MacIntyre
Providing support...your way

Linda, Frontline Manager
Case Study

Dying to Talk Project – Phase 1

Introduction

Linda has worked for MacIntyre since July 2012. She joined as a Frontline Manager having previously worked in a variety of roles supporting adults with learning disabilities. Linda's past jobs include being a Deputy Manager, a Senior Day Centre Officer and a Care Assistant, all within council-run services. Linda has supported people with learning disabilities since she was 14 when she helped out at a social club.

Linda has never professionally supported a person through to the end of their life, but cared for her husband throughout his terminal illness in 2020/21.

Linda was interviewed for this case study.

What we have done

Listened to Linda

Creating this case study has been primarily about listening to Linda's experiences, both from a professional perspective but also – significantly - from a personal perspective. Linda's involvement in the Dying to Talk Project came very shortly after she had cared for her husband through to his death in June 2021.

Linda says of her husband's death:

"I was married to my husband for 47 years. If it wasn't for COVID-19 he would have started treatment for his cancer sooner and perhaps he would have survived. I see older couples together and wonder, why did this have to happen to us?"

Supported Linda personally

Of all the staff who attended our Dying to Talk training, Linda was the person who identified as being the most recently bereaved. Linda said to us prior to the training:

"I may get a little upset after losing my husband in June but I would like to do the training."

Knowing this information made us as a project team acutely aware that Linda may need additional support, which we have endeavoured to provide. Since the training Linda has said:

"The funny thing is, talking about it is helping me. I want to keep talking."

Supported Linda prior to the Dying to Talk Project

MacIntyre ran roundtable events during the Dementia Project, and Linda attended one on end of life care in September 2019.
Linda says of this event:

“The training in 2019 was the first time I’d seen the (then new) ‘My Plan for When I Die’ document. We watched a video as part of the training and I put that video on for the people we support in our service afterwards. We started to speak to individuals about their wishes, with one lady saying she wanted to die at home, have hand massages, listen to ACDC, and have the smell of her favourite perfume in her room. I documented all of her wishes, which was the first time I’d done this for a person I supported. Since then, I’ve asked the link-workers in our service to continue adding to the end of life plans for all of the people we support, and being involved in the Dying to Talk Project has brought the need to do this to the forefront of all of our minds again.”

Provided Dying to Talk training sessions

In common with all staff in the 4 pilot areas of the Dying to Talk Project, Linda has had access to 9 hours of training. These sessions were held on Zoom due to COVID restrictions and lasted 3 hours each. They were structured as follows:

- Session 1 introduced end of life care and looked at words, language and how to talk about death and dying.
- Session 2 looked at documentation and advanced care planning, providing the best support and working with families.
- Session 3 covered care in the last days and hours of life, loss, change and grief, care after death and sharing stories and remembering.

Linda attended Sessions 2 and 3 via Zoom. She didn’t attend Session 1 as the dates were too close to her husband’s death. However, all the sessions have been recorded and all staff in the pilot areas have access to these recordings.

Linda says of joining her first Dying to Talk training session:

“I wanted to be involved and know what was going on. I need to manage this work within our service and it’s no good my staff knowing things I don’t.”

What did we learn?

Personal experiences are very powerful

As human beings we bring both our personal and professional experiences into our work. When it comes to end of life training, care and support, our personal experiences are particularly powerful.

For Linda, her personal experiences of caring for her husband are something that she will be able to bring into her work:

"Now I've been through it with my husband and I know I did everything right, I feel able to support an adult with a learning disability through their death."

Some staff teams may need specialist support

Linda has identified that within her service one person supported will need specific help to be able to participate in the Dying to Talk Project work.
Linda says:

"We will need support from the Positive Behaviour Support (PBS) team for one person we support who has a real phobia of death."

Linda is one of many staff members who feel strongly about advocating for people with learning disabilities

Linda says:

"Before my time with MacIntyre, one person we support wasn't allowed to go to their mother's funeral by their family. Another family member is now ill and the family of the person we support feel they shouldn't attend this funeral either when the times comes. However, I feel strongly that this is part of the grieving process and we should fight this person's corner to enable them to attend, with support from the PBS team as needed. Ultimately, people with a learning disability need to know about death and be allowed to grieve."

What are we pleased about?

Linda's contribution to the Dying to Talk training

For the Dying to Talk training to have the maximum impact for staff, we knew it was important to create an atmosphere where staff felt able to share anything related to their experiences of death and dying.
Linda says:

"I felt comfortable talking about my personal experiences during the training sessions. It became clear I'd given my husband the right support, and I wanted to share that with colleagues so they could see that what they were learning was right."

Linda's feedback from the Dying to Talk training

Linda says:

"The training was brilliant. Session 3 was very practical, and overall the training has given me the tools I need for my work. I feel I could talk to adults with learning disabilities about death and what they want. I am looking forward to any more training that the Dying to Talk team provide."

Meeting Linda's expectations of the Dying to Talk training

An important way to gauge the success of training is to understand if we've met learners' expectations. We asked Linda what she'd hoped to get out of the training.
Linda says:

"In all honesty, I came into the training wanting confirmation that I'd done everything I could have done for my husband. As we were going through the training, I kept reflecting on everything I'd done for my husband and thinking; 'I did that, I did that.' It was an eye-opener for me that I'd done everything for my husband instinctively and it was confirmed to me that I'd got it right. I wondered; 'Where did I get that knowledge from?' It was lovely to hear that I'd done everything correctly for him."

How sharing knowledge can help staff to feel more positive about death and dying

Linda says:

"The training is important because everyone needs to know how to give someone a good death. Although the grieving is bad after every death, to know you've done the best by that person is a lovely feeling."

What are we concerned about?

Ensuring bereaved staff have the support they need

Linda identified that the Dying to Talk training could have provided her with more information on bereavement.
Linda says:

"I'd have liked to spend more time on the grieving process because of how it is affecting me. I'm not dealing with grieving very well. The circle of grief – which I knew about before the Dying to Talk training - keeps going round and round. Some days I struggle to cope and my mental health is suffering."

In addition, Linda mentioned during her interview for this case study that she hadn't been able to access Lifeworks, MacIntyre's confidential counselling and support service for staff. This has since been addressed by MacIntyre's HR department. Linda has also independently sought counselling.

Making sure staff in our pilot areas can access all aspects of the Dying to Talk Project

Linda says:

"I saw an advert for a Dying to Talk event, but you had to go to Milton Keynes and I don't drive."

Linda's Area Manager has since put Linda forward to become an end of life buddy as part of the Dying to Talk Project.

How we support staff who haven't participated in the Dying to Talk training

Linda says:

"Some of my staff aren't comfortable with talking about death and dying, especially those who've had no dealings with death. They will find it hard to say to someone that they will die. I'm hoping the training will have helped, but unfortunately not all staff have done it."

What next?

Phase 2 of the Dying to Talk Project – Linda’s involvement

Linda will be involved in Phase 2 of the Dying to Talk Project, which will include Linda and her staff team (alongside the Project team) working one-to-one with the people supported in their service in a variety of different ways. Materials will be provided by the Project team, and these will be tailored to the individual needs of the people supported following information from Linda and her staff team. As a Project team we will be guided by Linda and her staff team to understand how to work in ways that make sense to each person supported, and at a pace that allows them to meaningfully engage with this work.
Linda says:

“I’m so interested in continuing this work with my team, and on a personal level it’s really helping me too.”