Learning Disabilities and Palliative Care: Building Bridges - Supporting Care

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All people, regardless of their condition and where they are being cared for, have the right to good end of life care and control over their care – that applies as much to people with learning disabilities as to anyone else. To achieve that, communication and partnership working between the individual, the family and all those involved in their care are even more important in end of life care situations”

(National End of Life Care Programme)
Palliative Care

An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering, by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

(World Health Organisation 2010)
Living and Dying Well 2008

Old concept

Treatment

Curative care

Palliative care

Death

Better concept

Treatment

Disease modifying or potentially curative

Supportive and palliative care

Supportive and palliative care

Bereavement care

Death

Time

Time
Palliative Care

The palliative care framework supports people irrespective of stage of disease or condition:

- early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy,
- living with complex health needs and comorbid conditions
- living with chronic disease
- approaching end of life care and
- support for those who grieve
“The secret to caring for the patient is caring for the patient”

Francis Peabody
1881-1927
Early involvement allows the opportunity for
• Person centred holistic assessment of physical, social, emotional and spiritual aspects of care
• Coordination of care and health advocacy.
• Partnership and collaborative working to improve the patients outcomes.
• Support the individual to gain an understanding of condition and prognosis.
• Anticipatory care planning (ACP)
• Difficult conversations.
• Early symptom recognition and management.
Early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy….

An opportunity to Challenge

• Assumptions about a persons ability to cope with treatments
• Assumptions about consent to treatment
• Subjective decisions about quality of life influencing treatment options.
Living with complex health needs and co-morbid conditions ….
living with chronic disease

People with Learning Disabilities often experience health inequalities and discrimination.

- PWLD have poorer health than the general population and die younger.
- High Prevalence of comorbid conditions.
- Different Disease Profiles.
- Life Limiting Illness more prevalent
  - 4 times more likely to die from a preventable cause.
  - CIPOLD - 42% of the deaths considered “premature”.
  - 58 times more likely to die before the age of 50.
- Less likely to receive adequate pain relief
- Less likely to access specialist palliative care services.
Living with complex health needs and co-morbid conditions ..... living with chronic disease

Communication Difficulties
Visual Difficulties
Hearing Impairment
Physical Disabilities
Multiple Disabilities
Mental Health
Challenging Behaviour
Autistic Spectrum Disorder
Poor oral Health
Dysphagia
Osteoporosis

Epilepsy
Gastrointestinal Disorders
Respiratory Disease
Cancer
Dementia
Metabolic and Endocrine Disorders.
Cardiovascular Disease
Obesity- Implications for heart disease and diabetes.
Musculoskeletal Accidents/Injuries and Falls
People with Learning Disabilities are

- Less likely to be informed of their diagnosis and prognosis.
- More likely to experience Disenfranchised Dying.
- Less likely to be encouraged to explore sensitive issues around loss, death and dying
- A concern that prognostic indicators are often overlooked.
support for those who grieve

- PWLD experience multiple loss.
- Help them maintain memories
- Use accessible information
- Talk about death but keep language simple.
- Show your own emotions in relation to the loss.
- Sensitivity.
support for those who grieve

• Some people may have difficulty remembering things and will require the information to be consistently repeated over a period of time.
• Rituals may be important.
• Some people with LD will have little or no understanding of death but they do have a perception of change.
• www.pamis.org.uk

We recommend The Pamis Bereavement and Loss: learning Resource Pack. Launched in 2014 it supports both people with learning disabilities and their parents with bereavement and loss.
The Project

To bring two specialities together using a practice development approach to support staff in the provision of the best quality care for people with Learning Disabilities who have Palliative Care needs.
Recommendation 26
That the Glasgow palliative care pathway is evaluated and rolled out nationally by 2015 to improve the care outcomes for patients with learning disabilities
Partnership and collaborative working

• Integrated learning and collaborative working lead to better outcomes.

• It is only through inclusion, education, by making reasonable adjustments and developing robust partnerships that lead to collaborative working that people with learning disabilities will experience equity in accessing services.
The Project Model

EDUCATION

SUPPORT

CARE PATHWAY

Partnership and collaborative working
Education

- Education has been a crucial component of this project.
- Utilising respective skills and knowledge whilst having mutual respect for each others contribution.
- A variety of educational events have been facilitated at local and strategic levels involving staff across all sectors.
Building the Work Force

Key Practitioners have been identified; this role is held by learning disability nurses and palliative care nurses selected from their respective teams and hospices.
Reasonable adjustments
Supporting people with learning disabilities through the palliative care journey

Glasgow Learning Disabilities and Palliative Care Pathway

**Identification Of Concern**
- Known Palliative Care (PC) need
- Symptoms, Decline, Screening

**Assessment, Care Planning, Review and Co-ordination**
- Holistic assessment of care needs including Do Not Attempt Life-Sustaining Treatment (DnA)
- Refer to Specialist Palliative Care Team

**Support patient to live with condition and plan for sudden deterioration**
- If appropriate discuss and identify patient wishes
- Preferred care plan (including Advanced Care Plan, Anticipatory Care Plan, etc.)
- Consider current needs in relation to aids and equipment

**Care in the last weeks of life (Time is short)**
- In partnership with Primary Care Team or Palliative Care Team as appropriate
- Out of Hours support is established including contact details
- Anticipatory prescribing is considered: just-in-case box
- Verdict of death documentation considered
- DNACPR considered and discussed with all
- Gold Standard Framework (GSF)
- Palliative Care Electronic Register

**Care in the last days of life**
- Support Patient's wishes referring to Advanced Care Plan

**Care after death**
- When someone dies at home
  - Referral to LD Nurse if not already done
  - Contact nearest relative if not already done
  - Contact relevant spiritual support if appropriate

**Legal framework**
- Patient / Family / Care / Peer Support considered as philosophy of care changes

**Communication**
- Communicate plans to all

**Collaboration**
- Plan for crisis/sudden deterioration / crisis considering also the priorities in the last weeks of life
- Symptom Management
- Oncological Emergencies
- Environmental Issues
- Other Professional Involvement

**Co-ordination**
- Review, including the “Surprise Question” and Gold Standards Framework (GSF) if appropriate
- Communicate plans to all

All underpinned by:

**Recognise Triggers**
- Referral to GP for Clinical Assessment
- Admission to Acute Setting

**Plan**
- Comprehensive Investigations

**Support to Learning Disabilities (LD) Nurse through Community Learning Disabilities Team (CLDT)**
- Support with Health Needs, Discharge as appropriate when outcomes are met

**Identified Palliative Care Needs, Health Equality Framework (HEF) completed, Diary commenced**
- Review, including the “Surprise Question” and Gold Standards Framework (GSF) if appropriate
- Communicate plans to all
A skilled, knowledgeable and confident workforce:
The Future Pilot Study

- Small pilot study of the Care Pathway across GG&C and Ayrshire and Arran to evaluate and measure outcomes.
- Evaluate the effectiveness of the care pathway using:
  - Health Equalities Framework (HEF)
  - Questionnaires
  - Diary System for patients and carers
  - Data base for recording outcomes.
The Project Aims

People with LD are at the heart of this project, with the ultimate aim being to improve their care.
“Some people in other services are as scared of learning disability as we are of people dying…so it’s about breaking the barriers down”.

Learning Disability Nurse
DVD

Robert’s Story
Improving outcomes for people with learning disabilities who have palliative care needs

Care Inspectorate
Stirling
24th March 2015
Aims of the workshop

- Identify current good practice and consider future interventions that would lead to better outcomes for people with learning disabilities and palliative care needs.
Introducing the kit – Write /draw on leaves
1 idea per leaf, write so others can read
Coloured leaves for different questions (write on the coloured side)
Time on your OWN to develop ideas…
...before reading out ideas one-by-one, going around the circle & placing on the felt
You can move ideas around
Branches provide themes, some blanks
You can add more ideas as you go along, simply write them on leaves
Remember the pens are magic!

• Please put your pens back in your bags!

• Only use the magic pens!
Themes:

- What works well?
- What can we improve upon?
- What are the challenges in achieving this?
- What possible solutions are there to the challenges identified?
Leaves for ideas

• Any comments or questions?
What works well?
What can we improve upon?
What are the challenges in achieving this?
What possible solutions are there to the challenges identified?
Collaborative Working

The literature clearly identifies collaborative working as a fundamental feature to good quality palliative care for people with learning disabilities.

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