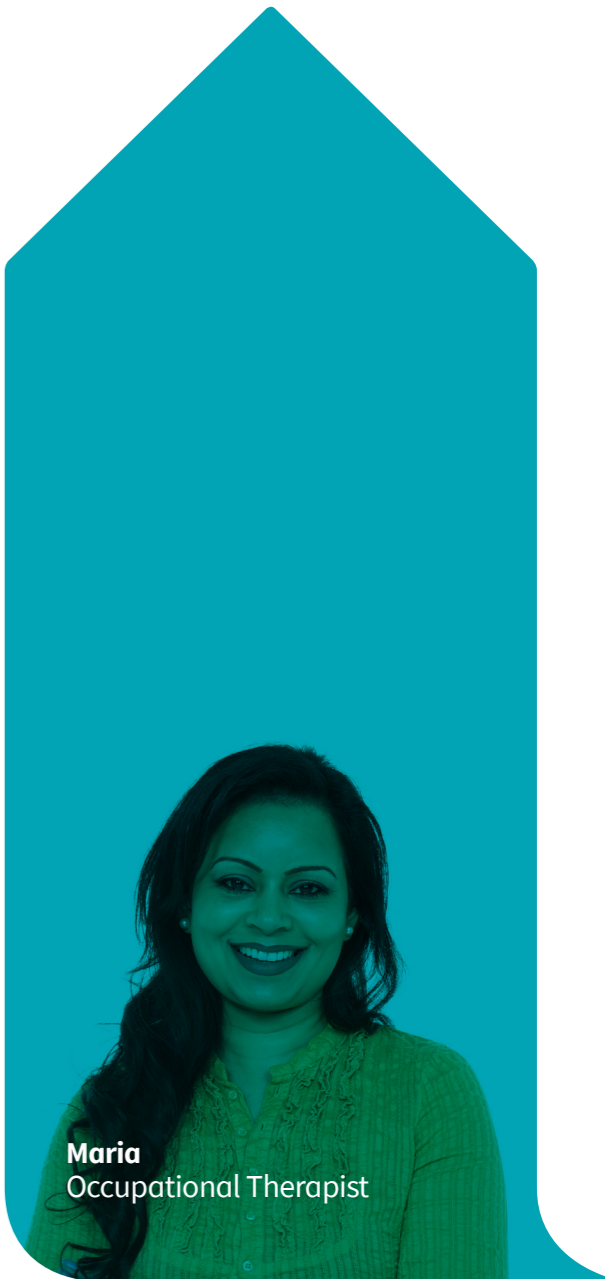
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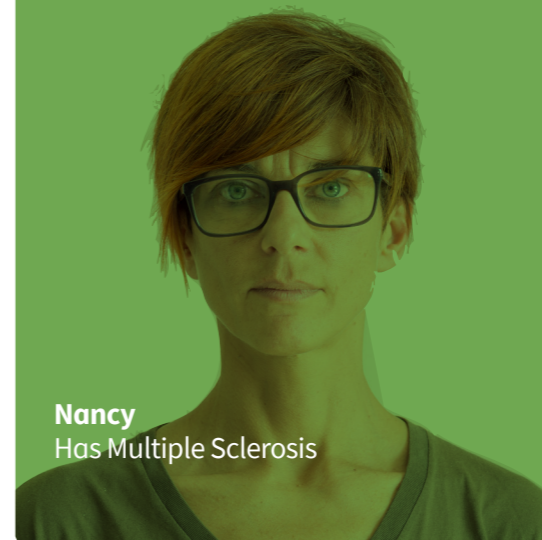
Click on each person to discover  
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It's my job to look after mum, she needs me. I'm good at doing all the house stuff now. I don't need any help. When I leave school I want to be a physiotherapist. I would like to bring some mates home after school sometimes though but I don't want to bother Mum.



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Click on each person to discover what's important for them.

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**Nancy**  
Has M



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I don't like having to rely on Cameron, it's not fair. But I'm afraid of what will happen if I say things are getting too difficult for us to manage. The old me was so strong. I did everything for the kids and was proud of bringing them up on my own without any support. I wish I was still like that. I need to make sure that Cameron gets to focus on his exams.

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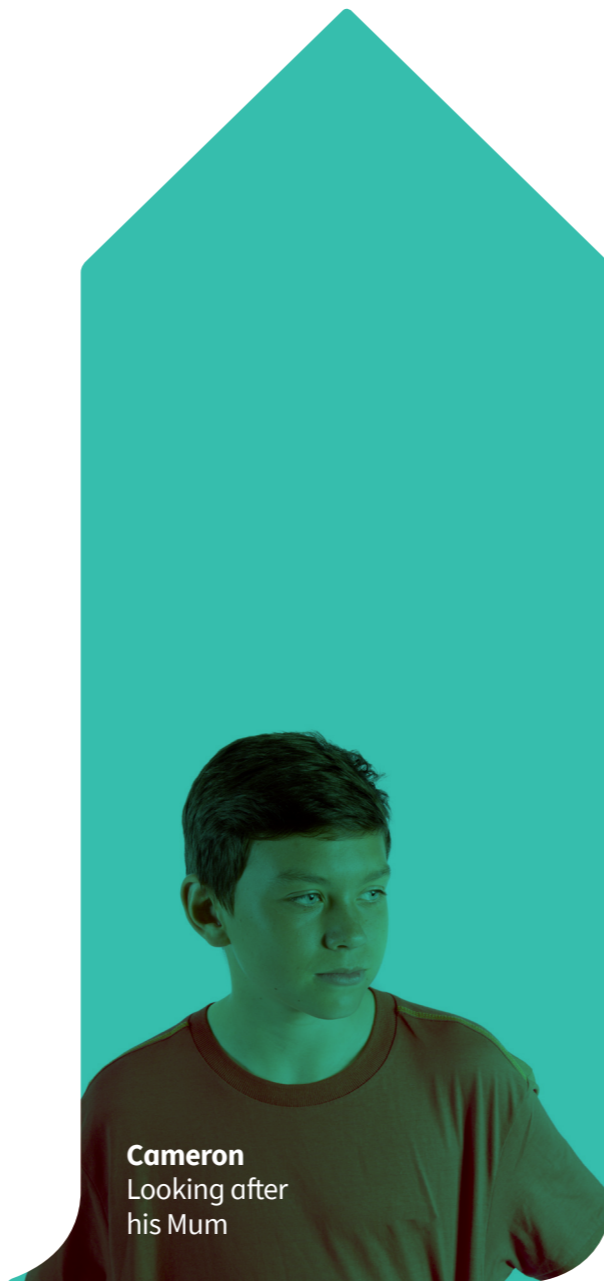
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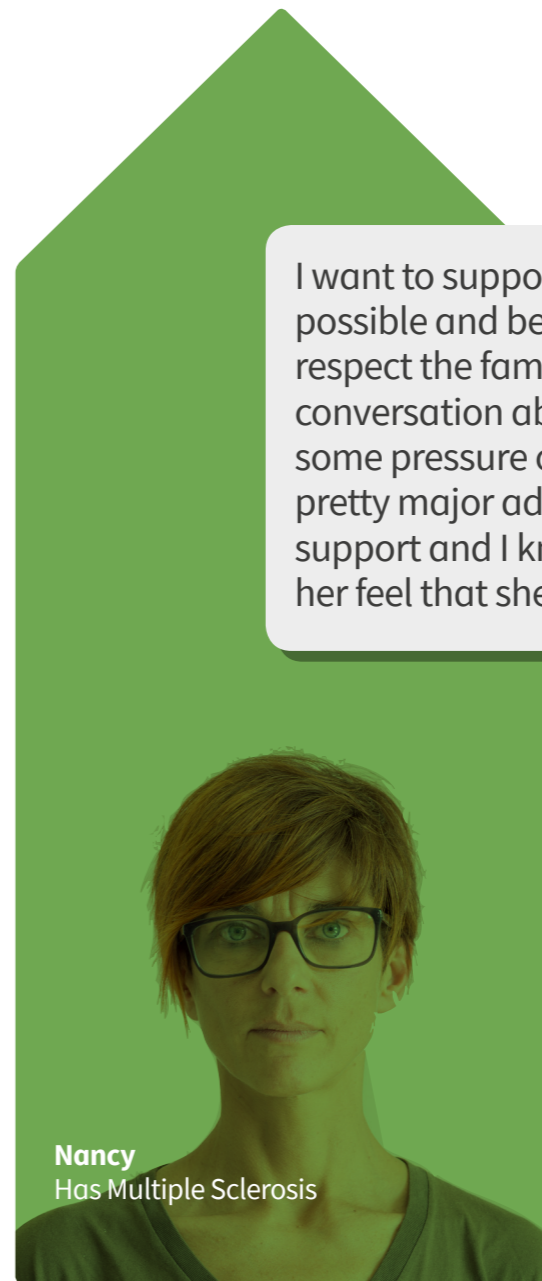
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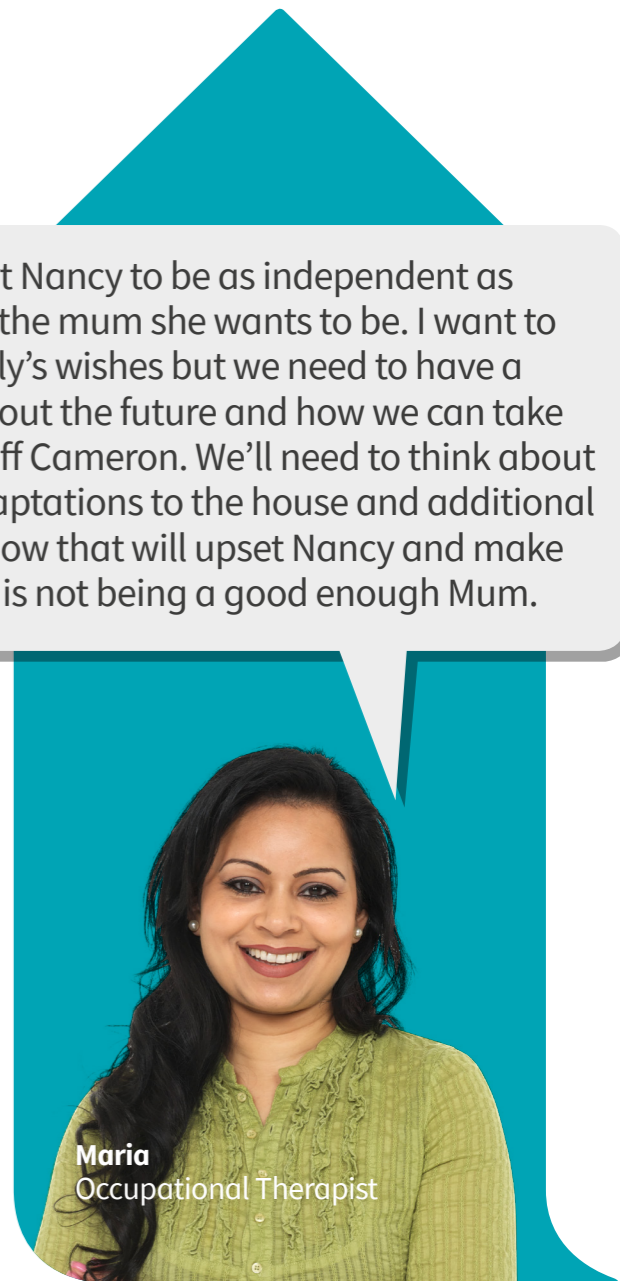
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**Cameron**  
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I want to support Nancy to be as independent as possible and be the mum she wants to be. I want to respect the family's wishes but we need to have a conversation about the future and how we can take some pressure off Cameron. We'll need to think about pretty major adaptations to the house and additional support and I know that will upset Nancy and make her feel that she is not being a good enough Mum.



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### The exchange model

As you can see from the three scenarios (and from your own experience) different things can matter to different people at different times. Listening to these differing perspectives is a vital aspect of supporting good conversations. It sounds simple but learning to 'tune in' to what matters to people, their views and perspectives, underpinning values, fears and experiences takes time and conscious effort on your part. The Exchange Model has been identified as particularly helpful in considering different points of view.<sup>8</sup> The model shows that there is often a need to engage with different perspectives to achieve a shared sense of purpose (outcomes for people), whether developing a plan with a family, or working towards a better understanding of what matters in making decisions in a particular situation. Using the exchange model alongside your existing coaching and facilitation skills can help to negotiate agreed outcomes.





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## The exchange model

As workers we have a responsibility to support ways of working that respect everyone's perspectives and support people to achieve the outcomes important to them.

How do you currently work to understand what matters to everyone in the caring relationship?  
How can the exchange model help with this?

Use one of the scenarios (or a situation from your work life) to consider how the exchange model might help you to reach shared outcomes in situations where there are a number of different perspectives and wishes.



In pairs or groups of three pick one of the scenarios from the beginning of this section.

Discuss what matters to each of the characters. Draw on examples from your own experience to discuss how you respond to similar situations

How could the exchange model support your thinking or help you to reach shared outcomes in situations such as the ones you are discussing?



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### When conflicts and tensions arise

Under any circumstances life can be complicated and people often find themselves in situations where they hold firmly to different points of views. Of course, this applies equally to the dynamic of caring. In any one of the scenarios above the situation could start to become more tense. It might be that the caring role is becomes more intense and demanding or there may be increasing uncertainty about the diagnosis/prognosis.

Perhaps the carer can't get the information they need to help make sense of the situation. Perhaps another family member becomes involved with equally strong but different views on the situation. There might be times when the carer feels that their views are not being heard, expectations not being met or perhaps mistakes have been made. A range of situations might result in a carer (or carers) feeling overwhelmed, angry, anxious or upset. This can lead to rising conflict for example;

- within families, or between families and friends
- across or within service providers
- between services and families
- or any combination of the above



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### When conflicts and tensions arise

In service settings rising tensions can lead to people being characterised in certain ways. A carer who is struggling with anxiety may be seen as ‘angry’ or ‘hostile.’ A family holding divergent views about the cared for person might be seen as being ‘at war’ with each other. Staff from another team/organisation who have different perceptions of risk might be deemed to be downright uncooperative. **Staff tell us they find it particularly challenging to deal with situations where there is conflict and high levels of tension.** In the following example a manager notes that her staff had been unhappy about a carer whose wife was in psychiatric care, until the carer’s situation was better understood by the team:

“

*The staff complained about Jan’s husband. Whenever he visited, it was mid evening with few staff on duty. He was intimidating, aggressive, loud and impatient. I investigated and discovered that the man was going home after a long day shift, feeding the children and organising the home before visiting his wife. After he had told his story and I had shared it with the team, future encounters were much better.*

**Modern matron**  
quoted in The Triangle of Care<sup>9</sup>

”



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- a) Brainstorm and record on flip chart;  
What comes to mind when you hear  
the term conflict?
- b) Ask the group; Which words or phrases  
reflect a positive view of conflict? - circle  
those on the flipchart.
- c) Then ask the group; Which words or phrases reflect a  
negative view of conflict? - circle those on the flipchart  
(using different colour pen to the one used to circle  
positive words/phrases)
- d) Now brainstorm and record on flip chart:  
How do we typically react to conflict?
- e) Ask the group to reflect on what their responses  
say about our cultural view of conflict.



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### Understanding our own responses to conflict

In order to be able to use good communication skills when we sense conflict it can be very helpful to first reflect on our own response to it. We are not suggesting that you will behave the same way in every given situation or with different people. Reactions can vary depending on your mood or how your day has been going, your general level of stress, or how resilient you are feeling. However, a helpful starting point in developing good communication in face of conflict can be to notice tendencies which influence your own behaviour.

#### Do you... tend to avoid it at all costs?

For example, you might try to shut the challenging conversation down and move on to safer subjects, or purposefully avoid bringing up something you suspect will result in tension. This can lead to immediate relief of the stress you might be feeling. However, avoiding an issue won't make it go away, but could make it even more challenging to deal with later on, creating a vicious circle.

#### Do you... tend to wade in with a solution?

You might find that you try to fix the situation, get it 'sorted out', 'persuade' others involved into a particular course of action and/or take control. This can be done with the best of intentions, but it can lead to win/lose situations, or action plans that are not actually owned by the people involved.

#### Do you... tend to take a fixed position?

You might find that you feel you have to hold to your position and then tend to seek data that reinforces or maintains that view. When this happens people can get very focused on detail, the ins and outs of who said what, what happened etc and use this to affirm their position. It can result in people 'taking sides' and only paying attention to data that supports this view.

#### Do you... tend to become stressed?

Sometimes our instinctive response can get our adrenaline pumping and we feel angry and stressed ourselves. Or perhaps it can make us feel scared to say anything for fear of making the situation worse. Even when we recognise that this won't help the situation, it can be difficult to stay calm.



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## Understanding our own responses to conflict

In pairs or small group think about a time when you have managed conflict well.

Share examples of what you did to manage the fear, tension, frustration, anxiety it may have evoked so that you were able to respond in the best way possible.



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### Moving towards conflict

Good facilitation and communication requires us to be more able to ‘move towards’ conflict rather than avoiding it or reacting against it.

This means seeking shared agreement, reflecting and thinking about the needs of oneself and others, sharing power, considering others’ ideas...seeing conflict as an opportunity and managing the discomfort it may cause (for ourselves and others).

Being more aware of how you think, feel, communicate and act when tensions mount, can help you explore what you need to do to move towards conflict. This means that we don’t avoid it, fear it, try to control or react unhelpfully towards it.

You can shift unhelpful tendencies or patterns by noticing these, taking about them and being prepared to address them.

It is possible to view conflict as an opportunity for facilitating greater understanding. We can develop and use our skills to seek shared agreement, which may also involve accepting some differences as part of the negotiation.

There are other skills and approaches which you can use to keep the conversation helpful and positive for everyone involved. Let’s look at these with our caring relationships...

Think of the conversation as a space for **clarifying, collaborating and co-creating outcomes** with the person and the carer.



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## Moving towards conflict

Click on an area to learn tips for facilitating conversations when there is conflict.

1. Name the issue that is causing tension/conflict

2. Similarly, be clear what the conflict is about

3. Keep bringing it back to what matters

4. Be curious

5. Differentiate positions from interests

6. Surface different values

7. Assume strengths and experience

8. Instead of

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### 1. Name the issue that is causing tension/conflict

Naming the actual issue causing conflict can prevent it from spreading to other situations or becoming more personal. Gently reminding everyone that the conflict is about the issue rather than the person(s) can help to shift perceptions.

#### For example

*‘It seems that you both want to support your sister to live independently but the issue here is about boundaries, how much you need to know and how much she wants to share with you’*



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### 2. Similarly, be clear what the conflict is about

Identify what is similar and what is different about the views and opinions. Showing people that they do not disagree on everything allows for a more productive and objective conversation.

#### For example

*So, despite your differences you both agree that...*



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### 3. Keep bringing it back to what matters

Give everyone a chance to express what's important about the situation. Focusing on what matters to each of them (rather than the detail of the conflict) can often show that there is more common ground than differences.

#### For example

*'I'm a bit unclear, could you tell me a bit more about what's most important to you about...'*



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#### 4. Be curious

But remember, it's not always easy to come up with a ready answer if asked what was important to us. So we need to stay curious and interested, using prompt questions to gain a better understanding. Give people time and space for people to articulate how they feel. Don't rush to fill any silences.

#### For example

*Can you tell me more? What else? Is there something more?  
What else would you prefer?*



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### 5. Differentiate positions from interests

Sometimes people get locked in to a particular stance or position about something. Positions are centred on what the person wants. Interests are the underlying fears, hopes or concerns that motivate us to hold that position. It can help to focus on interests instead of positions. This can allow others to understand what is needed to create a mutually acceptable resolution and may uncover some shared values.

#### For example

*Instead of focusing on the question ‘what do you want’ try asking ‘why do you want that? What difference would it make? How would it help if that happened? What’s most important about that?’*

*‘Can you help me to understand why xxx is so important’*



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### 6. Surface different values

Some disagreements, conflicts and challenging situations are not simply about what people do or say, but are about significant differences in underlying values or beliefs. It is important to gently and carefully articulate these and acknowledge them for conflict to be addressed.

#### For example

*‘I know it’s difficult at the moment so how can we understand more about each other’s views on this’*



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## 7. Assume strengths and experience

It can be easy to jump into the role of being the fixer or expert and to offer your own solutions. But many carers have years of experience of dealing with difficult and challenging situations. So instead of saying ‘why don’t you...’ start with what has worked in the past.

### For example

*‘You two seem pretty close. How have you managed difficult situations like this in the past?’*



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### 8. Instead of

Asking people what they want instead of the current conflict situation can be a very simple way of supporting them to move on from what they disagree on to helping them to see common ground.

### For example

*‘So instead of this what would you like to see happen?’*

*‘OK...so can we explore different ways to approach this situation?’*



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### 9. Notice

People may get emotional during the conversation. Notice how they are reacting and point it out but try to resist jumping in with your own interpretation. Let people say what is really happening for them rather than you naming it.

### For example

*‘I notice you are not saying very much’ rather than ‘you seem upset and withdrawn from this conversation’*



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### 10. Reframe

Sometimes we see things in opposition to each other i.e. person A wants to do something BUT person B wants to do something else. Acknowledge both positions, then try changing the BUT to an AND. Instead of two positions that seem to conflict, you can support mutual problem solving.

#### For example

*So, Mrs J you want to have more time out to do the things you need to do AND Mr J you don't like having people coming in to look after you. How can we approach this?*



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### Risk

It's also helpful to notice people's attitude to risk. Some people are more open to risk while others are more risk averse. Talking about this, generally and then specifically, can help the carer and the person understand one another's views and work towards a more balanced outcome. People are experts in their own lives. Focusing on their strengths can often help them come up with their own solutions.

As you facilitate the discussion, take what matters to everyone into account and hold these until a way forward which works for everyone seems like a real possibility.

Co-creating outcomes means giving people the time and space to come up with their own solutions, **before** offering any information which might be helpful.





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### Potential conflict scenario

A situation that many carers identify as difficult is where the carer feels that they badly need a break from their caring role but the person they care for does not wish to engage with services or have strangers looking after them (more on short breaks in the section on planning). However, if the carer is struggling to cope the lack of breaks could potentially cause 'burn out.' A key concern is that both the cared for person and the carer might end up needing care if the carer becomes unwell. The outcomes for each person need to be considered.



Thinking about the different ways of responding to conflict that we have outlined in this section, how would you normally respond to a scenario like this?

Are there other strategies could you use to support people to come to a compromise or agreement?

### Thoughts from a carer on managing conflict

The following carer shared some thoughts about how he learned to communicate differently with his son after he came home from a long term stay in a psychiatric hospital. Ahmed is a carer who has looked after his adult son since he developed a psychotic illness in his teens. Ahmed has learned different strategies to avoid small differences of opinion turning into areas of conflict. He wanted to share some thoughts on this with other carers:

“

*It's a learning curve. If something doesn't gel I've learned to watch, bide my time. I've learned to just plant a seed with him and just let it grow and grow, and if you are very patient over time, whether it takes hours, or days or weeks, things often do move. You need to give the person time if you are trying to introduce a new idea that seems at odds to them. If they don't, well, that's ok, but it often is a matter of time and patience.*

Ahmed,  
Carer

”



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### When there is no resolution, and risk of harm

In situations where the caring situation becomes unmanageable or has a harmful impact on the wellbeing of the carer or that of the cared-for person, it may be necessary to raise an adult protection concern in line with local multi-agency adult protection guidelines.



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### Confidentiality, capacity and mental health

Confidentiality can present challenges to families and professionals in health and social care settings. Professionals have a duty of confidentiality and can face disciplinary procedures if they breach this duty. Staff also understand that carers can play a valuable role in the care of a person. But if the person being cared for does not consent to information being shared, this can present dilemmas for staff in balancing their duties to the patient with the need to speak to carers. There can be particular challenges where there are capacity issues.

The Triangle of Care (ToC) emphasises a therapeutic relationship between the individual, staff member, and carer that promotes safety, supports communication, and sustains wellbeing. The ToC guide identifies key elements (standards) required to achieve better collaboration and partnership with carers in mental health services. It includes recommendations to improve carer awareness, engagement and support as well as protocols for sharing information and confidentiality.

In the following example, Kate talks about herself and her brother caring for many years for their sister Helen, who has severe mental health problems. Helen did not want the family and psychiatric services to share information. For a long time, the service erred on the side of caution and did not communicate with the family. Kate describes the difference it made when the family first received support from a voluntary service:

“

*I remember the first time we were listened to as a family. My sister had been very ill for years. After she almost succeeded in trying to end her own life, you can imagine how anxious we all felt. While Helen was in hospital, Doreen came to speak to the family. She understood where we were coming from. And she helped us to get things in perspective. I remember my brother saying he could feel his shoulders relax for the first time in months immediately after that meeting with Doreen*

**Kate,**  
Carer, Glasgow

”



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### Confidentiality, capacity and mental health

There can be additional concerns where young carers are involved. A child or young person may be the main carer and have valuable knowledge of the condition of the person they care for. Young carers often report that they are ignored by the professionals involved with the person they care for. While workers can identify young carers and involve them in discussions and decisions about the person they care for, care is needed to ensure that care plans do not rely on the young person having an inappropriate caring role.

The Mental Welfare Commission has produced a guide to help carers, families and practitioners understand consent, confidentiality, and sharing of information, where the person they care for has a mental illness, dementia, learning disability, autism, personality disorder, or other related condition. It provides clear guidance to help navigate some of the possible tensions involved.

A link to the Mental Welfare Commission guide is provided in the resources section at the end of this resource.



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# Planning with carers & families

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## What to expect from this section

- ✓ Understand more about what is meant by **outcomes for carers and young carers.**
- ✓ Understand the **carer's right** to an adult carer support plan or the young carer's right to a young carer's statement.
- ✓ Revisit the fact that most caring situations involve **mutual caring** relationships.
- ✓ Remember that there **is value in engaging with carers which can have benefits in itself**, and that planning provides an opportunity for good quality engagement.
- ✓ Explore diverse resources which can help carers to have **a life alongside caring** and to be as well as they can, including short breaks for carers.

You can read more about outcomes and planning in our partner resource Personal Outcomes Planning. There is a link to this in the resource section.

There is a separate but linked section to follow this one which covers recording outcomes.





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### Personal outcomes for carers, what does that mean?

The word outcome can mean different things depending on your context and perspective. It may sound like jargon but in the context of planning with carers, we are talking about personal outcomes, and for carers that simply means the things that matter to them.

The diagram below illustrates three types of outcomes important to carers, and emphasises the importance of conversation in finding out what matters to carers.

- managing the caring role (pink)
- their own wellbeing and having a life alongside caring (green)
- being treated as a partner by services (yellow)

Planning provides opportunities for the carer to be listened to, feel valued, get information and engage meaningfully (yellow). A conversation at an early stage can help to identify what matters to the carer including what they want to keep going or change (green and pink). A later conversation can review the outcomes and whether the plan needs to change.

Another outcome that is important to carers relates to the quality of life of the person they care for. Carers often want to be included in decision-making about the cared for person, because of the potential impacts both on the person they care for and for the carer too.

We will talk more about this in the section on recording.





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# Planning with carers & families

## Outcomes for young carers

The overarching policy for children and young people in Scotland is **Getting It Right for Every Child (GIRFEC)**, which is intended to improve outcomes. GIRFEC is underpinned by The United Nations Convention on the Rights of the Child (UNCRC), an international law which sets out the rights of children and young people.

Young carer support plans need to be considered with reference to the indicators associated with GIRFEC. They are known as SHANARRI = safe, healthy, achieving, nurtured, active, respected, responsible, included.

In the following example, Amy, who works with young carers in primary and secondary schools, describes the difference made to a young secondary school pupil who benefits from attending a peer support group.



*We have one young boy who gets picked on in school. As my role is school liaison I only see him there. But when he comes to our young carer groups here, my colleagues tell me he is very relaxed, outgoing and is seen as the cool one! It's because he gets to be himself here and he knows the other kids are in the same boat.*

**Amy Alexander**

Action for Children, Lanarkshire



You can read more about outcomes and planning in our partner resource Personal Outcomes Planning in the resource section. Here we briefly set out carers' rights to an adult carer support plan or young carer statement.

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# Planning with carers & families

## Adult carer support plans

Carers now have the right to be given, or to request an Adult Carer Support Plan (ACSP). For young carers this is called a Young Carer Statement (YCS). First we consider the adult plans.

These are similar to what was previously termed a Carers Assessment, however it is not reliant on the cared-for person receiving a service.

Each local authority will have their own way of producing an Adult Carer Support Plan, however it must cover a number of key areas including:

- the extent of the care provided, the nature of this care, and how the impacts it has on the carers wellbeing
- how willing a carer is to continue their role
- what outcomes the carer wishes to work towards
- information about the support required to meet those outcomes, and when the plan should be reviewed
- It must also cover emergency and future plans, and whether support should include a short break from caring/regular planned breaks from caring

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# Planning with carers & families

## Young carer statements (YCS)

The Carers (Scotland) Act 2016 places a duty on responsible authorities to offer a YCS to all identified young carers and prepare a YCS for those that take up the offer, as well as for any young carer who requests one.

It is intended that the principles of GIRFEC are maintained in preparing a YCS. The YCS is intended to ensure that young carers are seen as children and young people first and are protected from undertaking caring responsibilities and tasks which are inappropriate with regard to their age and maturity.

The YCS becomes a record which the young carer will receive a copy of and can choose to share this information with any other person in their life. To promote effective transitions, any YCS continues to have effect until the carer is provided with an adult carer support plan.

It is worth remembering that young carers often identify positive impacts of caring. They may feel proud about their caring role and associated achievements. However, while the skills and contribution of the young carer's role should be acknowledged, recognition of the positive impacts of care should not inadvertently lead to continuation of inappropriate care. In the following example a social worker describes how she had used a scoring tool to assess SHANARRI wellbeing indicators for an eight year old child. The child gave herself a top score for being responsible but hadn't made the connection that other areas of her life were scoring low because of the high level of caring responsibility she held:

“

*She's doing a lot for her mum. But she thinks it's really good that she was [scoring] 10, being responsible. I see that as being a concern [because other indicators were low]*

**Social Worker,**

Angus, interviewed for Meaningful and Measurable project

”

We now briefly revisit a point that is always worth remembering in thinking through different caring situations, which is that caring is rarely a one way street.

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### Remember that caring is often mutual or reciprocal

There are few caring relationships which do not involve at least some degree of reciprocity. In the following example, Helen and Harry, who have been married for 53 years, describe how they support each other.

#### Helen and Harry:

**Helen:** Between us we've lost count of how many health conditions we've got. Me with arthritis and my lung condition to start. Harry has the problems with his stomach which means we can't go very far, and he has his heart problem too. I've my cancer check coming up in a few weeks. But we can both still walk and we do our best to get out every day

**Harry:** I worry about Helen and making sure she takes her cancer medication. Our daughter has set an alarm on my phone to help us remember.

**Helen:** Memory wise we both struggle, but luckily we tend to remember different things so we can just about piece it together!

So, who is the carer? Clearly both Harry and Helen are both carers and cared for, but it's highly possible neither would think of themselves in that light...they're 'just' husband and wife. And then there is the daughter, from the description it's not clear what her role is but it may be significant. The example of Harry and Helen serve to remind us that caring relationships are very often mutual and multifaceted, which needs to be taken into account when developing support plans.



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# Planning with carers & families

## Exploring diverse resources with the carer

Service led ways of working have tended to mean that often we automatically think about traditional service solutions when thinking about the support that people need. However, carers often say that they want their own role to be recognised more and often want access to support to improve their own knowledge and skills to help with their role. There are also diverse resources in the community which can help carers to achieve better outcomes. While formal services might have a role, this should not always be the starting point.

Lanarkshire Carers Centre have produced a pack for staff and carers to use together to explore outcomes. It is based on the idea of a round cake cut into slices. Starting with a blank 'cake' carers can choose from three different colours of slices to help them think about how to improve their outcomes. The different colours represent three different categories; carers own resources, universal services or carers centre services. The carer (or group of carers) agree an outcome and then work through the three categories to identify how that outcome might be achieved. Once they have made their 'cake' a photograph is taken which the carer can keep if they want as a record of the resources/support available to them in relation to that outcome.

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# Planning with carers & families

## Exploring diverse resources with the carer

Some of the feedback gathered from carers about using the 'cake' resource is as follows:

Gives you lots of ideas.

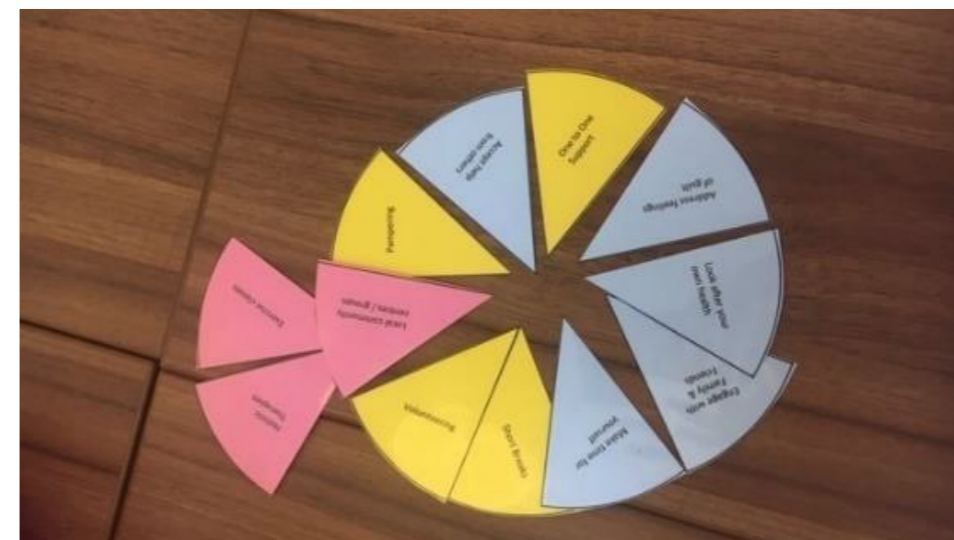
Lets you remember that there is lots of help available and we do need to begin to explore different ways of going forward.

Huge help, really interesting to find out what's available. Also good to have chance to think about what you can do to help yourself.”  
(Lanarkshire carers centre carers)

One of the carer support workers identified the impact of the game from her perspective:

What struck us was at first the outcome sometimes seemed unachievable to carers. Once they looked at the cake slices, they started to think 'I can do this'. They start realising there are resources, there are ways. You can see their mindset changing. (Lanarkshire Carer Centre Staff Member)

The photo below is an example of outcome cake prepared by Lanarkshire Carers Centre.



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# Planning with carers & families

## Considering eligibility criteria

Not everyone working with carers will have direct involvement with assessing their eligibility for services. However, it is worth knowing that under the Act, local authorities have a duty to provide support to carers who meet eligibility criteria as well as power to preventatively support carers who do not meet eligibility criteria. All carers are entitled to information and advice.

If eligible needs are identified for a carer, the responsible local authority must give the carer the opportunity to choose one of the options for self-directed support (SDS) unless the authority considers that the carer is ineligible to receive direct payments. There is separate guidance for assistance relating to the Social Care (Self-directed Support) (Scotland) Act 2013.

With regard to support for young carers to have as normal a life as possible, it is important to note that the eligibility criteria which can apply to adults receiving care from their local authority, do not apply to children.

In the next section we consider examples of recording of outcomes for carers, including in a carers plan. First we briefly consider one outcome which is important to many carers, which is financial wellbeing, before going on to conclude by considering the role of short breaks. Short breaks have been identified as a key resource enabling carers to have a life alongside caring, and which are covered by specific provisions in the Carers (Scotland) Act 2016.

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# Planning with carers & families

## Considering financial wellbeing

There can be significant financial impacts of caring, and in some cases two or more incomes may be affected simultaneously when a family member becomes ill. Money advice is available for people of all ages regardless of working status. For the cared for person, ill health can effect wages, entitlement to benefits, and worries about paying everyday bills. For carers, caring requirements may trigger anxiety about meeting work demands, and some carers will also be worried about their own health conditions too. The role of staff is to reassure that support is available, gain consent for referral, and refer to the service.

It is worth knowing that Carer's Allowance is a benefit paid to carers by the UK Government through the Department of Work and Pensions. Carer's Allowance is not means tested, which means it is not based on income and capital, nor is it dependent on National Insurance records. However, there is a cap on how much you can earn from work and still be entitled to Carer's Allowance.

The Young carer grant, available from 2019 onwards to young carers aged 16 to 18, is intended to support periods of transition in the young carer's life, and is associated with eligibility for concessionary bus travel.

More information is available at several of the links at the end of this resource.

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# Planning with carers & families

## Short breaks

Short breaks, or what would have formerly been described as respite care, means a carer and the person they care for are supported to have a break from their caring situation. This is an essential part of the support that families and carers need to continue caring. Short breaks should deliver positive outcomes for all involved in the caring relationship. This can make the difference for the carer of avoiding exhaustion and developing long term health problems, enabling them to continue to care.

A short break can mean the carer has a break away from the person they care for, the person has a break away from home, or they are supported to take a break together. Local carer support services can help identify short break opportunities.

If it is the person's choice to be cared for by one person, then the carer may need regular breaks to make sure this is sustainable. In many cases, the initial distrust of 'strangers' can be overcome if the care provided focuses on the person's needs and outcomes and supports them to build a relationship with the new provider. A short break for the carer can become something that the person they care for enjoys too.



*We've transformed the way we provide short breaks in the past few years. We were trying to fit carers into what was available before but that's changed since we moved to the brokerage model. Having a conversation with carers is key and we find carers already benefit from that chance to think about their life, to think about the impact of caring, and what might help to keep them well and enjoying life. The short break could be just about anything. And we do go back and check with carers to find out whether their outcomes are achieved. Because we take the time to really listen and think creatively, the breaks are making a big difference.*

**Ian Boyle and Lisa Stevens**  
Dundee Short Break Brokerage



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## Carers are engaged in planning and shaping services

Engaging carers in planning and shaping services can result in better services and better outcomes for all involved. To help services improve the way they engage with carers, the Coalition of Carers in Scotland developed Best Practice Standards. These include the need for meaningful, not tokenistic involvement which influences strategy. They emphasise that carer engagement should be fully resourced, including training and support.

“

*I think you need to participate with a strategic perspective rather than only an individual perspective, though your personal experience helps too. You can see it as you go through the ranks. If you are really entrenched in an intense caring role, it's hard to see beyond the parapet. Then a stage later you can see over the parapet but not very far. I'm in the lucky situation in that my caring role is less demanding than it was. Though having said that I'm now keeping an eye on my mum more now. But I've met so many carers over the years, and I do try to speak for their wider interests.*

**Ahmed,**  
Strategic Carer Representative

”

## Involving carers in training

As far as possible carers should be involved in planning training, as they are well placed to identify what workers need to know. If you have a carers reference group you can involve members of the group as partners in the process or you could invite input from a local carers centre. Carers can also be involved in the delivery of the training content and carers stories and experiences can form part of the content. The carers voice helps to bring the reality of the caring experience alive for learners.



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## Recording

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### What to expect from this section

- ✓ Consider **why recording is important** and why it needs attention in its own right.
- ✓ Review different **examples of recording of carer reported outcomes**, and of outcomes focused carer plans.



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# Recording

## Why recording carers outcomes matters

Most practitioners need to record something about the work they do. This can vary from brief notes to case recording to support plans. What matters to people using services is often left out because of the need to record all tasks, treatments and performance data. Also, there is often no space in recording tools for what matters to the person. Recording what matters or personal outcomes for carers can be brief but can inform how everyone involved interacts with the person. In the planning section we talked about different types of outcomes for carers:

- managing the caring role
- their own wellbeing and having a life alongside caring
- being treated as a partner by services
- quality of life of the person they care for

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# Recording

## Why recording carers outcomes matters

On the previous page we described four types or categories of outcomes that matter to carers. The list below is examples of recorded outcomes for carers of different ages, genders and in different caring relationships. They are personalised and contextualised to the individual but still broadly sit in the four categories.

- to better manage my anxiety so I don't wake up so often at night
- to be able to let my close friends at school know about my mum's condition without getting embarrassed about it
- to continue to have my husband live at home with me as long as possible
- to have enough energy and the headspace to start my painting again

- to have someone I can talk to once in a while when the pressure builds up
- to be able to explain to the new nurse about how my son's aspergers affects his ability to attend the clinic
- to know that the care home staff all accept that my brother is gay as he has faced a lot of prejudice in his life
- to feel confident that my father will have carers who he knows, so that he does not get anxious and I end up being called home from work
- to meet other carers of adults with early onset dementia so that we can learn from and support each other
- to be able to see my pals at the weekend
- to be able to talk to my mum about the fact I know she is dying because I think we will both be less afraid if we can talk about it.

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# Recording

## Why recording carers outcomes matters

Reflect on the personal outcomes listed on the previous page.

What do you notice about the language?

How does it differ from what we usually write in notes, files etc?

What impact does the way they are written have?

How do they relate to the outcome categories or themes mentioned in this section and the section on Planning?



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# Recording

## Why recording carers outcomes matters

Finding space to note these outcomes can be beneficial for everyone. Here is one example of a special note being made available to all staff in a hospital ward where a young man with learning disabilities and an anxiety disorder is recovering from a hip fracture:

*Callum's mum Jane sits with him for a while after visiting hour until he settles down at night. This helps him feel much less anxious and means that he has stopped phoning her continuously to come back in, which she finds exhausting.*

Recording what matters to the person/family in jargon free language supports a shared understanding of purpose. This informs actions to be taken by the person and family members, as well as practitioners. Being treated as a person who has skills, knowledge, feelings and a valuable contribution to make as well as challenges and needs can make a huge difference to whether and how people are able to cope with adversity. What is recorded about that person also influences how everyone who reads the record views that person. Taking a little time to find out what the person thinks and is concerned about before recording can be beneficial to everyone.

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## Recording

### Meaningful outcomes recording – some criteria

A research project involving diverse partners across Scotland in 2014-15 focused on outcomes and information. The project was called **Meaningful and Measurable**. Recording outcomes became a major theme of the project as partners realised that practice in this area was highly variable and needed more attention. Together the partners and researchers agreed on five criteria for recording personal outcomes as follows:

- There should be outcomes (agreed purpose) not just outputs (services)
- The outcomes should be personalised
- The person's/family's contribution should be noted
- The person's voice included as appropriate (rather than jargon or professional language)
- The outcomes should (usually) be action oriented

We will consider these criteria again after considering a specific carer story relating to a former carer called Kevin, and examples of recorded outcomes related to that story.

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## Looking back: Kevin's ideal support plan

In the partner resource to this one, which is an e-book on personal outcomes planning, we include a real life carer story about a man in his early forties whose partner Ella is diagnosed with terminal melanoma. Kevin talks about the caring journey, from diagnosis through hospital at home, hospital and hospice and then to life after Ella dies, only four months after diagnosis. Kevin has a daughter called Carrie and he talks about how they had to move through this journey together.

Despite being a qualified nurse himself, Kevin did not see himself as a carer at the time. He did not know about support available to carers. He has commented on the possibilities offered by the Carers (Scotland) Act 2016:

“

*It's good to know that there is a new Carers Act in Scotland. This could be a big step forward, with opportunities to involve carers more from an early stage. This can only benefit the person being cared for, the main carer and often many other people involved as well as staff...*

”

Kevin explained his thoughts on what he would have wanted to include if he could have had a carer's plan at the time.

His thoughts are shown in the table on the next page.



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## Looking back: Kevin's ideal support plan

Outcome	What would have helped?
Seeing myself as a carer so I can let others help me and find the support I need	I would definitely identify as a carer sooner, knowing what I do now. I made things hard on myself by not letting people in to help me until quite late on. I also now understand that doors can open to information, advice and support, if you know where to find it.
Feeling better informed about melanoma, especially at the diagnosis stage	The diagnosis stage can be unbearable. I went down unhelpful routes through reading distressing stories online. I am more aware now about using well informed websites and I would ask the professionals involved to help with this.
Being more able to adapt to rapidly changing family dynamics	I needed a link to an identified professional to reassure me that I was doing ok and to help me prioritise the complexities of such a rapidly changing caring situation.
Knowing and feeling confident that I was doing the right thing for my child	Looking back, I think I did do quite a good job of this but it didn't feel like it at the time. A few encouraging words from a professional would have helped. My daughter was a young carer herself, while her mum was dying. I would seek out support for her in this role too.
Being supported to manage anxiety about not being able to make ends meet and to stay afloat	Money management was not my strong point then, as my partner managed the finances. A conversation with a money advisor could have helped me foresee some of the additional costs, and to plan for life as a single parent with one income. Help with transport to the hospice would have made a big difference, as I don't drive.
Understanding and thinking through the importance of being connected to diverse community resources	After Ella died, I was at serious risk of cutting myself off. As Carrie's only parent I was forced to engage with services like the school and the GP, and clubs like the scouts and dance classes. Looking back, those connections were very good for me, as well as for Carrie. Other parents checked in on me, and made sure I had lifts if there was a dance show on and so on. I don't think I realised at the time how important that was.



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## Looking back: Kevin's ideal support plan

Kevin retrospectively identifies six outcomes that were important to him in his caring situation, formulated with the benefit of hindsight.

Considering Kevin's outcomes (not including what would have helped at this stage) do you think that collectively, they meet the meaningful and measurable criteria identified above?



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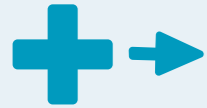
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### What to expect from this section

- ✓ Be aware of the **responsibilities relating to carers and hospital discharge** under the Carers (Scotland) Act 2016.
- ✓ Revisit the central idea of this resource, that there is **value in engaging with carers and there are always ways to do that**, including in hospital settings, and make links to the themes of identifying carers and checking in with carers (Section 2).
- ✓ Consider the **impacts and implications of hospital discharge** from a carers perspective.





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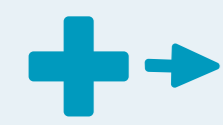
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## Engaging with carers in the hospital context

Sometimes an admission to hospital signals a moderate health intervention for someone who subsequently requires no or minimal additional support to get on with life when they return home. Often however, a hospital admission can signal a change in someone’s overall health status and can mean that significant support is required when the person returns home, either on a temporary or long term basis. In the latter case, adjustments may be involved, for the person and for any family members, neighbours or friends who might find themselves providing care and support to the person.

The Carers (Scotland) Act 2016 requires that carers be identified without delay to ensure they can be involved in discussions and decisions for care and discharge planning.



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## Hospital to home

### Brief explanation of the hospital discharge section of the Act

The Carers (Scotland) Act 2016 requires hospital staff to ensure, where reasonable and practicable, that those providing unpaid care for a relative/friend are involved in discharge planning and that staff should be able to evidence this. This is just one component of the Act that applies specifically to the hospital setting.

#### Overall the Act aims to:

- Improve outcomes for both the cared for and carer
- Protect carers health and wellbeing
- Enable carers to care if they are willing and able
- Enable more people to be cared for at home

The Act says that health boards must involve adult carers and young carers before the cared-for person is discharged from hospital. Health boards must:

- a) Take steps as they consider appropriate to: inform the carer as soon as reasonably practicable of the intention to discharge the cared-for person; and invite views of carers about the discharge; and
- b) Take 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.

This duty 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 does not apply if the patient:

- is an outpatient or attending A&E
- has received a suspension of detention or conditional discharge under the Mental Health (Care and Treatment) Act 2003 (in such cases)

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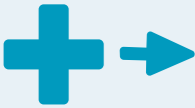
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## Brief explanation of the hospital discharge section of the Act

### What this means in practice

- **Identify** at the earliest stage possible, patients who already have a carer or who are likely to require support from a carer post discharge
- **Identify** who already provides this support, or is likely to provide it
- With the consent of the patient, **involve** this carer in care and discharge planning
- **Inform** the carer of their rights and how to access support with their caring role
- Record relevant information appropriately

### Carers (Scotland) Act 2016



When a person needs care following discharge from hospital, health boards must:

- **Identify** carers and young carers\*
- **Involve** carers and young carers in discharge planning
- **Inform** carers and young carers about services available to support them
- **Record** relevant information appropriately

\* Remember young carers are children and young people first and foremost

The two videos below share some of the work that is happening in Scotland to support the involvement of carers in hospital discharge

NHS Ayrshire and Arran



NHS Greater Glasgow and Clyde



For more information about the hospital discharge section in the Carers (Scotland) Act 2016 please see our partner resource Carer Involvement in Hospital Discharge (link in resource section).



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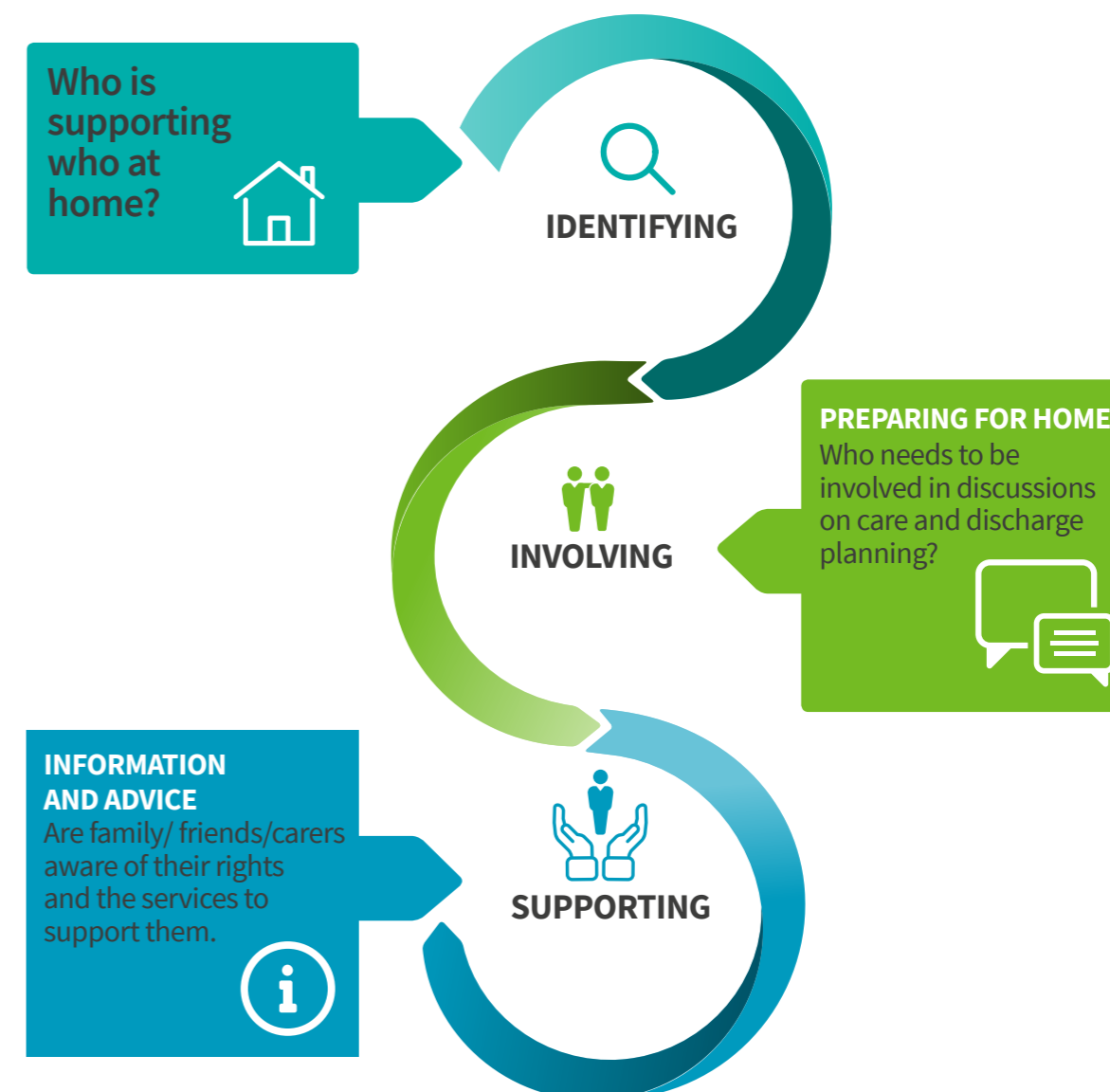
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NHS Greater Glasgow and Clyde developed this image to support staff to ask about carers and ensure their involvement in discharge planning.

## Supporting you, supporting carers





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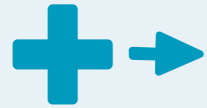
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## Hospital to home

### Thinking about returning home from hospital

The return home from hospital can present a step change in the journey of both the person being discharged and the carer(s). The following comment is from Jess, a partnership training officer who supports health and social care staff to think about the impacts of caring, with a specific focus on hospital discharge. One of her training exercises is included at the end of this section, and can be used in staff development sessions:



*People tend to have that lightbulb moment of recognising themselves as carers at different stages of the caring journey. Very often though, it is when the person they are caring for is returning from hospital to home. The reality of what is ahead then starts to hit them. There are real opportunities here to plant seeds for the carer, so that they know that information and support is available, even if they can't think about what that exact need is yet*

**Jess Kearslake**

Partnership Training Officer, Voice of Carers Across Lothian



Hospital admission, and the duration of a hospital stay present real opportunities to identify and check in with people in such caring situations, whether they recognise themselves as carers or not. The section on carer identification describes how to find out if a person is in a caring role and make sure they know that information advice and support is available. Knowing how to do this does not require a heavy addition to workload but does mean that you are compliant with the Act.

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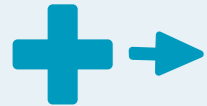
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## Hospital to home

### Thinking about returning home from hospital

In addition, the following points are worth bearing in mind in a hospital setting:

- What tends to be recorded in NHS information systems is the next of kin. It is important not to assume that the next of kin is the main carer, as this is often not the case
- Sometimes people are so keen to get home from hospital that they may present an optimistic picture of the support available to them at home. It is worth checking in to find out whether the suggested support is going to be available as hoped
- If discharge is not well planned, there can be risks of readmission of the cared for person, and negative impacts on the health and wellbeing of the carer

All discharges are planned in advance, although for various reasons this can be a very rapid process. What works or seems reasonable from a service perspective may feel quite different from the carer's perspective. Which leads us again to reiterate that good communication is vital. Sometimes this can feel challenging and take time and effort, but don't forget too that little things can make a big difference.

For example, a conversation which starts with 'We're planning to discharge your mum on Friday, can we have a chat about how

to do that?' sends a very different message to one which starts with 'We're discharging your mum on Friday, could you please come and pick her up after 11.00am...

Some discharges take place following lengthy periods of hospitalisation. Planning is equally important in these situations, to enable a successful transition from institutional life back to the community. The following carer describes how a planned approach helped his son return home successfully after a long-term period in psychiatric care:



*My son was in hospital for 15 months from age 15 to 16. Then it was a staged release, slowly building up to make sure that he could cope at home. The medication helped a lot. The staff involved us in planning. They accompanied him to start with until we got into the way of things. Sometimes he didn't want to come back and that was awkward. The staff would talk to him on the phone. That bit of negotiation helped a lot.*

**Ahmed,**  
Carer



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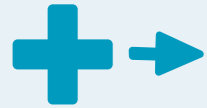
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## Hospital to home

### Involving young carers in hospital discharge

There can be additional specific challenges for young carers in hospital settings. This stems from the fact that children and young people are often overlooked as potential carers. Again, the section on Carer Identification describes how to find out if a young person is in a caring role. The following example is a discussion between two young carer support staff who talk about some of the challenges young carers face regarding hospital discharge:

**Hannah:** Involving young carers in hospital discharge is a must do too. Staff can feel uncomfortable about it because it doesn't feel right and they don't want to burden the young person, but they need to do it. There can be a mistaken intention to protect the young person, but that can end up causing harm. We find lots of situations where hospital discharge for young carers can come at the worst times, the day before an exam, or something significant going on at school.

**Paul:** It can happen so fast that the young carer cannot prioritise the demands on them. If they are not involved in planning the stress can be intense. There is also a need to recognize the emotional impact. The hospitalisation might signal a deterioration in the cared for person's condition

**Hannah:** What does that moment signify? There is usually a spike in caring afterwards. There can be losses that are not going to be recovered. Being aware of that in making decisions and making that connection to a young carer service can make a big difference.  
(Hannah Martin and Paul Traynor, Carers Trust Scotland)

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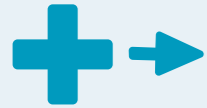
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# Hospital to home

## Involving young carers in hospital discharge

### Hospital discharge case study

(developed by VOCAL and NHS Lothian)

The purpose of this exercise is to get people thinking about the impact of hospital discharge for a busy carer. It is built around the premise that although staff might have limited information, there is nearly always a back story which will affect the success, or otherwise, of the discharge process. While it is not always possible to engage with the full story, the intention is to encourage staff to think about checking in with the carer and ensuring that the carer has access to information, advice and support as necessary.

1. Divide the participants into two groups.
2. Give one group the brief version of Kirsty's story (Case Study Group 1) and the other group the fuller version (Case Study Group 2). It is important that the two groups do not know that they have been given different information.

3. Ask each group to discuss how the situation might be impacting on Kirsty.

4. Bring the two groups back together and ask for feedback...start with the group that had the least information then the group that had the fuller story.

5. After both groups have fed back ask what people noticed, how it felt, what was difficult etc.

6. After you have had this conversation tell the participants that the two groups had different information. Discuss what different this made.

7. Share with the group that the purpose of an exercise such as this is to encourage people to be mindful that there is usually a back story. Even where it is not possible to know or find out the fuller story it is still important to check and ensure that the carer knows where to get advice, information and support when needed.

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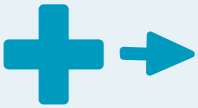
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Case studies

## Case Study for Group 1 (for group exercise)

### Kirsty

#### Carer

Kirsty

#### Lives with

Partner and three children  
in Allermuir

#### Dependents

Three children

#### Cared for

Alex (Kirsty's Dad)

#### Lives with

Alone - Allermuir

#### Health issue

Stroke, six weeks ago,  
currently in hospital  
awaiting discharge

Requires assistance to stand

Able to walk very short distance  
with assistance of one person

Can communicate  
with assistance of  
communication aids

#### Practitioner recommendation

Care package to include  
two specialist stroke  
recovery carers

Paid home carers attend  
to daily (still to be  
implemented)

#### Discharge due

ASAP

What are the impacts  
for Kirsty?



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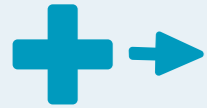
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## Hospital to home

### Case Study for Group 2 (for group exercise)

Kirsty lives with her partner and three children in Allermuir and works in Holyrood.

Kirsty's dad Alex lives alone in his flat a short drive from Kirsty and her family. Alex had been enjoying being recently retired after working for many years as a gas fitter and is good friends with his former colleagues. He loves music and had played the guitar for many years. Since retiring he had joined a band and was performing at gigs in local pubs.

A week ago Alex suffered a major stroke. He received emergency hospital treatment and specialist care which may have saved his life.

Alex now requires assistance to stand and can only walk very short distances with assistance. He also struggles to make himself understood as his speech has been greatly affected. Alex is due to be discharged from hospital within the next couple of days. Practitioners recommend that Alex's care package includes two rehabilitation support workers and paid home carers attend daily.

Kirsty has never assisted anyone who has had a stroke before. She will also need to travel from Holyrood to Allermuir in her lunch break to check on him, as well as juggle her parenting responsibilities.

Kirsty plans to visit Alex every day after picking up her children from the afterschool club. She will prepare his evening meals and assist him to eat, administer his medication, do his laundry and housework, take care of his paperwork and do his shopping.

#### What are the impacts for Kirsty?

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# Resource Section

## For more about self-directed support

<http://www.selfdirectedsupportscotland.org.uk/>

<https://www.gov.scot/publications/statutory-guidance-accompany-social-care-self-directed-support-scotland-act-2013/>

## For more about consent and confidentiality

<https://www.mwscot.org.uk/good-practice/guidance-advice>

<https://www.wihb.scot.nhs.uk/carers-act-2016/confidentiality-sharing-information-and-consent>

## For more about outcome focused planning

<https://www.sssc.uk.com/supporting-the-workforce/self-directed-support-and-integration/personal-outcomes/>

## For more about Hospital Discharge (Section 28 of the Carers (Scotland) Act

<https://learn.nes.nhs.scot/Search/SearchResults?searchterm=Carer%20involvement%20in%20hospital%20discharge%20%3A%20Carers%20%28Scotland%29%20Act%202016&page=1>



## Acknowledgement

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WHO global strategy on people-centred and integrated health services.  
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- 3 **Calderwood, C. (2017) Realising Realistic Medicine: Chief Medical Officer for Scotland annual report 2015-2016, Edinburgh: Scottish Government**
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- 5 **Carers UK (2016) Missing out: the identification challenge, London: Carers UK**
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<http://talkworks.wikidot.com/listening-actively> (Accessed July 2019)
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- 8 **Developed by Smale and Tucson (1993) recently adapted by Miller and Barrie (2016)**
- 9 **Carers Trust (2013) The Triangle of Care, Carers Included: A Guide to Best Practice in Mental Health Care in England Second Edition**  
[https://professionals.carers.org/sites/default/files/thetriangleofcare\\_guideto-bestpracticeinmentalhealthcare\\_england.pdf](https://professionals.carers.org/sites/default/files/thetriangleofcare_guideto-bestpracticeinmentalhealthcare_england.pdf) (accessed July 2019)



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