

Information for Carers

How to help people with learning disabilities to keep healthy



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The Health Issue

Getting to appointments is too difficult.

What can help?

People on benefits can claim back their expenses for some health appointments. It may be possible to claim for escorts - check with the hospital or PALS.

Residential carers have a duty of care and must support people to attend health appointments as part of their contract.

Some health professionals (even opticians) will do home visits.

Some areas have car schemes or can offer ambulance transport - ask at your doctors.

Talk to PALS (Patient Advice and Liaison Service) for advice.

Tel: **0800 032 3235**

The Health Issue

Some people have a known cause for their learning disability (eg a syndrome) – most people do not know the cause.

What can help?

You probably know more about the person's difficulties than the health care professional, so please tell them what you know about how the person is usually and any changes.

If you know someone has a syndrome or condition, there will be some known health problems that many people with the same condition have. Please tell the doctor about these, as the syndrome may be something that they haven't come across before.

Your Community Team for people with learning disabilities can advise you about specific conditions or syndromes.

The Health Issue

People with learning disabilities are more likely to have poor eyesight.

What can help?

See an optician at least every 2 years.

Even if people cannot read charts, or won't wear glasses, the optician can check the health of the eye and spot other health problems.

People can have other eye problems (especially people with Down Syndrome), such as dry, red or runny eyes.

This is not a natural state for their eyes. See the optician or doctor as this needs treatment.



The Health Issue

People with learning disabilities are more likely to have dental problems.

Did you know that gum disease:

- gives you bad breathe
- can affect the jaw bone
- can even cause a stroke
- makes diabetes harder to treat
- affects the stomach and lungs
- can cause a heart attack.

What can help?

6 monthly check ups with a dentist.

Community dentists (usually at Health Centres) are recommended.

Ensure teeth are cleaned at least twice per day.

Limit sugar (sweets, cakes, biscuits) and fizzy drinks.

Change toothbrush (and head of electric tooth brushes) every 3 months.

Use floss and mouthwash as well as (not instead of) brushing.

Many people make appointments and miss them – please don't do this as sometimes dentists allow extra time for people with learning disabilities. Missed appointments are a waste of the Dentists' time and cost the NHS money.

Talk to the dentist before the appointment about changes they could make that are reasonable and would help to achieve a successful appointment.

The Health Issue

Increased likelihood of having a hearing problem. People with Downs Syndrome, Cerebral Palsy and Rubella Syndrome are especially prone to hearing problems.

What can help?

Keep the ear canal dry (ask us if you need advice on this). A hearing test at least every 3-5 years, especially if over 50.

Ask your GP or the Specialist Learning Disability Service to refer for a hearing test. We recommend the Special Hearing Clinic at Royal Derby Hospital (the consultant is called Mr Parker). They do clinics around South Derbyshire, so you don't always have to travel to Derby.

Have ears checked for wax build up – via Practice Nurse, Community Learning Disability Nurse or Speech & Language Therapist, at least every year. Some people should have a 3-monthly check. Attend an information session (ask us for details).



The Health Issue

Some people have to take medication:

- usually this is ok
- sometimes it's no longer needed but carried on
- sometimes people have side effects from the medication
- some people have medicine that is usually given for schizophrenia but they're given it to calm their behaviour.

What can help?

Your doctor should review the medicine/tablets every 6 months, which means they should check if it's working, still required or causing any problems. You should see the doctor for this review. Sometimes pharmacists do this for the doctor.

Ask questions about what it is for, how long to take it and the side effects. If the side effects are too bad ask if there is a different medicine the person can switch to. Pharmacists can advise you.

Ask if there is another way to help with behaviour- maybe the person has pain and is unable to tell you. Consider ear or dental problems.



The Health Issue

Many people with learning disabilities have epilepsy; some people with Down Syndrome will get epilepsy as they get older. Most people with profound and multiple learning disability will have epilepsy.

What can help?

A medical practitioner needs to take overall responsibility for renewing and supporting the epilepsy. Make sure you know who this is.

Medication is the usual treatment for epilepsy – there are new medicines each year. Have regular checks with your doctor and if the person keeps having seizures that the medicine doesn't control, ask for a referral to a specialist. If the medicine controls the seizures but you think the side effects are too bad (maybe the person is very drowsy) ask the doctor about other medicines, or again a referral to a specialist.

Keep a record of the seizures/fits and when they are so you know if the medicine is working, and the doctor knows when the best time to give the medicine is.

Don't just give tablets when the person has a fit, or administer extra unless you have been given some special rescue/emergency medicine. You should be giving the medicine at regular times as advised by the doctor.

Have a plan about what to do if the person has a lot of fits or a very long fit- know what is usual for them. Make sure everyone who helps them knows the plan. It's a good idea for them to have a medic alert card with them.

Make a plan with them about keeping safe – not smothering them in cotton wool just some sensible precautions eg shower instead of bath, cooking with a microwave.

Community Learning Disability and Epilepsy Nurses can help you with this.

The Health Issue

Some people need help to remain continent.

What can help?

The District Nurse usually assesses for continence aids, and advises on how to help.

You should have a full assessment and be advised how to put on a pad properly. Ask for a demonstration.

The Practice Nurse can also help.

If you need further advice each area has a special Continence Advisor. Ask PALs for contact details.

Join the campaign for fully accessible changing toilets – write to your MP and local Council. Go online to know where your fully accessible toilets are at www.changing-places.org

The Health Issue

Some people with learning disabilities have Gastro-oesophageal reflux disease (GORD/Heartburn).

This can cause stomach ulcers, there is also a bacteria that many people with learning disabilities have called *Helicobacter pylori* – this can be cancer causing.

What can help?

Ask the doctor to check the person for GORD and *Helicobacter pylori*. *Helicobacter pylori* is treated by 3 lots of antibiotics.

Ask the dietician about good/bad foods – some foods make heartburn feel worse.

Ask for an assessment from a Speech & Language therapist. They can advise on the best textures of food/drink and the best position to be in when eating.

The Health Issue

Some people cannot swallow properly – which means that food goes to their lungs and causes repeated infections.

What can help?

This can be assessed by a Speech and Language therapist, supported by an Enteral Feeding Advisor and a Dietician.

You might need the help of a physiotherapist, again for advice about positioning, but also about treatments to prevent mucus sitting in the lungs and airways.

Follow the advice given about swallowing difficulties - people who can not swallow properly often need their liquids thickened. This may look unpleasant to us but it can be a life saver and is tasteless.



The Health Issue

Adults with Down Syndrome can have the following problems:

- hearing/wax
- vision
- thyroid
- atlanto axial subluxation
- feet
- dementia
- obesity
- dry skin

What can help?

See advice in other sections for hearing and vision.

Thyroid function should be checked 2 yearly by a blood test. A slow functioning thyroid is very common in people with Down Syndrome - this can cause them to be very slow in thinking and tired, with dry skin, brittle nails and loose hair, as well as healing slowly and feeling the cold more.

Atlanto axial subluxation means that part of the neck is affected. They should have a once in a lifetime check (X-ray) to identify the problem. If they have atlanto axial subluxation they are advised not to participate in trampolining, horse riding and activities that may jolt the neck. The anaesthetist needs to know if they have an operation - usually people will wear a special collar for operations to support the neck. Talk to your doctor about this – they may have a record in the doctor's notes if this has already been done.

People with Down Syndrome should see a Chiropodist.

People with Down Syndrome tend to age quicker than other people. We also know that there is a link between Down Syndrome and dementia. Not everyone with Down Syndrome will show the symptoms of dementia. We suggest each person has a screening check (questions and puzzles) with a Clinical Psychologist at age 35. This shows how they are doing – the Psychologist will then check them each year to see if there has been any changes.

It is not inevitable for people with Down Syndrome to be obese. Problems with weight may be due to thyroid function problems, but are usually due to inactivity and poor eating habits. See the advice in the section on obesity and healthy lifestyle.

The Health Issue

Most people with Learning Disabilities are overweight, many obese. Obesity increases the risk of diabetes, heart disease, mobility and breathing problems, alongside personal hygiene issues. All in all being obese means life expectancy is reduced.

What can help?

Dieticians and practice nurses can advise, but think about who is supporting them with shopping, cooking and menu planning – is it you that needs advice?

Everyone should have at least 30 minutes physical activity per day – this can be gardening, car washing etc.

A balanced diet includes plenty of fruit and veg (tinned and frozen is ok), with little fat.

Please think about the part you are playing.



The Health Issue

Coronary heart disease is the second biggest killer of people with learning disabilities - second only to respiratory problems.

What can help?

Have a health check that includes blood pressure, weight and waist circumference. Have 30 minutes exercise a day and eat healthy. Keep waist circumference at 32" or below for a woman, 37" or below for a man.

The Health Issue

Some people with learning disabilities also have a physical disability.

What can help?

Ask physiotherapists and occupational therapists for advice about helping people with physical disabilities. There may be aids, adaptations and available treatments.

Some areas have a special Consultant (eg Dr Lin) who will advise on the care of people who have a lot of difficulties. Your physiotherapist will know if there is a Consultant in your area.

A person's body shape can change and become twisted if they have the wrong supported seating. Consider how much time they spend in bed – they may need a sleep system to keep their body shape straight.

Think about any pain the person may have and discuss this with therapists and the doctor, as they may need pain relief.

The Health Issue

Mental health problems are hard to diagnose in people with learning disabilities. Though many do have mental health problems such as depression, anxiety, phobias, obsessions, compulsions, schizophrenia etc. Sometimes people are treated for mental health problems without a proper assessment or diagnosis. Communication difficulties can make mental health problems more difficult to diagnose.

Compulsions and rituals some people may have can be treated in mental health services.

What can help?

Keep a safe and well plan – this details how the person is usually and what helps them/makes them worse.

Each area has a Psychiatrist that specialises in working with people with learning disabilities. Clinical Psychologists and Learning Disability Nurses can also help, alongside mainstream mental health services.

If you have any concerns please discuss them with a health professional.



The Health Issue

People with learning disabilities are not always included in health screening – but they do get cancer and other illnesses.

What can help?

There are 4 national screening programmes:

- Breast screening
- Cervical Smear screening
- Bowel screening.
- Abdominal Aortic Aneurism screening

Though sometimes unpleasant these are important as they identify who is at risk of developing illness/who has it and can lead to early treatment and preventable death.

People should not be excluded just because they have a learning disability and it isn't 'nice.' Learning disability nurses can help you; maybe the person does not understand or is scared of the procedure. Maybe this isn't right for the person – there is national guidance on what to do.

When you receive an invite – do not bin it, have a chat to one of the Nurses in the Learning Disability Teams, who can give advice and guidance about the screening.



The Health Issue

People with learning disabilities need help to be healthy.

Not every one has a Health Action Plan which belongs to them and they understand.

What can help?

Most GPs offer a yearly health check for adults with learning disabilities.

Derbyshire has 'tools' (documents) that can help to identify what the individual's health needs may be.

This includes an assessment, this leaflet, an easy to understand health check sheet, and My Health file.

Come to a training day, or talk to Strategic Health facilitators or your Community Learning Disability Team.



The Health Issue

Postural Care

'Any person who finds it difficult to vary and control their position during the day or at night may be in need of postural care. This may mean that they are limited to a restricted number of positions. If you care for someone who has any of the following then you should seek advice about postural care:

- head seem to turn mainly to one side?
- body seem to fall sideways?
- body seem to fall forwards or backwards?
- knees seem to fall mainly to one side?
- knees seem to fall inwards or outwards?
- the body shape already asymmetric (windswept/lopsided)?

(Taken from The Mansfield Checklist of Need for Postural Care)

What can help?

Good positioning during the night in bed and good positioning throughout the day.

Physiotherapy can help with positioning issues such as supply of wheelchair/special seating and a postural care plan.

The OT (Occupational Therapist) can also provide equipment.

The Speech Therapist and Dietician can also help, with eating and drinking needs.

Your family Doctor (GP) can support with pain relief/medications for spasticity.

Consider also the condition of the skin and the possibility of pressure sores. Ask your family Doctor or Practice Nurse for advice.

The Health Issue

Breathing

People with a learning disability are much more likely to have respiratory disease.

This is the leading cause of death in the learning disability population.

A symptom of this is a persistent cough that never seems to go.

What can help?

Breathing can be checked at your Doctor's surgery as part of the annual health check.

Contact with family Doctor or Practice Nurse for monitoring of Asthma on a 6 monthly basis.

Your Doctor can also help with diagnosis of other breathing problems and can provide regular check-ups.

Seek diagnosis from the Doctor for a persistent cough. Could it be to do with what the person is eating and drinking? Check the person is able to swallow properly with a Speech and Language therapist.

Get advice from the Doctor or Nurse about help to give up smoking.



The Health Issue

Healthy lifestyle

People with a learning disability often have poor nutrition, are inactive and overweight, particularly in the case of people with Down Syndrome and Prader Willi Syndrome.

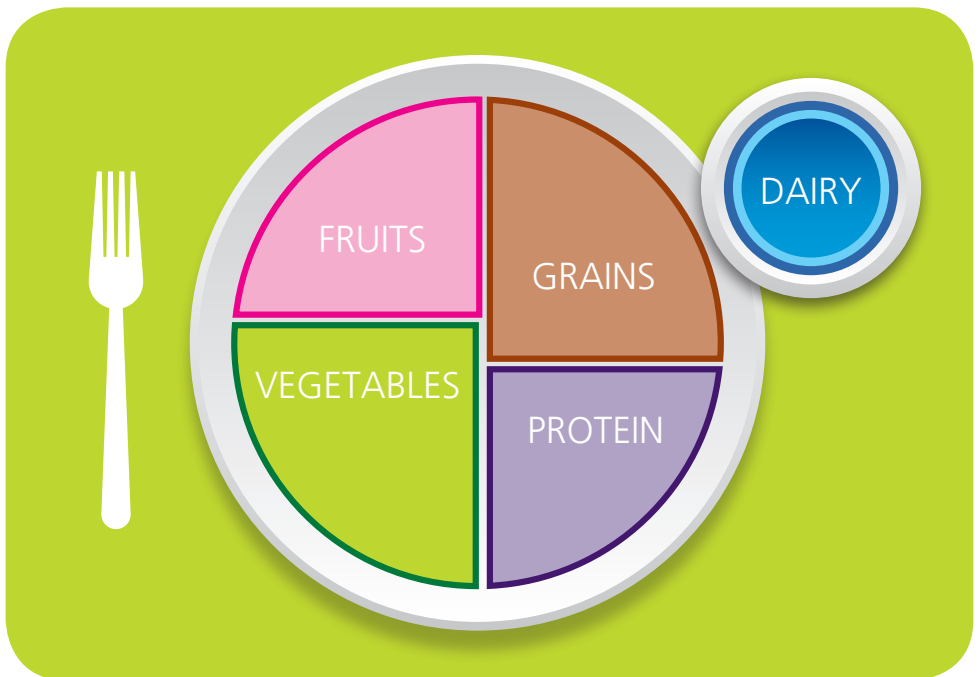
People are often socially isolated which can affect healthy lifestyle choices.

People could also be underweight due to eating and drinking problems, swallowing problems, peg feeding.

What can help?

Having an annual health check with the family Doctor can provide advice on giving up smoking, exercise, diet and alcohol consumption.

A Dietician, Physiotherapist, Community Learning Disability Specialist or Occupational Therapist can also help.



The Health Issue

Women's health

Women with a learning disability are less likely to be invited for mammograms and cervical screening.

What can help?

You should not presume a woman has never been sexually active and therefore she is at decreased risk of cervical cancer.

Women who do not have cervical smear testing are at increased risk of developing cervical cancer.

Smear tests are available from age 25. A woman should not be removed from the screening register just because she has a learning disability

Breast screening is available from age 50.

At the Annual health check get advice from the family doctor or nurse on how to manage menstruation (periods and menopause).



The Health Issue

Men's health

There is a lack of awareness of men's cancers in the learning disability population.

What can help?

Prostate cancer is common in men aged over 50. Symptoms include needing the toilet to wee a lot. A blood test can be done to check for prostate cancer.

Testicular cancer is more common in men under 40. Men should be encouraged to 'check their balls'. You can get advice about this from your Doctor or Nurse at the annual health check.

The Health Issue

Contraception

People with a learning disability may find it harder to ask for advice but may still want to have relationships and have children.

What can help?

A visit to a Family Planning Clinic (Sexual Health Services)

The Practice Nurse or Community LD Nurse can help with advice.

Free tests for Chlamydia are available for under 25s from Doctors or Pharmacists.

Over 25s can still get a free test from their family Doctor or Sexual Health Clinic.

The Health Issue

Skin

Problems may occur with dry skin, tissue viability (pressure sores) and photosensitivity (skin burns easily in the sun) due to certain medications.

What can help?

Family doctor or nurse can advise on skin problems. Some creams can be bought from the chemist (pharmacy) or you may need to see a special skin doctor (Dermatologist).



The Health Issue

Sleep

Broken or little sleep can be difficult for both the individual and their family and carers.

What can help?

Consider a good bedtime routine.

Your doctor, nurse or pharmacy can advise on good sleep 'hygiene'. Things like turning off the TV, having a warm bath and a milky drink all may help.

The Health Issue

Foot Care

Our feet are very important, but often get over looked. Carers should regularly check feet, looking at length of toenails and changes to the foot.

What can help?

You can ask a podiatrist to provide a foot care education session, including demonstrations on general foot care, and relevant advice.

You can ask the GP to refer to the podiatry clinic, or phone the podiatrist clinic and seek advice. GP's can also refer for free chiropody for those with diabetes.

For more information on private chiropody please check:

www.hpc-uk.org



Contact

If you require further assistance with this document please contact:

Learning Disabilities Strategic Health Facilitation Team
St Andrews House 3rd Floor
201 London Road
Derby
DE1 2TZ

Telephone: 01332 268455

Monday to Friday 9am to 5pm

Consent

Before a Health worker can examine or treat a patient, they usually need his or her consent or agreement. Under English law no-one, not even parents can give consent to treatment for another adult.

As long as the person you care for can understand what's involved in the treatment, like anyone else over 18, he or she is the only person who can give consent. People with learning disabilities do not always understand.

What can help?

For people who are unable to understand, treatment can be given in the person's 'best interests'. Their best interest will be about more than just their physical health; this will also include their general well-being and beliefs. Health workers have to follow the Mental Capacity Act and should have received training.

A Carer should be consulted and included in the best interest decision. You should never be asked to sign a consent form on behalf of the person you are looking after. However you may be asked to sign a form to say that you have been consulted.

The Department of Health produce a a guide for carers about consent:
Consent – what you have a right to expect: A guide for relatives and carers