

# Reasonable adjustments in healthcare

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**You may or may not have heard about 'reasonable adjustments', but they can make a huge difference for people who have Down's syndrome who need to go to hospital or visit the GP.**

The Equality Act, 2010, is a law that was passed to help prevent discrimination against people with physical and/or learning disabilities. It states that businesses and organisations must make reasonable adjustments to allow disabled people to access their services or work within them as an employee. That is to say, they must do what they reasonably can, to help people who would otherwise struggle to get the same experience, care, opportunities, or level of service as other people.

So, what does that mean for healthcare? There are some really good examples of the way reasonable adjustments have been put into action, but there's still a lot of work to be done.

Some reasonable adjustments might be quite generic and of use to everyone, but others depend on knowing what sort of support an individual might need.

For some people, waiting in a busy, noisy waiting area might be too difficult, so a reasonable adjustment might involve finding somewhere quieter to wait (if possible), or giving them the first appointment of the day so the waiting room is likely to be less busy, with less likelihood of a long waiting time.



The key word is 'reasonable' – sometimes it's not possible to find a quieter space, particularly in busy A&E departments, but the hospital has a duty to try. Physical access is also important and reasonable adjustments might include ramps, lifts, wider doorways, and railings.

A longer appointment time might also be a useful reasonable adjustment, to allow more time for a person with a learning disability or sensory challenges to be able to get used to the doctor or nurse, feel comfortable in the room, understand what is going on and take part in any examination or tests.

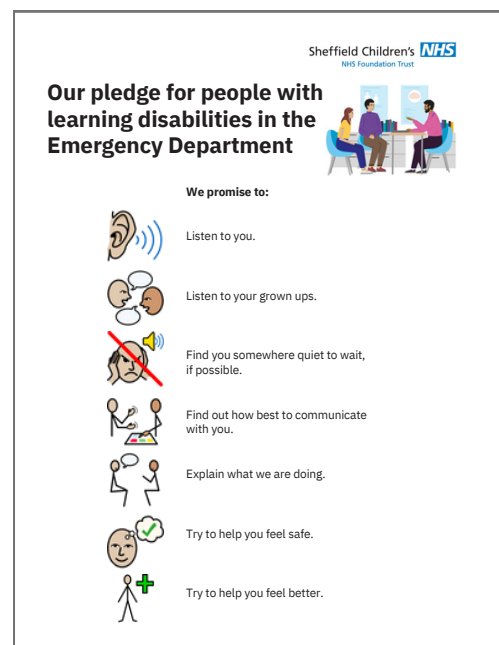
Communication is vitally important for anyone when seeking help with their health. For someone with speech and language difficulties, reasonable adjustments might include the use of 'easy read' leaflets, pictures, photos or symbols, Makaton, or sign language. It might involve just speaking a little more slowly and clearly, avoiding using jargon or complicated phrases, explaining things well and avoiding being in a noisy environment.

Another reasonable adjustment that was particularly important during the COVID-19 pandemic was to allow people with a learning disability to bring someone along to healthcare appointments with them, at a time when most people had to attend alone.

For some people, it might be reasonable for a hospital team to allow a family member or carer to stay overnight with a person if they need to be admitted to hospital but would find being on their own particularly difficult, whether due to anxiety, understanding or communication, for example.

Some healthcare teams have put a lot of thought and work into what they can do beyond the basics, to make access to healthcare easier for people with a learning disability. For example, the team at an MRI scanning unit put together a series of photos for a young man who needed an MRI scan but who was very nervous about going to new places. The photos helped form a social story, so the man could learn about the department and what would happen, before he got there. Videos can also be useful, [like this one from Sheffield Children's Hospital](#).

Desensitisation is another way to help make things like blood tests or EEGs (which use electrodes to measure the electrical activity in the brain, a bit like an ECG for the heart) a bit easier to tolerate. This is often led by learning disability nurses and involves breaking down the procedure, explaining things clearly and giving an opportunity to get used to pieces of equipment or sometimes rooms or environments.





Although reasonable adjustments are required by law, they are not always well known about. Lots of work has been done in recent years to raise awareness and remind healthcare professionals about the, often very simple, things they can do to make a difference for their patients. Often, those same adjustments can make things easier for the healthcare professional, too!

The TEACH mnemonic is a widely used example of this and covers a variety of things that can make a difference.

Another version is STEP IT UP – aimed for use with neurodivergent patients, so including those who are autistic or have difficulties processing sensations, this focuses particularly on communication.

Another framework, particularly for autistic patients, is the Autistic SPACE:

- S:** sensory needs
- P:** predictability
- A:** acceptance
- C:** communication
- E:** empathy

**STEP IT UP: Improve your communication with Neurodivergent Patients**

- S** **Simple and Direct Questions**
  - Ask one question at a time
  - Use simple terms and avoid jargon
- T** **Take your time**
  - Wait for an answer
  - Allow and extra 10 minutes
- E** **Explain to Enable Compliance**
  - Provide a step-by-step explanation of a task and how it benefits the patient
  - Please consider visual aids to support understanding and communication
- P** **Precise Language**
  - Avoid Metaphors and euphemisms
  - Say exactly what you mean and be descriptive
- I** **Include Carers**
  - Consider the carer's opinion when making diagnosis
  - Ask for their help with procedures
  - Ask for a Hospital Passport/all about me/health and communication passport /traffic light system
- T** **Touch and Feel First**
  - Allow the patient to hold and touch equipment before use it on them
  - Warn the patient about sensations
- U** **Understand My Differences**
  - Neurodivergent patients experience and express pain differently
  - Don't assume that current behaviour is normal
- P** **Prepare a Low Sensory Environment**
  - Use a quiet, plain room with minimal staff
  - Keep ear defenders nearby

The LD Pledge was first used in the Accident and Emergency department in Hull as a way to remind not just patients, families and carers, but also staff about the simple things that can be done to help support patients with a learning disability. It is now in use in many other healthcare settings and has even been made into a YouTube video.

There are many different electronic patient record systems in use across the UK and there are national recommendations that alerts should be added to patient's electronic records if they require reasonable adjustments or if they are at increased risk of serious illness.

Projects are underway to evaluate how this could work in a more joined-up way nationally, but in the meantime many healthcare organisations have started to put this in to practice locally. In Hull, Downright Special (the local support group) has worked with hospital clinicians to get an alert added to the records of children who have Down's syndrome to highlight that they may be at increased risk from sepsis.

How can families and carers help with identifying reasonable adjustments that could be made?

Hospital, or health, passports can be useful for this. These are carried by the patient and contain some really useful information that can be used by healthcare professionals, such as how best to communicate with someone, how a person might show they are in pain, what might make a person feel less anxious, what might make them feel scared, etc. If you don't have a hospital passport, ask at your local hospital or your community learning disability team and they can help you get hold of one. Downright Special has put together their own version, which is short and to the point, so easy to read and update when needed.

**HELLO, I'M I AM YEARS OLD (DOB xxxxxx)**

Important people or things in my life are:

Things I like (e.g. food/drink, sensory, interests, motivators):

Things I don't like that upset me (e.g. food/drink, sensory, procedures):

INSERT PICTURE HERE

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**IMPORTANT**

Things that might comfort or distract me when I feel scared:

How you will know I am in pain/unwell/tired?

How I communicate? (See the other sheet in this document for tips):

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**PHYSICAL HEALTH**  
(e.g. medication, health conditions, allergies, Equipment).

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**HOW YOU CAN HELP ME:**

Getting about:

Toileting:

Eating/drinking:

This hospital passport for children with Down Syndrome has been created by [www.downrightspecial.co.uk](http://www.downrightspecial.co.uk)

Most kids with Down's Syndrome (trisomy 21) have some physiological and behavioural differences that make it difficult to assess how sick they actually are:

- Poor temp control:** They will develop a fever if ill, or may be hypothermic instead.
- Weak immune system:** Infections that normally cause only minor illness can be dangerous in kids with DS. Any (on the photo below) spend a week hospitalized at PICU when she had chicken pox!
- Middle easily:** Kids with DS have poor control of their vocal cords ("larynx") with temperature change as well as a respiratory assessment likely.
- Co-morbidities common:** Respirator cardiac problems, GERD, celiac, and autism (do not forget the drug history!)
- Leukemia is more common:** and may present atypically.

**Top tips for triaging & treating kids with Down's Syndrome**

- Ask what's normal for this individual child:** Assessing levels of alertness, responsiveness, how they use all the different joints, and generally practice individual child as baseline. Ask parents: they know their child best!
- Narrow tube, sticky mucus:** Kids with DS get more chest infections, and generally practice more soiled!
- Explain and measure:** Kids with DS often have sensory processing difficulties and can be very fearful. Take time for explain and measure.
- Optimise communication:** Speech & language development lags behind more than they can express. They're often great communicators but have poor short-term auditory memory and fluctuating hearing loss so use sign, pictures and gestures. Speak slowly. Allow for sensory processing or other of general needs. Don't hurry to reply.

**Keep calm! Just don't forget the extra chromosome**

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**Communication tips-children with Down Syndrome**

To help us to understand each other please:

**Speak slowly and clearly**

**I may have some hearing loss.**

**Give me time to process**

**Be quiet while I think and formulate a reply.**

**Repeat**

**Don't hesitate to ask me to say/sign things again.**

**Look at my signs, gestures and body language**

**They give clues about what I feel and think**

**Use signs or universal gestures**

**Show me while you tell me**

**Use lots of facial expression that matches your words**

**Visually support what you say**

**Use pictures/symbols or give me pictures/symbol**

**To visually support what you say**

**Ask a parent/carer to help but try to talk to me first.**

**Try not to ask leading questions. I may give the answer I think you want to hear by default or to please. Ask a parent carer to validate if unsure.**

**Use short, literal sentences-say what you mean**

hospital	Doctor	Nurse	yes	no	poorly
bed	pain	sad	medicine	sit down	lay down
clothes off	clothes on	better	now	next	finished
food	drink	wee	poo	sleep	home

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Hello	Hospital	Name	Doctor	Nurse
Ill/Poorly	Pain	Medicine	Injection	Blood Test
To Eat	Toilet	To Sleep	Next	To Finish

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You could also share some of the resources and examples in this factsheet with your local hospital or GP surgery. It would be great to hear from people who have come across other good examples, too.



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