

DYING MATTERS



**FOR PEOPLE WITH LEARNING DISABILITIES
IN BRADFORD DISTRICT AND CRAVEN**

Report on the 2023 Dying Matters event for people with learning disabilities.

This report talks about what happened, people's feedback and what we will do next. It includes Natalie & Carol's speeches about why our event is so important. If you would like to know more, please contact victoria.donnely@bdct.nhs.uk or any of the self-advocacy organisations involved.



Introduction:

This event was held on the 2nd May 2023 and was the 2nd Dying Matters event held in Bradford district & Craven for people with learning disabilities. It was organised by representatives from the specialist learning disabilities team at BDCFT, SNOOP, Keighley & Craven People First, Exclusively Inclusive, Bradford People First, family carers of people with learning disabilities, the Hospice staff at Marie Curie (Bradford) & Sue Ryder Manorlands (Keighley), BTHFT Palliative care team, BTM & Healthwatch Bradford.

It was funded by the Strategic Clinical Network Palliative and End of Life Care (All age) NHS England, North East and Yorkshire Regional Team.

The event aimed to raise awareness and support improving conversations around death and dying for people with learning disabilities, their family and carers and the wider support providers who may encounter people with learning disabilities who are end of life, or who may be grieving for someone who has died.

Who attended:

The event was open to people with learning disabilities and anyone supporting people with learning disabilities across the Bradford district.

Over 100 people attended the day. This included at least 9 family carers, over 40 people with learning disabilities, 20 support staff and 20 clinicians. It was oversubscribed and more people wanted to come than we had space for.



This is why we had the Dying Matters Day :

Hello, my name is Natalie Sargent.

It is nearly 3 years since my sister Zoe died. Only now I am starting to talk about her more and understand that she's gone forever.

Everybody is different and so grief for me is different to someone else.

It is really important to talk about things more. It makes it easier.

If only I had been able to come to a Death & Dying Matters Day, I would have been able to understand more about what was going to happen and be more prepared for my sister dying.

My sister Zoe was my best friend. I loved her and miss her all the time. When Zoe was dying, she talked to me about what was happening. She said "it is time to let me go" and that it was ok, and she said she was not scared. She talked about what she wanted to happen for her funeral, and we planned her wedding and me being her bridesmaid, about our dresses and about wearing matching white converse.!

Only now I am able to be open and honest about things and how I feel – that is because as a family we talk, we plan, we listen to each other, and we remember Zoe every day.

I write my special messages to her in my journal.

Dying might feel scary but my sister proved to us that if you talk about everything and you plan what is going to happen and you say everything you need to say to each other, then it not as scary at all.

Thank you for coming today and we hope you find it helpful. It's ok to feel sad and its ok to laugh today too. Today is a good day!

Agenda:

We had a busy agenda (included further on in report) with 12 different presentations. These included practical & thought-provoking ways that people could be supported to remember their loved ones, planning for the future, fun ways to start difficult conversations and a Q&A session. At least 6 of the presentations were led by or included people with learning disabilities.

We also had a number of stalls with information from the local Hospices, self-advocacy groups, Wills & Trusts information, the health promotion library with accessible resources, the Alzheimer's Society and Healthwatch.



Feedback:

Nearly everyone who attended gave really positive feedback about the event. In nearly all the feedback people wrote about how much they had enjoyed listening to everyone's different experiences – this was a really important part of the day. One person reported they found it hard to listen to people's experiences.

More than 20 people said they would like to be involved in more conversations in the future.

They wanted to see more sessions where people with learning disabilities could talk about friends or family who had died and be supported with how to deal with this.

They wanted sessions to think more about funeral planning, think about how to start having difficult conversations, think about planning for health emergencies. Some staff & family carers wanted to know more about how to help people they were supporting who were grieving.

Some quotes from the day:

I didn't know about the Respect form before so that was helpful

The one thing I will remember from today is the loss a person with learning disabilities experiences

An excellent event and has inspired me to start some conversations

Emotive & thought provoking, inspiring, open & honest, I laughed & I cried – thankyou

Thanks to all involved - very informative event.

I thought all the talks were interesting and I know more about dying now

**Heart-warming – I loved hearing people's experiences
I will remember the generosity of those sharing their experiences**

Next Steps:

Some of the things we are going to do next:

- 1) Run a monthly drop-in session with different topics related to death & dying – these sessions will be open to anyone who wants to attend. They might look at:
 - 1) Before I die, how do I want to live - topics such as a) Starting conversations b) Thinking about future planning & ReSPECT,
 - 2) After I die - what do I need to have in place – a) Planning a funeral b) Wills & Trusts
 - 3) Understanding & talking about death - Bereavement support.The sessions will also include time for people to talk with others and be a safe relaxing space. We are in the process of developing a flyer to advertise these sessions which will start in September 2023.
- 2) Develop a resource pack for people - this will include a copy of the “starting conversations” game, a guide to local and national resources and an understanding difficult words about death & dying resource.
- 3) Identify what the local offer is for people with learning disabilities who may need bereavement support.
- 4) Keep in touch with other organisations doing similar things elsewhere such as Merseyside People First and Leeds.
- 5) Find out more from Amy & Christopher re the research project work.

Other things to think about :

- 1) Do we need to include ReSPECT on the annual health check ? (Vicky & Amy)
- 2) Do we need to think about how emergency planning/ ReSPECT can start for children and young people & does this need to be mentioned on the Local Offer pages ? (Carol & Vicky)
- 3) Could we do a Top Tips for family/ support staff re helping someone be involved in a loved ones funeral ? (Katie?)
- 4) Using the David Projects Utube videos in our drop in sessions
- 5) Self-advocacy groups to think about having a project like the David project ?
- 6) Link with Martins House hospice to see what documents they use with people.

Agenda

Positive Conversations about Death & Dying with People with Learning Disabilities

9.30 Arrival and drinks

10.00 Natalie & Carol Beardmore - Why do we need conversations about death & dying?

10.15 – The Big Soup - Life Cycle

10.50 Amy Russell & Christopher Porter -

“Planning for a health emergency” research project

11.00 Katie Peacock - ‘Farewell to Mumma’ – How Gareth’s support team enabled him to be at the centre of his Mum’s funeral

Quick coffee break and stalls

11.40 2 workshops –

1) *Exclusively Inclusive* - Board game & conversation starters

2) *Dorcas Lambert (BTHFT) What’s important when thinking about future planning (ReSPECT)*

12.10– 1.00 pm – Lunch & stalls

1.00pm People First Merseyside - The DAVD project

1.30 - Carl Challinor, BDCFT library - Resources talk

1.35 – Nadia Clarke talks about how she remembers her twin brother Liam

1.40 2 workshops -

1) *Marilou Armada, End of Life educator talks about the support available to care providers working with people with learning disabilities*

2) *Bradford People First - Making memory box’s*

2.15 pm Keighley People First & Dr Mike Hughes Question & Answer session

2.35 pm Slater & Gordon Solicitors - Wills, Trust funds & finances

2.55 Carol & Natalie finish the day & think about Next Steps

3.15 pm Finish

Carol's, Natalie's mum, talks about why Death & Dying Matters

Talking about death, dying, funerals, whether it is planning our own or we have lost someone close to us, is hard enough for anyone, but for an adult with learning disabilities it is even more difficult to understand and process. For the parent/carers and support staff of adults with learning disabilities it is often a difficult choice to decide whether to be honest and open with the person about the person dying, whether they should say goodbye or not, whether to go to the funeral / memorial or not. For some parent/carers and support staff it may feel easier not to talk about it at all because we want to protect them. This, however, often results in avoiding the whole issue completely. But it is important to remember that people with learning disabilities feel and will grieve, though it may not be easy to spot and can be misinterpreted. This is because everyone is an individual and every one deals with things in a different way. There is no right or wrong way, a person's grief may not follow the expected pattern at all, but they are still experiencing grief and loss, even though they may not be able to express it in a way we can understand.

Grief is not just about sadness or anger. It is a whole range of emotions, which we each process over however long it takes to process and there is no set time limit. Time is not necessarily a great healer either, though this is often said by people who are trying to offer comfort and care. If a person with learning disabilities finds expressing and understanding their feelings and emotions in the everyday, the additional burden of grief and loss can make it so much more difficult. So, their feelings and mood changes, saying they feel unwell or refusing to do something, and changes in their behavior should not be misinterpreted. These can all be due to the grieving process for that person.

The feeling of 'loss' is something which is often overlooked by those around the person with learning disabilities. It is not as simple as the loss of a physical person they loved, but it is the difficult issue of 'never ever again'. This is often when anxiety and panic begins to be felt. Never, ever again, will I go to that person's house each week, so where will I go and who will take me?; I'm never going to hear their voice or laugh or be able to hug them or speak to them. That idea of 'never, ever again' can be a frightening prospect. Death and dying can mean huge change when change is not easy and there has been no time to prepare or plan for it. Wouldn't you want to talk to someone about these feelings.

We often underestimate the impact on the person with learning disabilities, physically, emotionally and psychologically and then what seems a random comment by them, out of the blue, makes us realise that they too are struggling. I say, 'they too' because you too may be experiencing grief and loss and can only deal with your own feelings and emotions and that is okay, but it would be good to make sure that someone is helping the person with learning disabilities when you can't but they still need it.

The dreaded question..... 'Why did this happen?'

Perhaps explaining that death and dying is simply a part of life. We are all born, we grow from babies, to toddlers, to teenagers, to adults, we go to school, we go to college, we get a partner to care about, we might go to a wedding, or a sibling may have a baby, we do lots of new things and we grow older. This is called our lifecycle. Everyone is born and has a birthday, and everyone dies, and we remember the day they died. And we remember them and still talk about them even though they have passed away. It is simply a part of life. Just in the same way no one can tell you the exact day, date and time a baby is going to be born, no one knows the exact day, date and time a person is going to die. It can happen at any time during that life cycle.

To say 'goodbye' or not?

This is a very personal thing, but isn't it surely the decision of the individual and not for someone else to decide? We often worry whether we should let the person with learning disabilities go to the funeral or memorial because we fear what we might have to try to explain, such as 'why is in that box?'. We worry they might be too upset or not understand what is happening so wouldn't it be easier to explain things to them so they can make their own decision as to whether to go to a funeral/memorial service or not. As adults they do need choice and control over their decisions where at all possible and we do underestimate people with learning disabilities. Please think about this.

Thinking Ahead.....

It might be helpful if we all took the time to consider what we want to happen when we die and also what the person with learning disabilities we care for, wants when they die. What is important to them, favourite songs, flowers, people, favourite places, memories, holidays, special things they have kept since childhood. This can be so helpful to those who need to plan and prepare. Why not think of these conversations, being open and honest, with people making plans like this.....

"You find a beautiful warm coat in the summer sales, and it is a ridiculously low price, one you would be foolish to miss, so you buy it. You know you won't get chance to wear it for months and months, but those months pass by so quickly and suddenly it's cold and wet and you remember your coat in your wardrobe. You had forgotten about it, but you are so glad you thought ahead all those months ago. And aren't you glad you have that coat now! "

Think about talking about death and dying as that warm coat..... Such a good plan!

Carol Beardmore – CEO and Consultant in Learning Disabilities

SNOOP Charity 15/2/23