Easy read

Death by *indifference*

Following up the *Treat me right!* report

MENCAP

Understanding learning disability

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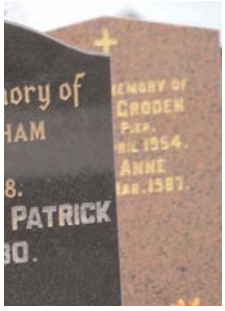
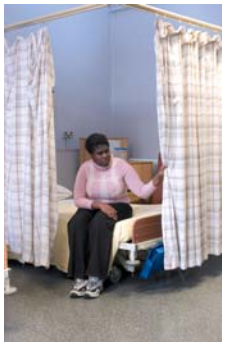
Introduction

In 2004, Mencap wrote a report called *Treat me right!*

It said that people with a learning disability have worse health than other people. Mencap thinks this is because people with a learning disability do not get the healthcare and treatment they need.



Sometimes this can mean that people with a learning disability die when they could have got better if they had the right treatment. It can mean that people die at a younger age than someone without a learning disability. Mencap thinks this is terrible and should not be allowed to happen.



Treat me right! said important changes should be made so people with a learning disability have better healthcare and treatment. Not enough has changed.

Since we wrote *Treat me right!*, Mencap has heard many stories about people with a learning disability who died because they did not get the healthcare and treatment they needed. You can read 2 of these stories in this report.

If you are worried about what is in this report, or about going to the doctor or to hospital you should talk to someone you know. You may like to ask someone to read through this report with you and talk with you about it.

For extra help you can contact the learning disability helpline on 0808 808 1111.

Emma

"Determined, fun, caring, loving... these are the things I think about when I think of Emma."

"She had a great sense of humour and loved pulling faces for a laugh!"

"She had wonderful smiles that could light up a room."

Emma died of cancer in 2004. She had a severe learning disability that made it hard for her to let people know how she felt.

She was only 26 years old when she died.

Emma's Mum took her to see her doctor because she was feeling unwell. She had not eaten for 8 days.

The doctor said Emma had a virus.

Her Mum was worried, so she took Emma to see another doctor. Emma was taken to hospital for some tests. Emma was upset and in pain. She was not eating, so could not take a tablet to help with the pain. The hospital sent her home. They did not give her any medicine to help take the pain away.

Emma and her Mum went back to the hospital to find out what the tests showed.

They were told Emma had cancer. There was a chance that she could be treated and stay alive, but the doctors thought that Emma could not agree to have treatment so they did not do anything to stop the cancer.

Emma was sent home again with nothing to help her with the pain she was in.

A few days later Emma had stopped drinking but the doctors still did not help her. Emma's mum went to court to get a judge to make the doctors help Emma. A different doctor visited Emma, and said that because the cancer had got worse there was nothing they could do to keep her alive.

Emma was taken to a hospice where people who are dying are looked after. At the hospice she was looked after really well and the doctors made sure she was not in pain. After a month in the hospice, Emma died.

Mencap wants to know

- If the doctors had treated Emma straight away, would she still be alive?
- Why was Emma not treated when it might have saved her?
- Why was Emma not given help for the pain she was in?

Martin

"Martin was often smiling – he loved to go out, liked the movement of the coach and listening to the music. When he was young, he liked being in our car as well. He loved getting behind the wheel and turning it around."

"Martin will always be the light of my life. He had a quirky sense of humour and oodles of charm."

Martin died in hospital where he had not been given any food for 26 days. He was 43 years old.

Martin had a severe learning disability and had no speech.

Martin had a stroke. A stroke usually affects your brain and can leave you with serious disabilities. Martin was taken to hospital.

In hospital, he got pneumonia. Pneumonia is an infection in your lungs which makes it hard to breathe.

Martin's stroke meant he could not swallow so he was visited by someone who is specially trained to help. They said he could not eat or drink, so the doctors should find other ways to give him food or drink.

Martin was on a drip. This means water with sugar in it was put in to his blood through a needle. A drip does not give enough food to stay healthy for a long time. After 5 days, doctors are supposed to find a way of giving more food to people who can not eat through their mouths.

But Martin was on a drip for nearly 3 weeks.

The doctors thought Martin's nurses were feeding Martin through his nose, but they did not check.

Martin had no food for 26 days before he died.

Mencap wants to know

- Why did Martin have no food for 26 days?
- Why did the hospital not take better care of Martin?

About this report

Mencap has written this new report because we believe that people with a learning disability are being treated unfairly in all parts of the healthcare service. We believe that this is because of institutional discrimination.

Discrimination is when some one treats some one else badly because of their age, disability, religious beliefs and so on.

Institutional discrimination happens when the people working in a place or organisation

- do not value all people equally
- do not understand that different people have different needs
- do not change the way they deliver a service so that it meets different needs.

This happens for a long time and staff become used to it and do not notice it is wrong.

For example – Mencap believes that people with a learning disability are not equally valued in the health service. People who work in the health service often do not understand the needs of people with a learning disability. This means that their needs are not met.

Mencap believes that

1. People who make decisions about healthcare do not think people with a learning disability are very important.

In 2006 the government said that people with a learning disability do not always get treated equally. But they have not made changes to make sure they do.

2. Healthcare professionals (people who work in the health services like doctors and nurses) do not understand much about learning disability.

Staff are not given training to understand learning disability. If staff have wrong ideas about learning disability, no one tells them they are wrong.

The Disability Rights Commission has found that healthcare professionals sometimes confuse the signs that show someone is ill with their learning disability. This is called diagnostic overshadowing.

3. Healthcare professionals do not listen to the family and carers of people with a learning disability when they try to say what is wrong.

People who care for people with a learning disability know them really well. They notice if the person they care for is acting differently and can see if they are upset or in pain. This is really important if the person with a learning disability can not talk to the doctor or nurse looking after them.

In all the cases Mencap looked at for this report, the families of the person who was ill were ignored, but they knew that something was wrong. Families and carers should always be listened to when they think the person they care for is showing they are in pain.

4. Healthcare professionals do not understand the law about capacity and consent to treatment.

There are laws about giving treatment to people

- who are not able to understand they need help to get better
- who are not able to say they want to be treated.

Healthcare professionals do not understand these laws properly.

Everyone who gives treatment should understand the laws about consent. If they understood the laws better, people with a learning disability would get help that is in their best interests.

5. Healthcare professionals do not always see the lives of people with a learning disability as worth saving.

Healthcare professionals sometimes think that people with a learning disability do not have a very good life. This means they do not always do all they can to save them.

The lives of people with a learning disability should always be seen as important. Healthcare professionals should never decide that a person's life is not worth living just because they have a learning disability.

What Mencap wants to happen

1. Mencap wants the cases in the report to be looked at in an independent inquiry.

There are 6 stories about people with a learning disability in the main report. These are called cases. Mencap wants all 6 of these cases to be looked at in an independent inquiry.

This means people who have not been involved in the cases will look at all the cases together. They will try to find out the reasons why the people with a learning disability died early, and find out what needs to change to stop this happening again.

2. Mencap wants the government to keep its promise about looking at the early deaths of people with a learning disability.

In 2001 the government promised to look at the early deaths of people with a learning disability, but this has not happened.

They have looked at how to do this, but they have not said when it will happen.

Mencap wants the government to keep its promise. This would tell us how many people with a learning disability have died early because they were treated unfairly by healthcare services.

This will help to make healthcare services change so people with a learning disability get equal treatment.

3. Mencap wants it to be easier to make a complaint about healthcare treatment.

If people think they or someone in their family has not been given the right treatment by the health service, they can complain to the Healthcare Commission.

The Healthcare Commission is meant to find out

- if mistakes were made
- if things need to change to stop mistakes happening again.

At the moment it takes too long for a complaint to be heard. Families who are upset because someone they love has died have to wait a long time to find out what happened and why.

Mencap wants the Healthcare Commission to have more money to do its job better. We want it to be simpler and quicker to make a complaint and get an answer.

Nothing can bring back people who have died – like the people in this report. Their families want to know why the people they loved died early when they might have got better with the right treatment.

Mencap has written this report because we want to stop people with a learning disability dying early because they do not get the treatment they need.

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To ask for this document in a different format, contact the Helpline number above.

You can also get this document from the Mencap website at **www.mencap.org.uk**

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