

# **Making it easier to access end of life care for people with:**

- Dementia
- Learning disabilities and
- People with religious and non-religious beliefs

## **A report on what we found out and what we did**



This is an easy read version of: 'Improving access to palliative care for people with dementia, learning disabilities and people with different or no religious beliefs'

August 2018



# How to use this document

This is an easy read version. The words and their meaning are easy to read and understand.



You may need support to read and understand this document. Ask someone you know to help you.

Some words may be hard to understand. They are in **bold blue writing**. They have been explained in a box below the word.

If the hard word is used again it is in **normal blue writing**. You can check what they mean in Hard words on page 20.



Where the document says 'we', this means **Marie Curie**.

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This document was written by Easy Read Wales using Photosymbols.

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# About the project

In January 2016 we started a project called **‘Including Diverse Communities in End of Life Care’**.



The project was funded for 3 years by the **Big Lottery**.



The project worked in Cardiff and the Vale of Glamorgan.



We wanted to find out how to make it easier for people who are living with an illness or condition that cannot be cured to access our services.

Our services provide **palliative care** and **end of life care**.



**Palliative care** is care to help with symptoms and make life more comfortable as their illness or condition gets worse.



**End of life care** is like **palliative care** that happens near the end of someone's life.

The people we thought needed the most help to access our services were:

- People with **dementia**.

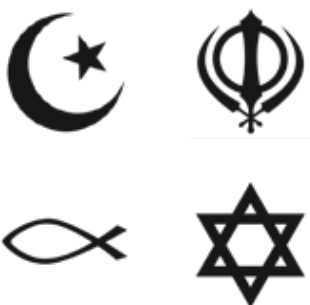


**Dementia** is a condition that affects the brain. People have problems with memory and can be confused.

- People with **learning disabilities**.



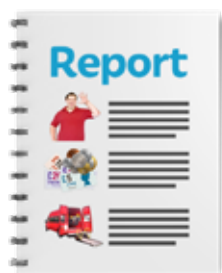
People with **learning disabilities** find it hard to learn some things and do everyday activities.



- People with different **religious beliefs** and **non-religious beliefs**.

**Religious beliefs** are people who are from different faiths.

**Non-religious beliefs** are people who do not have a faith but hold their own beliefs.



This report is all about:

- what we found out



- what we have done and



- the changes we think must happen.

We have talked to:



- lots of people who have **dementia**, **learning disabilities** and **religious beliefs** and **non-religious beliefs** for their views.



- carers and people who work in health and social care.



- **researchers.**

A **researcher** is someone who looks for new information about something to help people know more about it.



Many people said that Marie Curie give a lot of support to people who use their services and their carers.



Many people said that the Marie Curie staff are very good.





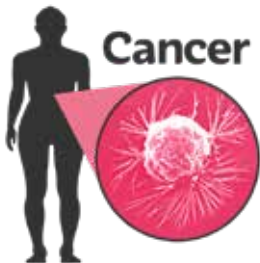
# What stops people using our services

The 3 groups we think need more help have a lot of different needs.

All 3 groups have the same reasons that stop them accessing our help:



## People do not know who can use our services.



- A lot of people seem to think we only help people with cancer. They didn't know we help people with lots of different conditions that cannot be cured.



## People think that hospices are where people go to die.

- They didn't know that people go to them to help make them to manage their symptoms.
- They did not know we support people to live the rest of their life.







**Social Care staff did not understand what we do at the hospice either.**



- This means people may not get the right information.



- Some people think we support **assisted dying**.

**Assisted dying** is where a doctor helps a person to choose when to end their life. This is illegal in the United Kingdom.

We **do not** support **assisted dying**.

**These are the problems each group faced in using our services:**



## **Problems for people with dementia**

There is no plan in place to help people with **dementia** access our services.



Some people find it hard to get the support they need from any services.



**Dementia** is not always seen as a condition that cannot be cured. This means that health staff often do not talk about planning for the future or **end of life care** with patients.



There are not many services for **end of life care**. This makes it hard to access the services that are available.



Sometimes getting money for services is slow.



## **Problems for people with learning disabilities**

Some carers and social care staff do not tell the person they are dying. This is because they do not want to frighten them.



But this means they cannot make choices about **end of life care**.



People with a **learning disability** have the right to know about their health and make choices about it.



There is not enough information given in a way people can understand. This can be scary for people. It can stop them using the service.



Social care staff are sometimes not listened to.

## Problems for people with religious and non-religious beliefs.

### Religious beliefs



- Staff do not understand their beliefs and choices.



- There is not enough support from people who have the same beliefs.



- Language differences make it harder to access services.



- There can be a lot more pressure on the family when there is not enough support with languages.

## Non-religious beliefs



- There is not enough support for people who are **non-religious**.



- People who are **non-religious** fear they might be judged.



- They wanted to be supported by someone who shared their beliefs.



# What needs to change?

We have listened to what people said and this is what we think needs to change.

## Community involvement



We need to visit the community to talk to people more about what we do.



We need to make sure we have information in ways lots of people can understand.



We need to teach health and social care staff more about [end of life care](#).



## Involving people in services

We need to find out more about people's **religious** and **non-religious beliefs** and make sure people are supported.



Staff need help to understand more about different **religious** and **non-religious beliefs**.



Staff need to talk more to people about their **religious** and **non-religious beliefs**.



Staff need to understand more about how people are affected by **dementia** and **learning disabilities**.



Hospices need to make sure the building is accessible.



## Better services

Staff who work in **end of life care** and social care staff need to work together more.



Marie Curie need to work together with health and social care services to find out the best ways to help people.



Marie Curie should try to help more people to have **advanced care plans**.

An **advanced care plan** is when someone makes choices about what they would like to happen in the future to plan for their **end of life care** needs.





## Other changes and plans

Marie Curie is working to become **Dementia Friendly**.



**Dementia Friendly** means making a service easier for someone with **dementia** to use.

For example we have used pictures to show the main rooms.



Marie Curie staff have had training about **dementia**.

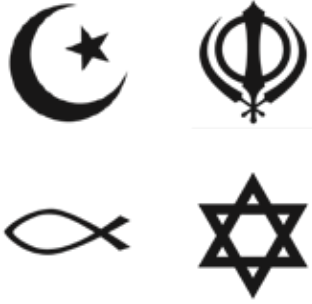


We are working with people with **learning disabilities** to make videos. These will help people to learn more about what we do.

**Cardiff People First** are helping us to make the videos.



The videos will be on our website.



We have a new service called a **spiritual care** service.

A **spiritual care** service helps to make sure people's **religious** and **non-religious beliefs** are understood and met.

We have employed someone to help with people's **spiritual care** needs.



This person will support staff to understand people's **religious** and **non-religious beliefs** better.



They are going to employ volunteers with **religious** and **non-religious beliefs** to help with this.



We now collect information about people's **religious** and **non-religious beliefs** and where they are from.



Staff have been trained on what questions to ask people.



Marie Curie would like to do this in our other hospices too.



We are giving information about [end of life care](#) to people in the community and health and social care staff.

We have talked to over 2000 people. People are finding this very helpful.



This project has helped Marie Curie understand more about the problems people face in using [end of life](#) services.



The information we have learnt will support us to help more people.

We hope it will help other [end of life](#) services too.

# People we would like to thank



We would like to say thank you to everyone who has helped with this project.

The organisations who have helped are:

- Ahmadiyaa Muslim Women's Association
- Alzheimer's Society
- Beulah United Reformed Church, Rhiwbina
- Buddhist Council of Wales
- Cardiff 50 Plus Forum
- Cardiff People First
- Cardiff Parents' Federation
- Church in Wales, Diocese of Llandaff
- Dementia Engagement and Empowerment Project (DEEP)
- Dimensions
- Diverse Cymru
- Humanists UK
- Interfaith Council for Wales
- Learning Disability Wales
- The Mentor Ring
- Mirus
- NHS Centre for Equality and Human Rights
- South Wales Jewish Representatives Council
- Velindre NHS Trust
- Vision 21



We would also like to thank every person who has shared their views and experiences with us.

This will help us to give people better care.

# Hard words

## Advanced care plan

An advanced care plan is when someone makes choices about what they would like to happen in the future, to plan for their end of life care needs.

## Assisted dying

Assisted dying is where a doctor helps a person to choose when to end their life. This is illegal in the United Kingdom.

## Dementia

Dementia is a condition that affects the brain. People have problems with memory and can be confused.

## Dementia Friendly

Dementia Friendly means making a service easier for someone with dementia to use.

## End of life care

End of life care is care that happens towards the end of someone's life.

## Learning disabilities

People with learning disabilities find it hard to learn some things and do everyday activities.

## Palliative care

Palliative care to help with symptoms and make life more comfortable as their illness or condition gets worse.

## Religious beliefs

Religious beliefs are people who are from different faiths.

## Non-religious beliefs

Non-religious beliefs are people who do not have a faith but hold their own beliefs.

## Researcher

A researcher is someone who looks for new information about something to help people know more about it.

## Spiritual care service

A spiritual care service helps to make sure people's religious and non-religious beliefs are understood and met.