

# INFORMATION SHEET

## Health and Challenging Behaviour

### Introduction

Everyone feels unwell from time to time, and children, young people and adults who have a learning disability are no exception. In fact, people who have a learning disability are even more likely to develop health problems than people who do not. It is therefore very important that people are supported to have access to good healthcare, receive regular health checks and live healthy, active lives.

All our information sheets are available to download free of charge.

To enable us to continue our work [please support us](#) or donate £3 by texting CBF to 70450.

Is this resource helpful? Please spend a few minutes giving us some feedback: [www.surveymonkey.co.uk/r/cbfresources](http://www.surveymonkey.co.uk/r/cbfresources)

This information sheet will tell you about:



- Some of the common health problems experienced by people with learning disabilities
- How health problems might increase challenging behaviour
- How some challenging behaviours can contribute to health problems
- How you can help a person with a learning disability stay healthy

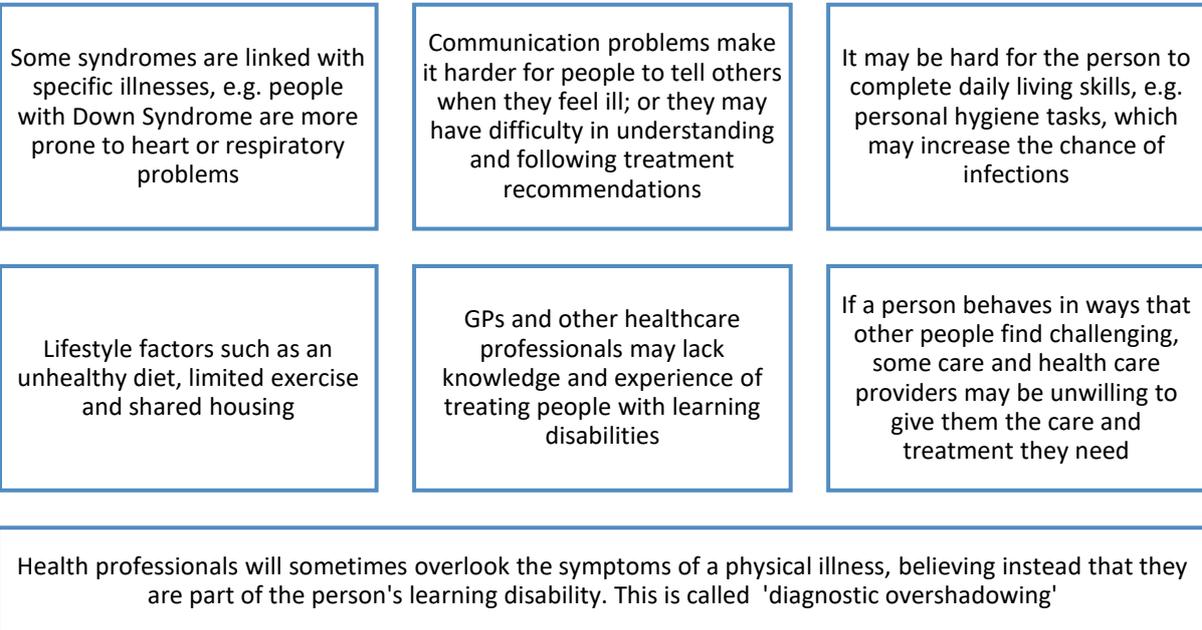
This information sheet will not tell you about mental health.

If you would like to find out about this topic, please see our information sheet [Mental health problems in people with a learning disability](#).

### Health problems in people with learning disabilities

People with a learning disability are more likely to experience health problems than people who do not have a learning disability. There are a number of reasons why this might be the case:





A number of recent reports have shown health inequalities amongst people with a learning disability.

Overall, people with learning disabilities have a higher risk of:

- ↑ Dementia
- ↑ Epilepsy
- ↑ Respiratory diseases & illnesses e.g. asthma & pneumonia
- ↑ Hearing and sight impairments
- ↑ Dysphagia (swallowing problems)
- ↑ Weight problems (being overweight or underweight)
- ↑ Constipation
- ↑ Helicobacter Pylori (a bacterial infection that can lead to stomach ulcers)
- ↑ Injuries because of accidents or falls
- ↑ Sepsis (blood poisoning)

Also, people with specific syndromes are at more risk of developing certain health problems. For example:

- ↑ People with Down syndrome have a higher risk of congenital heart defects, dementia, leukaemia, testicular cancer, eye tumours and other eye conditions
- ↓ However, people with Down syndrome have a lower risk of developing other types of cancer
- ↑ People with Rett syndrome are at more risk of developing some types of bone cancer
- ↑ People with Tuberous Sclerosis have an increased risk of developing kidney and brain tumours

The gap between the life expectancy of people with learning disabilities and the general population could be reduced by identifying and treating preventable health conditions. In particular:

- ✓ Aspiration pneumonia
- ✓ Bacterial pneumonia
- ✓ Heart disease
- ✓ Epilepsy
- ✓ Stroke

### **Covid-19**

*Covid-19 has had more of an impact on people with a learning disability than the general population. People with a learning disability can be supported to stay safe and well at this challenging time.*

Hand washing is one of the best ways to protect the person you support from the Covid-19 infection. This is not an easy or simple task for many children and adults with severe learning disabilities, however, practical resources are available to provide new ideas on how to achieve this.

People with learning disabilities have the same right to access treatment for covid-19 as everyone else. Hospitals have a legal duty to make 'reasonable adjustments' to enable people with a learning disability to access treatment.

Visiting policies have been introduced at many hospitals to prevent the spread of Covid-19. If a person with a learning disability needs support from family or paid carers who know them well whilst staying in hospital or to attend an outpatient appointment (e.g. to communicate or meet their health needs), then the person may be accompanied by carer(s).

*Do Not Attempt Resuscitation (DNAR) orders should not be applied to a group of people e.g. everyone living in a particular care home or just because a person has a learning disability. Decisions should be made on an individual basis. If the person lacks capacity to make this decision family members must be consulted.*

*The Challenging Behaviour Foundation and other organisations have produced a wide range of resources to support and guide family carers through this challenging period. Details can be found in further information at the end of this factsheet.*

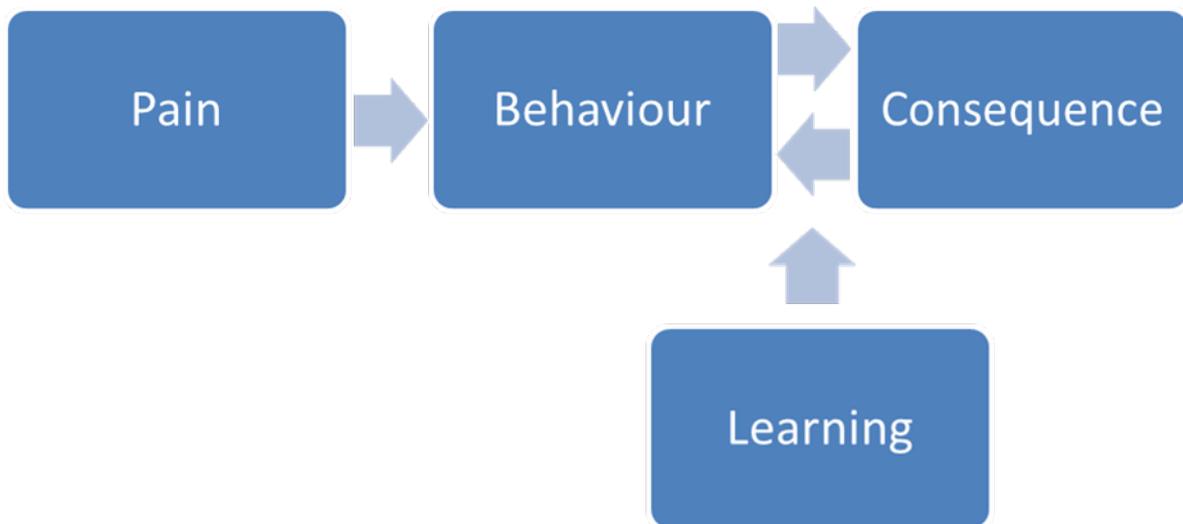
### **How health problems can contribute to challenging behaviour**



When we feel anxious or in pain we are more sensitive to our environment, and so may react in ways that are out of character. We might lose our temper more easily, not want to go out, want some attention or want to be left alone. It is no different for a person with a learning disability who may react with challenging behaviour.

Illness and pain may help to explain some of the behaviours that are totally unexpected or out of character. You may tell a person that their breakfast is ready and they come to the table on every occasion, then suddenly out of the blue they refuse, shout at you and throw something across the room. It is always worth considering health factors: do they have a headache, toothache, feel low, or feel anxious? It could be that a request that would normally be followed may on this occasion act as a trigger for challenging behaviour.

Challenging behaviour in response to pain or illness may become a ‘learned behaviour’ over time. For example, a person may gently rock and bang their head on the wall to ease the pain of an earache. To begin with, they may only bang their head when they have earache. However, if the person finds that, as a consequence of banging their head they get taken out of a busy environment to somewhere that is quiet, they may learn that this is a very quick and effective way of saying “I need some peace and quiet” or “get me out of here!”. For some people with limited verbal communication, this can be a very effective way of getting their needs met, so why not use it? It’s important to understand the reasons behind challenging behaviour for change to happen!



## Rob and Lisa’s Story

Meet Rob and Lisa whose stories are sadly not uncommon.



## Rob's Story

Rob is 29 and lives in his own flat with 24-hour support. He has a severe learning disability, is unable to express himself verbally and can only understand basic language. He has managed to learn a few signs but unfortunately most of his carers are unable to understand them. Rob enjoys the company of others and participates well in his local community. He does not usually present with any challenging behaviour but on the odd occasion may show some aggression which his carers don't understand.

One Tuesday afternoon Rob's carer is getting ready to take him on his usual trip to the local college. Unfortunately, and unbeknown to the carer Rob isn't feeling too good. Rob has a headache but is not able to tell his carer he is unwell. Rob's carer asks him to get his coat on to go out. Rob usually loves to go out – but as he has a headache, he doesn't feel like going out today. Not only can Rob not tell his carer he has a headache, he also can't tell him he doesn't feel like going out because of the headache. The carer persists in asking Rob to get his coat on, raising his voice a little. Rob wants the carer to go away, he is getting anxious and his head is now throbbing. The carer persists in asking Rob and then moves towards Rob. Rob can't stand any more so he does the only thing left to him, he hits the carer to make him go away. The carer shouts "No" and tells Rob in no uncertain terms that he is not going anywhere now. Rob sits back to relax his aching head!

The incident report may look like this:

### Antecedent

Asked Rob to get his coat on

### Behaviour

Rob shouted and hit me for no apparent reason

### Consequence

Left Rob sitting in the chair. Rob went to sleep

The next day Rob's headache had gone, he felt much better and wanted to go out. He got his coat and took it to his carer, as this usually prompted the carer to take him out. The carer firmly informed Rob that he was not going anywhere and that he should go and watch television. Rob did not want to watch television, he wanted to go out. His coat was taken away from him and the carer left the room. Rob was annoyed. He felt it was unjust to stop him from going out. Rob ran after the carer to make him understand and grabbed his coat from the carer, twisting the carer's arm. The carer, in pain, raises his voice to Rob and tells him to go to his room. Rob runs to his room, slams the door and proceeds to kick his wardrobe and throw everything from his dresser onto the floor.

A pattern of challenging behaviour has begun, caused, shaped and maintained by the carer and all because Rob had a headache!

In reviewing Rob's situation it is easy to point the finger of blame at the carer. In fact, most of the time carers do their very best, often in the most difficult circumstances. Therefore, we have to look to the care provider for answers. Rob could be better supported to do his job through training, regular supervision and a clear idea of his role and responsibilities.

### Lisa's story

Lisa has a severe learning disability. She lives in a residential home with four other people who have similar needs. Lisa's parents have sadly both died in a car accident but Tanya, her godmother had promised to look after Lisa's welfare as best she could after their death. Lisa visits Tanya most weekends.

The staff had become concerned as a few days following each visit to Tanya, Lisa became very aggressive towards the staff at the residential home. They discussed this with Tanya and asked if anything had changed about the visits. Tanya assured them that they were doing the same things, activities that she knew Lisa enjoyed. Tanya could offer no reason for this change in Lisa's behaviour. After about three months, staff became suspicious and accompanied Lisa on a visit to Tanya's. They found no evidence of anything which may be upsetting for Lisa. They were baffled but decided to stop Lisa going to Tanya's for a few weeks to see what happened. To their amazement the challenging behaviour stopped occurring, no more aggression, no more attacks towards staff. This confirmed their worst fears but they were at a loss to know what to do. Should they stop her visits to Tanya altogether, and if so how would they go about this?

It was at this time that staff noticed that Lisa appeared to be drinking more than usual. They decided to take her to the GP and request a blood test. The results showed diabetes. They discussed Lisa's behaviour with the GP who enquired what foods Lisa had been having at Tanya's. They said that when they visited she had bought in lots of sweets and cakes for her. The GP then explained that Lisa had probably had hypoglycaemia which can lead to aggressive behaviour.

The moral of this particular story is that had Lisa not had the blood test and subsequent diagnosis, the staff may have stopped her visits to Tanya altogether thereby cutting off her only close support outside the residential home.

Luckily for Lisa this did not happen, but the staff learned some lessons. As a consequence they paid particular attention to Lisa's physical health, arranged for assessment and intervention from a Speech and Language Therapist to help Lisa communicate any difficulties she was experiencing, and ensured other significant people in her life were also aware of potential difficulties.

## Why might people whose behaviour challenges be more at risk of health problems?

As well as health problems sometimes causing challenging behaviour, some challenging behaviours can also result in serious health problems. For this reason, it is very important to seek professional support for challenging behaviour.

Here are some behaviours (and consequences of challenging behaviours) that may have an impact on a person's health:

### Self-Injurious Behaviour:

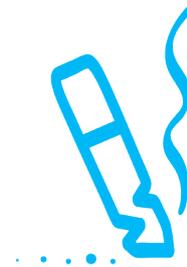
Self-injurious behaviours include things like head banging, eye poking, self-biting, self-hitting and skin picking. It is important to seek professional help as soon as you can as these behaviours can have a significant impact on a person's physical health. For example, if a person repeatedly bangs or hits their head, they may cause a brain injury, even if there is no visible bruising. In extreme cases head banging behaviour can also result in blindness, deafness, irreversible brain damage and even death. People who repeatedly poke their eyes can cause eye damage or blindness. When people who self-injure frequently break their skin, they are at risk of infections and sepsis, so it is important to make sure any damaged skin is kept clean. Other physical harm may include bleeding, bruising, bone fractures as well as other types of injury.



### Pica and Polydipsia:

Pica behaviour is where a person may eat inedible objects including cigarette butts, stones and coins, and is more common in people with learning disabilities. Pica behaviour can lead to significant health problems including vomiting, infections and blockages in the gut. It is important to think about what might be causing this behaviour. For example, pica may be linked to iron and zinc deficiencies.

Alternatively, people who display pica behaviour may do so because they enjoy the sensation of eating, or for a more behavioural reason such as wanting attention.



Polydipsia involves drinking excessive amounts of liquid. If a person is drinking more water than can be processed by their kidneys, this can have serious health consequences. Again, while polydipsia can cause health problems, a person may be drinking excessively because of an underlying health condition such as diabetes.

### Overeating, under eating and restricted diets:

Having a healthy, balanced diet is important to stay well. Unfortunately, many people with learning disabilities have poor diets. This is because they may not be able to understand the importance of healthy eating, only like eating a small selection of foods, or may eat too much or too little. Sometimes, carers might be reluctant to encourage healthy eating because the person can become challenging if they cannot eat the foods they would like to.

Some people with learning disabilities may also have sensory differences that may affect how much food and the type of food they eat. For example, a person with autism may only like to eat foods of a particular texture or that taste bland. This may lead to the person having a very restricted diet that can cause a number of health problems. There are also some specific syndromes that may cause a person to want to overeat or eat a very restricted diet. For example, people with Prader-Willi Syndrome will develop an insatiable appetite. This means that the person may always be hungry, want to eat more often and want to eat larger portions of food. Because of this, people with Prader-Willi Syndrome are at greater risk of being obese and developing type 2 diabetes.

### Side effects of medications:

Many medications have side effects and some side effects can be very serious. For example some psychotropic medications used to 'treat' challenging behaviour may cause the person to gain a great deal of weight or to suffer from constipation. People with a severe learning disability may not be able to tell anyone if they are experiencing nasty side effects such as dizziness or nausea. Or, they may not realise that they are feeling unwell because of the medicine they have been taking. Also, people with a severe learning disability may not have the capacity to weigh up the 'pros and cons' of taking a medication or be able to decide what medications they will take. For this reason, the decision to prescribe someone a medication should be made in someone's 'best-interests' in accordance with the Mental Capacity Act (2005).

### Restricted access to services / activities:



People with severe learning disabilities are sometimes prevented from accessing services and leisure facilities because their behaviour is seen as being 'too challenging'. These services may include respite services, social or sporting activities and day centres, even if they are set up specifically for people with learning disabilities. If a person is excluded from activities they may become unhealthy because of a lack of physical activity. Having little social contact with



others can also lead to the person feeling lonely and isolated which can affect their health and wellbeing.

## What can I do to help someone with a severe learning disability stay healthy?

- ✓ Seek professional support for challenging behaviours that could impact on the person's health. You could start by speaking to your family member's GP to ask if they could make a referral to your local CAMHS or Community Learning Disability Team. For more information about how to get support with your family member's behaviour see our ['Getting Behaviour Support FAQs'](#).
- ✓ Consider the possibility of a medical reason behind behaviours that challenge. If you see a sudden change in your family members behaviour or if you think that they might be unwell, seek advice from a GP or other health professional.
- ✓ Ask health professionals to make reasonable adjustments so the person you're supporting can get the help they need. For example, if the person you care for has difficulty attending medical appointments, you could ask for a home visit. If the person you support cannot tolerate sitting in a noisy waiting room, you could ask that they have the first appointment in the day so they don't have to wait or that they are given a quiet place to wait.
- ✓ Join the Learning Disability Register. Anyone who has a learning disability can join the learning disability register. It is helpful for children to join as well as adults. Being on the learning disability register will help the person you support to get the [reasonable adjustments](#) they need and an annual health check.
- ✓ Support the person to get a [Health Action Plan](#). This is a personal plan about what a person needs to do to stay healthy. It lists any help that they might need in order to stay healthy and makes it clear about what support they might need. You can ask your Community Learning Disability Team about this.
- ✓ Make sure the person receives an [Annual Health Check](#). Adults and young people aged 14 or above with learning disabilities who need more health support and who may otherwise have health conditions that go undetected qualify for an Annual Health Check.
- ✓ Support the person to have an annual flu vaccine. If the person is afraid of needles explore 'reasonable adjustments' such as having the vaccine as a spray instead. Family carers and paid support workers can also be eligible for a free flu vaccine. Ask your doctors surgery or pharmacy if you qualify.

- ✓ Support the person to attend health screening appointments e.g. breast screening for women aged 50-70 years old and cervical screening for women aged 25-64 years old.
- ✓ If the person you care for needs to go to hospital, ask if they can have their own [‘Hospital Passport’](#). These are designed to help people with autism or learning disabilities communicate their needs to doctors, nurses and other healthcare professionals. 
- ✓ If the person you care for refuses medical treatment and they are 16 years or older, make sure health professionals assess their capacity to make that decision in accordance with the Mental Capacity Act (2005). If someone is found to lack the capacity to make decisions about medical treatment, then a decision must be made on their behalf. [The decision must be made in their ‘best interests’](#) by carefully considering the pros and cons of providing the treatment versus not providing it. Alternatives should also be considered. The Mental Capacity Act requires all professionals to consult with family members when an adult lacks the mental capacity to make the relevant decision themselves.
- ✓ Make sure you are aware of any potential side-effects of the medications the person is taking and monitor them carefully. Seek professional advice if you think the person is experiencing side-effects.
- ✓ Support the person to [stay active](#).
- ✓ Support the person to make [healthy food](#) choices.
- ✓ Seek advice from a dietician if you are worried about a person’s weight or eating habits.

## Further information

### Annual Health Checks

[About having a health check](#) (Easy Read) by Mencap

[Annual health check](#) by NHS England

[Health checks](#) by Easyhealth

### Aspiration pneumonia

[Aspiration pneumonia](#): Briefing for carers by the Learning Disability Mortality Review Programme.

### Being Active

[Let’s Get Moving \(Easy read\)](#) by NHS

[Special Olympics GB](#)



[Enjoying Sport and Exercise](#) by Books Beyond Words

### **Challenging Behaviour**

[Understanding challenging behaviour](#)

[Finding the reasons for challenging behaviour](#)

[Positive Behaviour Support planning](#)

[Frequently asked questions about behaviour support](#)

[Pica & Polydipsia](#)

[Self-injurious behaviour](#)

All by the Challenging Behaviour Foundation

### **Constipation**

[Constipation: Briefing for carers](#) by The Learning Disability Mortality Review Programme

[Poo & You](#) Brief guide to constipation by Dimensions

[The trouble with Poo](#) by Books Beyond Words

### **Coronavirus**

[Covid-19 information and resources](#) by the Challenging Behaviour Foundation. Includes links to resources by other organisations.

[Having a home test for coronavirus](#) by Books Beyond Words

### **Flu**

[We are here to help you stay well this winter](#). Easy read guide by the NHS hosted by Mencap

### **Health Action Plans**

[Health Action Plans](#) by Easyhealth

### **Health Screening**

[Having a smear test](#). An easy guide about a health test for women aged 25 to 64 by the NHS

[Having a smear test. What is it about?](#) Easy read booklet by Jo's Cervical Cancer Trust

[Looking after my balls](#) by Books Beyond Words

[Looking after my breasts](#) by Books Beyond Words

### **Healthy Eating**

[Managing weight with a learning disability](#) by NHS England

[Cooking with Friends](#) by Books Beyond Words



### **Hospital Passports**

[My health passport](#) by the National Autistic Society

[Hospital passport](#) by Mencap

### **Learning Disability Register**

[Don't miss out: better healthcare for people with a learning disability](#) *Supporter's guide* by Mencap

### **Making decisions**

[Making decisions](#) by the Challenging Behaviour Foundation

[The Mental Capacity Act 2005](#). Briefing for carers by the Learning Disability Mortality Review Programme.

### **Medication**

[The Use of Medication](#) by the Challenging Behaviour Foundation

[Medication Pathway](#) for Family Carers by the Challenging Behaviour Foundation

### **Mental health problems**

[Mental health problems in people with a learning disability](#) by the Challenging Behaviour Foundation

### **Reasonable Adjustments**

[Healthcare](#) by the Challenging Behaviour Foundation

[Reasonable Adjustments for People with Learning Disabilities](#) by Public Health England

### **Sepsis**

[About Sepsis](#) by the UK Sepsis Trust

[Infection \(including sepsis\)](#) by the Learning Disability Mortality Review Programme

[Signs that a person is becoming unwell](#) by the Learning Disability Mortality Review Programme

The information in this resource has come from academic research papers. Please contact the Challenging Behaviour Foundation if you would like to receive a list of the publications that helped us write this resource.

The Challenging Behaviour Foundation would like to thank Diane Langridge, Nurse Consultant for Challenging Behaviour, South Essex Partnership NHS Foundation Trust for her contribution to this resource.

*Last updated: February 2021*



**The Challenging  
Behaviour Foundation**

making a difference to the lives of people with severe learning disabilities

### **The Challenging Behaviour Foundation**

We are a registered UK charity specifically focussed on the needs of children, young people and adults with severe learning disabilities whose behaviour challenges, and their families.

We will make a difference to the lives of people with severe learning disabilities, whose behaviour challenges, and their families by:

- Championing their rights
- Ensuring timely information and support
- Raising awareness and understanding
- Promoting and sharing best practice

To access our information and support, call 01634 838739, email

[info@thecbf.org.uk](mailto:info@thecbf.org.uk) or visit our website: <https://www.challengingbehaviour.org.uk>