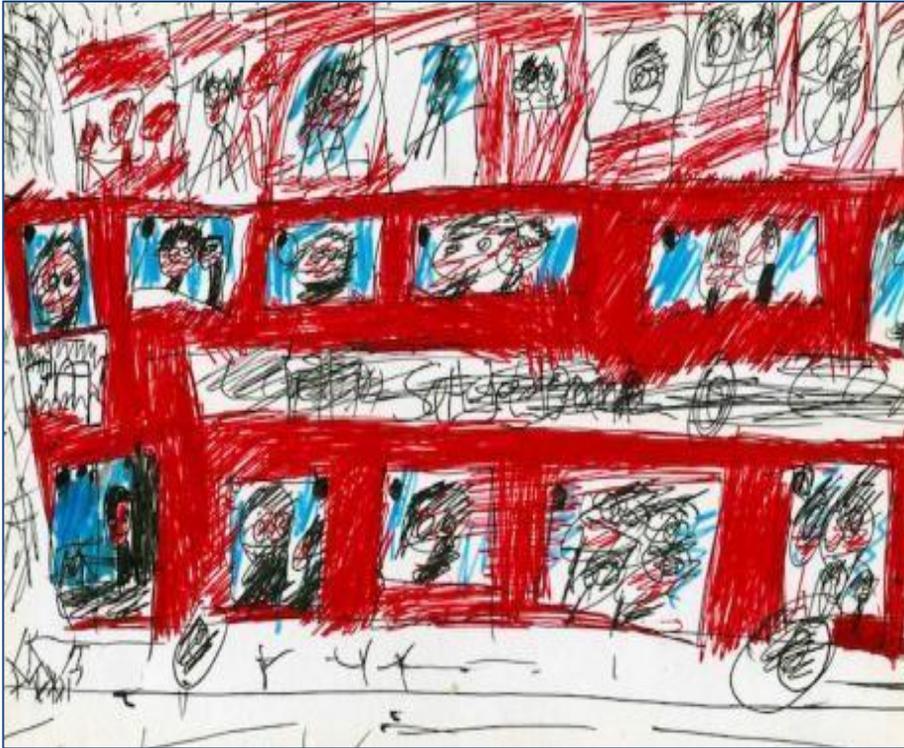


How inclusive is inclusion?



Stop People with a Learning Disability Dying Too Young



The Stop People with a Learning Disability Dying Too Young group is a committed team of people with a learning disability, family carers and people who work with us.

We use our own experiences to look closely at the Learning Disability Mortality Review Programme. The programme is known as Leder.

We look at the reasons why people with a learning disability die too young.





We meet monthly to look at what needs to change.

Men can die 23 years younger and women can die 29 years younger than people who do not have a learning disability.

Women usually live longer than men.

What is happening to the health of women with a learning disability?





In May last year, the Government published its annual report into the deaths of people with a learning disability.

Our team had a lot of discussion and wrote a statement in response.

We want to read it to you.



The Annual report showed that life expectancy had dropped. This is our response.



We think it is shocking. The way that people perceive us, it just doesn't bear thinking about.

This is so hard to think about and talk about. Why should we expect to live 23 years less, or 29 years less than someone without a learning disability?



People need to see the person and not just talk about health. Take time to listen to people. To know the person.

How much harder is it for a person with a learning disability to get an accurate diagnosis?



People don't get the same respect or time given. Sometimes we are pushed to the back of the queue.

Equality for all is still a long way off.

People who have trained as self advocates might have more chance to speak up for themselves. It is so important to invest in this.



We hear about stress on the NHS because we are all living longer.

This doesn't apply to us.





What do we know about people with a learning disability dying from cancer?

Not very much.

The information from Leder does not say what the cause of death was, so it is hard to know what needs to change.

We think that the reviews of people who died of cancer could be looked at.

There might be things to be learned.





What we do know is that being able to access services and getting reasonable adjustments made is very important.

There also needs to be more training on cancer prevention and cancer care.

We don't think that people understand the Mental Capacity Act properly. There needs to be more training.

There also needs to be better communication between everyone.





We believe that people with a learning disability should be directly involved in all the work to help people live longer.

We bring a lot of experience and should be supported and trained to be part of the work.

At Sunderland People First, self advocates have been trained as Peer Educators to offer training around cancer awareness.



BRIEFINGS FOR CARERS
INFECTION
(including SEPSIS)

What is it?

Infections are caused by germs (such as harmful bacteria or viruses) invading a person's body and multiplying. Our bodies usually fight infections with our immune system, which causes inflammation. It is the inflammation that makes us feel ill when we have an infection, e.g. a swelling at the site of the infection or having a high temperature or skin rash.

Sepsis is a rare but serious reaction to an infection. Sepsis is when our immune system response becomes overactive and starts to cause damage to the body itself. It can be hard to tell if you have sepsis. You might not have a fever or high temperature, you may just feel very unwell. Sepsis needs to be treated urgently because it can quickly get worse and lead to severe sepsis or septic shock. Septic shock is very serious, as it can cause organ failure and death.

Signs of infection

- Generally feeling unwell
- Unusually high or low temperature
- New/increased/continual pain
- Change in body functions e.g. new cough, vomiting etc

Early signs of sepsis

- Unusually high or low temperature
- Chills and shivering or centrally hot with cold hands and feet
- Fast heartbeat and/or breathing
- Rash
- Change in behaviour e.g. restless or lethargic

Signs of severe sepsis

- Change in skin colour
- Confusion, dizziness, slurred speech or collapse
- Not passing urine

The national LeDeR team have produced information for carers around the common causes of early death.

There are now posters about things like pneumonia and sepsis.

We have asked for accessible information to be provided for people with a learning disability.

We need the information as well to stay well.

Plus, we are carers too.





Some things we think need to be done are...

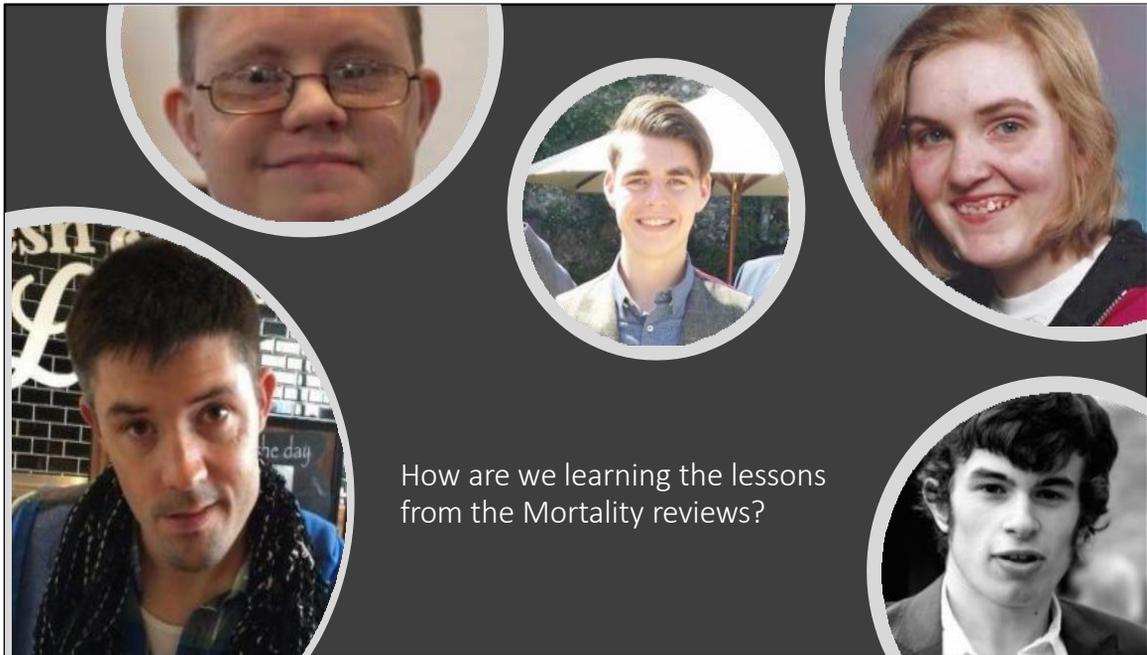
Provide and share easy read information about cancer screening

Make reasonable adjustments to make it easier and less stressful for people to attend screening

Use Health Passports better

Value our lives as much as anyone else's





As a team we would like to know how organisations and health services are learning from the lessons of the Leder reviews.

Based on what you learn today, what will you do differently at work tomorrow to stop people dying too young?

