

Top to Toe Handbook

A guide to support early recognition of the signs and symptoms of ill health in people with learning disabilities



Produced by Hertfordshire Community Learning
Disability Nursing Service (HCS)





Top to Toe Handbook

Symptoms and Guidance

Acknowledgements

We would like to thank everyone who contributed to Handbook

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Foreword

Recognising the important role that carers have in supporting people with a learning disability around health needs, the Top to Toe Handbook has been designed to support paid carers to recognise and act on early signs and symptoms of ill health.

Numerous studies find that people with a learning disability are more likely to experience ill health than others in the general population and a recent report highlighted the shocking statistics that if you have a learning disability, you are likely to die 16 years earlier than people in the general population, (CIPOLD 2013).

Research has shown that there are a multiplicity of reasons why risks increase including; inadequate diagnosis and treatment of specific medical conditions; diagnostic overshadowing; communication difficulties; inequitable access to health care and those who know the person well, not being listened to by health professionals.

In their report about the deaths of 74 individuals, MENCAP (2012) emphasised the important role of the carer in improving health outcomes. "Diagnosis may be difficult in people with learning disabilities if they cannot describe signs and symptoms clearly. Watch and wait will only work if the watching is skillful, with a clear history taken from those who know the person well".

There is evidence that when carers recognise ill health they seek appropriate and timely medical advice. However, health professionals locally have expressed concern about appointments/consultations being wasted at times because those supporting individuals may not know the person well, do not provide relevant information and are unable to give a clear account of presenting symptoms or history. Additionally concerns are expressed by both family and paid carers, that their reports on occasion are not taken seriously enough by medical professionals. They describe feeling "intimidated" and "as though they had little expertise, confidence or authority to take on this role" (CIPOLD 2013). It is in this context this tool has been developed

This Handbook aims to empower carers to be able to undertake their role more effectively, raising awareness about some of the common health conditions more likely to be experienced by people with a learning disability and providing information that will help carers recognise and respond promptly to symptoms seeking early medical help and enabling a more knowledgeable exchange of information. Ultimately this will support improved health and well-being of the individual with a learning disability and may prevent premature death.

The handbook includes information about

- Asthma
- High Blood Pressure
- Bowel Disorder
- Chest Infection
- Dementia
- Diabetes
- Dysphasia
- Epilepsy
- Pain
- Urinary Tract Infection (UTI)



Alison Fitzgerald
Strategic Lead Nurse HCS

Additionally information is included about

- Aortic Aneurysm Screening
- Bowel Screening
- Annual Health Checks
- Top Tips for Supporting Someone with a Learning Disability to a Health Appointment
- Health Charter for Social Care Providers

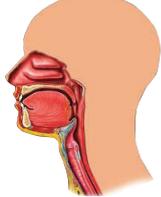


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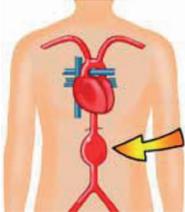
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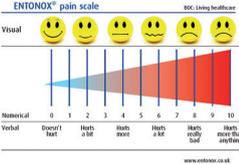
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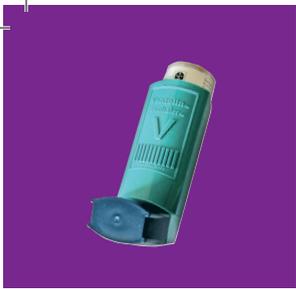
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Asthma



Symptoms	Description
 Change in breathing	<ul style="list-style-type: none">• Recent change in breathing.• Wheezing - a wheeze noise when the person breathes (whistling sound).• Cough.• Breathless - The person becomes breathless easily and quickly.
 Coughing	<ul style="list-style-type: none">• The person coughs more than usual.• Increased coughing after short exercise.• Coughing a lot during the night.
 Shortness of breath	<ul style="list-style-type: none">• Unable to talk in long sentences.• Unable to sing for a long period of time.• More quiet than usual.
 Tight chest	<ul style="list-style-type: none">• Holding the chest.• Complaining of chest pain.• Complaining of not being able to breathe.• Change in behaviour.
 Allergies	<ul style="list-style-type: none">• Sudden shortness of breath when near animals or exposed to pollen.

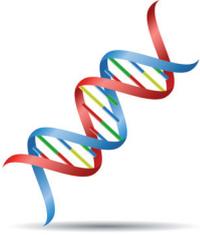


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Possible Causes of Asthma

It's not clear exactly what causes asthma, although it is likely to be a combination of factors. Some of there may be genetic. However, a number of environmental factors are thought to play a role in the development of asthma.

Causes	Description
 Genetic	If asthma is known to the family, it is likely to be inherited and passed on to children.
 Smoking	Being exposed to tobacco smoke either by smoking or second hand smoke.
 Premature birth	Being born prematurely, especially if you needed a ventilator to support your breathing after birth.



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How to Support Someone with Asthma



Do	Why
Take medications as prescribed	Ensure the person takes their medications at the times prescribed.
Reliever inhaler	Ensure you or the person has a reliever inhaler (normally blue) in case an asthma attack occurs.
Support smoking cessation	To prevent the risk of cancer and onset of an asthma attack or symptoms such as breathlessness becoming worse, you should encourage the person to stop smoking. Support the person to join a smoking cessation programme.
Reduce stress	Being stressed can cause a sudden onset of an asthma attack and make breathing and wheezing worse.
Personal asthma action plan	You should have a personal asthma action plan agreed with your doctor or nurse that includes information about the medicines you need to take, how to recognize when your symptoms are getting worse, and what steps to take when they do so.
Consult GP	If in doubt always consult the GP.





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How to Manage Asthma

Do	Why
 <p>Take medications as prescribed</p>	<p>Inhalers prescribed by the doctor have to be taken regularly most commonly morning and night. Taking the inhalers or prescribed medications will decrease the risk of having an asthma attack.</p>
 <p>Be healthy</p>	<p>Keeping fit and exercise regularly is healthy.</p>
 <p>Stop smoking</p>	<p>To prevent the risk of cancer and onset of an asthma attack or symptoms such as breathlessness becoming worse.</p>
 <p>Reduce stress</p>	<p>Being stressed can cause a sudden onset of an asthma attack and make breathing and wheezing worse.</p>
 <p>Consult GP</p>	<p>If in doubt always consult the GP.</p>



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How to Manage Asthma



Do

Recognize symptoms early

Breathing difficulties,
Speaking difficulties,
Wheezing,
Coughing,
Distress, blue tinge to lips

Why

- Reassure the person.
- Ask them to breath slowly.
- Help them use reliever inhaler.
- Sit them down.
- If it doesn't get better within a few minutes, it may be severe.
- Get them to take two puffs of their inhaler every two minutes, until they have had 10 puffs.

A mild attack should ease within a few minutes. If it doesn't, or the inhaler has no effect, call 999.



Recognising a severe attack

Chest tightness,
severe wheezing, too breathless to eat, breathing faster, rapid heart beat, drowsy, dizzy, exhausted

If they lose consciousness at any point, open their airway, check their breathing and prepare to treat someone who's become unconscious. Severe attacks may require hospital treatment and can be life threatening. Call 999 to seek immediate help.



Person should see their GP if:-

Had an asthma attack that has lasted longer than 20 minutes or more than one in a day. Symptoms become worse, A yearly review to ensure medications are still correct for the person.



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High Blood Pressure (BP)



Symptoms	Description
 Shortness of breath	The individual is wheezing, struggling to breath or breathing heavily.
 Persistent headache	The person may complain of a headache or their behaviour may change - please see the check list for pain.
 Blurred/ double vision	They might seem a little clumsy, have unexplained injuries or not be able to see things they normally would.
 Blood shot eye	White of eye becomes blood shot due to high pressure from blood.



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Possible Causes of High Blood Pressure

Causes	Explanation
	<p>Age</p> <p>The risk of high BP increases as you get older.</p>
	<p>Family history</p> <p>The condition appears to run in families.</p>
	<p>African/ Caribbean origin</p> <p>African and Caribbean people have a higher risk of high BP.</p>
	<p>High level of salt</p> <p>If you eat salty foods or put a lot of salt on your food.</p>
	<p>Lack of exercise</p> <p>Not exercising enough can lead to fatty deposits in the arteries.</p>
	<p>Being overweight</p> <p>Also affects arteries and increases the risk.</p>
	<p>Smoking</p> <p>Restricts the arteries.</p>
	<p>Drinking lots of alcohol</p> <p>Too much alcohol can lead to high BP, stick to the recommended daily allowance.</p>



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How to Support Someone with High Blood Pressure



Do	Why
Lifestyle changes	Encourage physical activity, reduce salt in diet, cut down on alcohol, balanced healthy diet, cut down caffeine and quit smoking.
Weight loss	Encourage weight loss and help to attend support groups such as Slimming World or Weight Watchers.
Reduce Stress	People who are in healthy relationships and have lots of support are more likely to maintain the lifestyle changes necessary to control their BP.
Make reasonable adjustments	If the service user finds it difficult to understand what BP is or what they can do, look for other ways to explain to them and use "T.E.A.C.H" (See Appendix 5).



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How to Manage and Monitor High Blood Pressure

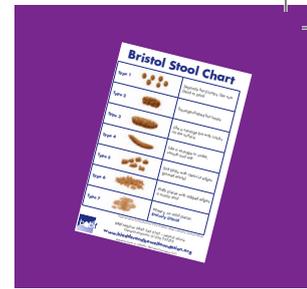
Do	Why
 <p data-bbox="406 653 625 754">Regular BP checks</p>	<p data-bbox="690 630 1414 778">This can be done by the individual's GP and should be part of the Annual Health Check.</p>
 <p data-bbox="406 936 625 1037">Use medication</p>	<p data-bbox="690 936 1475 1084">Support the person to take their regular high blood pressure medication prescribed by their doctor.</p>
 <p data-bbox="406 1359 645 1413">Eat healthy</p>	<p data-bbox="690 1232 1479 1585">Plenty of fruits and vegetables, reduce salt intake, eat a low fat diet, eat a lot of fibre, reduce fatty foods, increase fruit and vegetable intake, eat fish high in Omega 3 fatty acids at least twice a week, swap white flour product to whole grains.</p>
 <p data-bbox="406 1759 594 1860">Lifestyle changes</p>	<p data-bbox="690 1759 1448 1860">Limit alcohol intake, stop smoking and exercise regularly.</p>



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Bowel Problems

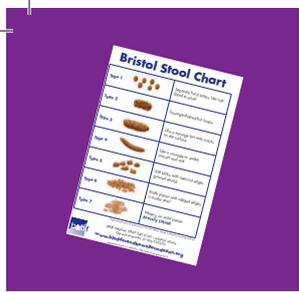


Symptoms	Description
Change in Behaviour	Changes in a persons behaviour or mood including frequent crying, aggression, change in sleeping patterns.
Changes in colour or texture	Change in the colour or texture of the poo including: is it runny, is it really hard and lumpy, is it like water (Refer to Bristol Stool Chart).
Blood	Visible blood in the poo.
Pain	Person may show signs of pain (refer to 'Indicators of Pain').
Tenderness in abdomen	Tummy is tender or feels hard.
Frequency	Going to the loo more or less often than usual.
Tired/ Lethargic	Falling asleep during the day. Changes in sleep pattern. finding it difficult to get out of bed.



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Bowel Problems

Symptoms	Description
 <p>Temperature/ Sweating</p>	Sweating more than usual or feel hot to touch. Temperature of more than 37.5 degrees Celsius.
 <p>Time</p>	Spending more or less time in the toilet compared to their normal bowel pattern.
 <p>Weight changes</p>	Lost or gained weight with no obvious reason.
 <p>Family history</p>	Family history of bowel problems.
 <p>Food/ Allergies</p>	Food allergies or food intolerances. Identify food eaten in the last 24 hours.
 <p>Appetite</p>	Uninterested in food. Refusing to drink or eat.



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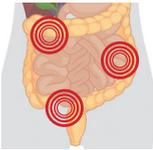


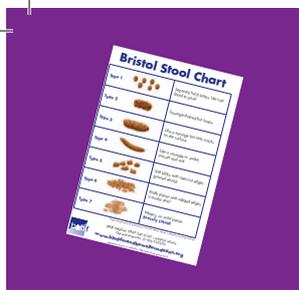
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Possible Causes of Bowel Problems



Causes	Explanation
 <p>Stress</p>	<p>Can cause problems due to anxiety and worrying.</p>
 <p>Irritable Bowel Syndrome (IBS)</p>	<p>A condition that causes a range of digestive problems, such as diarrhoea and bloating.</p>
 <p>Ulcerative colitis</p>	<p>Inflammation of the large bowel.</p>
 <p>Unhealthy diet</p>	<p>Not eating a balance diet and not enough fibre.</p>
 <p>Crohn's disease</p>	<p>Inflammation of the digestive system.</p>



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How to Support Someone with Bowel Problems

Do	Why
 <p>Support them to the GP</p>	If the individual has not had a bowel movement for 3 days, or opened their bowels less than 3 times a week on a regular basis. If they have had diarrhoea for more than 3 days. If you see blood in their stool.
 <p>Ensure they have the right investigations</p>	Screening is available for 60-75 year olds. This is done by testing the poo. Bowel screening kit can be completed at home.

How to Manage and Monitor Bowel Problems

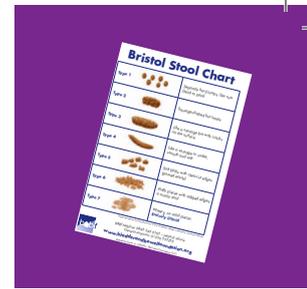
Do	Why
 <p>Communicate</p>	Use pictures or Makaton to help the person communicate.
 <p>Observation</p>	Monitor and record bowel movements, bring this when you visit GP.
 <p>Drink plenty of water (keep hydrated)</p>	Water helps ease bowel movement. Water helps to make your poo soft, which make it easier to pass through your body.



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How to Manage and Monitor Bowel Problems



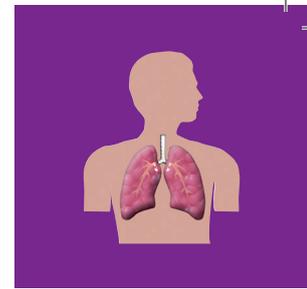
Do	Why
 Open bowel regularly	Opening bowels regularly is a good practice. It cleans and gets rid of body toxic.
 Encourage healthy eating	Eat fruits and vegetables. Eat foods that are high in fibre. Fibre helps ease the bowel movement.
 Exercise often	Keeping fit and exercise regularly is healthy.
 Stop smoking	To prevent the risk of cancer.
 Laxatives	Maybe needed when finding it difficult to poo. It can help ensure regular opening of bowels.
 Consult GP	If in doubt always consult the GP.



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Chest Infection

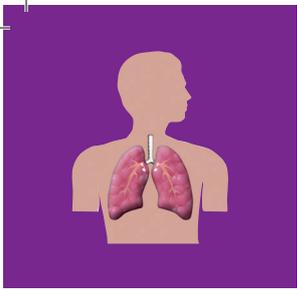


Symptoms	Description
 Persistent cough	Coughing after eating or drinking. Most coughs clear up within three weeks and don't require any treatment. Persistent coughs see GP.
 Coughing up yellow, green phlegm	Coughing is your body's natural way of cleaning the infection. Phlegm coughed up is yellow or green or contains blood.
 Breathlessness rapid heartbeat and shallow breathing.	Find it hard to breath. Hold chest or throat with hand. Cannot talk. Does not want to talk. Chest rising up and down very fast or very slow. Appears very uncomfortable or agitated when breathing. Lips blue.
 Wheezing	Breathing is noisy or rattling. Difficulty speaking.
 High temperature (fever)	Generally unwell. Behaviour change. Sweating that is not usual.
 Pain	Chest pain. Joint pain. Headache. What does pain look like for this person? Bang head, irritable, hit or strike chest.



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Chest Infection

Symptoms	Description
 Fatigue	No energy. Not wanting to get out of bed. Refusing usual activities. Withdrawn. Not wanting to participate in any usual activities. Falling asleep or sleepy.
 Sweating	Beads of sweat on forehead or top or more general perspiration. Not usual for person.
 Loss of appetite	Refusing food. Only eating small amounts. Pushing food away, rushing food.
 Lack of mobility	Unable to stand, unsteady on feet, lack of body tone, floppy, cannot hold body up right, not moving, move less.

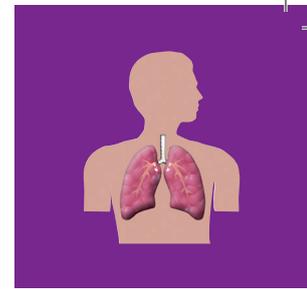


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Possible Causes of Chest Infection



Causes
Cold and flu

Explanation
Usual sneezing, coughing



Causes
Other person with infection

Explanation
Someone else with a chest infection coughing or sneezing near you. This launches tiny droplets of flu containing the virus or bacteria into the air, where they can be breathed in by others.



Causes
Poor hygiene

Explanation
Tiny droplets of fluid will remain on the surfaces which are then picked up by other people if the area has not been cleaned. Touching surfaces that haven't been cleaned after someone with a chest infection has coughed or sneezed on them.



Causes
Dysphagia

Explanation
People who have difficulty swallowing are more prone to chest infections. Food and fluids can enter the lungs.



Causes
Poor posture

Explanation
Wheelchair users who are unable to sit in the correct position.



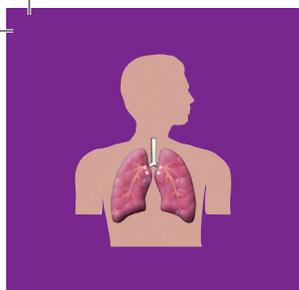
Causes
Low weight

Explanation
Malnourished. Other health conditions can make people susceptible to infection, chemotherapy treatment.



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How to Prevent a Chest Infection

Causes	Explanation
 <p>Good personal hygiene/ Infection control</p>	<p>Chest infection can be passed on through coughing and sneezing. Cover your mouth when you cough or sneeze. Wash your hands regularly. Put tissues in the bin immediately.</p>
 <p>Stop smoking</p>	<p>Stop smoking. Smoking damages your lungs and weakens defences against infection.</p>
 <p>Alcohol and diet</p>	<p>Tiny droplets of fluid will remain on the surfaces which are then picked up by other people if the area has not been cleaned. Touching surfaces that haven't been cleaned after someone with a chest infection has coughed or sneezed on them.</p>
 <p>Healthy diet</p>	<p>Eating a healthy balanced diet can help strengthen your immune system, making you less vulnerable to develop chest infections.</p>
 <p>Good posture</p>	<p>Follow the advice from a speech and language professional regarding feeding and nutrition.</p>

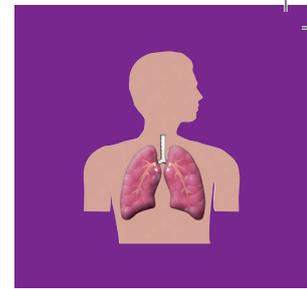


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How to Support Someone with a Chest Infection

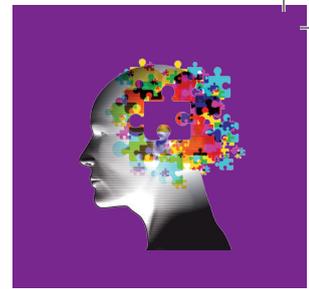


Do	Why
Plenty of rest	Allows the body to repair.
Good posture	Raising the head up with extra pillows while sleeping to make breathing easier.
Encourage water	Prevents dehydration and thins the mucus in the lungs, making it easier to cough up.
Take prescribed medication	Antibiotics are not recommended for many chest infections, because they are only effective if the infection is caused by bacteria rather than virus. The GP will usually only prescribe antibiotics if they think you have, or you are at risk of complications.
Treatment	Treat headaches, fever and aches and pains with painkillers such as paracetamol or ibuprofen as suggested by GP.

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Dementia



Symptoms	Description
 Memory loss	Has difficulty with short term memory. May forget where they have put something only a short while ago. Forget what they have been asked to do.
 Change in behaviour	Appears more withdrawn. May become upset more frequently. Increased, listlessness, loss of motivation. General slowing down.
 Disorientation	In time and place.
 Loss of skills	Finds everyday living skills, washing, dressing, toileting, household tasks more difficult. May forget the sequence of the task.
 Language difficulties	May find it difficult to find the right word, gesture, sing to express themselves.
 Sleep disturbances	Changes in sleep pattern. Awake at night, asleep more during the day.

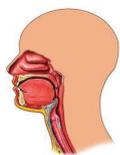




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Dementia

Symptoms	Description
 Decline in mobility	Becomes more hesitant moving around. Increased trips and falls, generally unsteady, holding on for support.
 Swallowing difficulties	May have difficulty swallowing tablets. May cough during mealtimes. Have reoccurring chest infections. Taking longer during mealtimes. Holds food in mouth. Choking on food and liquids.
 Seizures	May develop in later stages.
 Psychotic symptoms	May experience hallucinations and delusions.
 Behavioural challenges	May lose inhibitions. Become resistant to change or support to do tasks. Become aggressive (not as common as believed). Repetitive/ritualistic behaviours.



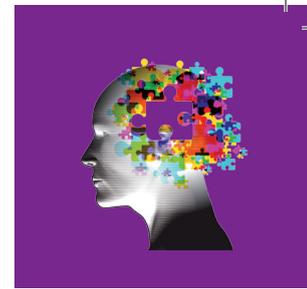
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Possible Causes of Dementia



Causes	Explanation
Brain structure	<p>Dementia is a disease of the brain that results in the loss of normal brain structure, resulting in the persons day to day functioning and personality to deteriorate progressively over time.</p>
Down's Syndrome	<p>Between 15-20% of the learning disabilities population have Down's Syndrome. People with Down's Syndrome have a much higher risk of developing dementia - with an onset age of between 30 - 40 yrs. At least 55% of people with Down's Syndrome will be affected by dementia aged between 60 - 69 yrs. (compared to 5% for the rest of the population). It is recommended that people with Down's Syndrome are screened by the age of 40 yrs. Please contact your Learning Disability Team to request an initial baseline assessment for anyone who has Down's Syndrome, and is aged 40, or sooner if you have concerns.</p>





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How to Support Someone with Dementia



Do	Why
Consult the GP	If you have noticed any of the symptoms listed above, support the individual to see their GP.
Report to Service Manager	Discuss the signs and symptoms you have observed.
Understand other conditions	There may be other conditions such as infection, under active thyroid and depression that may mimic dementia.

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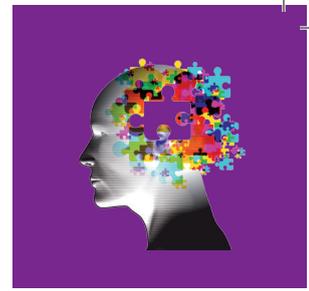
Do	Why
GP appointment	Health Check - To exclude any physical health problems for deterioration in memory. Infection, under active thyroid, depression, sensory difficulties, hearing, sight and swallowing problems. May require further investigations: blood test, MRI/CT scan, ECG, EEG.
Keep detailed record of any symptoms noticed	This information will be crucial in discussion with GP and other professionals, in picking up on early presenting signs, and in getting the correct diagnosis.



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Do

Why

Support & Advice

Contact your local Community Learning Disability Team for signposting to other support services in the area, or access or support with referrals to other Multi-Disciplinary Team members.



Training

Training is available to support staff and carers. Contact the Community Learning Disability Team for further information.



Carers assessment

A carers assessment is available via health and social care services.



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Diabetes



In Type 1 Diabetes the signs and symptoms are usually very obvious and develop very quickly, typically over a few weeks. The symptoms are quickly relieved once the Diabetes is treated and under control.

In Type 2 Diabetes the signs and symptoms may not be so obvious, as the condition develops slowly over a period of years and may only be picked up in a routine medical check-up. Symptoms are quickly relieved once diabetes is treated and under control. Early diagnosis is very beneficial. If you suspect any of the signs and symptoms listed above; book a GP appointment for the service user.



Symptoms

Description

Urination frequency

- Going to the toilet more often than usual.
- Using the toilet excessively.
- Using the toilet more at night.



Increased thirst

Drinking more than usual. Drinking from a tap, bath, shower, hose. Asking for more drinks. Presenting with dry mouth.



Extreme tiredness

Appears more lethargic than usual. Tired during the day whilst doing normal activities. Struggling to get up out of bed. Sleeping/napping more throughout the day. Wanting to go to bed earlier.



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Diabetes



Unexplained weight loss

Lost weight with no particular signs of diet change. Rapid weight loss for no obvious reason.



Genital itching or regular occurrences of thrush

Increased scratching on their genital areas. Multiple diagnosis of thrush in the last few months.



Blurred vision

Complaining of not being able to see. More clumsy than usual e.g. falling over, walking into objects. Refusing to move/go out. Clinging onto people.



Slow healing of cuts and wounds.

Wounds taking longer to heal.

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Possible Causes of Diabetes

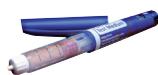
Causes	Description
	<p>Being overweight</p> <p>Obesity is strongly associated with the development of type 2 diabetes. Obesity causes insulin resistance and is common in people with type 2 diabetes.</p>
	<p>Unhealthy diet</p> <p>Having a unhealthy diet is normally linked to being obese. Being overweight or obese can cause diabetes.</p>
	<p>Lack of exercise</p> <p>Being physically inactive can cause people to be overweight, which can contribute to diabetes.</p>
	<p>Genetic factors</p> <p>Genes are passed down from biological parent to child. Having certain genes or combinations of genes may increase or decrease a person's risk of developing the disease.</p>
	<p>Smoking</p> <p>Diabetes complications already include heart disease, stroke and circulation problems. Smoking adds to the risk of developing all of these things.</p>
	<p>Polycystic ovary syndrome</p> <p>Polycystic ovary syndrome is a condition that can affect a woman's ability to produce eggs. PCOS is linked with higher levels of circulating insulin, which is characteristic in type 2 diabetes.</p>
	<p>Lack of insulin</p> <p>A lack of insulin being produced in the pancreas can cause type 1 diabetes.</p>



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Possible Causes of Diabetes



Insulin resistance	When the body's muscle, fat and liver cells do not use insulin effectively, this can cause type 2 diabetes.
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Age	Being over the age of 40 (over 25 for South Asian people) is a risk for type 2 diabetes.
-----	--



Ethnicity	Being of South Asian, Chinese, African-Caribbean or black African origin (even if you were born in UK) is a risk for type 2 diabetes.
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How to Support Someone with Diabetes



Do	Why
Eat regularly	Ensure the person eats 3 healthy meals a day. Ensure the meals are nutritious and well balanced.



Exercise	Ensure the person is exercising regularly if able. A 20 minute walk a day will help prevent diabetes.
----------	---



Alcohol	If the person drinks alcohol, try and ensure this is in moderation and within the recommended limits.
---------	---



Smoking	If the person smokes, help them to stop/cut down. If you have diabetes you already have a increased risk of developing circulatory problems and cardiovascular disease. Smoking further increases your risk of developing these diseases.
---------	---



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How to Manage and Monitor Someone with Diabetes



Do	Why
Monitoring	Ensure you are monitoring the person's blood sugar levels closely if trained to do so. If you suspect they may be low, test first.
Be aware of the symptoms	Ensure the carers and the person are aware of the symptoms of a hypoglycaemia and a hyperglycaemia as this will help stop it quicker if it happens.
Medication	If the person is prescribed medication, ensure the person receives their diabetic medication on a regular basis as prescribed by the doctor. Ensure the person has their injected insulin as and when prescribed by the doctor.
Clinics	Ensure the person attends regular diabetic clinics to ensure they are still on the right medication and any issues can be discussed.



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How to Manage and Monitor Someone with Diabetes



Eye screening

Attend eye screening appointments as having diabetes can increase the risk of sight loss and diabetic retinopathy.



Foot health

Ensure regular chiropody appointments.
Check feet regularly



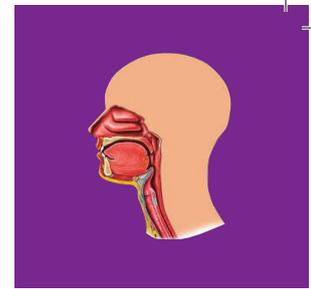
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Symptoms and Guidance

Dysphagia (Swallowing Problems)



Finding it hard to eat and drink

The person may avoid eating. The person may take longer over meals than normal. The person may get upset when seeing food or when eating. Some people stop being able to recognise their food, some people have difficulty placing their food in their mouth, some people are not able to control the food or saliva they have in their mouth.



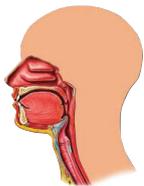
Cough during or after meals

If a person coughs when they eat/drink, or shortly afterwards, this can indicate the food has gone "the wrong way".



Having a wet/gurgled voice

If there is not enough control to clear the throat properly, people may get a wet or gurgled voice.



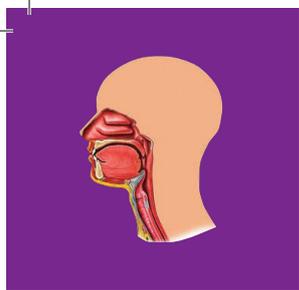
Repeated swallowing during eating and drinking

Extra swallows are needed when eating and drinking to clear the mouth and throat.



Food falling from the mouth

Lack of control of the mouth and throat.



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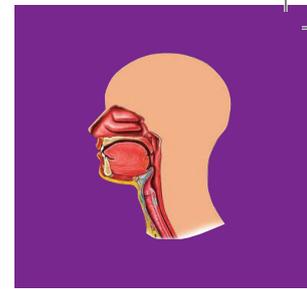
Dysphagia (Swallowing Problems)

Symptoms	Description
 <p>Bringing food back up (regurgitation)</p>	When there is not enough control for the food to go down, food gets stuck so it is brought back up.
 <p>Choking</p>	When food has gone the wrong way it can block the airway partially or completely, and the person is unable to breathe normally until the blockage is cleared.
 <p>Chest infections</p>	They can be frequent if food is "going down the wrong way" i.e. into the lungs and not the stomach.
 <p>Weight loss</p>	When someone has swallowing difficulties eating can take much longer (anything up to an hour or more) and be painful so people go off their food.
 <p>Constipation</p>	May occur if the person is not drinking enough fluid or eating enough to form good bowel motions.
 <p>Hospital admissions</p>	Overall health declines or pneumonia is present. Sometimes there are multiple infections (such as a chest infection and urine infection).



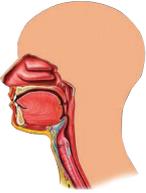
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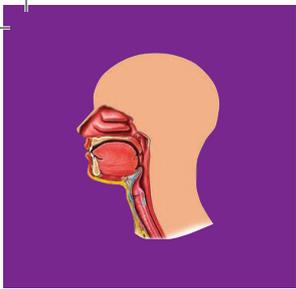


Possible Causes of Dysphagia

People with a learning disability are at increased risk of swallowing problems (2007 National Patient Safety Agency). This can affect their general health and wellbeing and in extreme circumstances lead to death.

Causes	Explanation
 <p data-bbox="517 785 799 978">Issues with the structure of the mouth and throat</p>	<p data-bbox="819 602 1576 1154">Cleft palette. This is a very common birth defect which, even after corrective surgery can have associated with it missing teeth and gaps, overcrowding in the mouth and malformed teeth as well as issue with the soft and hard palette which is used in the mechanics of swallowing. The hard palette may also have residual hole in it so food/fluids may go the wrong way - into the air way.</p>
 <p data-bbox="517 1201 790 1495">Processing difficulties (coordination of the messages to the brain)</p>	<p data-bbox="819 1178 1547 1519">This may slow down due to a number of reasons and can be linked to medication, mental health issues, degenerative illness and epilepsy. The messages from the brain to the muscles may slow down and be impaired.</p>
 <p data-bbox="517 1719 795 1813">Institutional/ poor care</p>	<p data-bbox="819 1542 1555 1985">People who have lived in institutions may rush their food. There is also institutional discrimination (poor care) where the needs of people with a learning disability are not recognised, there is poor communication amongst staff, care plans are not followed and there is a lack of basic care and attention.</p>





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Possible Causes of Dysphagia

Causes	Explanation
 <p>Poor oral health</p>	<p>Bacteria builds up in the mouth and enters the respiratory system (the lungs).</p>
 <p>The effect of medication</p>	<p>Medications that are used in mental health problems and epilepsy can have a sedating effect which can increase the risk of swallowing problem as the levels of alertness, muscle tone and co-ordination may be impaired. Other medications can dry up saliva. Saliva is needed to keep the PH of the mouth correct and is needed to help in swallowing.</p> <p>Some drugs can also suppress the gag reflex so if someone did have difficulties in swallowing their ability to cough and remove the object from the throat would potentially be impaired.</p>
 <p>Dementia</p>	<p>Any condition that affects muscle tone and co-ordination will potentially have an impact on swallowing. Swallowing takes the co-ordination of 31 muscles and 6 major nerves.</p>

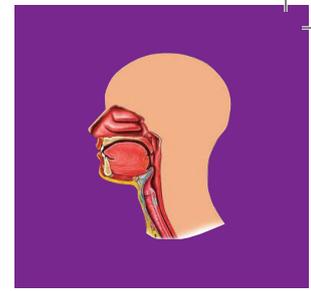


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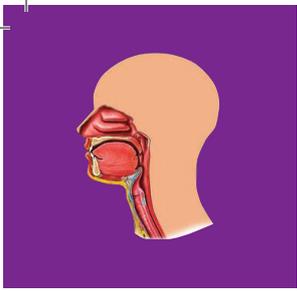
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How to Support Someone with Dysphagia

Do	Why
 <p>Follow the Speech and Language Therapists (SaLT) advice on changing food and drink texture</p>	<p>Some people with swallowing problems need to have a diet of mashed or puréed food, or have thickened drinks. The SaLT will assess where the swallowing problem is, how serious it is, and what could help. Sometimes making drinks thicker, or food smoother, will prevent it going down the wrong way.</p>
 <p>Ensure that good oral health is maintained</p>	<p>Swallowing problems can mean bits of food, drink or saliva build up in the mouth, growing harmful bacteria. If swallowed the wrong way, it can cause very serious chest infections. Give extra care before and after meals, using a dry toothbrush and a little toothpaste (low-foam and no-foam toothpastes are available as well) - all of this is to minimize foaming that can go the wrong way down. Help the person to clean their teeth, gums and tongue, do not rinse, leave the paste on - fluoride benefits the teeth as rising water may go down the airway.</p>
 <p>Reduce distractions at meal times (TV/chatting)</p>	<p>If you help the person to concentrate in eating and swallowing, this may improve swallow function and make the meal more enjoyable.</p>



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How to Support Someone with Dysphagia

Do	Why
 <p>Encourage an upright posture</p>	<p>This will help the swallow function and reduces the risk of food going down the wrong way. Small mouthfuls of food/sips of drink which are more manageable.</p>
 <p>Check the NPA website: www.npsa.nhs.uk/resources/</p>	<p>This website contains information on dysphagia case plans and meal time information sheets.</p>

How to Manage and Monitor Someone with Dysphagia

Do	Why
 <p>Ensure you know your role</p>	<p>You have a key role in identifying swallowing issues in the people that you work with. Never accept coughing at meals times as normal. Make a note of what you see and tell your manager; ask for referral to a SaLT. Support the person to reduce risk of serious health hazards, as above.</p>
 <p>Liaise with key worker/manager</p>	<p>A risk assessment may be needed. Ensure the matter is looked at by a SaLT- refer directly through SPA or through the GP.</p>

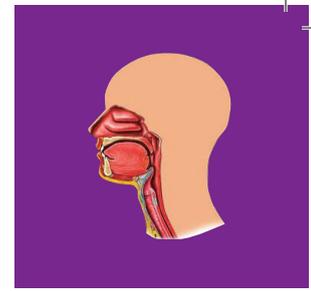


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How to Manage and Monitor Someone with Dysphagia

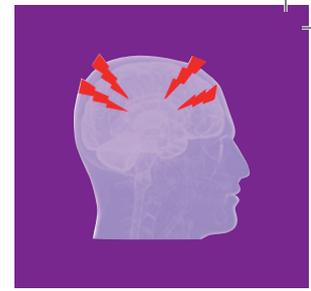


Do	Why
Liaise with GP	The GP can review medication and make referrals for investigations. The GP will also check if anything else has changed recently, like medication, and if this could have caused trouble swallowing.
Liaise with key worker/manager	The SaLT can receive a referral directly through SPA or via GP. They will complete a specialist dysphagia assessment and make recommendations about food textures. They work closely with the dysphagia dietician.

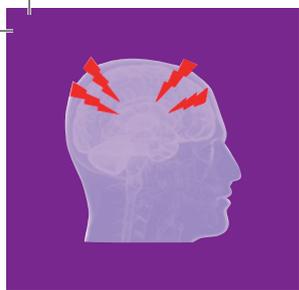
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Symptoms and Guidance

Epilepsy



Symptoms	Description
 Tiredness or lethargy	Disturbed sleep if seizures are happening at night and may be missed. Tiredness for no obvious reason. Lack of energy. Disengaging from activities. Falling asleep during the day.
 Forgetfulness/ memory difficulties	Forgetting names of people. Forgetting places familiar to the person. Lapses in memory. Repeating words or conversations. General forgetfulness unusual to the person. Forgetting names of people.
 Loss of appetite	Loss of appetite due to feeling drowsy or tired following a seizure.
 Incontinence	Loss of control of bladder and bowels during a seizure. Regular incontinence. Unable to explain incontinence.



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Symptoms and Guidance

Epilepsy

Symptoms	Description
 Unexplained injuries or falls	Bruising or injury caused by jerking or falling during seizures.
 Headaches	Headaches before or after a seizure. What does a headache look like in someone who has no verbal communication .i.e. holding their head. Regular complaints of headaches/migraines.
 Day dreaming or staring blankly	Staring blankly into space. People may hear you but will be unable to respond. (This is sometimes known as an absence seizure). Not responding when being spoken to. Can appear confused.
 Unusual behaviour	Any behaviour that is unusual to the person. Agitation for no apparent reason.



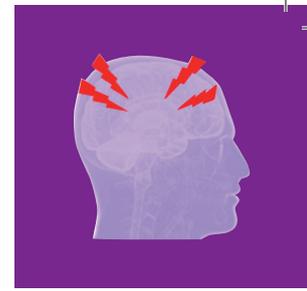
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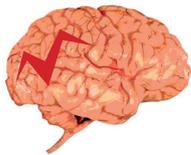
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Possible Causes of Epilepsy



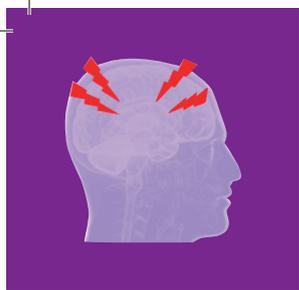
In over half of epilepsy cases, a cause cannot be found. If there is an identifiable cause, it usually involves the brain being affected by a condition. There are two main categories of epilepsy:

Idiopathic (or primary) epilepsy - where no apparent cause for epilepsy can be found, but there may be a family history, suggesting that the condition is inherited
Symptomatic (or secondary) epilepsy - where there is a known cause for a person's epilepsy.



Causes	Explanation
Brain or head injury	A severe head injury may cause a build-up of pressure in the brain because of bleeding, blood clots or a build-up of fluid. Severe head injuries should always be treated in hospital.
Infection	Meningitis/Encephalitis High fever/high temperature can result in seizures. In some cases UTI's can cause seizures due to a raise in temperature.





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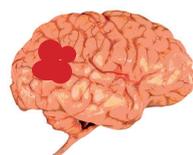
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Possible Causes of Epilepsy



Cerebro-vascular diseases

Conditions caused by problems that affect the blood supply to the brain.
Examples are stroke and vascular dementia.



Brain Tumours
A brain tumour is a growth of cells in the brain that multiplies in an abnormal, uncontrollable way. It can either be cancerous (malignant) or non-cancerous (benign).

Severe, persistent headaches.
Seizures (fits).
Persistent nausea.
Vomiting and drowsiness.
Mental ill health or behavioural changes.
Memory problems.
Changes in personality.
Progressive weakness or paralysis on one side of the body.
Vision problem or speech problems.



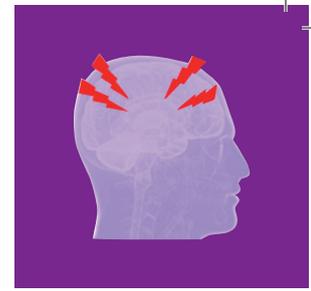
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How to Support Someone with Epilepsy



Do
Identify Triggers and Warning signs

Why

Document triggers and warning signs. Recognising situations that cause or 'set off' a seizure i.e. stress or tiredness.



Do
Follow Treatment Plans

Epilepsy medications help control seizures, but they don't cure epilepsy. Medication must be taken regularly and on time. However people can still continue to have seizures which may result in injury or even death.



Do
Recording and monitoring

If you suspect epilepsy, it can be helpful to film it, or write down details of what happens, if the person agrees that you can do this (*consider capacity assessment*). Complete seizure monitoring forms.



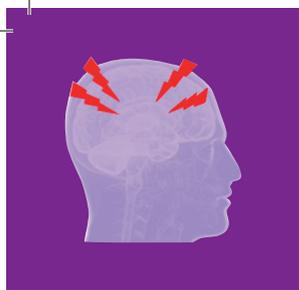
Do
Consider the person's environment

Light, sound and temperature can all trigger seizures. Having a safe environment, free from clutter, sharp objects, pipes are covered is very important. Environment is kept clean and spacious. A risk assessment should be in place.



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Symptoms and Guidance

How to Support Someone with Epilepsy



Well-being

Having a balanced diet, keeping physically active, sleeping well and finding ways to relax and manage any stress.
 Some people find complementary therapies or psychological therapies help with their overall wellbeing.
 Monitor alcohol intake. Stick to daily recommended advice.



Health appointments

Always support the person to attend regular neurology/GP/health appointments. Use and bring Purple Folder.
 Ensure that all information is brought to appointments i.e. recordings, monitoring forms etc.
 There are different tests that someone may have to undergo. CT/CAT scan, Ambulatory EEG, Video telemetry.



During a seizure

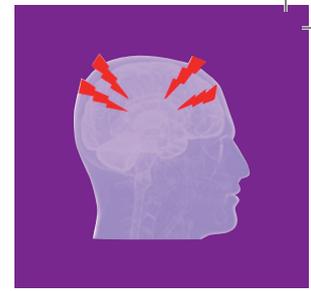
Ensure the environment is safe and remove any dangers if safe to do so. Place a cushion or a soft material under the head.
 Do not hold the person down.
 Do not put anything in the mouth.
 Once the seizure has stopped, check the person's mouth to ensure nothing is blocking the air way.
 If appropriate, place the person into the recovery position.
 Observe the person until fully recovered, check for injuries.
 If this is a first seizure, call 999.



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Sudden Unexpected Death in Epilepsy (SUDEP)



Sudden
Unexpected
Death
in Epilepsy
(SUDEP)

When a person with epilepsy dies suddenly, and after post mortem examination no cause is found.

How to minimise the risk of SUDEP

- Good seizure control.
- Take medication as prescribed and on time.
- Avoid excessive use of alcohol.
- Aware if the person suffers from night time seizures.
- Maintain a healthy lifestyle.



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Symptoms and Guidance

Indicators of Pain



Symptoms	Description
	Unusually quiet or withdrawn; not participating in the activities they used to.
	Behaviour out of character: hitting out/being aggressive to others or hitting/punching themselves, rocking to and fro.
	This means anything from a lack of sleep to going to bed at usual times to having nightmares/crying out in the night.
	To get people to understand them but are unable to explain what is going on.
	Unusual pacing or agitation refusing to settle down.
	Not interested in food or eating. Leaves food on the plate or experiencing pain when eating.



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Indicators of Pain



Screaming/
crying

Person cries or screams with no visual sign of pain or is out of character.



Confusion

If they are unable to understand why they are feeling the pain, an individual may seem lost or dazed.



Injury

Obvious injury, unusual swelling or bruising or pain.



Mobility
changes

Posture, limping, dragging, unable to walk, huddled.



Observations

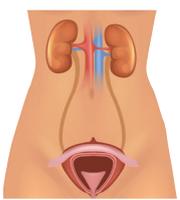
Rash, skin changes, infections, pale, flushed etc.

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Possible Causes of Pain



Causes	Explanation
	<p>Musculoskeletal disease</p> <p>Happens more as the individual gets older, more likely in women and contributes to osteoarthritis and osteoporosis.</p>
	<p>Dental problems</p> <p>Deterioration in dental health with age, causes by poor or inconsistent dental care, common in people with learning disabilities and people may be reluctant to attend the dentist.</p>
	<p>Impacted earwax</p> <p>Can lead to ear infection, people with a learning disability are twice as likely to have this and people who have problems chewing are more susceptible.</p>
	<p>Eye infections</p> <p>People with Downs Syndrome are more likely to have dry, infected eyes and blepharitis (inflammation of the eyelid) increases risk of infection.</p>
	<p>Urinary tract infections (UTI)</p> <p>Older people with a learning disability can often have recurrent UTI's, these infections are often easily treated. Diabetes along with reduced food and fluid intake increases the risk.</p>
	<p>Constipation</p> <p>The gastrointestinal system slows down with age, the pain can be severe and lead to misinterpreted behaviour, some people may not drink a sufficient amount of water.</p>

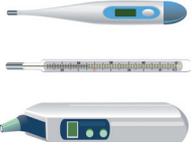




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How to Support Someone with Pain

Do	Why
 <p>Find a quiet place</p>	<p>A noisy environment could make the individual's pain worse; they may prefer to be alone.</p>
 <p>Communicate</p>	<p>Use pictures or Makaton to help the person communicate.</p>
 <p>Monitor temperature</p>	<p>Use a thermometer to see if the person has a temperature (above 38°C), which can be a sign of infection.</p>
 <p>Observation</p>	<p>Monitor and record possible incidents of pain to detect pattern. Check file and medication chart for any incidents.</p>
 <p>Reassure</p>	<p>Helps to calm and comfort the person.</p>
 <p>Support to the GP</p>	<p>If the person is in serious pain or it has lasted for over 48 hours, take them to the doctors.</p>



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How to Manage and Monitor Someone with Pain



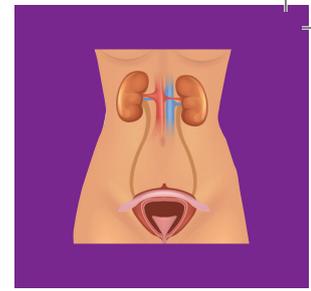
Do	Why
Use DisDAT	Use the Disability Distress Assessment Tool (see Appendix 3) as a first step to identifying distress in someone with limited communication.
Review	Review pain management interventions to check pain relief is still effective and look for side effects of medication.
Monitor	Ensure you are using the correct tool to measure the impact and effectiveness of pain interventions.
Record	Record important information and keep this with the pain management record in Purple Folder, how they behave when in pain and times they are likely to experience pain (e.g. menstruation).
Communicate	Inform other staff members when there is a change, for example in the care plan or medication.
Update	Ensure the pain management plan is always updated when anything is changed including during the review.



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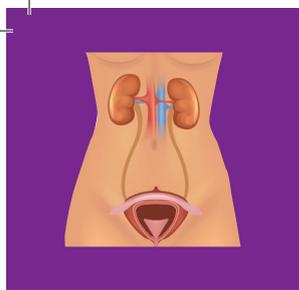
Symptoms and Guidance

Urinary Tract Infection (UTI)



Symptoms	Description
	<p>Person may become confused. Confusion that is out of character. Unusually forgetful, disoriented or not wanting to take part in usual activities.</p>
	<p>Behaviour that is out of character. May not want to get out of bed. Or be angry or agitated. Importance of taking medication and refusing.</p>
	<p>Urine may smell unusual.</p>
	<p>Urine looks unusual. May be darker than usual; red or spots of red, cloudy.</p>
	<p>Person may be going to the loo more often than usual. Or not going to the loo.</p>
	<p>Pain in tummy or groin area. How does the person usually indicate pain?</p>
	<p>Falling asleep, pale, no energy.</p>





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Urinary Tract Infection (UTI)



Temp/
Sweating

Sweating or appears unusually hot.



Difficulty
urinating

Cannot pee, or appears to have difficulty peeing by spending long periods of time sitting on the toilet.



Incontinent

Wetting self-that's not usual or leaking urine.



Holding groin
area

Holding groin area with hand, may claw, dig or try to stimulate area.



Change in
appearance

May be stooped over. May rock back and forth to stimulate.



Appetite
change

Not interested in food, leaves food on plate, feeling sick or wanting to vomit.



Urgency

Running to the toilet because they suddenly need to go.



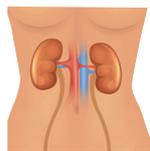
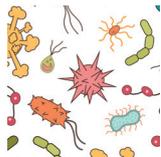
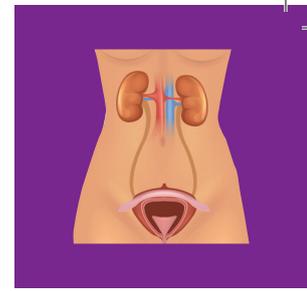
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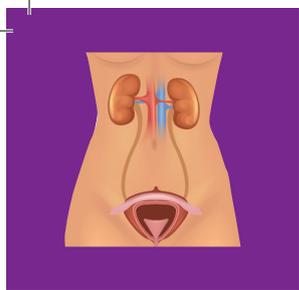
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Possible causes of Urinary Tract Infection (UTI)



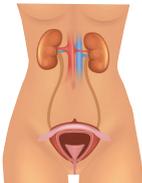
Causes	Explanation
Bacteria	Bacteria can spread to the urethra via the anus. For example, if toilet paper touches your anus and then touches your genitals, the bacteria can multiply and move through your urinary tract, causing infection of your urethra.
Kidney stones	A condition that obstructs or blocks your urinary tract, such as kidney stones.
Not emptying the bladder	A condition that prevents you fully emptying your bladder (it's easier for bacteria to multiply if urine stays in the bladder for too long).
Catheter	A urinary catheter - a tube inserted into your bladder to drain away the urine.
Gender	Women are more likely than men to have a UTI. This is because in women, the urethra is closer to the anus than it is in men. Also, the urethra is much shorter in women, making it easier for bacteria to reach the bladder.



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How to Support Someone with a Urinary Tract Infection (UTI)

Do	Why
 <p>Be aware of possible difficulties</p>	<p>If UTI's go untreated they can develop into very serious and potentially life-threatening kidney infections (pyelonephritis) that can permanently scar or damage the kidneys, leading to renal hypertension and eventual kidney failure. The infection may also spread into the blood stream (called sepsis) and then elsewhere in the body (NHS choices 2015).</p>
 <p>Encourage plenty of water</p>	<p>Keep hydrated: water helps flush the urinary tract.</p>
 <p>Observation</p>	<p>Monitor and record fluid intake and output. Bring charts to the GP when you go.</p>
 <p>Empty bladder</p>	<p>Any bacteria present can develop into a full UTI. Encourage individual to go to the toilet regularly and not hold it.</p>

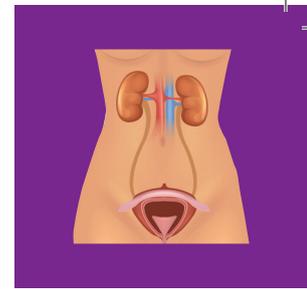


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How to Manage and Monitor Someone with Urinary Tract Infection (UTI)



Do

Wear cotton underwear

Why

Cotton fabric lets moisture escape while other fabrics retain moisture can trap moisture, creating a potential breeding ground for bacteria.

Change pads regularly.



Review current medication

Certain medications cause urinary retention which causes a UTI. See medicines information sheets for details and specific drugs.



Treatments/
Investigations

Do not accept that UTI's are a regular normal health problem, some people keep getting UTIs: this is called having recurring UTIs. Some people are given a low dose antibiotic to take every day. People with LD should be re tested after a course of antibiotic as the infection may still be live. Further investigation of the underlying cause is very important.

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Helpful Links and Resources:

Asthma

<http://www.asthma.org.uk/>

<http://healthtalk.org/peoples-experiences/chronic-health-issues/asthma/adult-onset>

<http://www.nhs.uk/Conditions/Asthma/Pages/Causes.aspx>

High Blood Pressure (BP)

<https://www.bhf.org.uk/heart-health/risk-factors/high-blood-pressure>

National Institute for Health and Clinical Excellence (NICE) guidelines (2006)

Beevers DG, Lip GYH and O'Brien E 2007 (eds.), *ABC of Hypertension*, 5th edition Blackwell

Blood Pressure Monitoring (www.bpmonitoring.com)

Bowel Problems

<http://www.nhs.uk/Conditions/Cancer-of-the-colon-rectum-or-bowel/Pages/Introduction.aspx>

<http://www.patient.co.uk/health/irritable-bowel-syndrome-leaflet>

<http://www.cancerresearchuk.org/about-cancer/type/bowel-cancer>



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Helpful Links and Resources:

Chest Infections

References

Niederman M (2009) *Community Acquired Pneumonia in Adults Guidelines for the management of community acquired pneumonia in adults*. The British Thoracic Society

Further Information

<http://patient.info/health/common-cold-and-other-upper-respiratory-tract-infections>

Dementia

References

Dodd et al (2002), *Down's Syndrome and Dementia resource pack for carers and support staff*. BILD publications.

Older people with learning disabilities and dementia - a good practice guide for health and social care - NHS

Down's Syndrome Association www.downs-syndrome.org.uk

Alzheimer's Society www.alzheimers.org.uk

Dysphagia

References

National Pharmacy Association Ltd

Michael E. Groher (2015) *Dysphagia: Clinical Management in Adults and Children*, Mosby.

<http://www.hertsdirect.org/services/healthsoc/healthherts/>



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Helpful Links and Resources:

Epilepsy

Epilepsy Society - www.epilepsysociety.org.uk

Epilepsy Action - www.epilepsy.org.uk

Pain

Joseph Rowntree Foundation.(2008). *Do you recognise pain in someone with a learning difficulty and dementia?* London: OLM-Pavilion

Leat, M. et al. (2014). *Health Action Planning Toolkit: Pain Management*. Surrey: The Clear Communication People Ltd.

Regnard C, Matthews D, Gibson L, Clarke C, Watson B. (2006). The Disability Distress Assessment Tool (DisDAT). London: Northumberland Tyne & Wear NHS Trust and St. Oswald's Hospice

Regnard C, Reynolds J, Watson B, Matthews D, Gibson L, Clarke C. (2006). Understanding distress in people with severe communication difficulties: developing and assessing the Disability Distress Assessment Tool (DisDAT). *Journal of Intellectual Disability Research*, 51(4), 277-292.

Urinary Tract Infection (UTI)

References

Gupta K, (2014) *Urinary Tract Infections, An issue of infectious disease clinics*, Elsevier.

NHS Choices (2015)

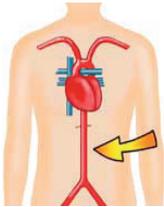


Abdominal Aortic Aneurysm (AAA) Screening

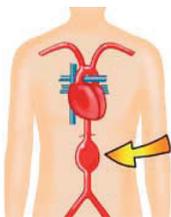


Information about a health test for men who are 65 or older

What is an abdominal aortic aneurysm?



The **aorta** is a big blood vessel that takes blood from your heart round your body.



As some people get older, the aorta can get weak and swell up. This sort of swelling is called an **abdominal aortic aneurysm**.



Men aged 65 and older are most likely to get this sort of **aneurysm**.

Is an aneurysm serious?



If you have a **large aneurysm** it could be **very** serious. If the wall of your **aorta** gets very weak it could burst. If this happens, you may die.



If you have a **small aneurysm**, it is **not** dangerous. But it is still important to keep checking that your aneurysm is not getting any bigger.



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Why is it important to have the test?



You cannot usually tell if you have an **aneurysm**. You will **not** usually feel any pain or notice anything different.



The NHS offers **AAA Screening tests** so we can find aneurysms early and keep checking them. Or we can treat the aneurysm if we need to.



Checking helps us to make sure an aneurysm will not give you serious problems in the future.

What will happen at the test?



We use a simple test called an ultrasound scan. The test takes less than 10 minutes. The test does not hurt.



For the test you lie down and lift up or open your shirt. We put a cool jelly on your tummy and move a small scanner over your skin.



We will tell you your result straight away and also tell your own doctor.

Where can I get more information?



Phone your **local screening centre** on **01727 897719**

Visit www.aaa.screening.nhs.uk.

Contact **The Circulation Foundation** charity on **020 7304 4779**.



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NHS Bowel Cancer Screening

The NHS Bowel Cancer Screening Programme offers screening every two years to all men and women aged 60 to 74.

People in the invitation age range are automatically sent an invitation, then their screening kit, so they can do the test at home.

If you have not been sent a kit or have lost it you can request another kit by calling the **FREE PHONE HELPLINE 0800 707 6060**.

How is the screening (FOB) test carried out?



You carry out the FOB test in the privacy of your own home. The screening kit provides a simple way for you to collect small samples of your bowel motions.

You wipe the samples on a special card, which you then send in a hygienically sealed Freepost envelope to a laboratory for testing. There are detailed instructions with each kit.

You may think that doing the test sounds a bit embarrassing or unpleasant, but it will only take a few minutes and it is an effective way to detect bowel cancer early.

You should receive a results letter from the laboratory within two weeks of sending in your sample.



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If you are supporting someone to complete the kit or need support yourself then please call the **FREE PHONE HELPLINE 0800 707 6060**. We will be happy to offer support and advice.

We are able to supply assisted materials and a picture booklet to help you complete the kit. All Publications come in different languages and large print.



What are the symptoms of bowel cancer?

The most common symptoms of bowel cancer to look out for are:

- A persistent change in bowel habit, especially going to the toilet more often or diarrhoea for several weeks;
- Bleeding from the back passage without any obvious reason;
- Abdominal pain, especially if it is severe; and
- A lump in your abdomen. Please remember that these symptoms do not necessarily mean that you have bowel cancer, but if you have one or more of these symptoms for four to six weeks, you should see your GP.

More information and support please contact your programme hub on

Freephone 0800 707 60 60;



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Top Tips For Supporting Someone With A Learning Disability To A Health Appointment



DID YOU KNOW?

Research shows that people with learning disabilities die 16 years sooner on average than the general population.

Some of the most common reasons for this is thought to be problems with investigating, diagnosing and treating illnesses in people with learning disabilities.

(CIPOLD, 2013)

People with learning disabilities often do not get the most out of their health appointments.

As a carer, you have a key role in supporting people with learning disabilities to have better health outcomes.



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BEFORE THE APPOINTMENT

- 1) Organise for an appropriate individual to go with the person for support.

Ask the individual to choose who they feel will be the best person to go with them, such as a paid carer, friend or relative. Make sure they know the person well, can support their communication needs, and have up to date information about their health. Is there a preference to male or female staff? Would they prefer to attend alone if they are able to?

- 2) Notify the hospital/ department if you feel reasonable adjustments need to be made. Are there any specific requirements needed?

Think **TEACH**:

T – Timing

This might include:

- Is a longer appointment time needed? It may be worth requesting a double slot.

E – Environment

- Needing a quieter environment while waiting and during their appointment?

A – Attitude

- Specific equipment such as wheelchairs or hoists?

C – Communication

- Avoiding waiting times by requesting the appointment is at the beginning or end of day, or is fast tracked.

H – Help

- Do they require hospital transport to get to and from?
- Would they benefit from a hospital pre-visit to get used to the environment?

- 3) Thoroughly read through the appointment letter. Be clear on where the appointment will be, what time, who they will be seeing and other specific information about what will happen during the appointment.



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DURING THE APPOINTMENT

Many appointments are wasted because important information is missing.

MAKE SURE YOU TAKE THE KEY THINGS FROM THE CHECKLIST WITH YOU.

APPOINTMENT CHECKLIST

<input type="checkbox"/>	Purple Folder
<input type="checkbox"/>	Food/fluid intake diary
<input type="checkbox"/>	Seizure charts/monitoring forms
<input type="checkbox"/>	Current medication list/MARs sheets
<input type="checkbox"/>	Menstruation charts
<input type="checkbox"/>	Bowel charts
<input type="checkbox"/>	Weight/BMI records
<input type="checkbox"/>	Discharge summaries from recent hospital stays.
<input type="checkbox"/>	Care and treatment plans i.e. psychology and physiotherapy.

1) Support the individual to communicate. This may be with specific communication needs and methods, or may just be reminding staff to allow for more time to answer questions.

2) Support the individual to understand what is happening. This may be by repeating what others say with words/phrases you know they can understand. It may also be prompting staff to ask open questions such as 'what do you think this means?' instead of 'do you understand?'. Are they able to consent to treatments or procedures, or does the health professional need to complete capacity assessment and organise a best interest decision/meeting.

3) Ask questions. Don't be afraid to ask questions, or check things over if you are not sure about something. Encourage the individual to ask questions. It may be useful to bring a list of questions you may need to ask.



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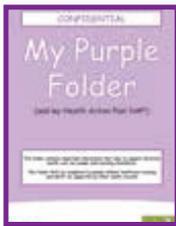
AFTER THE APPOINTMENT

1) Keep records:

Record any outcome's of the appointment. Have they been referred for any investigations or has a follow up appointment been booked? Will a follow up GP appointment need to be booked?

2) Purple Folder:

Make sure the Purple Folder is updated. Ask health professionals to record that they have seen the person in the 'Health Action Plan' section of their Purple Folder including the action. Keep notes of what was discussed including any outcomes.



3) Make appropriate referrals:

Is a referral to the Community Learning Disability Nursing Service or the Health Liaison Team needed?

If so contact the:

Community Learning Disability Nursing Service

on **03001234042** if you feel they require a Community Nurse to support with managing their health needs and liaising with GP's and other health professionals.

Health Liaison Team on

01438 845372 or email **healthliaisonteam.referrals@hertfordshire.gov.uk** if you feel the individual needs specialist support to ensure hospitals are providing reasonable adjustment. You can also contact the team if a Purple Folder and extra pages are needed.

Epilepsy Nursing Service on

01442 453 017 for expert advice and support with managing and treating epilepsy and seizures.

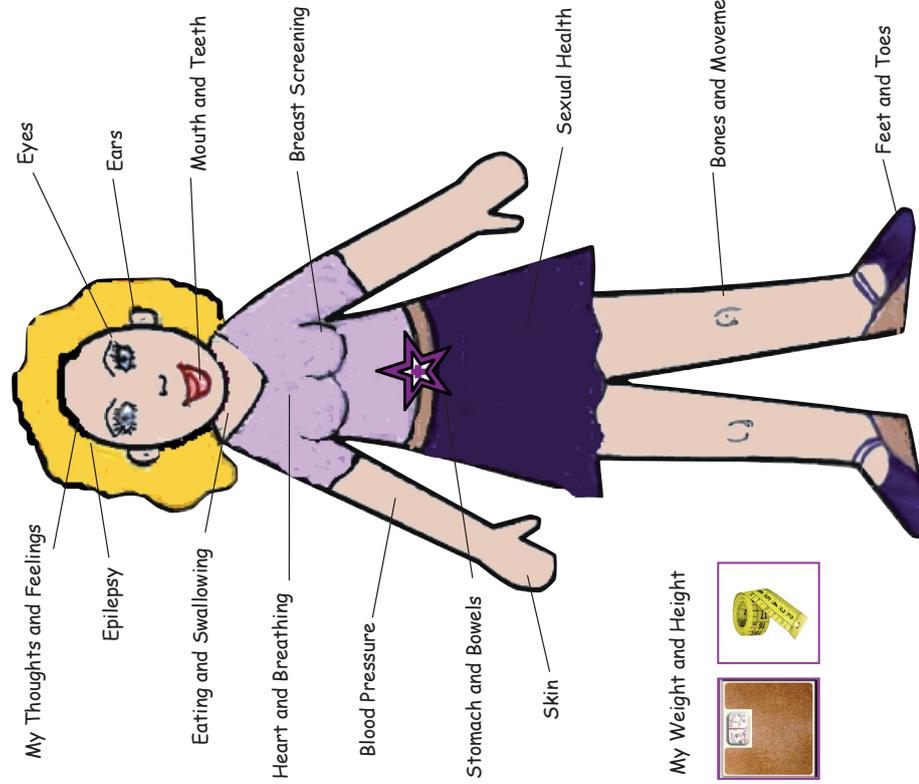
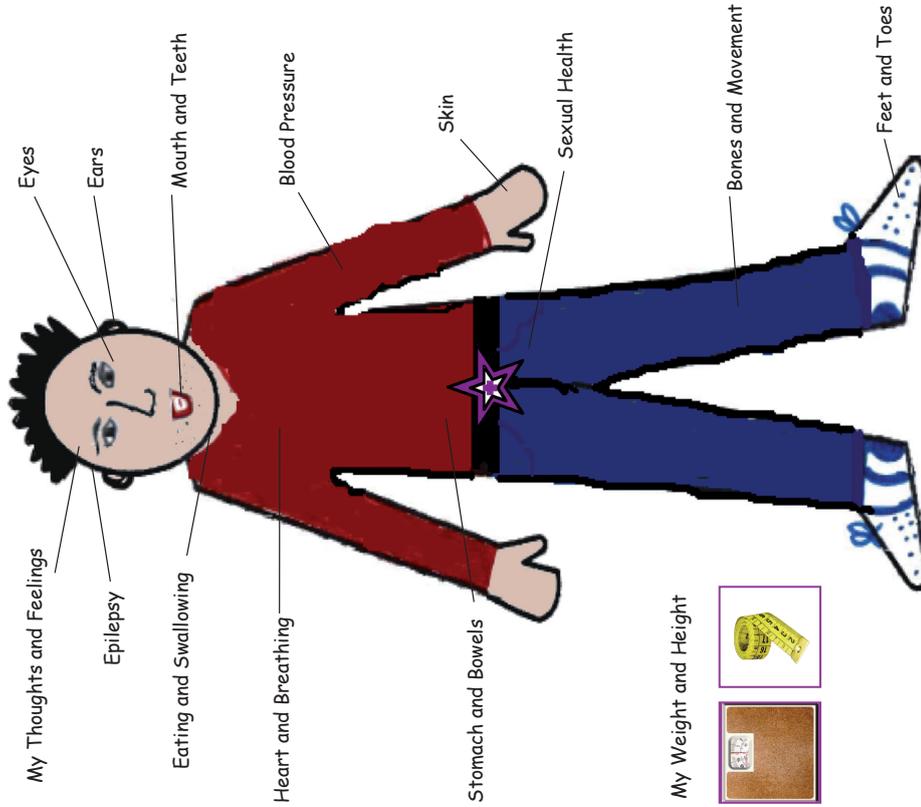


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Annual Health Check



Healthy Harry

Healthy Harriet



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Bristol Stool Chart

Type 1		Separate hard lumps, like nuts (hard to pass)
Type 2		Sausage-shaped but lumpy
Type 3		Like a sausage but with cracks on the surface
Type 4		Like a sausage or snake, smooth and soft
Type 5		Soft blobs with clear-cut edges (passed easily)
Type 6		Fluffy pieces with ragged edges, a mushy stool
Type 7		Watery, no solid pieces. Entirely Liquid

Image reproduced by kind permission of Dr K W Heaton, Reader in Medicine, University of Bristol.



B&Bf Helpline: 0845 345 0165 – medical advice
General enquiries: 01536 533255

www.bladderandbowelfoundation.org

Registered charity, no.1085095 BBF/Stool Chart/March 2012





Disability Distress Assessment Tool - DisDAT

People with learning disabilities have widely differing capacities for receiving, understanding, remembering and expressing their experiences through language. The Department of Health (1993) suggest that at least 50% of adults with a learning disability have significant impairments in communication. Meaningful communication with this group of people therefore, depends upon our ability as health care professionals, support staff or carers to recognise and translate a language that is not our own but is unique to that individual.

In the late 1990's a combined learning disability and palliative care team at Northgate Hospital in Northumberland, UK, began to explore the issue of identifying distress in people with severe communication difficulties.

The team gradually realised that what was needed was the development of a process that:

- Identified distress, rather than pain
- Documented signs and behaviours when a person was content and when they were distressed
- Helped to put the distress into context by providing a checklist that suggested possible causes of distress

The team piloted an early version of DisDAT in 2001 and in 2003 completed a validation study under the auspices of Northumbria University which was published in 2006

These studies found that:

- distress signs and behaviours are not specific to the cause
- each person has their own 'vocabulary' of distress signs and behaviours
- teams pick up more signs and behaviours than any one individual

What kind of tool is DisDAT?

- It documents an individual's signs and behaviours of distress as the basis for identifying the cause of distress and monitoring the distress over time.
- It starts from the assumption that each individual expresses their distress in a unique way and that this must be understood before the cause can be identified and a solution found.
- It is a working document which changes as the individual experiences new events and the carers (professional, partner and family) become more skilled at identifying signs and behaviours of distress.
- The first page summarises the more detailed observations and can be copied for individuals and teams who do not know the individual.
- It has been found to documents distress accurately and carers find it easy to use
- It enables families and carers see the person up closer

The current version and further information is available on www.disdat.co.uk



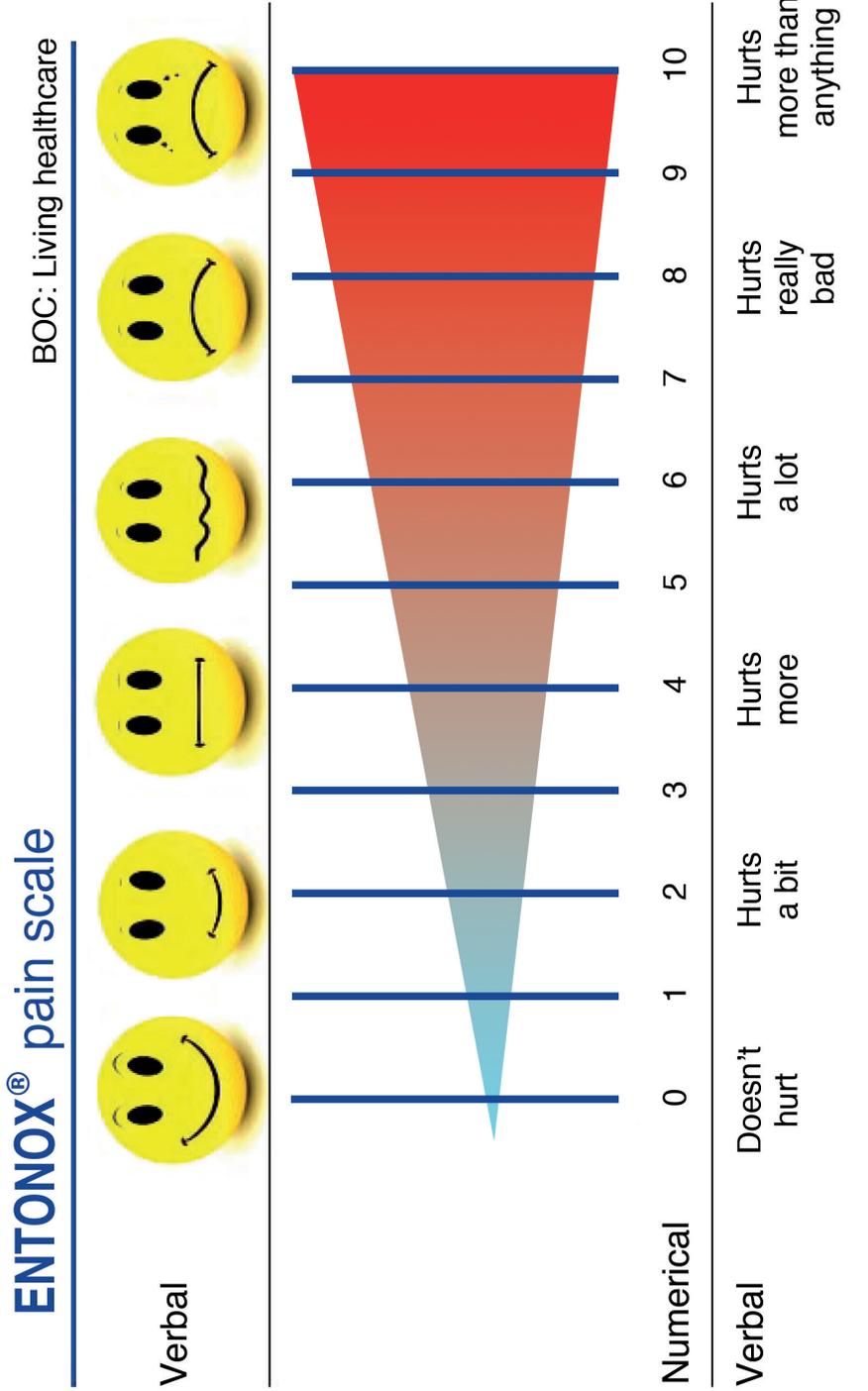
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www.entonox.co.uk

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Appendix 5



Health charter for social care providers



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Summary

People with learning disabilities have worse health than the general population. The Confidential Inquiry into Premature Deaths of People with Learning Disabilities found on average men die 13 years earlier and women 20 years earlier than the general population. 42% of the deaths considered were premature. This charter has been developed for adult social care providers and staff who have an important role in helping people access good healthcare and lead a healthy lifestyle.

By signing up to this charter, we pledge to:

- make sure that all staff in the organisation understand and apply the principles of Mental Capacity Act
- listen to, respect and involve family carers to achieve the best possible outcomes for the individual
- provide ongoing training to staff on basic health and wellbeing issues including pain recognition and the implications of specific syndromes and health conditions
- provide information on health and wellbeing that is accessible to people with a learning disability
- make sure support is available from someone who can, if necessary, advocate on behalf of the individual so that people can attend and benefit from all types of health appointments
- promote access to screening tests by:
 - helping staff and the people we support to understand their importance
 - Working in partnership with clinical services to ensure support is available before, during and after screening checks
- provide clear guidance to staff relating to each individual that will allow them to administer prescription and non prescription remedies safely
- facilitate access to an annual health check for every eligible person with a learning disability by:
 - supporting the person to understand the importance of a health check
 - supporting the person to ask the GP for a health check
- supporting the person to fill out the pre-check questionnaire



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- working with community teams and GP practice staff to put in place reasonable adjustments needed for a successful health check
- arranging for someone who communicates well with the person to go along to the health check, provided the person is agreeable to this
- if a person has health needs, supporting him/her to ask for a Health Action Checklist from the GP and then provide support for these actions to be actively followed up and reviewed
- informing the relevant Clinical Commissioning Group if there are problems accessing health checks
- ensure each person supported by our organisation and who wants one, has a health action plan and hospital passport
 - we will use the locally agreed format for health action plans and hospital passports where they exist
 - we will ensure health action plans are co-produced with the person with learning disabilities and, whenever possible, are maintained in a format that is understandable to the individual concerned
 - at the time of writing the health action plan or hospital passport, a record should be made of whether the person had capacity and gave permission for the plan to be shared with relevant health and social care staff
 - in accordance with the record of consent, we will ensure that health action plans and Hospital Passports are shared, and accompany the person to any health appointments or into hospital
 - if these documents are not used and the individual is put at risk, we will seek further advice from the local safeguarding team
- if a person has more than one long term health condition including mobility issues, we will request that a healthcare coordinator is made available and named in the person's health action plan
- make sure that all staff, people with learning disabilities and their families are aware of this charter



What is T.E.A.C.H?



The law says that people who work in health and community care have to make “reasonable adjustments” to help people with disabilities including learning disabilities.



“Reasonable adjustments” means making changes and doing things differently to meet the needs of the individual.

Sometimes people need to be taught about how to give good services to people with learning disabilities, services that have “reasonable adjustments”.



The Health Liaison team train lots of people about “reasonable adjustments” and the health needs of people with learning disabilities.

The Health Liaison Team train lots of people like Doctors, Nurses, Dentists, Pharmacists and Opticians.

T.E.A.C.H. is a way of learning how to make reasonable adjustments.

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Each letter of T.E.A.C.H. starts a key word to remember when helping the individual.

T

T - Time - This might be having a longer appointment time with your Doctor or having an early morning appointment when the Doctor's waiting room is quiet.

E

E - Environment - This might mean the Dentist seeing you at home or the Operating Theatre Nurses meeting you without their gowns and masks on.

A

A - Attitude - This means everyone treating you with dignity and respect and as an individual.

C

C - Communication - This means using easy words, picture signs and symbols to make sure you understand what is being said and what your choices are. Use your Purple Folder if you have one.

H

H - Help - This means getting help from others like your Carers, Community Learning Disability Nurse or Social Worker.

Remember, these are just examples of T.E.A.C.H. The type of help you need would be based on your needs at the time.



Health Liaison Team 01438 845372



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