

# **An Introduction to Planning for the Last Years of Life Training Programme in Islington**

**Report 2017/18**

**Gentle Dusk**

**[www.gentledusk.org.uk](http://www.gentledusk.org.uk)**

**twitter @gentledusk**

## Introduction

In 2017/18, Islington Clinical Commissioning Group commissioned Gentle Dusk, for a third year, to deliver a combination of 1-day and ½ day 'Introduction to Planning for the Last Years of Life' training courses to staff working and volunteering in Islington. The training was designed to run alongside the Future Matters project, which Gentle Dusk delivers in partnership with Age UK Islington, and which raises awareness of the importance of planning for the last years of life amongst the public.

The aim of the training was to:

- Increase participants understanding of the importance of planning for the last years of life and equip them with the knowledge, skills and confidence to enable them to initiate conversations.

### Learning outcomes for the training programme

By the end of the training, participants will be able to:

- Explain what planning for the last years of life is and why we need to do it;
- Discuss what makes it difficult to talk with service users about dying and end of life care;
- Reflect on what might be important to them towards the end of your life;
- Discuss how someone can record their end of life wishes in an advance care plan and explain their role in the advance care planning process;
- Use a range of strategies and skills to initiate conversations about dying and planning for the end of life;
- Identify where they can signpost service users for further information and support; and
- Identify key actions you will implement to help your service users plan for the end of life.



I had not thought about advance care planning before; although I had considered some aspects of it. Having the document will help me (and those I support) have a comprehensive plan in place!

*Course participant*

## Key achievements

- Three 1 day and six ½ day 'Introduction to Planning for the Last Years of Life' courses were delivered
- 102 people attended the courses from 21 different Islington based organisations.
- 99% of participants rated their level of understanding as 'very good' or 'good' at the end of the training compared to 24% at the start of the training.
- 78.5% of the training participants rated the overall facilitation of the training as 'very good' (the top rating) and the other 21.5% rated it as 'good'
- 77.5% of the training participants gave their overall rating of the training as 'very good' (the top rating) and the other 22.5% rated the training as 'good'
- Our work with Centre 404 to ensure people with learning disabilities are involved in advance care planning has been Highly Commended in the Linda McEnhill Award, 2018. We have been delivering training for Centre 404 since 2014 and this has given staff the skills and confidence to approach difficult conversations about death & end of life care planning with sensitivity and assurance.

*"After the training, I completed an End of Life Care Plan with David {name changed} who has a mild learning disability and is recovering from an aggressive cancer. In the past he has been reluctant to talk about death but, following a piece of advice taught on the course, I used an Eastenders storyline as a prompt. The next time I had a support session with David he asked me if anyone I knew had died. I shared the experience of losing my grandfather. He revealed to me that no one he knew had ever died before and that it was a concern of his. The fact that he now feels free to express his fears is a sign of real progress."*

Matt, Senior Support Worker at Centre 404



## Outcomes

### Training attendance

The training programme was delivered between July 2017 and March 2018 and in total 102 people from 21 different organisations attended.

The following courses were delivered:

- One 1-day course delivered 'in-house' to Centre 404 and which focused on adults with learning disabilities;
- Two 1-day courses that were open to individuals from any Islington based organisation.
- One of these 1-day courses focused on Planning for the Last Years of Life for adults with learning disabilities;
- One ½ day courses delivered 'in-house' to Marie Curie Hospice; and
- Five ½ day courses that were open to individuals from any Islington based organisation.

Table 1 below shows a comparison between the courses delivered and number of participants that attended over the 4 years that we have been delivering the training.

<b>Table 1. Number of courses delivered and number of participants attended each year since 2014</b>			
	<b>Courses delivered</b>	<b>Number of participants attended</b>	<b>Number of organisations represented</b>
<b>Year 1</b> (14/15)	2 x 1-day & 6 x ½ day courses	97	20
<b>Year 2</b> (15/16)	3 x 1-day & 6 x ½ day courses	84	23
<b>Year 3</b> (16/17)	3 x 1-day & 6 x ½ day courses	94	23
<b>Year 4</b> (17/18)	3 x 1-day & 6 x ½ day courses	102	21

Tables 2 to 4 below outline the organisations that received the 'in-house' training programmes this year (17/18) and those that attended the 'open' sessions. The tables also indicate the numbers of people who booked onto the courses and the actual number that attended.

<b>Table 2. 1 day course delivered 'in-house'</b>				
	<b>Organisation</b>	<b>Date</b>	<b>No. of staff booked</b>	<b>No. of staff attended</b>
1	Centre 404	10.10.17	8	6

<b>Table 3. ½ day course delivered 'in-house'</b>				
	<b>Organisation</b>	<b>Date</b>	<b>No. of staff booked</b>	<b>No. of staff attended</b>
1	Marie Curie Hospice	12.12.17	20	20

<b>Table 4. 1 day and ½ day ‘open’ courses</b>				
	<b>Length of Course</b>	<b>Date</b>	<b>No. of staff booked</b>	<b>No. of staff attended</b>
1	1-day	07.11.17	17	15
2	1-day (focus on Learning Disabilities)	16.01.18	11	10
3	½ day	13.07.17	12	9
4	½ day	12.10.17	8	8
5	½ day	05.12.17	15	13
6	½ day	08.02.18	11	10
7	½ day	01.03.18	14	11

Table 4. below outlines the 21 different organisations that were represented on the training courses and the number of people from each of these organisations that attended any one of the courses.

<b>Table 4. Numbers of participants attending any training programme by organisation</b>		
	<b>Organisations represented on the training</b>	<b>No. of staff attended</b>
1	London Borough of Islington	37
2	Marie Curie Hospice	12
3	Camden Carers (attended the Marie Curie Hospice training)	9
4	Camden & Islington NHS Foundation Trust	8
5	Age UK Islington	7
6	Centre 404	7
7	Centra Care & Support	3
8	Origin Housing	2
9	St Mungos	2
10	Outward Housing	2
11	Peabody Housing Association	2
12	Islington and Shoreditch Housing Association	2
13	Equinox Care	1
14	Positive Care Link	1
15	Islington Stroke Association	1
16	St Martin of Tours	1
17	Manor Gardens Centre	1
18	Whittington NHS Health Trust	1
19	Keyring Living Support Networks	1
20	Islington Carers Hub	1
21	Islington Alzheimer’s Association	1
	<b>TOTAL</b>	<b>102</b>

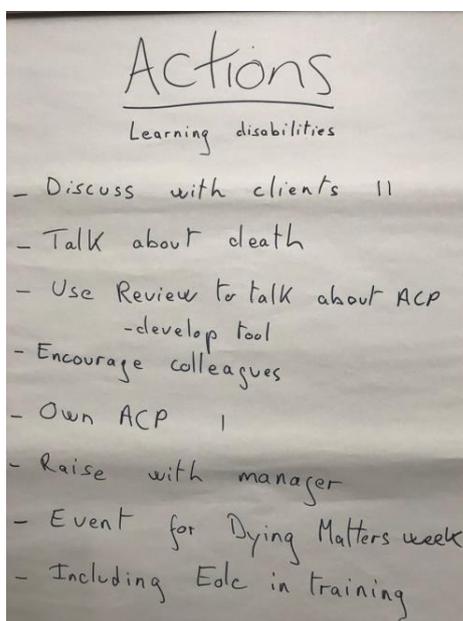


## Participant's self-identified actions they will take away

As part of the training, participants were asked to discuss and identify 5 key actions they will implement as a result of the training. The boxes below outline a summary of actions they identified.

### Key Actions identified by those supporting people with learning disabilities

1. Organise an event for Dying Matters Week
2. Discuss having Gentle Dusk deliver team training/briefing
3. Discuss end of life care planning at a team meeting & discuss how the advance care plan can be used with service users
4. Include end of life care in staff training
5. Raise issue with manager
6. Encourage colleagues to have conversations
7. Ultimate goal – to initiate best interests meeting to discuss end of life care plan for a service user with no mental capacity.
8. Take service users to a Death Café
9. Talk more about death with service users
10. Find out what end of life care plans are in place for a particular service user
11. Use reviews to talk about advance care planning and develop a tool
12. Complete my own advance care plan



Key actions that staff are going to implement as a result of attending the training



Sharing ideas for how they can start conversations with their service users about death, dying and end of life care

## Key Actions identified by other staff

### *Actions to implement in the workplace*

- Provide in-service training for the workforce
- Discuss at a team meeting
- Share information with colleagues
- Raise issue at team meeting and discuss with manager
- Discuss at service user/family meeting
- Organise a residents house meeting to discuss the topic
- Identify a death champion for the organisation
- Consider advance care planning in social worker assessments
- Add advance care planning to assessments
- Give copies of advance care plan to service users
- Encourage carers to talk with their family member that they support and support them to do this.
- Write an article about end of life care planning in newsletter
- Contract Manager to raise with providers
- Encourage signposting and referrals to the Future Matters service
- Book Future Matters to come and talk at the Alzheimer's Dementia café
- Organise a workshop for carers
- Run a Death café

### *Personal actions to implement*

- Become more confident with the language
- Start a conversation with a client
- Be more open when someone brings up the topic
- Engage tenants in conversations
- Provide leaflets and information for service users and discuss with them
- Talk to one of my service users this afternoon as it is a topic we need to discuss
- Attend a Death Cafe
- Put my own end of life care plans in place – wills, power of attorney and ACP
- Discuss with my family and support them to put plans in place



## Participant's feedback from the training

All of the sessions worked well together and were very useful. Very well blended with presentations and group work so kept momentum of level of interest.

Very good event event though a very difficult topic. I feel more confident to discuss and complete my own advance care plan.

Very relaxed, informative and honest discussions.

I really liked that the people in the group had a lot of different backgrounds. It is good to see how different people approach the questions and hear the experiences they have had.

## Recommendations for 2018/19

1. **Continue to liaise with our contract manager and the commissioners at LBI to identify key services/organisations to be targeted for the training.**
2. **Explore with our London Borough of Islington commissioners and contract manager whether 'in-house' training can be offered to key organisations.** This model of in-house training delivery needs to be promoted and encouraged as it enables changes in policy and practice to be made at an organisational rather than at an individual level.
3. **Assess the long-term impact of the training for professionals.** Our training is rated very highly by participants and evaluations forms show large changes in levels of understanding at the end of the courses. However, we need to understand the long-term impact of the training on practice such as whether staff/volunteers are having more conversations about death, dying & end of life care planning with their service users and whether staff are supporting service users to write advance care plans. Further funding would be needed for this to take place.