

ABC 4 LD

Final Report for the Delivery of the ABC 4 LD End of Life Programme

Preparation & Planning Dates: Oct to Dec 2016

Delivery Dates: 19/01/17 to 03/03/17

Facilitators: Helen Miller (IH), Claire Nicell (HoSF), Louise Jenkins (HCC), David O'Driscoll (HFPT)

INTRODUCTION

The Hospice of St Francis, in collaboration with Herts County Council, Hertfordshire Care Providers Association, Isabel Hospice, Rennie Grove Hospice Care and Garden House Hospice Care have begun an 18-month pilot End of Life Palliative Care Education Programme in two Hertfordshire supported living homes for those adults with learning disabilities.

Chambers Grove in Welwyn Garden City and Crosby Close in St Albans - identified by the Learning Disabilities Team (Herts County Council) as those with current best practice – have both accepted the training programme, and each home's LD community nurse and respective Palliative Care CNS's will be supporting the facilitation of the 2 ½ day programme. The aim will be to establish them as "beacon" homes and future support buddies as part of on-going roll-out after pilot. The intention is that they will support other homes based on a "train the trainer" model.

The education programme focused on educating, training and supporting staff to deliver a high standard of end of life/ palliative care - based on the hospice care model - to residents in their home setting.

The ABC 4 LD Education Programme, led by the Hospice of St Francis was launched in January 2017 following a pre-audit period and design of resources and workbooks for both homes. The education programme focused on the following 8 modules:

1. Principles of end of life care
2. Communication and breaking bad news
3. Symptom control, pain management and distress management

4. Assessment and care planning with family involvement
5. Advance Care Planning, including DNACPR (do not attempt resuscitation), establishing capacity and family involvement
6. End of life care in the last days
7. Bereavement and grieving including complicated grief
8. Building emotional resilience in the workforce

Expected Impacts Where we performed against the expected outcomes	Evidence/Outcomes
<ul style="list-style-type: none"> • Advance peoples physical and mental health, wellbeing and safety. • Improve health (physical, mental and emotional). • Support vulnerable people. 	<ul style="list-style-type: none"> • Contacts sheet was developed for both geographical patches to enable the care homes to contact local professionals. • GP visit with CLDN and Palliative Care Nurse to discuss ceiling of care for service user approaching end of life as it became apparent that this had not been proactively discussed. • GP surgery linked to care home is now applying for their Purple Star Strategy Award. • Personal Health budgets and use of these is being explored with Commissioner. • Annual Review paperwork for HCC Chambers Grove and 2 other Supported living environments now includes End of Life as part of the annual review process. • Introduction of Children’s Bereavement Services and the use of the Macmillan ‘Preparing a child for loss’ booklet for service users with limited comprehension. • See appendix 1 for summary of learner feedback questionnaires.

<p>What unexpected outcomes/objections/challenges we faced and how we handled them</p>	<ul style="list-style-type: none"> • The co-facilitating educator left her post for personal reasons and an alternative experienced facilitator, who was not involved in the preparation work, had to pick up the face-to-face delivery work. • Regardless of whether the learner was a qualified nurse or carer, the shift in confidence was the same. • Time to develop, design and produce resources relevant to the staff attending the training and their context.
<p>Clear measure of impact/change for different groups</p>	<ul style="list-style-type: none"> • At the time of the report three referrals were made to palliative care services at The Hospice of St Francis and three referrals were made to palliative care services at Isabel Hospice • Referral to David O’Driscoll for two service users; active casework started for one service user who had been given a terminal diagnosis, and active casework started with team to understand and manage symptoms of trauma that were identified through the training. • A pain profile, shared on the training course, is now being used for all residents in Chambers Grove and has identified many non-verbal communication symptoms that were previously not recognised as pain.
<p>Home Manager Comments</p>	<ul style="list-style-type: none"> • “Staff felt valued and invested in which has raised confidence and will build a more resilient workforce.” Deputy Home Manager said “ It’s been good to get the whole team trained at once as usually staff members go at separate times and so the effect is reduced, shared responsibility and easier to implement changes as all on the same page” • “There’s been a definite marked improvement in team working and communication. We are now following a new handover process that has helped team working” • “ My own attitude to my own funeral has changed as previously I didn’t care about having a funeral but now see

	it's for my family and those left behind"
Next steps/plan	<ul style="list-style-type: none"> • "Just-in-case medication" - two further training sessions organised for Nurses in care home and Community LD Nurses have also joined session. • Meetings arranged between End of Life link nurse from Isabel Hospice and CLDN to discuss the 1% caseload. Similar meetings to be replicated across The Hospice of St Francis and Rennie Grove Hospice Care. • Suggested future work with schools around increasing awareness and breakdown of taboo on end of life planning for everyone. • GP visit with CLDN and Palliative Care Nurse to discuss ceiling of care for service user approaching end of life as it became apparent that this had not been proactively discussed. • To disseminate our report findings at Hospice UK conference. • To publish the outcomes of the education programme in a learning disabilities journal. • To source further funding to establish a Hertfordshire-wide ABC 4 LD programme in collaboration with five hospices and Hertfordshire County Council.

Appendix 1 – Learner Feedback Questionnaire (44 attendees)

Row Labels	Stongly Agree	Agree	Not Sure	Disagree	No Answer
Q1 I felt the end of life education programme was worthwhile for me	32	12			
Q2 I would recommend the end of life care education programme to others	36	8			
Q3 I felt the end of life care education programme was relevant for me	31	12			1
Q4 I felt the end of life care education delivery was flexible enough for my availability needs	28	14			2
Q5 I felt the programme gave me more knowledge and skills in end of life care	35	8			1
Q6 I felt the combination of taught sessions with the trainer worked well	31	12			1
Q7 I feel that the end of life care education programme either has, or will make a difference to the care that I give	34	8			2
Q8 I feel that the end of life care education programme either has, or will help us to work better as multi-professional staff	32	10			2

Appendix 2 – Pre and Post Confidence Questionnaire (see sample questionnaire on next page) (44 attendees)

Questionnaire	Before Confidence Questionnaire (44 attendees)					After Confidence Questionnaire (44 attendees)				
	Very Confident (Before)	Confident (Before)	A Little Confident (Before)	Not at all Confident (Before)	No Answer (Before)	Very Confident (After)	Confident (After)	A Little Confident (After)	Not at all Confident (After)	No answer (After)
Advance Care Planning Q1		10	24	9	1	10	30	4		
Advance Care Planning Q2		10	27	5	2	7	30	5		1
Bereavement, Loss and Grief Q1		21	17	5	1	11	28	3		1
Bereavement, Loss and Grief Q2		13	21	3	7	11	28	2		3
Bereavement, Loss and Grief Q3		8	27	5	4	5	27	3		
Care in the Last Days of Life Q1	3	14	18	8	1	11	20	12	1	
Care in the Last Days of Life Q2		13	24	7		10	21	12	1	
Communication Skills Q1	5	23	13	2	1	19	22	3		
Communication Skills Q2	4	24	10	3	3	18	24	1		
Emotional and Psychological Care Q1		19	22	1	2	10	32	2		
Emotional and Psychological Care Q2		15	23	4	2	9	32	3		
EoL Holistic Assessment and Person Centred Care Q1		18	23	1	2	9	33	2		
Influencing Care in Your own Work Setting Q1	2	26	11	5		12	25	7		
Influencing Care in Your own Work Setting Q2	6	20	15	3		12	25	7		
Recognising Physical Symptoms of Deterioration Q1	3	17	21	1	2	8	32	4		
Recognising Physical Symptoms of Deterioration Q2		14	21	6	3	7	33	3		1
Social Care Q1		24	15	1	4	12	31	1		
Social Care Q2	1	22	14	5	2	13	28	3		
Spiritual Care Q1	2	14	24	2	2	7	33	4		
Spiritual Care Q2		16	24	3	1	8	29	5		2

ABC End of Life Care Learner "Before" Confidence Questionnaire:

Learners to complete before starting and after finishing ABC End of Life Care Education programme

Name:

Job Title:

Work Address:

Time in current post:

Previous EoL education details:

Date Completing this Questionnaire:

How confident do you feel about	Very Confident	Confident	A Little Confident	Not at all Confident
End of Life Holistic Assessment and Person Centred Care				
<i>Putting in a plan of care based upon the individual's needs?</i>				
Recognising Physical Symptoms of Deterioration				
<i>Recognising physical health changes at the end of life?</i>				
<i>Putting in a plan of care based upon the individual's needs?</i>				
Emotional and Psychological Care				
<i>Recognising the emotional & psychological needs of those you care for?</i>				
<i>Putting in a plan of care based upon the individual's needs?</i>				
Social Care				
<i>Recognising the social needs of those you care for?</i>				
<i>Putting in a plan of care based upon the individual's needs?</i>				
Spiritual Care				
<i>Assessing the spiritual needs of those you care for?</i>				
<i>Putting in a plan of care based upon the individual's needs?</i>				
Communication Skills				
<i>Communicating with those you care for and their families?</i>				
<i>Communicating with your own and other health and social care teams?</i>				
Advance Care Planning				
<i>The definitions and documents used in advance care planning?</i>				
<i>Engaging in discussions with families to make joint end of life best interest decisions?</i>				
Bereavement, Loss and Grief				
<i>Recognising the signs of bereavement, loss and grief?</i>				
<i>Putting in a plan of care based upon the individual's needs?</i>				
<i>Engaging in discussions with families and service users about an end of life diagnosis of a family member or friend?</i>				
Care in the Last Days of Life				
<i>Recognising that the last days of life are imminent?</i>				
<i>Putting in a plan of care based upon the individual's needs?</i>				
Influencing Care in your own work setting				
<i>Being able to influence the care in your own work setting?</i>				
<i>Contacting GP services, out of hours and district nurses/hospices for support?</i>				

ABC End of Life Care Learner “After” Confidence Questionnaire:

Learners to complete before starting and after finishing ABC End of Life Care Education programme

Name:				
Job Title:		Work Address:		
Time in current post				
Previous EoL Education Details:		Date Completing this Questionnaire:		
How confident do you feel about	Very Confident	Confident	A Little Confident	Not at all Confident
End of Life Holistic Assessment and Person Centred Care				
<i>Putting in a plan of care based upon the individual's needs?</i>				
Recognising Physical Symptoms of Deterioration				
<i>Recognising physical health changes at the end of life?</i>				
<i>Putting in a plan of care based upon the individual's needs?</i>				
Emotional and Psychological Care				
<i>Recognising the emotional & psychological needs of those you care for?</i>				
<i>Putting in a plan of care based upon the individual's needs?</i>				
Social Care				
<i>Recognising the social needs of those you care for?</i>				
<i>Putting in a plan of care based upon the individual's needs?</i>				
Spiritual Care				
<i>Assessing the spiritual needs of those you care for?</i>				
<i>Putting in a plan of care based upon the individual's needs?</i>				
Communication Skills				
<i>Communicating with those you care for and their families?</i>				
<i>Communicating with your own and other health and social care teams?</i>				
Advance Care Planning				
<i>The definitions and documents used in advance care planning?</i>				
<i>Engaging in discussions with families to make joint end of life best interest decisions?</i>				
Bereavement, Loss and Grief				
<i>Recognising the signs of bereavement, loss and grief?</i>				
<i>Putting in a plan of care based upon the individual's needs?</i>				
<i>Engaging in discussions with families and service users about an end of life diagnosis of a family member or friend?</i>				
Care in the Last Days of Life				
<i>Recognising that the last days of life are imminent?</i>				
<i>Putting in a plan of care based upon the individual's needs?</i>				
Influencing Care in your own work setting				
<i>Being able to influence the care in your own work setting?</i>				
<i>Contacting GP services, out of hours and district nurses/hospices for support?</i>				

Appendix 3 – Participant Feedback

- **“I think this course would be an enormous help to all carers to help them understand and address what is often seen as a taboo subject. To give them confidence & understanding to plan and help the individual prepare for a good death”**
- **“Very helpful. Helen knew we worked with people with severe LD and planned the day accordingly”**
- **“The delivery was well structured & very informative”**
- **“Very knowledgeable trainer with actual work experience was very valuable”**
- **“This for me was an eye opening experience where I felt more equipped and confident and may be more less likely to panic”**
- **Everyone working with people should be equipped and able to deal with end of life care in work setting”**
- **“The discussions and life experiences and how safe and comfortable it was delivered**
- **“This would be a good tool for other services so it could be a consistent approach offered by HCC to all the people supported by us”**
- **“A lot of important information was given out that I did not know about and explained very well, good teacher”**
- **“Trainer very knowledgeable – very good”**
- **“This programme can only enlighten people more & is very much needed!”**
- **“I feel this will give both myself & my team the confidence to work better with all professionals with end of life care”**
- **“Overall a very good course – this should go out to all nursing care homes”**
- **“Very good information & understanding in simple language”**
- **“Very informative, open for discussion, able to ask questions. Good knowledge of the facilitators”**
- **“Openness to discuss anything no matter how sensitive the topic”**
- **“Worked well in a small group. Trainers very informative”**
- **“Increased my knowledge of symptom control, just in case medication ACP’s & DNACPR”**
- **“It has made me more aware of ways to help the people we support”**
- **“I think it’s a good course to teach people more information and keep up to date with the way things change”**

- **“I will definitely look at the advanced care plans. I feel much more confident to support people with the end of their lives”**
- **“The fact that the groups were of staff from all levels learning and discussing issues together was of particular importance”**
- **“The way the palliative care advice was linked to learning disability”**
- **“I felt the 2 day courses I attended were very well run – with lots of relevant information – which I intend to share with larger team I work with”**
- **“Very good training session and I will be able to use what I have learnt within my nursing training”**
- **“It has been well thought out – continually considering people with a learning disability”**
- **“Very well presented”**
- **“A very well presented course by the trainers everyone in care should have. Thank you”**
- **Very good and informative, would highly recommend course**
- **“I have seen a difference in staff”**
- **“Informative easy to understand, well explained”**
- **“Both for LD and generally, this training has been v. helpful and should be shared widely”**
- **“Helen’s knowledge is extensive and she conveys it very well. Louis’s contributions also added to the sessions”**

David O’Driscoll – Managing Complex Grief and Loss – Half Day Session

- **“This was a very interesting and interactive session which identified some of the difficulties PWLD face re: grief and how this can be supported”**
- **“Strategies in helping people understand grief. Recognition of how grief can affect people with LD and affect staff”**
- **“It has reinforced knowledge and introduced new information/learning”**
- **“Made me more aware of the processes of grief and approaches needed”**
- **“It has given me more knowledge and confidence”**
- **“Increase in knowledge & know where to get information & advice”**

- **“Made me realise how complex and difficult death can be to understand and explain so has given me more patience in listening and speaking”**
- **“Made me think about effects of death, dying, advance care planning”**
- **“Pain profiles, advance care plan discuss staff feelings at staff mtg”**
- **“It will help me to be more observant & think before exploring the conversations around death & grieving”**
- **“It has helped me identify emotions & behaviours in a more in depth way”**
- **“It has helped improve my understanding of services available in the community”**
- **“We will be looking at setting up some advance care plans for the service users”**
- **“Change of way of dealing with end of life”**
- **“It will enable me to recognise signs & symptoms of grief”**
- **“Be able to support sister and other staff members”**
- **“Look out for signs of grief ie challenging behaviour could be an expression of depression through loss”**
- **“Using more of a holistic approach with regards to end of life ensuring the service users are involved as much as possible”**
- **“Good points made around using clear language to describe death and dying and not just assuming they understand the language being used”**
- **“To be aware of possible trauma and utilising the various tools of loss/separation/bereavement”**
- **“Reinforcing how others react to their situation. Being able to share experiences that may provide support to those we work with”**
- **“Much more awareness & openness. Talk to people with profound learning disabilities more about this even if unsure of comprehension”**
- **“I think it’ll make it easier to explain things to the people I support in a way they can understand”**
- **“I feel more confident to speak to people about end of life”**
- **“It has made me understand more ways I can support people with anything to do with end of life care”**
- **“Better understanding of grief & bereavement”**
- **“How to handle a situation when someone dies when I’m on duty, how to care for them”**

- **“To use the easy read literature. Not to be afraid to work closely with family on decision making”**
- **“How to deal with my own feelings about a s/user’s ill health and to deal with families/professionals”**
- **“I believe that we will discuss things openly and make information more readily available”**
- **“Recognising signs that may be displayed”**
- **“Feel more confident to support our service users cope with end of life”**
- **“I think that the EoL training course will assist staff to unite/understand in the event of death and help to provide quality EoL care”**
- **“This EoL training will help ‘us’ as a team to provide good quality care at the EoL times”**
- **“It’s made me realise that I need to explore their understanding of death more and to discover their past experience of death and funerals”**
- **“More understanding in my ways to help me to cope and help others”**
- **“As a human being we must all talk more about death”**
- **“For people with learning disabilities I will now be able to communicate better with them and provide the support they need to grieve easier”**
- **“Will make me think and reflect”**