**CARING FOR PEOPLE WITH LEARNING DISABILITIES –**

**END OF LIFE CARE TRAINING PROGRAMME**

## 1. INTRODUCTION

Thank you for participating in this programme focusing on End of Life Care for People with Learning Disabilities. We hope that you enjoy your learning and both gain and affirm skills that can be applied to your practice.

This combined work and resource book supports the course material that will be presented over the course of the programme. It provides an opportunity to reflect on your learning and to participate in additional exercises and e-learning to progress your skills and competency. We hope that this is helpful to you and that you are able use this to cascade your learning from the programme to colleagues.

Once the workbook's action plan is completed and submitted for review, your certificate of completion will be sent to you.

We are very keen to capture evaluation of this programme and encourage you to support this project by taking the time to complete the evaluation processes.

We realise that in a short programme not all topics related to End of Life Care for People with Learning Disability can be covered in depth. Prior to designing this programme we undertook a scoping exercise to enable us to focus on themes perceived as important to those in this area of practice and these are reflected in the programme structure.

This collaborative project has been financially supported by Health Education England across Kent Surrey and Sussex working with Kent Community Health Foundation Trust, Pilgrims Hospice and Canterbury Christ Church University.

Mary, Nicola, Pene, Shane and Stephen

Mary Kirk, Pene Stevens and Shane Webber KCHFT

Nicola Le Prevost Pilgrims Hospice

Stephen O'Connor CCCU                                                     November 2017

"But end of life care is not just for people who have reached advanced age……………… For those diagnosed at a younger age with a life-limiting condition, early planning for their care in the end phase of life and respect for their wishes surrounding their death, perhaps long before they reach that point, can be an empowering activity – one that validates the person, maintains dignity  and enables them to retain a sense of control. Similar things apply to people with a learning disability, who for too long been excluded from such discussions due to assumptions of those around them that they lack the capacity and the desire to understand and to engage with issues surrounding death and dying; when bereaved, the grief of the person with a learning disability may not have been recognised, even after a significant loss …….."

[2014, Hayes, A., Henry, C. et al Pathways through Care at the End of Life JKP]

## 2. CONTENTS

3. **OUTLINE OF COURSE PROGRAMME**

**Day 1 Morning**

*Welcome and introductions*

*Context setting the scene - understanding LD and EoLC relevance*

*Nature and impact of LD, health issues and main causes of death*

*Understanding death and dying*

**Day 1 Afternoon**

*Communication skills*

Advance Care Planning
*Ascertaining needs & wishes of LD people at EoL, communication styles*

*Consent and capacity in EoLC*

*Action Planning and evaluation*

**Day 2 Morning**

*Assessing and managing symptoms*

*Care planning*

*Appropriate referrals and inter-professional & interagency working*

**Day 2 Afternoon**

*Managing social, psychosocial and spiritual needs of families*

*Bereavement and loss*

*Caring for ourselves*

Look at the programme in more detail in the next few pages and you will see the aims and learning outcomes for each session described. There are also some learning activities included for you to undertake as course work which will assist with some of the discussion we will be having during our sessions. Later in the book you will find references to resources and personal development to support your learning related to each of the sessions' content and also additional reference material.

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## 4. PROGRAMME

**Programme facilitators:**

Rosalyn Chapman        Senior Community Learning Disabilities Nurse, South Kent Coast & Thanet Learning Disability Team, KCHFT

Nicola Le Prevost        Clinical Lecturer, Pilgrims Hospice

Linda Rendle        Clinical Lecturer, Pilgrims Hospice

Tracey Rose        Senior Community Learning Disabilities Nurse, Dartford Gravesend Swanley and Swale Learning Disability Team, KCHFT

Natalie Sargent        Learning Disability Team KCHFT

Cathy Siggery        Senior Community Learning Disabilities Nurse West Kent Learning Disability Team, KCHFT

Pene Stevens        Consultant Nurse/Professional Lead Learning Disability Nursing, KCHFT

**Programme evaluation**

Dr. Stephen O'Connor        Reader in Cancer, Palliative and End of Life Care, England Centre for Practice Development, Faculty of Health and Wellbeing, CCCU

**Programme timetable:**

| Day 1 | | |
|---|---|---|
| **Time** | **Session** | **Facilitators** |
| **09.00** | *Coffee and registration* | |
| **09.15** | Welcome and housekeeping | Nicola/Linda/ Pene, |
| **09.25** | Introductions | Nicola/Linda |
| **09.45** | Context, setting the scene for LD and EoLC | Roz/Cathy/Tracey |
| **11.00 - 11.15** | *Coffee break* | |
| **11.15** | Understanding death and dying | Nicola/Linda |
| **12.30 - 13.15** | *Lunch break* | |
| **13.15** | Communication skills | Nicola/Linda Roz/Cathy/Tracey |
| **14.30-14.45** | *Tea break* | |
| **14.45** | Advance Care Planning [ACP] | Nicola/Linda |
| **15.45** | Consent and capacity in End of Life Care | Roz/Cathy/Tracey |
| **16.45 – 17.00** | Round up and close | Nicola/Linda/Pene |

| Day 2 | | |
| --- | --- | --- |
| Time | Session | Facilitators |
| 09.00 | *Coffee and registration* | Nicola/Linda/Pene |
| 09.15 | Assessing and managing symptoms | Nicola/Linda, |
| 10.45 - 11.00 | *Coffee break* | |
| 11.00 | Care planning | Nicola/Linda |
| 12.30 - 13.15 | *Lunch break* | |
| 13.15 | Supporting people with learning disabilities, their families and carers | Roz/Cathy/Tracey |
| 14.30-14.45 | *Tea break* | |
| 14.45 | Bereavement and loss | Nicola/Linda |
| 15.45 | Caring for ourselves | Nicola/Linda |
| 16.15 – 17.00 | Action planning and evaluation, close | Nicola/Linda/Pene/Stephen |

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## 5   AIMS AND LEARNING OUTCOMES

**Day 1**

**Context setting the scene - understanding LD and EoLC relevance**

Nature and impact of LD, health issues and main causes of death

**Aims**
- For participants to develop an understanding of the national and local context of end of life care policy and how this influences care provision.
- To understand how the health of people with learning disabilities is more likely to result in reduced life expectancy.

**Learning outcomes**
By the end of the session participants will be able to:
- Describe the national frameworks that influence and structure end of life care service provision.
- Understand the health issues for people with learning disability that contribute to chronic illness and shortened life expectancy.

**Understanding death and dying**

**Aims**
For participants to have an understanding of attitudes towards death and dying.
To be able to recognise that an individual is entering the last days of life, up to and until natural death occurs.

**Learning outcomes**
By the end of the session participants are able to:
- Know different perspectives on death and dying.
- Recognise the point when the individual enters the dying phase
- Consider ways to  identify and record which individuals may be approaching end of life

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**Day 1 Afternoon**

**Communication skills**

**Aim**
Participants are able to hold end of life care conversations using appropriate communication skills and understand how their skills can influence the outcome of conversations.

**Learning outcomes**
Participants demonstrate:
- Understanding of the various factors and influences in their use of communication skills that can affect the quality of the conversation
- The use of techniques that support conversations about end of life care and discussing dying.

**Advance Care Planning [ACP]**
*Ascertaining needs & wishes of LD people at EoL, communication styles*
**Aim**
To improve confidence in End of Life Care discussions and be familiar with the tools to support Advance Care Planning

**Learning outcomes**
By the end of the session participants will:
- Have an awareness of the use of advance care planning documents and the implications for individuals and staff.
- Understand  how to support people with learning disability with advance care planning in their practice area
- Feel able to hold conversations, relevant to their role demonstrating understanding of the various factors and influences that can affect an individual's end of life choices.

**Consent and capacity in End of Life Care**

**Aim**
To have developed understanding of the issues involved in consent and capacity as people with learning disability are approaching end of life.

**Learning Outcome**
The participants at the end of the session will have explored Issues relating to MCA and consent which influence decision making in end of life care

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**Day 2 Morning**

**Assessing and managing symptoms**
*Pain and commonest non-pain symptom management for LD including tools and decision making pathways*

**Aims**
- To have awareness of the totality of the impact of pain and symptoms on individuals.
- To identify appropriate assessment tools for use with people with learning disabilities.

**Learning outcomes**
By the end of the session participants will recognise the importance of applying:
- Holistic assessment in conjunction with health and social care practitioners to support symptom management
- The use of specific assessment tools such as DisDAT and Abbey Pain Scale
- Knowledge regarding the care of the dying person and how end of life care medication can be administered

**Care planning**
*Appropriate referrals and inter-professional & interagency working*

**Aim:**
Participants are aware of how to provide excellent support and care to people with learning disability

**Learning outcomes:**
By the end of the session participants will have developed their knowledge so that they:
- Give  practical support to people they  are caring for including care of the individual following death
- Recognise the complex combination of services across different care settings and how to access appropriate services
- Be aware of the need for increased communication between  health and social care providers involved in care delivery
- Be able to respond rapidly to changes in circumstance as the end of life approaches i.e. increased care need s, complex care needs
- Recognise how to  involve families and significant others in some aspects of the care giving and in discussions as death is approaching


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**Day 2 Afternoon**

**Supporting people with learning disabilities, their families and carers**
*Managing social, psychosocial and spiritual needs*

**Aim**
For participants  to be able to provide support to people with learning disability, their families and carers, noting any particular religious, spiritual, cultural and care needs identified as part of the end of life care plan.

**Learning outcomes**

By the end of the session participants will:
- Respect individual faiths and beliefs to address individual wishes
- Know how to ensure the persons spiritual, religious and cultural needs are met

**Bereavement and loss**

**Aim**

For participants to have an understanding of:
- The theory supporting understanding of loss and grief
- How to provide support to those experiencing loss

**Learning outcomes**

By the end of the session participants will:
- Have an understanding of the theories of grief
- Can provide guidance on how to access support for bereaved relatives, residents and staff
- Be more confident in providing support individuals and others through their experience of loss and grief

**Caring for ourselves**

**Aim**

To improve participants awareness of the importance of taking care of the care –givers.

**Learning Outcomes**

The participants will be:
- Able to define compassion and self-compassion
- Identify strategies to support emotional resilience.

**Action planning and evaluation**

**Aim**

To evaluate that the course programme has resulted in building participants' knowledge and skills in end of life care for people with learning disability.

**Learning Outcomes**

By the end of the course participants will:
- Understand the importance of a completed action plan
- Have an action plan which demonstrates course content and application to practice improvement/development in end of life care in their work setting.
- Have knowledge of local education available and additional resources.

**6. LEARNING ACTIVITIES**

**Exercise 1: Awareness health quiz -** *circle the number /numbers that you think is the correct answer in the following tables.*

**1a]**

| How many more times likely are People with LD to die before 50 than the general population? | | | | | |
|---|---|---|---|---|---|
| 8 | 22 | 50 | 73 | 42 | 13 |
| 19.4 | 99 | 3.5 | 34 | 58 | 82 |

**2b]**          [Hint you need to circle 2 numbers]

| Respiratory diseases cause 15-17% of deaths in the general population. What is the percentage range in people with LD? | | | | | |
|---|---|---|---|---|---|
| 8 | 22 | 46 | 77 | 25.5 | 12 |
| 52 | 18 | 34.5 | 34 | 61 | 15 |

**2c]**

| In the general population over 65, the number of people with dementia is 5.7%. The percentage for people with LD is? | | | | | |
|---|---|---|---|---|---|
| 8 | 20 | 54 | 75 | 21.6 | 12 |
| 48 | 18 | 5 | 97 | 61 | 15.5 |

**Exercise 2: Discussing death –** *People generally seem to find death difficult to discuss for themselves and with others. Are there ways of making it easier to discuss?*

2a] List some ways that may be help you to have a discussion about death with someone you know well.

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2b] When someone with learning disability wishes to discuss death how might you help them have the conversation?

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2c] A simple and powerful way to communicate is often through the use of images, now take time to colour in the day of the dead pictures on the following pages.

After you have done this, take a few moments to reflect and complete this exercise.

How did you feel after completing the pictures?

………………………………………………………………………………………………………………………………………………………………..

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Do you think this is a way of opening up the discussion when working with someone with learning disability?

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**Exercise 3: Advance care planning** *-Advance care planning is something that many health and social care workers find difficult to approach with those whose care they are supporting and this can seem more difficult when working with people who have a learning disability and an illness which is life-limiting.*

3a] Complete the "Speak Up" advance care planning workbook which is included within this resource workbook.

3b] When you have done this, take a few minutes to reflect and complete this exercise:

How did you feel whilst completing the advanced care workbook?

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Now you have undertaken an advanced care plan, what would you like to do with it?

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What do you consider are the benefits of advance care planning for people with learning disability?

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7. **ACTION PLAN [to be completed and reflected upon]**

Individuals to complete how they will achieve their actions, review their progress and add any further action points, these will be submitted 3 months post-course date.

**A programme certificate of completion will be provided for you once this has been submitted to the programme team for review**.

You need to send your reflection by email to Aimee Babbs at Pilgrims Hospice: aimee.babbs@pilgrimshospices.org or by post to her at Pilgrims Hospice Training and Education Anne Robertson Centre 55 London Road Canterbury CT2 8HQ.

| My Personal Action and Development Plan | | |
|---|---|---|
| **Date** | | |
| **Goal I wish to achieve:** | | |
| **Why this is important to my practice:** | | |

| When I intend to do this: | Action Steps to be taken | Date I have completed: |
|---|---|---|
| | 1 | |
| | 2 | |
| | 3 | |
| | 4 | |
| | 5 | |
| | 6 | |
| | 7 | |
| | 8 | |
| | 9 | |
| | 10 | |

| Obstacles to my plan | Responses I made |
|---|---|
| | |

| Resources I need | Resources I used |
|---|---|
| | 15 |

| Date | Reflection on  my plan |
|---|---|
| | |

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## 8. RESOURCES AND PERSONAL DEVELOPMENT TO SUPPORT LEARNING

**Day 1 AM**

**Context setting the scene:**
- o Ambitions for Palliative and End of Life Care: http://endoflifecareambitions.org.uk/
- o 'Supporting People to Live and Die Well: a framework for social care at the end of life' in 2010 https://www.bl.uk/collection-items/supporting-people-to-live-and-die-well-a-framework-for-social-care-at-the-end-of-life
- o Department of Health (2010) The Routes to Success in End of Life Care: achieving quality in domiciliary care. National End of Life Care Programme. Department of Health, London http://www.leedspalliativecare.co.uk/wp-content/uploads/2014/05/Domiciliary-Care-16-March-2011.pdf
- o Common Core Competencies and Principles. A guide for health and social care workers working with adults at the end of life. (2009) DH, NEoLCP, Skills for Care, London. http://www.skillsforcare.org.uk/Documents/Topics/End-of-life-care/Common-core-principles-and-competences-for-social-care-and-health-workers-working-with-adults-at-the-end-of-life.pdf
- o **'**Making reasonable adjustments to end of life care for people with learning disabilities' and examples from practice. PHE 2014 https://www.improvinghealthandlives.org.uk/publications/1234/Making_reasonable_adjustments_to_end_of_life_care_for_people_with_learning_disabilities
- o The route to success in end of life care – achieving quality for people with learning disabilities http://webarchive.nationalarchives.gov.uk/20160805140351/http://www.nhsiq.nhs.uk/resource-search/publications/eolc-rts-learning-disabilities.aspx
- o Widening access to palliative care for people with learning disabilities: guidance and resources for professionals Linda McEnhill, published by Help the Hospices www.pcpld.org/links-and-resources/
- o Kent County Council End of life Care in Kent our progress on implementing End of Life Care against the national framework, identifying gaps and taking action https://www.kent.gov.uk/__data/assets/pdf_file/0020/71408/End-of-Life-guidance-document.pdf

**Understanding death and dying:**

- o Recognising the importance of physical health in mental health and intellectual disability Achieving parity of outcomes The aim of this report is to start to identify what actions need to be taken to support doctors and the medical profession in changing the status quo (that people with intellectual disability will live shorter lives and will suffer because of unmet health needs) Focuses on: the following key areas: promoting prevention and early intervention strategies delivering 'joined-up' care enhancing training and workforce planning encouraging a greater research focus on mental-physical multi-morbidity. BMA www.bma.org.uk
- o Dying matters http://www.dyingmatters.org/
- o Learning Disabilities Mortality Review (LeDeR) Programme Commissioned by HQIP on behalf of NHS England. Reported that for every one person in the general population who dies from a cause of death amenable to good quality care, three people with learning disabilities

will do so. Supports local reviews of deaths of people with learning disabilities aged 4-74 years of age across England. http://www.bristol.ac.uk/sps/leder/

- o Report of the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) www.pcpld.org/links-and-resources/
  https://www.youtube.com/watch?v=44slHRtyFL4 and
  https://www.youtube.com/watch?v=fEioGvvhSPM
- o Independent Inquiry into access to healthcare for people with learning disabilities Healthcare for All (2008) www.pcpld.org/links-and-resources/
- o Death by Indifference (2007) Mencap's campaign for equal healthcare for people with learning disabilities. It reports the death of six people with learning disabilities in NHS care. www.pcpld.org/links-and-resources/
- o Six lives: the provision of public services to people with learning disabilities (2009) The ombudsman report of the investigations of the six deaths in Mencap's "Death by Indifference" report. www.pcpld.org/links-and-resources/
- o People with a learning disability: A DIFFERENT ENDING:ADDRESSING INEQUALITIES IN END OF LIFE CARE (2016) CQC thematic analysis identifying the barriers people with learning disabilities face to accessing good quality end of life care Care Quality Commission www.cqc.org.uk/content/different-ending-end-life-care-review-0
- o Macmillan Changes that can happen at the end of life https://be.macmillan.org.uk/be/s-853-end-of-life-and-bereavement.aspx

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**Day 1 PM**

**Communication skills**

- o How to break bad news to people with intellectual disabilities: a guide for carers and professionals  A practical guide to help people with intellectual disabilities understand major changes in their lives, from death and bereavement to moving house and changes in routine by Irene Tuffrey-Wijne (2013) http://www.pcpld.org/links-and-resources/
- o http://www.breakingbadnews.org/tools/ training resources and information
- o The route to success in end of life care - achieving quality for people with learning disabilities' Includes chapters: Discussions as the end of life approaches, Assessment, care planning and review.  NHS England National End of Life Care team http://www.leedspalliativecare.co.uk/wp-content/uploads/2014/05/rts_learning_disabilities___web_final_draft___20110301.pdf
- o Books beyond words Am I going to die? Getting on with cancer? https://booksbeyondwords.co.uk
- o 'My information plan' A record of information which has been provided to the person and when it was provided. Also advises on how information should be communicated (e.g. in writing/pictures/film). Person can record anything else they would like information on. Claire Henley, Sherwood Forest Hospitals Foundation Trust Gemma Del Toro, Nottinghamshire Healthcare NHS Trust June 2013 http://nottscountypb.org/wp-content/uploads/2016/07/My-End-of-Life-Plan-2.pdf

- Time to talk, Doc?' aims to increase GPs' awareness of the best ways to initiate and progress conversations with people who have dementia, as well as their carers and families.  http://www.dyingmatters.org/page/dying-matters-time-to-talk-dvd
- Taking Control of My Health by Mary Codling.  A training manual for health and social care staff to deliver a course for people with learning disabilities who have health conditions https://www.pavpub.com/uploadedFiles/Redbox/Pavilion_Content/Store/PPandMBookshop/TakingControlofMyHealth_Lookinside.pdf
- Macmillan Getting ready to die booklet https://be.macmillan.org.uk/be/s-428-easy-read-titles.aspx?_ga=2.194445741.1880287755.1506087259-550331401.1506087259&

**Advance Care Planning:**

- http://www.nhs.uk/livewell/endoflifecare/documents/planning_your_future_care%5B1%5D.pdf
- http://www.ncpc.org.uk/news/latest-edition-planning-your-future-care-guidance-published
- http://www.advancecareplanning.ca/wp-content/uploads/2016/08/ACP-national-workbook-Eng-july2016-web.pdf
- http://www.wrha.mb.ca/acp/
- http://www.dyingmatters.org/
- http://www.dyingmatters.org/page/people-learning-disabilities
- 'Nottingham Advance Care Plan. Easier Read Version'; Claire Henley & Gemma del Toro, Nottinghamshire Community Health NHS Trust Gemma Del Toro, Nottinghamshire Healthcare NHS Trust Gemma del Toro Development Nurse (RNLD) Specialist Palliative Care Royal Derby Hospitals NHS Foundation Trust NO WEB LINK
- 'My end of life plan' Claire Henley, Sherwood Forest Hospitals Foundation Trust June 2013 NO WEB LINK
- 'My End of Life Plan' guidelines for completion & template Julie Crisp The Brandon Trust Denise Mellon Simon Shorrick Health Facilitation Team Learning Disability Service 2gether NHS Foundation Trust NO WEB LINK
- Macmillan Choosing where to die booklet https://be.macmillan.org.uk/be/s-428-easy-read-titles.aspx?_ga=2.194445741.1880287755.1506087259-550331401.1506087259&
- Age UK, short film and information page https://www.ageuk.org.uk/latest-news/articles/2017/september/dying-wishes/

**DNACPR**

- Useful up to date information with model forms:  https://www.resus.org.uk/dnacpr/do-not-attempt-cpr-model-forms/
-  http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_DNACPR_decision.asp
- Patient information easy read guide. Do Not Attempt Cardiopulmonary Resuscitation. (DNACPR) Derby Teaching Hospitals NHS Foundation Trust

**Consent and capacity**

- http://webarchive.nationalarchives.gov.uk/+/http://www.dca.gov.uk/legal-policy/mental-capacity/mca-cp.pdf

- o Making decisions the IMCA service
  https://www.gov.uk/government/publications/independent-mental-capacity-advocates
- o **'**Making it work: Shared decision-making and people with learning disabilities'
  https://www.rcn.org.uk/about-us/policy-briefings/pol-4112

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**Day 2 AM**

**Assessing and Managing symptoms**

Pain and symptom assessment –use of body maps + Doloplus
https://www.stchristophers.org.uk/wp-content/uploads/2015/11/steps_stepfive_Care_Home_Pain_Assessment_Chart_Doloplus_0315.pdf
- o Pain assessment in advanced dementia (PAINAD) scale Warden Hurley & Volicer (2003)
  https://geriatricpain.org/sites/geriatricpain.org/files/wysiwyg_uploads/painad_tool_with_sm_logo_3.pdf
- o Cornell Scale for Depression in Dementia https://www.racgp.org.au/your-practice/guidelines/silverbook/tools/cornell-scale-for-depression-in-dementia/
- o Show me where is a tool, which enables adults and children who have verbal disability or who are unable to speak English, to convey the location of pain or discomfort to other people http://www.cardiffandvaleuhb.wales.nhs.uk/show-me-where
- o Disability Distress Assessment tool (DisDAT) A method of recording a baseline of signs and behaviours when content, against which changes can be monitored when the person is distressed. It is particularly useful for people who don't use speech to communicate. Changes in the person's normal 'content' behaviours may indicate a physical, social, emotional or other problem, which will need further investigation.
  http://www.stoswaldsuk.org/how-we-help/we-educate/resources/disdat/disdat-tools.aspx
- o 'Assessment of my pain' Very simple 2-page outcome measure. Advice on what changes to look for in someone who might not be able to communicate how they are feeling. ?? author Claire Henley, Sherwood Forest Hospitals Foundation Trust,  Gemma Del Toro, Nottinghamshire Healthcare NHS Trust ? NO WEB LINK
- o **'**My pain profile' Simple 2-page record for baseline assessment, along with details of medication, possible causes of pain and things that may help ?? author Claire Henley, Sherwood Forest Hospitals Foundation Trust, Gemma Del Toro, Nottinghamshire Healthcare NHS Trust ? NO WEB LINK
- o Abbey Pain Scale
  http://www.health.gov.au/internet/publications/publishing.nsf/Content/triageqrg~triageqrg-pain~triageqrg-abbey  and NICE https://www.evidence.nhs.uk/search?q=abbey+pain+scale
- o Do You Recognise Pain in someone with a Learning Disability, A Guide for GP's, Joseph Rowntree Foundation. www.jrf.org.uk/report/do-you-recognise-pain-someone-learning-difficulty-and-dementia
- o RCN easy read leaflets about the management of pain: Help With Your Pain-
  https://www.rcn.org.uk/professional-development/publications/pub-004915
  Syringe Pumps For Pain- https://www.rcn.org.uk/professional-development/publications/pub-005591

Managing Long Term Pain- https://www.rcn.org.uk/professional-development/publications/pub-005590

- o Evidence-based EAPC guidelines on use of opioid analgesics in the treatment of cancer pain European Association for Palliative Care www.eapcnet.eu/Themes/Clinicalcare/EAPCOpioidGuidelines2012.aspx

**Care planning**

- o East Kent EoLC pathway
- o When I die' Sunderland People First www.pcpld.org/links-and-resources/
- o 'When I die' Calderstones NHS Trust www.pcpld.org/links-and-resources/
- o What if? – Celebrating my life (plan) / What if? – Celebrating my life (explanation Team, North East Lincolnshire  www.pcpld.org/links-and-resources/
- o 'The route to success in end of life care - achieving quality for people with learning disabilities' Includes chapters: Discussions as the end of life approaches, Assessment, care planning and review.  NHS England National End of Life Care team http://www.leedspalliativecare.co.uk/wp-content/uploads/2014/05/rts_learning_disabilities___web_final_draft___20110301.pdf
- o Preferred Priorities of Care (Accessible Version)**'** A record of the choices made by The person about the place of care and support wanted when coming to the end of life.  Claire Henley & Gemma del Toro, Nottinghamshire Community Health NHS Trust http://www.dyingmatters.org/sites/default/files/user/images/PPC%20final%20document.pdf
- o My information plan' A record of information which has been provided to the person and when it was provided. Also advises on how information should be communicated (e.g. in writing/pictures/film). Person can record anything else they would like information on. Claire Henley, Sherwood Forest Hospitals Foundation Trust Gemma Del Toro, Nottinghamshire Healthcare NHS Trust June 2013 http://nottscountypb.org/wp-content/uploads/2016/07/My-End-of-Life-Plan-2.pdf
- o 'End of Life Section for a Personal Health File' 21-page document to be used with the Nottinghamshire Personal Health File. File to be taken with the patient when they attend appointments and to be updated by them and their carer, like a diary. Details illness, tests, treatments, 'on a good day', 'on a bad day', things that may help and appointment details. Nottinghamshire Community Health NHS Trust Claire Henley & Gemma del Toro NO WEB LINK
- o **T**ools for GPs and associated health care professionals and can be adapted for use in your own area Resources: A Learning Disability Resource Pack (now included in the standard end of life care folder sent out to all GP surgeries and care homes across Nottinghamshire, designed to signpost and support people with learning disabilities and is based on the Nottinghamshire End of Life Pathway for All Diagnosis). An Information Plan for people with a learning disability A Pain Assessment Tool An accessible version of the Preferred Priorities of Care A promotional poster for use in GP surgeries, care homes, hospitals etc. Nottinghamshire Healthcare NHS Trust and Sherwood Forest Hospitals NHS Trust www.dyingmatters.org/gp_page/end-life-care-adults-learning-disability

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**Day 2 PM**

**Supporting people with LD, families and carers**
- o Macmillan - Distribute a range of Easy Read booklets about cancer for people with learning disabilities.  You can order these for free from our be.Macmillan website These illustrated books are for people with learning disabilities and their carers.
  https://be.macmillan.org.uk/be/s-428-easy-read-titles.aspx?_ga =2.194445741.1880287755.1506087259-550331401.1506087259&
- o Marie Curie easy read booklets for both as a patient and as family/friends, on a variety of subjects  https://www.mariecurie.org.uk/help/support/publications/easy-reads
- o Spirituality and Religion at the end of life.  Macmillan
   https://be.macmillan.org.uk/be/s-853-end-of-life-and-bereavement.aspx
- o Living and Dying with Dignity: best practice guide to end-of-life care for people with a learning disability (2008) Mencap (Heather Morris), Keele University (Sue Read)
  https://www.a2anetwork.co.uk/wp-content/uploads/2010/01/End-of-life-care-best-practice-guide2.pdf
- o Caring for carers , written for hospital but transferable information and clear tips on carer involvement and support.
  http://webarchive.nationalarchives.gov.uk/20160805132449/http://www.nhsiq.nhs.uk/media/2519527/caring_for_carers_-_staff_booklet.pdf

**Bereavement and loss**

- o What to do after a death Dept. work & pensions https://www.gov.uk/after-a-death
- o Dying matters website for useful links and information
  http://www.dyingmatters.org/page/resources-what-do-after-someone-dies
- o What to do when someone dies, tell us once: https://www.gov.uk/after-a-death/organisations-you-need-to-contact-and-tell-us-once
- o Cruse Bereavement Care, Bereavement Care Website covering for example what to do after someone dies, looking after yourself, claiming probate :
  http://www.crusebereavementcare.org.uk/
- o When somebody dies,  Sheila Hollins, Sandra Dowling and Noelle Blackman
  https://booksbeyondwords.co.uk/adults-with-learning-disabilities
- o 'Let's talk about death' This book has been written to support an adult with a learning disability after someone close to them has died. Down's Syndrome Scotland
  www.dsscotland.org.uk/resources/publications/for-parents-of-adults/
- o Books beyond words When dad died. When mum died. When somebody dies
  https://booksbeyondwords.co.uk
- o Booklet on grief Explains grief and the emotions associated with grief, in simple words and pictures. There is also a section for carers and professionals. Scope
- o Loss and learning disability by Noëlle Blackman (2003) This book is for care staff, therapists and counsellors working with people with learning disabilities. It talks about how people with learning disabilities can be affected by bereavement. It includes ways to prevent normal grief from becoming a bigger problem and ways of helping people when the grief process 'goes wrong'. http://www.pcpld.org/links-and-resources/

- Macmillan Grief and loss when someone dies and Going to a funeral
  https://be.macmillan.org.uk/be/s-428-easy-read-titles.aspx?_ga=2.194445741.1880287755.1506087259-550331401.1506087259&
- Macmillan How you may feel when someone dies  https://be.macmillan.org.uk/be/s-853-end-of-life-and-bereavement.aspx

**Caring for ourselves**

- Charitable organisation working to radically improve the way people are cared for and to support the staff who deliver care. They provide training and support for Schwartz rounds. https://www.pointofcarefoundation.org.uk/
- Mindfulness is the basic human ability to be fully present, aware of where we are and what we're doing, and not overly reactive or overwhelmed by what's going on around us https://www.mindful.org/meditation/mindfulness-getting-started/ https://www.nhs.uk/Conditions/stress-anxiety-depression/Pages/mindfulness.aspx

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## 9.   MORE USEFUL RESOURCES

**Age UK:** range of resources and factsheets available
https://www.ageuk.org.uk/services/information-advice/guides-and-factsheets/
Factsheet 20  NHS continuing healthcare and NHS-funded nursing care provides useful information
https://www.ageuk.org.uk/globalassets/age-uk/documents/factsheets/fs20_nhs_continuing_healthcare_and_nhs-funded_nursing_care_fcs.pdf

**Alzheimer's Society:** http://alzheimers.org.uk/

**BILD**
BILD uses its skills, knowledge and experience to turn policy into practice, solve problems and improve support. In working with Government departments, local authorities, health trusts, service providers and mainstream organisations, our aim is to improve the quality of the lives of people with disabilities http://www.bild.org.uk/
Supporting older people with learning disabilities: a toolkit for health and social care commissioners (2014) Sue Turner | Caroline Bernard
https://www.ndti.org.uk/uploads/files/9354_Supporting_Older_People_ST3.pdf

**Books beyond words:**
Useful selection of books available   https://booksbeyondwords.co.uk/adults-with-learning-disabilities

**Borders Partnership NHS Foundation Trust**:
Information about getting older and dying for people with learning disabilities
- https://www.pavpub.com/a-good-death-guide-1/ :
- https://www.pavpub.com/a-good-death-guide-2/
- https://www.pavpub.com/a-good-death-guide-3/

**DOH [Department of Health]**
End of Life Care Strategy 2008:
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf


**Dying matters**:
Specific content related to people with learning disabilities
 http://www.dyingmatters.org/page/people-learning-disabilities

**Easyhealth:**
 Source of accessible health information . 'Accessible' information is information that uses easy words with pictures   http://www.easyhealth.org.uk/

**End of Life Journal:**
This was a free online journal written by specialists for generalist End of Life Care practice containing useful articles about all aspects of end of life care which you can register for free.  This resource is to be relaunched in the near future.
To register interest http://www.stchristophers.org.uk/health-professionals/end-of-life-journal#gf_32

**Gold Standards Framework:**
Training programmes in end of life care and useful resources available
http://www.goldstandardsframework.org.uk/

**Hospice UK**
National charity for hospice care, useful publications available and find your nearest hospice.
https://www.hospiceuk.org/

**Macmillan Cancer Support**
National charity campaigning and providing information and support for people with cancer
https://www.macmillan.org.uk

**Marie Curie**
The Marie Curie Palliative Care Knowledge Zone also has free and easy to access online resources for professionals who are caring for people with learning disability at end of life.
https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/equality-diversity/learning-difficulty

**My Home Life**, UK wide imitative that promotes quality of life and delivers positive change in care homes for older people: http://myhomelife.org.uk/

**NCPC [National Council for Palliative Care, now merged with Hospice UK]**
EOLC-Advance-Decisions-to-Refuse-Treatment-cloud.pdf

**NHS England:**
Delivering high quality end of life care for people who have a learning disability.
Resources and tips for commissioners, service providers and health and social care staff
https://www.england.nhs.uk/wp-content/uploads/2017/08/delivering-end-of-life-care-for-people-with-learning-disability.pdf

**PCPLD Network:**
  - o This is a network of [mostly] practitioners in settings where they may encounter people with learning disabilities who are at the end of life. –both in specialist learning disability settings and in palliative care settings. Anyone who is interested can sign up for membership at no cost.
    http://www.pcpld.org/
  - o End-of-life care for children and adults with intellectual and developmental disabilities  A comprehensive textbook published by the American Association on Intellectual and Developmental Disabilities. It has a strong focus on ethics and medical decision making at the end of life, although there are also some helpful chapter on social, emotional and spiritual support by Sandra Friedman and David Helm. http://www.pcpld.org/links-and-resources/
  - o Living with learning disabilities, dying with cancer: thirteen personal stories A powerful and moving account of the experiences of thirteen people with learning disabilities who were living with cancer, most of whom died of the disease. An invaluable resource for anyone involved in the care of people with learning disabilities who are facing cancer or other life-threatening illness, including staff working in learning disability services, health professionals and family carers by Irene Tuffrey-Wijne (2010) http://www.pcpld.org/links-and-resources/
  - o Caring for people with learning disabilities who are dying A concise, clearly written and practical book full of advice for service managers and staff working in learning disability services by Noëlle Blackman and Stuart Todd (2005) www.pcpld.org/links-and-resources/

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## 10.  EDUCATION AND TRAINING RELEVANT FOR END OF LIFE CARE

**Canterbury Christ Church University**
Advance Care Planning Programme https://www.canterbury.ac.uk/health-and-wellbeing/advance-care-planning/home.aspx

**e-ELCA**
The e-learning programme End of Life Care for All (e-ELCA) aims to enhance the training and education of the health and social care workforce so that well-informed high quality care can be delivered by confident and competent staff and volunteers to support people wherever they happen to be. A variety of interactive sessions are available. Access is available for care home staff as well as NHS staff, there are some modules available on open access.
https://www.e-lfh.org.uk/programmes/end-of-life-care/

**Kent Hospices Education and Training [check individual hospice websites for up to date information and more details of the range of courses available]**

**Ellenor:**

https://ellenor.org/education

Compassion Awareness – half day workshop [some sessions are funded by HEEKSS]

Communication skill e.g. Sage and Thyme – half day foundation level communication skills workshop [some sessions are funded by HEEKSS]

Verification of Expected Death – half day workshop [some sessions are funded by HEEKSS]

**Heart of Kent Hospice:**

https://www.hokh.org/healthcare-professionals/education-and-training/training-programme

Verification of Expected Death – half day workshop [some sessions are funded by HEEKSS]

**Hospice in the Weald:**

http://www.hospiceintheweald.org.uk/health-and-social-care-professional-information/Education-and-Development

Verification of Expected Death – half day workshop [some sessions are funded by HEEKSS]

**Pilgrims Hospice:**

http://www.pilgrimshospices.org/training/education-training/

Advanced Care Planning and DNACPR – one  day workshop

Compassion Awareness – half day workshop [some sessions are funded by HEEKSS]

Principles & Practice in End of Life Care for non-registered practitioners

Principles & Practice in End of Life Care for registered practitioners

Sage and Thyme – half day foundation level communication skills workshop [some sessions are funded by HEEKSS]

Verification of Expected Death – half day workshop [some sessions are funded by HEEKSS]

**Wisdom Hospice:**

www.medwaycommunityhealthcare.nhs.uk/our-services/palliative-care/

Verification  of Expected Death – half day workshop [some sessions are funded by HEEKSS]

**SCIE,** Accredited training, consultancy, research and resources for the social care and health sectors from independent charity and improvement agency, the Social Care Institute for Excellence**:** https://www.scie.org.uk/

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## 11.  ACKNOWLEDGEMENTS

**Awareness Health Quiz**

Mark Bradley Health Facilitation Co-ordinator Bexley & Greenwich  Oxleas  NHS Foundation Trust

**Day of the dead colouring images**

Author: Artsashina

Original image credit:

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## 12. APPENDIX

Living and dying with dignity  the 12 main messages        mencap

**MY NOTES**

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