MacIntyre
Providing support...your way

Dying to Talk

Successes and learning: June 2021 to November 2022

Main messages

MacIntyre wants the people we support, their families and our staff to feel comfortable talking about death so people can plan for the future without feeling worried or afraid.

This report describes what we achieved in the ‘Dying to Talk’ project between June 2021 and November 2022.

We tested the best ways to talk about death and dying with adults with a learning disability, their families and the staff supporting them in our services in Chesterfield, Leicestershire, Herefordshire and Worcestershire. We plan to share what we learnt from these areas to all of our services.

Dying to Talk trained, supported or raised awareness with over 1000 people we support, family members, staff and professionals from other organisations. This is more than our original target to help 185 people. We also shared what we were learning with over 1,500 more people.

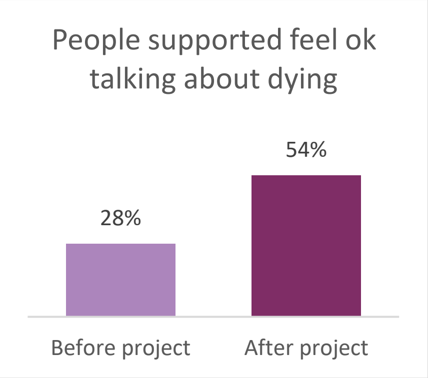
We **supported people with a learning disability and their families** by:
- helping **79 people we support** talk about death and plan what they wanted near the end of life during workshops and events at day services and supported living services
- helping **70 family members** of the people we support understand why it is important to help their loved ones prepare for death. We met family at coffee mornings, events and meetings

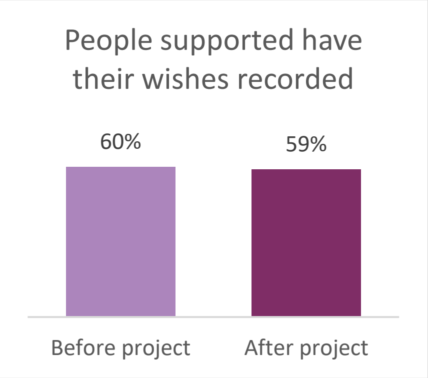
We **supported our staff** by:
- making sure that training and resources were based on what staff need, using feedback from over 200 people
- delivering 38 training sessions, with **134 staff trained** (half of all staff in the target areas)
- developing a **resource pack** and e-learning module to help staff have conversations
- sending **newsletters to 1,146** staff, family members and others to share tips

We **shared our learning with other organisations** by:
- showcasing our approach to **1,278 people from other organisations** such as charities, local authorities and health services at webinars, training and conference presentations
- sharing our learning using Twitter, blogs, videos, radio interviews, podcasts, newsletters and journal articles
- being nominated for three national awards for this work, to raise the profile

We succeeded in:

- **increasing the knowledge and confidence of the people we support** so they are not so scared to talk about death. At the start of the project 28% of people we support in participating services said they felt ok talking about dying. By the end of the project this almost doubled, to 54%
- **increasing the knowledge and confidence of staff** so they feel more comfortable talking about death with the people they support. Before Dying to Talk training 28% of staff said they felt very comfortable talking about death and dying with the people they support. This doubled, to 60% after training. Staff working in services not participating in Dying to Talk did not feel more confident
- **having more discussions about people's wishes near the end of life** as part of Dying to Talk workshops. This did not increase the number of people in supported living / residential services with an advance care plan, but staff said this was because some people do not have capacity to have discussions and some family members have asked that this is not discussed with their loved ones. We did increase the number of people at day services developing an advance care plan (97 people at day services started an advance care plan due to the project)
- **raising awareness in other organisations** that it is possible and useful to talk to people with a learning disability about death and dying. 80% of professionals from other organisations that took part in one of our training sessions said they used something they learnt in their work





Dying to Talk has helped to start changing people's mindsets. In participating services, it is now more normal to talk about the end of life. People we support and staff changed from not wanting to engage to now wanting to talk about their wishes and feelings. Some family members started to plan for what will happen when they are not around to support their loved one.

There is more to do. We have just scratched the surface. We want to share this approach widely so everyone with a learning disability has the opportunity to think about what is important to them near the end and talk about feelings of grief and bereavement. We used what we learnt in Dying to Talk to create a resource pack and e-learning module for staff in all MacIntyre services, which could also be shared with other organisations. We will continue to promote why it is important to talk about death and how to do this as part of our day to day work.

Contents

What did we do? 5

What did we achieve? 14

What did we learn? 30

Acknowledgements

Dying to Talk was run by MacIntyre and helpers, working in partnership with the people we support and their families.

The project was funded by the National Lottery Community Fund.

This summary of successes and learning was created by an independent team from The Evidence Centre

What did we do?

What was ‘Dying to Talk’ about?

The MacIntyre charity was established by the parents of a disabled child in 1966 to help people with a learning disability live a life that makes sense to them. We provide education, support and care for more than 1,200 children, young people and adults who have a learning disability and/or autism across England and Wales. A learning disability affects the way a person learns new things, how they understand information and how they communicate.

The people we support, their families and our staff told us that there are big gaps in people’s understanding of ageing and what happens near the end of life. Staff sometimes found it hard to have conversations with the people we support about getting older, end of life care, making a will, planning a funeral and dying. They were worried about upsetting people. Staff and family members told us they did not want to discuss death or dying, which left some people with a learning disability unaware of what death is, or feeling afraid and confused. These are important conversations to have if we want to respect an individual’s wishes and support person-centred care at all stages of life. This became even more important during the COVID-19 pandemic, when there were many restrictions and people were touched by death and fear.

In 2021 the National Lottery Community Fund have us a grant to test how to break down the barriers to talking about dying and the end of life for people with a learning disability and staff working with them. ‘Dying to Talk’ was a pilot project to find out how to increase people’s knowledge and confidence speaking about and planning for the end of life. We wanted to test what worked in a small number of services before sharing across all MacIntyre services in future.

> *“Thinking about the future can be a daunting process for people with a learning disability. Many people, including staff and families, don’t know where to begin or what approach to use. MacIntyre wants to do the best we can for each person to have choice and control over their own lives and their future wishes. We want to normalise talking about death and dying in ways that make sense to everyone.”*
>
> Dying to Talk project team member

What did we want to achieve?

We wanted two main things from the Dying to Talk project:

1

Understand how to improve staff knowledge and confidence about discussing death and dying with people with a learning disability

This included testing ways to:

- help **MacIntyre workers feel more comfortable** speaking with the people they support about death and dying
- create **resources** that other MacIntyre services could use in future
- help a small number of **professionals outside MacIntyre** understand the importance of talking about death and dying with people with a learning disability

2

Understand how to improve the confidence of people with a learning disability and their families to talk about death and dying

This included testing ways to:

- help people with a learning disability **feel less frightened** to hear the words death and dying
- help **people with a learning disability know more about death** so they can have greater personal choice about what happens near the end if they wish
- help **family members** of people with a learning disability feel more comfortable speaking to their loved one about death and dying

This was a 'pilot', or small test, so we did not try to reach large numbers of people. We wanted to test which ways of doing things worked best so we could decide which methods to use across MacIntyre services in future.

We did our testing in supported living, registered care and outreach/day services in four areas: Chesterfield (Derbyshire), Leicestershire, Herefordshire, Worcestershire. There are about 262 staff working in our 24 services in these areas, supporting 165 adults with a learning disability and their families.

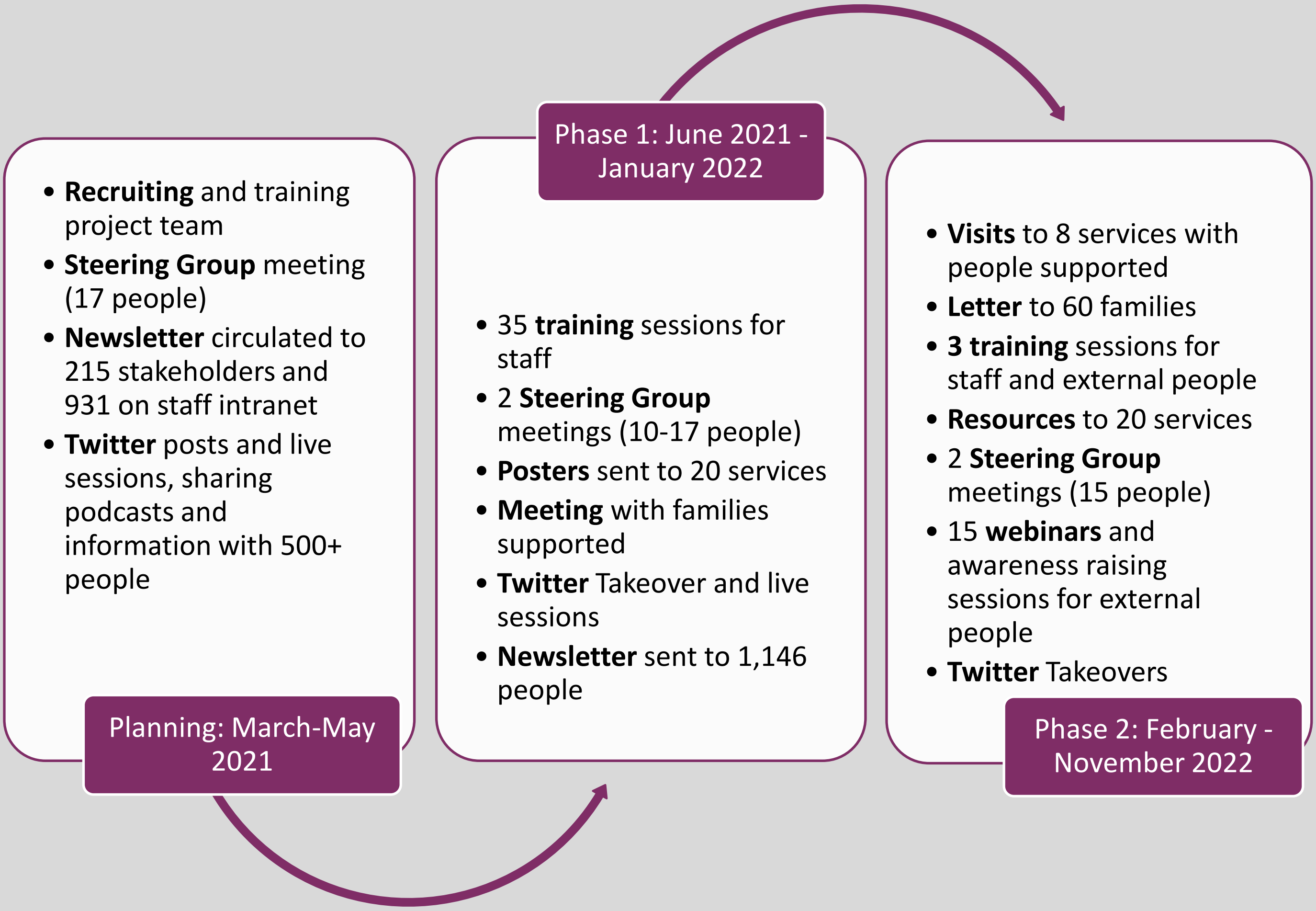
We hoped to reach a total of 185 people, including 50 people with a learning disability, 30 family members, 100 MacIntyre staff and 5 external health and social care professionals.

We compared what happened in our participating services in 'pilot test' areas with a comparison group of services in Hertfordshire, Essex and London that did not receive training and support (8 residential care and supported living services in our comparison group had 153 staff supporting about 60 people). We looked at whether staff confidence and activities in participating areas improved more than in our comparison services.

What activities did we do?

We started our project during COVID-19 restrictions. People with a learning disability were at high risk from COVID-19 so we needed to adapt our plans to keep people as safe as possible. This meant that we started in 2021 by providing training to staff online rather than working face-to-face with the people we support.

In 2022, we were able to start visiting services in person to do workshops with people with a learning disability and role model approaches for staff.



Planning: March-May 2021

- **Recruiting** and training project team
- **Steering Group** meeting (17 people)
- **Newsletter** circulated to 215 stakeholders and 931 on staff intranet
- **Twitter** posts and live sessions, sharing podcasts and information with 500+ people

Phase 1: June 2021 - January 2022

- 35 **training** sessions for staff
- 2 **Steering Group** meetings (10-17 people)
- **Posters** sent to 20 services
- **Meeting** with families supported
- **Twitter** Takeover and live sessions
- **Newsletter** sent to 1,146 people

Phase 2: February - November 2022

- **Visits** to 8 services with people supported
- **Letter** to 60 families
- **3 training** sessions for staff and external people
- **Resources** to 20 services
- 2 **Steering Group** meetings (15 people)
- 15 **webinars** and awareness raising sessions for external people
- **Twitter** Takeovers

Project team

The Dying to Talk project team was made up of:

- overall lead (part-time), Nicola Payne
- day-to-day manager who visited services and delivered training (full-time), Rachel Furniss
- administrator who arranged all sessions and resources and kept records (part-time), Nicky Thurgood
- people with a learning disability who contributed by developing and checking resources, helping to promote the project, testing workshop approaches and acting as champions
- three external helpers. We produced all resources, training and support alongside experts in the field. This helped us learn from the best, and helped experts understand how to adapt and apply good practice with people with a learning disability and their families
    - Professor Irene Tuffey-Wijne from Kingston University and St George's provided technical expertise for our training and resources
    - Independent consultant Beth Brittan helped us develop and implement a communications strategy. She collected stories from people attending training and edited our guidance resources for staff. She also helped to deliver training.
    - Caroline Loxton from Willen Hospice provided training and resources about what good end of life care looks like, what happens to the body as a person approaches death and how we can make sure people's wishes are respected


Nicola Payne
Oversaw the project


Rachel Furniss
Project Lead


Nicky Thurgood
Administrator

Activities to understand how to improve staff knowledge and confidence

To test the best ways to increase knowledge and confidence in our staff and people from other organisations we:

- **asked staff** what they wanted to know and what was getting in the way of talking about the end of life with the people we support. We spoke with frontline team members and managers. We also invited all staff in participating services and in our comparison services to answer a survey about their training needs. 156 staff shared their views (55% of staff from our target services and 29% of staff from our comparison services). We followed up towards the end of the project to see whether staff knowledge and confidence had changed and to ask staff what methods helped them most. We also had a reflections session with staff to talk through what they found useful and not so useful in the training. We showed staff draft resources that we planned to use in workshops with the people we support. We gathered staff ideas about how to deliver sessions for people with a learning disability because they know the people MacIntyre supports well.

- ran **38 live online training sessions** for staff between August 2021 and November 2022. We delivered training online to stay COVID-safe. We are also rolling out an e-learning module that staff in any MacIntyre service can use at any time

- **developed resources** such as awareness raising posters, website content, blogs, short videos, games and documents to help staff have conversations with the people we support. We sent a package of resources to our participating services which included advance care plans (easy-read and non-easy-read versions), a conversation starter card game, remembrance seed packs and resources from the training sessions

- **visited services** to talk with staff and run sessions with the people we support. The Dying to Talk team role modelled to show how staff could talk with people with a learning disability about death and dying in a way that was informal, fun and not too upsetting

- **audited services** in our pilot areas and comparison services at the start and end of the project to see whether services were having discussions and documenting people’s decisions related to end of life care, advance care plans and wills. We hoped that being asked to review people’s records would encourage staff to identify which people they needed to have discussions with about advance care plans

- had a **Steering Group** made up of area managers, communications leads, external supporters and the project team. The Steering Group met three times per year to review what was and was not working well and plan next steps

Online training sessions were a big part of how we introduced the topic of death and dying to our staff.

The training sessions were run by the Dying to Talk project team alongside external helpers, such as a representative from a hospice, a specialist in dementia care and a specialist in talking to people with a learning disability about death and dying.

We focused on raising awareness of why it is important to talk about death and dying, reducing stigma and sharing tools and strategies to build staff confidence to have discussions with the people they support.

We initially divided the training into three 3-hour sessions:

- Session 1 introduced the concepts of death and end of life care and looked at the words we use to talk about dying
- Session 2 looked at advance care plans and how to work with families
- Session 3 covered care in the last days and hours of life, loss and grief, care after death and sharing stories and remembering.

Dying to Talk Training Session 1 of 3

We ran each session 10 times on Zoom so that staff had lots of options for times to take part.

We found that it was difficult for staff to spare nine hours for training and some of the topics were duplicated. Therefore we ran eight extra two-hour sessions covering the main points.

We recorded training sessions so we could include the videos of the 'lecture' elements and slides as part of a resource pack that we sent to all participating services. We also placed the videos on YouTube for staff to view if they could not attend live sessions.

Activities to understand how to improve knowledge and confidence in people we support

To test the best ways to increase the knowledge and confidence of people we support and their families we:

- **coproduced** ways to talk about ageing and the end of life with the people we support. We worked closely with a group of people with a learning disability to test our approaches

- **employed two people** with a learning disability as part-time project assistants. They helped to develop easy-read resources and promote the project

- **developed materials** such as an article in an accessible magazine for people we support, easy-read leaflets and educational games

- **visited nine services** to run workshops with the people we support (we visited some of these services more than once). This is 38% of services in our target areas. At these workshops we played educational games, listened to music and got people talking about what would be important to them at the end of life. We made the workshops fun so that people wanted to take part. People with a learning disability have different levels of capacity so we tested what worked best for people with different levels of ability to engage. The Dying to Talk project team introduced discussions about the end of life in small groups or one-to-one so that staff at the services could see how we did this

- had **discussions with 70 family members** about things that would help them to have conversations with their loved one. We spoke with family members at coffee mornings, events and at existing meetings for families

- sent **letters** to 60 families to let them know about the project and raise their awareness about having conversations about ageing with their loved one

- **surveyed** the people we support near the start and the end of the project to see how much they knew about death and dying and how frightened they were talking about it. This helped us see whether we were making a difference or whether we needed to try other things.

Sharing our learning

Throughout the project we wanted to show other organisations that it was possible to talk about death and dying with people with a learning disability. This is because most other services told us they find it hard to do this. To share our learning we:

- ran a one-hour online **awareness raising session for health and social care professionals**
- delivered three two-hour online **training** sessions open to staff working in other organisations, such as other charities and health and social care services. We trained people from MacIntyre alongside people from other organisations at these sessions to help build relationships
- shared what we learnt on **social media**, such as ‘Twitter Takeover’ live sessions with Hospice UK and Marie Curie and internally (e.g. https://twitter.com/meetmacintyre/status/1567482723878461440?s=48&t=PZ9dSE6MH3RHU_dg5KuKfQ)
- shared two project **newsletters**, which each reached about 1,146 staff, family members and people from other organisations
- wrote 13 **blogs** about how to speak with the people we support, training staff, the value of connecting with local hospices and other topics (e.g. https://www.macintyrecharity.org/news-blogs/how-and-why-we-must-involve-people-with-learning-disabilities-in-talking-about-death-and-dying/)
- recorded a **podcast** and took part in interviews on local radio: Families Podcast | MacIntyre (macintyrecharity.org)

Dying to Talk Project Newsletter

Welcome to the first issue of the MacIntyre Dying to Talk Project Newsletter

Contents:

- **recorded** an episode of a chat show talking about planning for the end of life. The chat show is hosted by someone MacIntyre supports: https://youtu.be/S22cpV6oTBs
- filmed a short **video** showing how we have conversations with people supported and filmed staff, families and people supported speaking about the benefits of the project (https://youtu.be/xLB0W-36xN8)
- interviewed people supported, family members and staff to write up short case **stories**
- were **nominated for three awards** for this work, which helped us raise awareness about having conversations about death and dying. We were ‘highly commended’ at the Women Achieving Greatness in Social Care awards
- wrote an **article** for a professional academic journal

We worked with an external helper who has lots of experience in communication and promotion. This helped us promote Dying to Talk widely.

Examples of resources built with or available to other organisations

- Created easy-read version of **UK Bereavement Commission** annual report (with our checkers team of people with a learning disability)
- Created remembrance collages with people we support for **Marie Curie** as part of National Day of Reflection remembering those who died of COVID-19 (National Day of Reflection | Marie Curie). Maire Curie now promotes our easy-read advance care plans on their website ('Palliative and end of life care for people with learning disabilities' and 'Planning your care in advance')
- Took part in a number of live Twitter chats with **hospices**, Marie Curie and other experts (https://www.macintyrecharity.org/news-blogs/dying-to-talk-live-twitter-chat/ and https://www.hospiceuk.org/our-campaigns/dying-matters/i-remember)
- Ran Zoom workshops alongside **Learning Disability England** (https://www.macintyrecharity.org/events/creative-ways-to-talk-about-death-and-dying/)
- Took part in radio interviews (https://www.mkfm.com/on-air/podcasts/mkfm-podcasts/episode/rachel-furniss-dying-to-talk-project-lead-at-macintyre/)
- Presented at **Care Talk** conference (https://youtu.be/v5QmfdKAi40 - starts 24:50) and had article in their newsletter (https://www.caretalk.co.uk/wp-content/uploads/2022/04/caretalk-may-2022.pdf)
- Shared personal **case stories** (https://www.macintyrecharity.org/download/file/6970/ and https://www.macintyrecharity.org/download/file/7021/ and https://www.macintyrecharity.org/download/file/7023/)

What did we achieve?

Did we achieve our targets?

Dying to Talk aimed to support 185 people directly while we learnt the best ways to talk about death and dying with staff and the people we support. **We were able to help over 1000 people. This is many more than we planned.**

We trained or supported 377 people directly, verbally shared information to raise awareness with another 921 and shared written information or resources with over 1,500 others, some multiple times.

Half of the staff in our participating services took part in one or more training sessions.

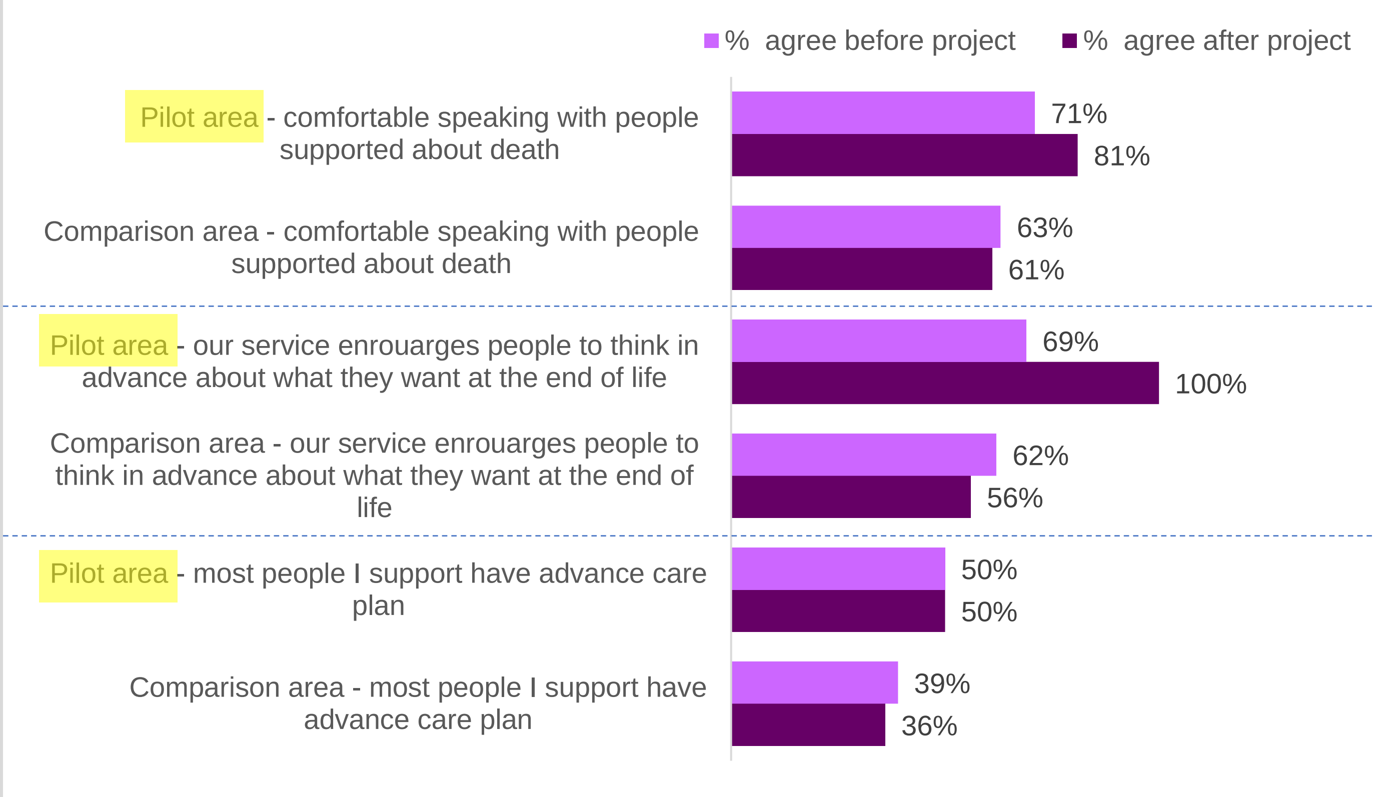
Beneficiaries	Target	What we achieved
People with a learning disability	50	• **79** (counts people supported more than once multiple times)
MacIntyre staff supporting people with a learning disability	100	• **134** through training • **413** through awareness raising, site visits and short talks • 1,146 through newsletters
Family members of people with a learning disability	30	• **70** (includes awareness raising)
Professionals from other organisations	5	• **94** through online training • **508** through awareness raising sessions and conference talks • 387 reading blogs • Over 500 viewing social media and website content
Total	Target of 185	• **377 directly helped/trained** • **Plus 921 with awareness raising** • Plus 1,500+ receiving information

Did we increase staff knowledge and confidence?

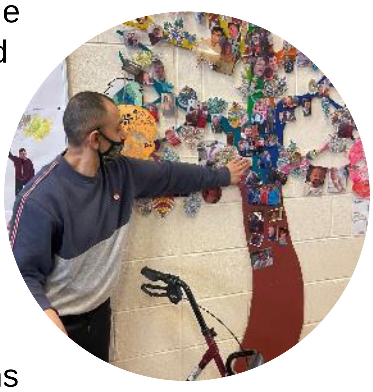
One of our main goals was to help MacIntyre staff feel more comfortable speaking with the people we support about death and dying. We made progress towards this.

We asked staff from services taking part in Dying to Talk and services in comparison areas to complete a survey at the beginning and end of the project. We wanted to compare whether staff from services taking part had more confidence than staff from services that were not taking part. It is hard to make comparisons because only small numbers of staff provided feedback at the end of the project, but there were positive trends. **At the start of the project 7 out of 10 staff in participating services said they felt comfortable talking about death and dying with the people they support. This increased to 8 out of 10 staff by the end of the project.**

Confidence of staff in participating services and comparison services



Note: Based on feedback from 112 staff from participating services (pilot area) before the project and 22 afterwards, plus 44 staff from comparison services before the project and 11 afterwards



Staff from services taking part in Dying to Talk were very positive about the project if they engaged with it. Staff who took part in training sessions said that they learnt things that they could apply in their work.

We filled 203 places on 38 online training sessions. Some staff took part in more than one session. In total **we trained 114 unique staff**.

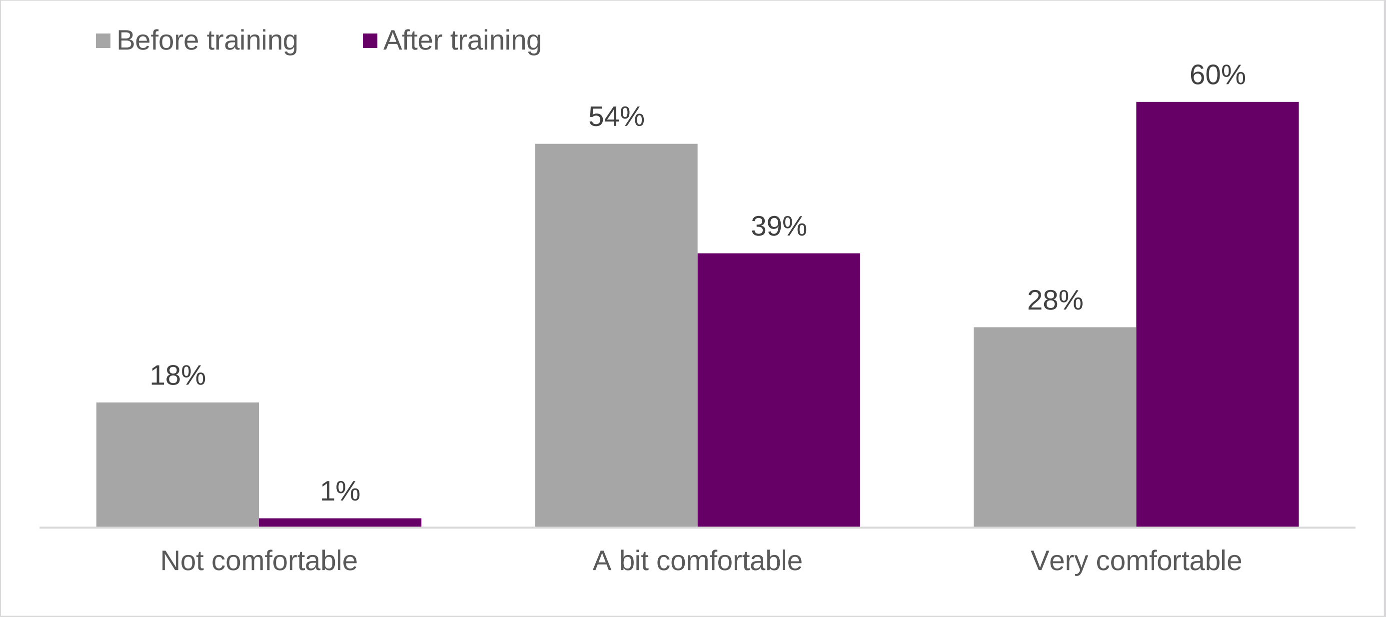
We initially split the training into three three-hour sessions because there was a lot to cover and staff were not able to take a whole day away from their care roles. We later revised this to run shorter two-hour sessions that included the key points from all training.

We used examples, role play and small breakout rooms so people could talk about their experiences. Staff were positive about the content and the training approach. They reported increased knowledge and confidence after the training.

Before taking part in any training, quarter of staff said that they felt 'very comfortable' speaking to the people they support about death and dying (28%). After training, this had doubled to almost two thirds (60% across all training).

Before training one out of five of staff said they were not very comfortable at all speaking about death with the people they support (18%). Only 1% of staff said this after training.

How comfortable do you feel speaking with the people you support about death and dying?



Note: Based on feedback from 85 people before training and 150 people after training. Some people attended more than one training session so are counted more than once.

> *“We found the course very interesting and thought provoking and it made us feel more confident to deal with death and talking about it.”*
>
> Frontline staff member

> *“This is something that is long overdue. There have always been issues completing advance care plans with people with a learning disability. It is positive to focus on this. This will have a good impact on everyone involved.”*
>
> Service manager

Many staff said that they were originally not looking forward to attending the training because this is a difficult and stigmatised topic, but they were pleasantly surprised and motivated by the training approach.

> *“I was apprehensive about doing this training but have found it very useful and you delivered in a very sensitive way.”*
>
> Frontline staff member

> *“Really useful to cover a subject most people fear. Initially fearful but found it interesting and sort of comforting.”*
>
> Frontline staff member

The more training sessions people took part in, the more comfortable they became. In our series of three sessions, 55% of staff said they felt very comfortable talking about death with the people they support after session 1, 69% after session 2 and 87% after session 3.

	Before	After session 1	After session 2	After session 3	Overall after sessions
Very comfortable	33%	55%	69%	87%	64%
A bit	52%	41%	31%	17%	34%
Not much	16%	4%	0%	0%	2%

Note: Based on feedback from 64 people before training and 129 people after training (73 after session 1, 32 after session 2 and 23 after session 3). These figures do not include people who took part in our two-hour single sessions.

Example of how a MacIntyre staff member used what they learnt from Dying to Talk

“Dying to Talk helped me support people better and deal with things in my own life. Not all staff are comfortable talking about death and dying, especially those who’ve had no dealings with death. They find it hard to tell someone that they will die. That’s why Dying to Talk is so important.

The training introduced me to the ‘My Plan for When I Die’ document (advance care plan). We watched a video as part of the training.

I put that video on for the people we support in our service afterwards. It was a good ice breaker. People started to speak about their wishes. One lady said she wanted to die at home, have hand massages, listen to AC/DC, 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 our link-workers are continuing to add to the end of life plans for all the people we support. Being involved in Dying to Talk brought the need to do this to the forefront of all of our minds.

The training was brilliant and very practical. It has given me the tools I need for my work. I now feel that I can talk to the people we support about death and what they want towards the end of their lives.

I feel strongly about advocating for people with a learning disability. One of the family members of a person we support is ill. The family don’t think the person we support should attend the funeral when the times comes. However, this is part of the grieving process and we should fight this person’s corner to enable them to attend, with support as needed. Ultimately, people with a learning disability need to know about death and be allowed to grieve.

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.

My husband died recently. I was a worried that I would be upset by the training but I still wanted to be involved. The funny thing is, talking about it is helping me personally. I want to keep talking.”

Staff told us that they were able to use what they learnt from Dying to Talk in their day-to-day work. For example, one staff member told us about an external person reading a story to one of the people we support. The staff member noticed that the story wording was not realistic about death. The story suggested that people would turn into butterflies when they die. The staff member raised this with the person we support and the person reading the story. The staff member was confident to speak up, discuss sensitive issues and address misinformation.

Other staff described how they used tips from the training to have conversations about dying with the people they support.

> *“It has been really difficult to have conversations about death and dying with a person I’m supporting. They are in their mid-70s and have significant anxieties about death and dying. Their mother became progressively unwell and died when the person I support was young. This had a big impact on them. In the past I have had to be very cautious about talking about end of life planning because anything to do with funerals, hospitals or ambulances are triggers for this person’s anxiety. I revisited this person’s advance care plan after the Dying to Talk training and had a breakthrough moment. I began a conversation 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. Applying the tips from training helped me have better conversations.”*
>
> Frontline staff member

Staff also used the resources we distributed to begin conversations with the people we support, including videos, conversation prompt cards with questions and ‘choice boards’ with images to point at for people where communication is limited. Staff said that having a variety of resources helped them start conversations about what people wanted at the end of life.

Managers working with frontline teams fed back that Dying to Talk helped to start changing the culture so it is more ‘normal’ to talk about death and advance care planning.

> *“Staff who did the training were impressed and enjoyed it. As an individual it is hard to make change, but this project has helped get momentum behind this. Staff feeling more passionate about this now.”*
>
> Service manager

Dying to Talk focused on helping staff speak with the people we support, but it also had the unexpected benefit of **helping staff in their personal lives**. Some staff told us the project led them to think about their own feelings and grief after bereavement, talk with their loved ones about their wishes and make wills. Some said they felt more valued at work because the Dying to Talk sessions offered a safe space to talk about their feelings and get support.

"Our primary intention was to help staff feel more equipped to talk about, plan for and provide care and support relating to a person's end of life in their professional roles within MacIntyre, but we have managed to provide a significant amount of pastoral and wellbeing support for staff who are coming to terms with grief and bereavement personally too. For me, this has been an unexpected but hugely positive outcome."

Beth Britton, project helper

"I really enjoyed the training, and it made me feel so much better knowing I did everything talked about on the training to give my own husband a good death."

Frontline staff member

"COVID was a difficult time for everyone. A lot of us were dealing with loss or fear or worrying about what could happen. Dying to Talk gave staff a safe space to talk about some of their worries and things going on in their personal lives. It made it more normal to talk about death and to focus on planning and positivity. It helped with staff wellbeing to have that outlet and everything was done very sensitively."

Service manager

Did we help the people MacIntyre supports?

Dying to Talk's other main goal was to understand the best ways to help people with a learning disability understand more about death and dying, so they can make choices for themselves if they wish.

We asked people supported by MacIntyre services taking part in Dying to Talk and people supported by services in comparison areas to complete an easy-read survey at the beginning and end of the project. We wanted to see whether people supported by services taking part would know more than people supported by services that were not taking part.

We cannot compare as we wanted because too few people in the comparison group took part. But **the fact that lots of people supported by participating services responded near the end of the project is a positive finding**. This might mean that people supported by services in participating areas were more open to thinking about death and our staff were happy to help people complete a survey about death. The number of people completing a survey was one of our 'indicators of success'.

- At the start of the project 35 people supported by participating services completed a survey. By the end of the project this had increased to 59. This is 97% of all people supported in the participating supported living / residential services. **The number of people willing to complete a survey about dying almost doubled by the end of the project.**

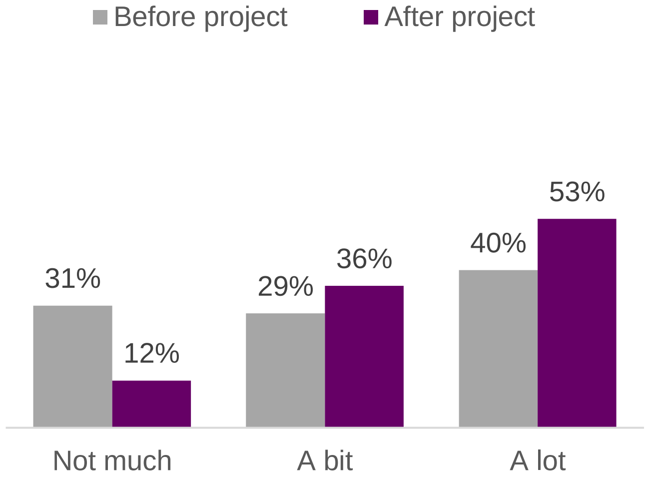
- At the start of the project 9 people supported by services in the comparison area completed a survey. By the end of the project this had decreased to 2. This is 4% of all people supported in residential services in the comparison areas.

By the end of Dying to Talk the people supported by participating services were more likely to say that they knew a lot about dying and they felt ok talking about dying.

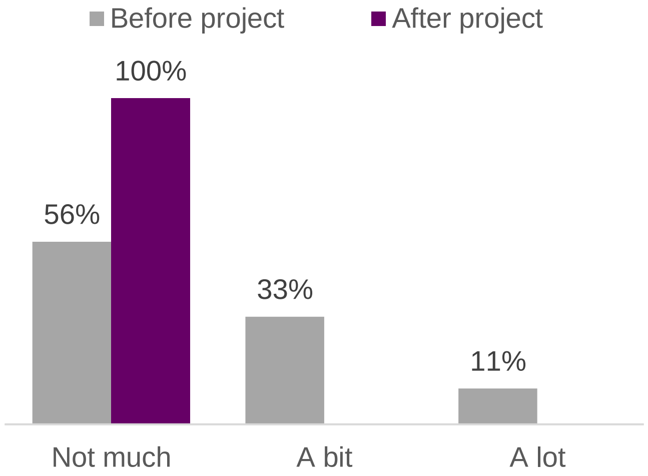
- **At the start of the project 7 out of 10 people supported by participating services said they knew a bit or a lot about dying (69%). This increased to 9 out of 10 by the end of the project (88%)**
- **At the start of the project quarter of people supported by participating services said they felt ok talking about dying (28%). This increased to half of all people by the end (54%).** The project might have helped to double the people supported who felt ok talking about dying

How much do you know about dying?

Participating services

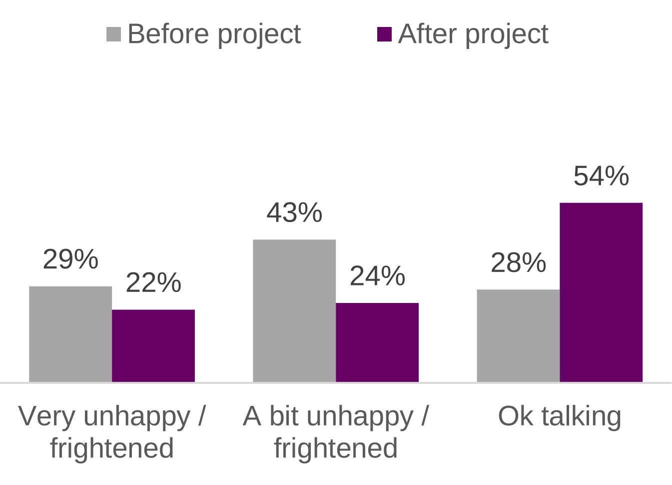


Comparison services

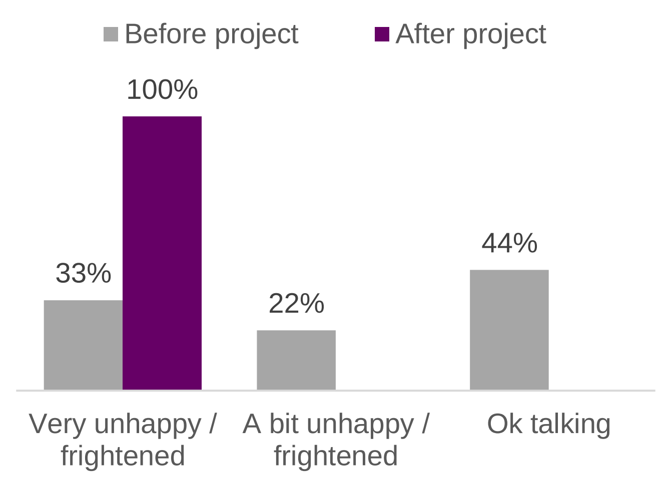


How do you feel talking about dying?

Participating services



Comparison services



Note: graphs are based on feedback from 35 people supported in the pilot area before and 59 afterwards, plus 9 people supported in the comparison area before and 2 after the project.

There were many examples of how we helped the people we support have conversations about death and dying.

Example of how we started conversations about dying when visiting a service

We spent a morning talking with people at a service in Chesterfield. We put up a Dying to Talk banner. A person we support walked up to the banner saying “This word ‘dying’. We cannot talk about it.” He started laughing nervously. One of the Dying to Talk team asked why it was funny and he said “dying, I don’t want to talk about dying” and left the room. Other people entered the room and saw the banner and ‘clammed up’. They didn’t make eye contact. This reinforced that dying is something which some people we support feel uncomfortable speaking about.

We started the session by inviting people supported and the MacIntyre staff at the service to sit at a table and take part in an activity. Some people were more willing than others. They were apprehensive about the topic, but we made things fun and light-hearted. Before the session began, we had asked each person what their favourite song was. We started the session by playing part of a song and asking people to guess who had picked this as their favourite. We used an activity that was not about death to set the tone. The group instantly became more relaxed. They smiled, laughed and sang along.

Then we introduced ‘Little more conversation’ cards which include prompts and random questions. We used the cards as a game so the people we support were eager to take part. After about an hour, the people supported started to talk about a member of staff who had died. One of the staff went and got a photo of the team member. The activities and question cards helped people open up and led to other conversations.

We checked everyone's feelings. One group member was ‘sad’ and other people told her not to be sad. The Dying to Talk team explained that it was ok to feel sad at times and that it was ok to cry.

We asked the group to write or draw something they would like to do. People put their writing and drawings into a ‘bucket of dreams’. We then drew pieces of paper out of the ‘bucket of dreams’, reading out things that made the group happy. This put everyone in a positive mood. Everyone engaged loudly. More people from other parts of the service came to join the conversation. In total, 7 people supported took part in the whole session and 3 others dipped in and out.

The group said they had enjoyed the conversations and wanted to know if sessions would happen every week. We left resources so staff could run more sessions.

Sandy has lived with MacIntyre for a while. She has a 17 year old son, Bob, who lives with Sandy's elderly mum. Sandy was very worried about where Bob would live if her mum died, but she didn't want to talk to anyone about this in case it was upsetting or 'caused bad luck'.

When we first asked Sandy if she wanted to talk about planning for the future or death she found it very difficulted and walked away. We used art as a way in, and invited Sandy to a creative workshop to make artwork with her friends. This was to remember people who had died of COVID-19.

Sandy said:

> *"It made me feel sad but I am glad I got to speak about it. Thank you, and I would like to talk about this again."*

We kept in touch with Sandy after the art workshop. She asked what we could do to help plan what might happen to her son when Sandy's mum died. Sandy was worried she or her mum might catch COVID-19 and die before Bob was an adult. The Macintyre team met with Sandy, Bob and her mum to start creating a plan.

Sandy said:

> *"I'm happy we've been able to meet with my mum and start looking at the future for Bob. I'm glad I came to the Dying to Talk sessions, talked to you about my worries, and that we are going to work on a plan now. I've been worrying about this for a long time, but I didn't know how to talk to staff or my mum because I didn't want to upset anyone or jinx our lives. I feel I can make decisions about my life now and that they will be acted upon."*

Sandy's mum said:

> *"As a result of Sandy's involvement in the Dying to Talk project she is no longer burying her head in the sand and is looking to the future, which is a huge relief for me."*

(Names have been changed)

Did we help improve care?

Talking with staff and managers and observing when we visited services showed that Dying to Talk has helped change people's attitudes and make it more normal to talk about death, feelings and wishes around the end of life.

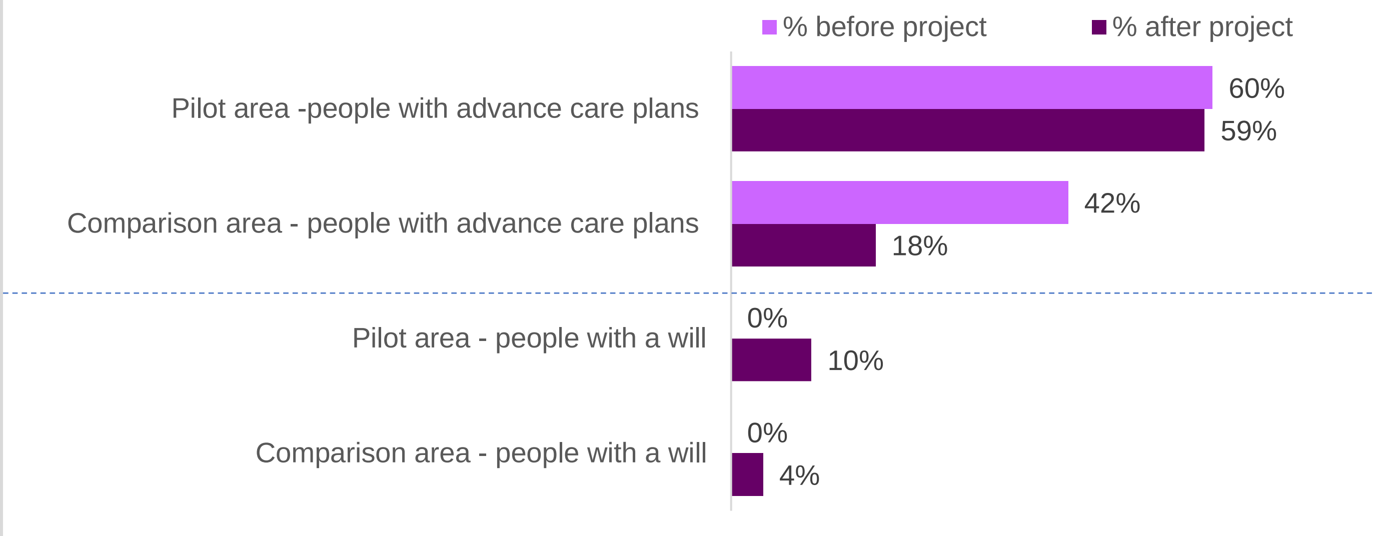
> *"Dying to Talk has empowered people with a learning disability to have a voice. Mindsets have changed from 'we don't to do this' to now staff and people supported want to talk about it. There has been a real change in mindset in people we had contact with. This proves it can be done, as long as there is enough time and resources."*
>
> Project team member

However during the 18-month project period, this has not resulted in more of the people living at our residential / supported living services having advance care plans and wills.

We compared whether supported living services participating in Dying to Talk were more likely to keep records of people's wishes than services not taking part. This would show whether staff were putting what they learnt into practice and talking to people about the end of life. We found that there was not much change at the end of the project.

- At the start of the project, 0% of people supported by participating supported living services **had a will**. By the end of the project this had increased to 10%. In services not taking part, 0% of people had a will at the start and 4% at the end so we cannot say the pilot services improved much more than what happened in other services
- At the start of the project, 60% of people supported by participating services **had an advance care plan**. This was the same at the end of the project (59%). In services not taking part the proportion with an advance care plan decreased, as new people moved in

Change in advance care plans and wills at the start and end of the project



	% of people supported in participating services		% of people supported in comparison services	
	Before project	After project	Before project	After project
Person has advance care plan in place	60%	59% 🟨	42%	18% ↓
MacIntyre knows preferred place of death	8%	10% ↑	53%	29% ↓
Person has a will	0%	10% ↑	0%	4% ↑
Person has a funeral plan	17%	15% 🟨	21%	11% ↓

Note: based on an audit of records of 60 people in participating residential / supported living services at the start of the project and 61 at the end, plus 59 people in comparison services at the start and 56 at the end. Some people moved in or out of services during the project. Figures are based on residents at the time the audits were done.

We asked participating services why there was no change in the proportion of people supported with an advance care plan, will or funeral plan. Staff said some people supported do not have capacity to have these discussions; some families had asked staff not to discuss the end of life with their loved one and some discussions and plans had been started, but were not complete.

It is disappointing that we did not see immediate changes in the proportion of people who had their wishes recorded, but in many cases staff had actively thought about this and had not been able to proceed due to family wishes. This shows how important it is to engage with family so they do not feel apprehensive about MacIntyre or themselves having conversations with their loved ones.

We had more success with day services, which had not kept any records about advance care plans before Dying to Talk. As a result of the project, 97 people supported at day services have started to create advance care plans.

As well as helping us raise awareness about planning for the future, Dying to Talk had wider benefits for MacIntyre. Working on the training made us think more about different cultures and beliefs. We got advice from external helpers about **diversity and inclusion**. This is changing how we think about diversity as an organisation and the language we use.

Did we raise awareness in other organisations?

602 people working in other charities, local authorities, hospices, NHS services and other organisations took part in Dying to Talk awareness raising and training sessions. We originally hoped to share our learning with 5 professionals from other organisations, so we helped many more than we planned.

We surveyed people from other organisations who took part in our formal training sessions before and after the training. All said they felt more comfortable talking about dying with the people they support after the training.

We also followed up 20 people from other organisations using interviews (10) and an online survey (10). 100% said that they found the Dying to Talk project valuable. **80% said they had used things that they learnt from us in their work.**

> *"I found this really useful and recognised that we can shy away from conversations about death and dying, often under the pretext that the person may get upset frightened when actually it is our own lack of knowledge and confidence in how to initiate and manage these conversations skilfully. As in all things we should be endeavouring to support our clients with the right information so they can make the choices they want about what they want at end of life."*

Local authority team

> *"After the webinar I am not afraid to bring up the subject of dying. I learnt to take the lead from the person you are talking to and break it down into small chunks, rather than broaching the subject once and giving up. It is great to know there is specialist support for people with learning disability and where to find it."*

NHS team

We used Dying to Talk as a stepping stone to build relationships with others.

> *"The Dying to Talk Project always set out to work closely alongside external health professionals, but the impact and connections we made has been wonderful and so much more than we thought we ever would achieve. We are proud to have worked alongside Marie Curie to make the Commission on Bereavement accessible for a national launch. Another highlight is our connections with local hospices. We let MacIntyre staff know that a local hospice offers support for everyone. We found that hospices don't have much confidence working with a person with a learning disability so they are requesting our support."*
>
> Project team member

We directly contacted local hospices and invited them to visit the people we support with us or share resources. Hospice teams said that listening to the people we support helped them think about revising their own services to be more inclusive and supportive.

> *"It was really useful for us as a hospice to start trying to see ourselves through the lenses of someone with a learning disability and think about how we might adapt or change our services to meet their needs. It was also very productive in terms of building links between our organisations… I found it really interesting to hear what people with learning disability knew about hospices – and it was great to be able to share some more information with them. It was so interesting and moving hearing their thoughts and reactions to the subject of death and dying."*
>
> Hospice representative

Dying to Talk worked closely with the hospices in our pilot areas. This has led to the hospices supporting training for our staff and families of the people supported, and MacIntyre sharing our expertise about how hospices can better support people with a learning disability, both around the end of life and during life.

For example, a hospice in one area was reluctant to allow people with a learning disability to volunteer in its charity shops. MacIntyre was able to help the hospice understand ways to communicate and raise awareness of roles and responsibilities when employing people with a learning disability. The hospice is now starting to let people with a learning disability volunteer for work experience. Having a (voluntary) job is something that many people take for granted but for a person with a learning disability it can be a big step, helping them to feel a part of the community and creating a sense of worth and importance.

> *“I have been very impressed with MacIntyre’s professionalism, creativity and responsiveness. They reached out to us and this has led to a productive and mutually beneficial relationship. I attended a group that MacIntyre runs and met with people who have a learning disability who have taken part in a Dying to Talk session. It was impressive to see how confidently they were able to talk about death and dying following the session. The staff were interacting with respect, kindness and great skill with the people supported. They helped me to convey sometimes complex information about the hospice to the group as well.*
>
> *I also took part in a coffee morning with MacIntyre families where some really meaningful interactions took place. The hospice team talked to people to dispel any fears or myths about hospice care.*
>
> *MacIntyre also helped us think about having volunteers with a learning disability. MacIntyre are providing our hospice with invaluable support to develop our strategy, resources and skills in terms of engaging and working with the learning disability community. We have plans to work together so that MacIntyre can ‘audit’ and evaluate our hospice and its services from an accessibility and inclusion perspective and they will deliver some training for our staff. MacIntyre are providing the hospice with much needed expertise, training and resource.”*
>
> Hospice representative

What did we learn?

What did we do very well?

The Dying to Talk team, Steering Group and external helpers reflected about what worked well, what we learnt and what we would do differently in future. Some of the things that we were most proud of during the project were:

- **coproducing** everything with the people we support, and drawing on external experts rather than thinking we know how to do everything alone. We also built links and worked alongside many other organisations such as Learning Disability England, hospices and other charities

- providing training and support during the COVID-19 pandemic, when our services were very busy and the people we support were scared and vulnerable. We **reached more people than our original target** and got good feedback about our training and resources. Staff used what they learnt to improve conversations with the people we support. We created an e-learning module and resource pack that will be a legacy to share the learning across McIntyre services

- putting a lot of energy into **promotion and communication**. This included collecting stories from people we support, family and staff; sharing information in new ways such as ‘Twitter takeovers’ and producing a steady stream of blogs, stories, videos, podcasts, radio interviews and website content throughout the project

- continuously learning and **adapting** in response to people’s feedback. We spoke with people informally, did surveys and had meetings to hear what people supported, families and staff wanted. We kept a success and lessons log and reviewed it regularly. We also had team review sessions and reflected with our external helpers

- building in **evaluation from the start** so we could look at whether anything changed over time. This included auditing whether services had records of advance care plans and wills, keeping a lessons log, and surveying the people we support and staff before and after the project. It was hard work to get survey feedback. We provided paper and online versions, telephoned managers and visited services to help people we support. Many staff do not use computers at work so we sent text messages with a survey link as well

Working with people we support

Dying to Talk aimed to find out which methods worked well and not so well to have conversations about planning for the future with the people we support.

We learnt that:

- **it is possible and worthwhile to talk about death with people with a learning disability**. We thought that people might shy away from talking about this, but as long as it was done in an informal, interactive and sensitive way people wanted to take part
- it works best to interact with the people we support **face-to-face** rather than online or through documents because people like working together side-by-side in groups. Creative activities with art and music worked particularly well
- it works best to approach the topic with **games, songs and fun activities** so that people want to take part

> *"I know what happens when I get old now. I liked the music and games. I'm still sad because people are not here. I am not scared. I understand more. I am thinking what I want now."*
>
> Person supported

- it **takes time** for people to feel comfortable talking about death and planning for the end of life. We ran sessions between two to five hours long with plenty of breaks and different activities so people could get comfortable with the topic. Visiting services more than once helped people to get more comfortable talking about these topics
- family members were more worried and upset about us talking to the people we support than the people with a .learning disability themselves Family members were concerned that we might upset the people we support. It was important to **talk with family members** so they know what we want to do and why so they can be part of the process. Specific awareness raising videos, sessions or leaflets for family members could help

MacIntyre Dying to Talk Project Coffee Morning

Queens Park Conservatory, Chesterfield
Thursday 28th April 2022
10am-12pm and 6pm-8pm

Free entry and refreshments
Resource table will be provided by the local hospice

- Want to know more about the Dying to Talk Project?
- Feel you need to make a plan for the future but don't know how to start?
- Want the chance to talk to other family members who MacIntyre support in the piloted areas of Derbyshire, Leicestershire and Worcestershire?

For more information, please contact Rachel Furniss:

People with a learning disability have different levels of capacity. We wanted to test ways of working with people with different levels of ability to engage.

In one of our pilot areas, a lot of the people we support are non-verbal with ageing or no families. The Dying to Talk team worked closely with a local manager to test advance care plans. The manager said that there was too much information needed in the plans and it was daunting to fill in. A lot of the people supported would need ‘best interest decisions’ made, which makes it difficult to complete advance care plans without having the families fully involved. We held a garden party to start conversations about this with families. We also developed ‘choice boards’ and other resources for people who communicate non-verbally.

In another area, we did a lot of work with the people we support in a day service. They became like an advisory group for the project, with people supported and staff helping to test resources and workshop activities before we used them in other services. This group shaped the way we delivered workshops for people supported and staff. We also helped people from this day service fill in advance care plans. Staff from the day service proactively drew on the Dying to Talk team when someone died or became ill. This is an example of how working side-by-side with local teams and making repeated visits helped people supported and staff become comfortable asking for help.

We found that it is essential to have a project manager, champion or someone to do the work ‘on the ground’ because it took time and passion to get services on board and role model how to have conversations in a sensitive and non-threatening way. It is probably not something that staff can do alone as part of their usual work, without some type of training, mentoring or support.

The Dying to Talk project had a good team who worked well together, bounced ideas off each other and brought different skills. We made most progress in areas where one of the team members was based, which shows the importance of having local champions.

> *“I believe we need to look at finding local champions who we can really invest in to carry this forward within MacIntyre. I also believe that we need to give management more targeted training so the message is filtered down to staff and so managers understand the importance of the subject and know that the people we support do want to take part and they do benefit. This isn’t a quick fix, it’s a long term shift in culture.”*

Project team member

Training professionals

We also learnt about how to train and support our staff and professionals from other organisations. Some of the main things we found were:

- it is essential to **get MacIntyre service managers and area managers on board** from the start so they encourage staff to attend, release them to take part and help staff put into practice what they learn. Managers and staff had lots of other priorities. Staff shortages meant that staff often needed to withdraw from training to fill gaps at the services and there was no incentive for managers to encourage staff to discuss people's wishes and fill in advance care plans after training

- **staff want training** in how to have conversations about the future with people we support and their families. More than half of all staff working in residential/supported care services in our pilot areas attended at least one training session. When we followed up after the training they said they would like more information about how to work with families

- staff can be worried or nervous about attending training about death so it is important to use the right **words and messages** to encourage people to take part. We worked with people's managers to encourage staff to attend. We also told people that we could send them resources if they did not want to attend training. People may be more open to talking about 'how to live well and plan for the future' rather than 'planning for the end of life'

- it needs to be **easy for staff to book** on to training. Staff sometimes said they did not have the time to book using our internal booking system. Care staff do not all use computers regularly in their roles. We therefore worked with managers when they were setting rotas to release staff for training. We did bulk bookings for staff teams, which worked well

- we need to get a **balance between the depth of training and providing short accessible sessions**. People learnt most and felt most confident when they attended three sessions of training, spread over time. However staff are very busy and many people were not able to attend three sessions. We shortened the training into a two-hour session. People liked this approach but it did not have as big an impact on increasing staff confidence

- **staff have lots of experience to share**, both personal and professional. We used a shared learning approach during training where we viewed staff as experts, alongside the facilitators. We used discussion points and prompted people to speak. Some staff said this worked well because otherwise they would not speak up

- having **smaller numbers in workshops** worked best to support conversations. Between 3-15 people attended each session. Sessions were most interactive when they included about five staff

- it worked well to have **interactive activities** throughout the online training, rather than a lot of talking and slides. We had three to four speakers at each session to add variety. Staff liked having online breakout rooms so they could have discussions in small groups. Some team members enjoyed role play and wanted more of this whereas others found this uncomfortable. We used videos during the training, including videos of people with a learning disability, which staff particularly enjoyed

- using **conversation starter cards** encouraged people to start discussions. We used commercially available cards which had prompts about topics such as death, funerals and grief. During training we randomly picked a card to start a discussion. As a result of the project we are rolling out our own version of the cards for people with a learning disability. Having a mix of videos, prompt cards and easy read documents to share worked well and recognised that staff have different learning styles

We found that it is possible to run sensitive training online. Usually we would have run staff training in person, but we used Zoom due to COVID-19 restrictions. Having online sessions reduced travel time and costs and it meant that some people were more comfortable attending because they could turn off their cameras or take time out from a session if they felt upset.

However there were downsides. It was sometimes challenging for facilitators to manage sensitive topics remotely if people became very upset. We let people know that they did not need to keep their cameras on, sent them direct personal messages and signposted them to internal and external resources for support, but this was not a substitute for giving someone a hug.

Another issue was technical. Many frontline staff don’t have their own devices with Zoom. Staff would often need to cluster around a single laptop at their work. This sometimes inhibited participation or did not give people privacy if they needed some ‘time out’ from the content. It also meant that we could not always get individual responses to our ‘after’ pop up survey question about what people had gained from the training

We felt that we achieved a lot when we visited services to run sessions with people supported so staff could see the approach live in practice. During visits we could have informal conversations with staff, review records to see whether people had advance care plans and reach staff who were not attending online sessions, either because they shied away from the topic or did not feel comfortable online. In future, we would consider offering a mix of in person and online training and support rather than thinking that everything always needs to be in-person.

Things went well when we were able to engage with staff, but we reflected that we need to find ways to let more staff know about the project. Sometimes managers did not pass on fliers or newsletters or release staff to take part in training or demonstrations, so in future we need ways to engage managers to pass on messages or ways to reach staff directly.

We also learnt that many professionals from other organisations are eager to have these types of conversations with the people they support. People from other organisations said that limited training or resources are available about this. Online sessions and social media worked well to engage with professionals from other organisations, however this was only awareness raising rather than getting into depth about how to have positive conversations.

What could we do differently?

Things that we might do differently in future include:

- working more closely with service managers and area managers because without **buy-in from frontline leaders** it is difficult to change the way that people work. For example, we could have an (online) meeting with area managers to get support before starting to visit services. We could have asked managers and staff what the potential barriers might be and how we should adapt our approach for each area. We could also have had managers, frontline workers and family members on our Steering Group so that they could help to govern the project and feel that they owned it

- doing more to get **family members** on board early. Some families were pleased that we were talking with the people we support about death. Other family members were anxious. Our staff told us they want to learn more about how to talk with families about this

- finding ways to communicate with staff directly rather than relying on managers and providing **more follow-up support** to help staff use what they were learning in their day-to-day work. We worked with four geographic areas, but this was a lot of services and staff to cover. It meant that a lot of our work was raising awareness and providing information rather than helping staff make changes in practice. It worked well when we visited services more than once to show how to do things or question why there were no records about people's advance care plans. In future pilot projects it might be best to work with one area so we can do a lot of detailed work and help people make changes

- having **clear learning objectives** for our training and 'testing' staff knowledge before and after training so we can demonstrate change. We could also follow up participants three months later to see what changes they made and encourage more action

- building a network of **local champions** using a train the trainer model, so a central team was not responsible for everything. This would also assist with sustainability

- looking at ways to **embed the work** into business as usual and seeking further funding earlier. This was a pilot project testing different approaches. We did not have funding to offer training and resources to all of our staff and services. We created a toolkit of resources and e-learning as a legacy, but we learnt that real change needs more than this type of awareness raising. It needs visits to services, role-modelling and repeated follow-up

What are we planning next?

Dying to Talk showed that it is possible to involve people with a learning disability in discussions and decisions about death and planning for the future. We found that there **are** benefits to building up staff members' skills and confidence to talk about the end of life with the people they support. We achieved what we set out to do:

1

Understand how to improve staff knowledge and confidence about discussing death and dying with people with a learning disability

We:

- found that a **mix of online and in-person approaches**, resource packs, videos and stories helped to improve staff knowledge and confidence
- **increased MacIntyre staff's confidence** speaking about death and dying with people supported. We trained 134 staff. 28% said they felt very comfortable having these conversations before training. This increased to 60% after training
- created **resources** so we can share what we learnt across MacIntyre
- provided direct training and awareness raising to 602 **professionals outside MacIntyre**. 80% of people from other organisations that took part in our training said they had used what they learnt when we followed them up months later

2

Understand how to improve the confidence of people with a learning disability and their families to talk about death and dying

We:

- found that **in-person interactive sessions** with games, music and fun worked best to start conversations, especially if we could talk about this more than once
- helped people with a learning disability **feel less frightened** to hear the words death and dying. 28% said they felt ok talking about dying before the project. This had increased to 54% by the end
- helped **people with a learning disability learn more about death**. By the end of the project 53% of people supported by participating services said they knew a lot about dying compared to 11% in services not taking part
- started to have conversations with **family members** about speaking with their loved one about death and dying

The funded Dying to Talk project ended in November 2022. From 2023 we will share what we learnt with services throughout MacIntyre. We are planning to:

- embed this approach in the **workplan** of one of our central (HQ) departments, so the work continues. We will link this to the overarching priorities and values of our organisation, such as involving the people we support at all stages of their lives and supporting staff wellbeing. We may focus first on services that express an interest in making change
- **share resources** with every MacIntyre service and encourage all services to have at least one staff member complete the e-learning module we developed during Dying to Talk. This will be available on our intranet for all staff
- discuss helping people plan for the future during at least one scheduled **meeting with families** each year
- train **champions** in each area to promote this approach
- consider whether it would be feasible to **offer training to external organisations** for a small fee, to cover costs

Building on the Dying to Talk project, MacIntyre is now involved in a two-year study to improve end of life care planning for people with a learning disability. The project is led by Kingston University and St George's, University of London and also involves the Open University, the Mary Stevens Hospice, Voluntary Organisations Disability Group and Dimensions. The research is developing resources for people with a learning disability. MacIntyre will help to test these resources with 30 people we support. The research will result in a free online toolkit, helping health and care staff and family members learn how to support people with a learning disability in different scenarios.

"I liked this. I liked talking about grandma. I liked talking about my best song. I liked having ideas on what I want. It made a lot of thoughts in me. I want to talk more. It is not scary or sad after all."

Person supported

"It is a long process to change the culture and what is 'normal' to talk about. We can't expect to have solved everything in a few months. MacIntyre is only one part of the equation. Families, GPs, hospices and other services all have a part to play. That said, it is phenomenal that we've shown that the people we support can and will plan what is most important to them as they and their families age. We've shown that our staff can have a big impact at every stage of a person's life, and that no other organisation really seems to be tackling this. We are leading the way, and want to share so everyone benefits."

MacIntyre senior manager