



Waiting lists for non-emergency healthcare treatment

This information sheet may be useful for families who:

- Have a family member with a severe learning disability
- Are planning to support their family member through upcoming non-emergency surgery or treatment



All our information sheets are available to download free of charge because we believe that money should not be a barrier to getting the information you need when you need it.

Please see the end of this information sheet for details of how to support us.

We want to make sure our resources are helpful. Please spend a few minutes giving us some feedback: [Feedback form](#)

Waiting lists

The Covid-19 pandemic has led to longer waiting times for non-emergency healthcare treatment.

In October 2022 7.2 million people were waiting for treatment. 2.9 million patients were waiting over 18 weeks for treatment and over 400,000 were waiting over a year for treatment (British Medical Association).

Before the pandemic people with learning disabilities were already experiencing difficulties accessing healthcare and were more likely to die prematurely.

To address the health inequalities faced by people with learning disabilities one local area, Calderdale & Huddersfield NHS Foundation Trust, made a decision to prioritise people with learning disabilities for some types of treatment e.g. cancer care. This means that rather than waiting lists being based purely on the date the person was added to it, the Trust is taking the person's learning disability into account leading to faster treatment. This decision was made as women with learning disabilities die on average 20 years sooner than women in the general population and men with a learning disability die on average 13 years sooner than men in the general



population. The Trust decided that *“the impact of waiting for treatment can further reduce this as well as disproportionately impact on their quality of life whilst waiting.”*

Reasonable adjustments

Under the Equality Act 2010 there is a legal duty for the National Health Service to make reasonable adjustments for people with a learning disability.



Equality is not always about treatment everyone the same – it is about treating people in such a way that the outcome for each person can be the same.

Adjustments such as ramps to enable wheelchair users to access a building or allowing guide dogs to accompany a person with a visual impairment in hospital are commonplace. However, adjustments can also be made to process and procedures to support people with disabilities to get their health needs met.

Reasonable adjustments can be changes like longer appointment times, seeing a patient on the first appointment after they arrive so they do not have to wait, accessible information and performing two medical procedures at the same time whilst a person is having a general anaesthetic.

Prioritisation on waiting lists is another way of making adjustments to processes and procedures to improve health outcomes for people with learning disabilities.

For more information on reasonable adjustments see:

- Reasonable adjustments (NHS England) - <https://www.england.nhs.uk>
- Treat me well. Reasonable adjustments for children and young people with a learning disability in hospital (Mencap) – <https://www.mencap.org.uk> or call 0808 808 1111
- Treat me well. Reasonable adjustments for people with a learning disability in hospital (Mencap) – <https://www.mencap.org.uk> or call 0808 808 1111

Working in partnership

Long waiting lists coupled with your relative needing adjustments to the usual service due to their learning disability may make the prospect of a planned admission to hospital or outpatient treatment feel worrying, stressful or daunting. It can help to identify allies who can help plan your relative’s operation/treatment in advance to put in place any adjustments that they need.

Learning disability liaison nurses work in most hospitals to help people with learning disabilities get the health care they need. They can liaise with the staff who will be carrying out the treatment and help explain any adjustments your relative needs. Part of their role is to listen to and involve families and other people who know the person well.

You can ask your GP or hospital if they have a learning disability liaison nurse that you can speak to. Some hospitals have contact details for the Learning Disability Liaison Nurse Team on their website.

If your relative is unable to access the treatment they need you may wish to contact one of the organisations below for advice

For further information and advice on accessing healthcare, please see:

- Patient and Advice Liaison Service - [What is PALS \(Patient Advice and Liaison Service\)? - NHS \(www.nhs.uk\)](https://www.nhs.uk/what-is-pals/)
- Learning Disability Helpline (Mencap) – [Learning Disability Helpline | Mencap](https://www.mencap.org.uk/learning-disability-helpline/)
- Challenging Behaviour Foundation Family Support Service – [Family Support Service - Challenging Behaviour Foundation](https://www.challengingbehaviour.org.uk/family-support-service/)

Summary

Children and adults with severe learning disabilities who display challenging behaviour have the same right to healthcare as everyone else. Taking the following steps may help your relative access the treatment they need:

- Ask if your relative can be **prioritised** on the waiting list.
- Ask for **reasonable adjustments**. What will help the operation/treatment go smoothly for your relative? What plans can be put in place before and after to help? Putting adjustments in place can help things go smoothly and can avoid having the treatment delayed further.
- **Find your allies & work in partnership**. Is there a learning disability liaison nurse who can help? Seek independent advice if you are worried or you come up against barriers.

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The Challenging Behaviour Foundation

We are the charity for people with severe learning disabilities who display challenging behaviour. We make a difference to the lives of children and adults across the UK by:

- Providing information about challenging behaviour
- Organising peer support for family carers and professionals
- Giving information and support by phone or email
- Running workshops which reduce challenging behaviour

To access our information and support, call 01634 838739, email info@thecbf.org.uk, or visit our website: www.challengingbehaviour.org.uk

If you have found this information useful, please consider making a donation. You can show your support at www.challengingbehaviour.org.uk/support-us. Make a £5 donation by texting CBF DN05 to 70085 Or email us to get involved at support_us@thecbf.org.uk