



Introduction

Jan has worked for MacIntyre since Aug 2010. He was a postman before going into care work, and was attracted to working for MacIntyre by the variety his role offered. He enjoys being able to do different things with the people he supports, and enabling the people in his service to access the community and participate in activities that they enjoy.

Jan was interviewed for this case study.

What we have done

Listened to Jan

Creating this case study has been primarily about listening to Jan's experiences, both professional and personal. He has been an enthusiastic participant in the [Dying to Talk Project](#) and in [the Dementia Project](#) previously. Jan says:

"My dad was diagnosed with dementia prior to my involvement in MacIntyre's Dementia Project. Now my dad is approaching the end of his life and I'm involved in the Dying to Talk Project. The specialist knowledge I've acquired through this Project work over the years has definitely helped me personally."

Supported Jan prior to the Dying to Talk Project

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

"The original advanced care planning documents for the people in our service dated back to 2009/10. The roundtable event in 2019, when the (then new) 'My Plan for When I Die' document was shared, was the trigger for updating end of life plans across our service. Being involved in the Dying to Talk Project has helped us to build on that work further."

Provided Dying to Talk training sessions

In common with all staff in the 4 pilot areas of the Dying to Talk Project, Jan 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.

What did we learn?

The resources we are using are helpful for frontline staff

One of the resources we introduced in the Dying to Talk training was Grave Talk cards. Jan says of these cards:

“I really like the Grave Talk cards. Since using them on the Dying to Talk training we’ve gone on to buy a pack for our service and have used them with the people we support, with some modifications where necessary.”

How important the relationship between staff and families is

Jan has identified that having a positive working relationship with family members is so important when it comes to advanced care planning. He says of the family of the person he link-works:

“I’ve tried to engage with this person’s family as much as possible, especially when we’ve been working on the person’s advanced care plan. The family have been so supportive and helpful, asking how they can help me and how they can help their family member.”

Staff need support inside and outside of their service

Jan has supportive colleagues within his service, and alongside this has access to MacIntyre’s Health Team and Dying to Talk consultants. Jan says of this support:

“Being able to call upon experiences within the staff team from a personal or professional perspective is invaluable. It’s really helpful to know you have a good support network outside of the service too. It gives me a lot of confidence.”



The Dying to Talk training is useful for staff both professionally and personally

Although Jan admits he hasn't had to personally cope with many bereavements in his life, and has never experienced a death in his work, he recognises how the Dying to Talk training is applicable both professionally and personally. Jan says:

"It's one of those subjects you can translate from your work to your personal life."

Jan would recommend the Dying to Talk training to other staff members

Jan says of the training:

"No matter how experienced you are, at whatever level you are, you will learn something new. Myself and my colleagues have been pleasantly surprised at the wealth of information available and how helpful the training was."

What are we pleased about?

Jan's advanced care planning work in his link-worker role

Jan describes his experiences of advanced care planning as follows:

"For the first person I linked-worked, the conversations were really difficult. The person was in their early 40's, and at that time they had no other conditions so it almost seemed too early to be talking about death and dying. However, the person went on to develop dementia and eventually had to move out of our service, so the fact that we'd tried to begin documenting their end of life wishes proved to be really important."

"For the second person I've linked-worked, and still link-work, it has been even more difficult to have conversations about death and dying. This person is in their mid 70's, is very observational, and has significant anxieties about death and dying. This person's mother became progressively unwell and died when this person was relatively young, and this resonated with this person extensively. We've had to take a measured and cautious approach to end of life planning because anything to do with funerals, hospitals or ambulances are triggers for this person's anxiety. This has meant we've had to avoid extensively talking about death and dying with this person, and it's taken us a long time to get to a point where this person's advanced care plan is now 60-70% complete."



How Jan's used the Dying to Talk resource lists

Following each Dying to Talk training session, every participant is sent a resource list with internal and external links. Jan says of this:

"I received the resource list after each session. Each one was around one and a half pages, so quite extensive, and I found them really helpful. They provided me with some good conversation starters to broach difficult subjects with the person I link-work."

Jan's feedback from the Dying to Talk training

Jan says:

"I really enjoyed the three sessions of the Dying to Talk training. There was a wealth and variety of information presented, and it was a nice way of dealing with a sensitive subject. It's been one of the more enlightening and enjoyable pilot programmes I've taken part in."

Meeting Jan'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 Jan what he'd hoped to get out of the training. Jan says:

"A better way of communicating in difficult conversations with someone who would display anxieties around talking about death and dying."

Jan's breakthrough moment following the Dying to Talk training

With advanced care planning being a continual process for people supported by MacIntyre, Jan revisited the plan of the person he link-works after the Dying to Talk training and experienced a breakthrough moment. Jan explains:

"I began a conversation with the person I link-work around music that they might want at their funeral. They weren't as anxious as they had been previously and it ended up being a positive conversation."



What are we concerned about?

The need to continue to be mindful of staff experiences in their personal lives

We've always been mindful that death and dying is a sensitive subject for staff. Some staff have talked openly about personal bereavements, whilst others, like Jan, are anticipating imminent bereavement due to unwell family members. It's therefore important in all of our activities with staff that we ensure they feel supported and able to talk to us, confidentially if preferred, about any issues in their personal life that we need to be mindful of.

Some staff can't access the Dying to Talk training

Because Dying to Talk is a 4-pilot area Project, many staff aren't able to access this training currently. Jan has identified that:

“Barriers in talking about and planning for end of life care are still significant for staff if they've not experienced death and dying personally or, perhaps even more so, if they haven't experienced it through work. The Dying to Talk training helps to break down these barriers to enable staff to have conversations with the people they support, so ideally all staff need access to these training sessions.”

What next?

Phase 2 of the Dying to Talk Project – Jan's involvement:

Jan will be involved in Phase 2 of the Dying to Talk Project, which will include Jan and his colleagues (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 Jan and his colleagues. As a Project team we will be guided by Jan and his colleagues 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.

Jan says:

“I'm looking forward to working with the Dying to Talk team in our service to continue the conversations about death and dying with the people we support.”