

Including people with learning disabilities in end of life care

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Including Diverse Communities in End of Life Care is a three-year project launched in Cardiff and the Vale in January 2016 in with funding from the Big Lottery Fund. In this project, we're looking at the needs of people with learning disabilities. The project is also addressing the needs of people with dementia and people with different religious views, including those with no religious beliefs.

At Marie Curie, we recognise that people from different groups have diverse needs and may face barriers when they want to access end of life care services. By working with local organisations and individuals, we want to:

- find out more about what particular needs these groups of people may have
- help them understand how we can help
- make it easier for them to get support from us when they need it.

What have we done so far?

We've been working with organisations that support these specific groups of people. This has given them opportunities to share their experiences and needs with us.

Our project is also supported by an **advisory group** that includes external representatives from organisations that support or represent these three groups of people. The group includes a service user and trustee of a local learning disabilities self-advocacy group, and a representative of Learning Disability Wales. Their involvement has been vital in linking up other organisations and in supporting other people with learning disabilities to be involved with the project.

- **In the first 18 months of our project, we consulted with 54 people about end of life care for people with learning disabilities.** These included people with learning disabilities, health and social care professionals, and carers.
- **We've analysed their views, identified the barriers they face in accessing end of life care services and developed a set of recommendations to address these barriers.**

What are the key barriers?

- **A limited understanding of palliative care** was recognised as a factor in reducing people's access to services. Many people told us they still perceive hospices as a place people go to die, instead of going in to have their symptoms controlled and support to live the rest of their life. They also told us that people feel that accepting palliative care services is admitting that this is the end.
- **Participants' understanding of who could access our services was often limited.** Many of them assume that we only support people with cancer.
- **Social care professionals shared this lack of knowledge and understanding about our services.** As social care services are often the point of entry for people with learning disabilities or dementia to get different types of support, this raises concerns about how they can be expected to access services that they need through social care professionals.

- **Limited availability of accessible information.** People with learning disabilities highlighted the need for accessible information resources to help them understand what support is available for them. In addition to Easy Read they suggested non-written formats including audio and video, which could help reduce people's fear of visiting a hospice.
- **People with learning disabilities not included in conversations about death.** This can be done by well-meaning professionals or loved ones who feel they are 'protecting' the person. This can make it incredibly challenging to access appropriate care and could mean that the person doesn't have the chance to express their own wishes.

What can we do to improve access?

Here's what participants affected by learning disabilities have told us about how we can improve people's access to palliative care services and help people have conversations about death and dying:

"Make it ok to talk about death. We need good information." Learning disabilities support worker

"If I was going to be in to the hospice, I would like to know the area, so I would feel comfortable. I would be told exactly where it is, what care would be provided while I was there; and I generally would just like to know people that work for it because then I would get a bit more comfortable." Person with a learning disability

"Help people to understand that Marie Curie work with death, they do this work all the time and are experts. Explain palliative care, the care pathway. Help them to understand that there will be many people involved but we will try and keep the team consistent. Routine should be kept to as much as possible." Learning disabilities support worker

Feedback from participants has highlighted the **importance of engaging with community groups and professionals** to improve people's understanding of, and access to, palliative care services.

What we've achieved

The project has reached **140 people** affected by learning disabilities or working to support them in Cardiff and the Vale through events including:

- **Information sessions** about Marie Curie's services to local learning disabilities teams and GP surgeries.
- **Training on learning disabilities** to bereavement volunteers.
- **Workshops on advance care planning** to people with learning disabilities, carers and professionals.
- **Hospice visits** for local self-advocacy groups to reduce people's fears about coming to the hospice.
- **Developing and sharing accessible information.** We're working with a local group of people with learning disabilities to produce a video to help those with learning disabilities understand what to expect at a hospice.

Learning disabilities and bereavement training

We delivered a training session to Cruse Bereavement Care's Children & Young Person's forum in South Wales. This was at the request of their members, who felt they lacked confidence about providing bereavement support to people with learning disabilities.

The presentation focused on giving an overview of:

- **Barriers** that people with learning disabilities may face in accessing bereavement services, such as being "protected" from awareness of death.
- **Communication needs** that they may have, including strategies to enable better communication.
- **Person-centred approaches** and remembering to see the person and their needs before the learning disabilities label.
- **Resources** to support people with learning disabilities to talk about death.

Following the course, all attendees felt their understanding of learning disabilities and bereavement had improved. Ninety per cent said that they felt more confident to provide bereavement support to someone with a learning disability. They also appreciated the opportunity to discuss this issue with their peers and discover new resources, and felt reassured that "supporting someone with a learning disability is not as different as you think".

Workshop at Learning Disability Wales' conference: Talking about when we die

We delivered a workshop at the Learning Disability Wales conference in 2017. This annual event is attended by people with learning disabilities, their families and carers, and service providers. The conference theme was 'Love your health', which explored a range of topics relating to the health of people with learning disabilities.

Our workshop, *Talking about when we die*, was designed to get people with learning disabilities to think and talk about their end of life wishes. It was co-facilitated by the Project Manager and a Hospice Nurse.

The workshop included:

- **Two Dying Matters short films** featuring people with learning disabilities talking about death.
- A group exercise using Easy Read advance care planning statements to facilitate discussions about people's wishes.
- Talks about what palliative care is, people's views on death and overcoming challenges such as communication difficulties when supporting people with learning disabilities.

Participants were given copies of Marie Curie's Easy Read booklets and information on further resources on talking about death and dying with people with learning disabilities.

"I came to the workshop hoping to gain ideas about how we help people with learning disabilities to prepare for death. It soon became apparent to me that, in fact, the work of Marie Curie is about life and supporting all people to live as comfortable a life as possible before they die." Joe Powell, National Director for All Wales People First

"Making choices in life and death is an individual's basic right. If someone does not wish to discuss topics like their funeral or what they would like to happen to their body after death then that is okay, but a lot of people would like to make those plans and just need to be given a platform to do so." Lauren James, Hospice Nurse

For more information

If you'd like to find out more about this project, please contact:

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