Useful contacts

GP is:
Name:
Contact details:

The nearest hospital is:
Name:
Contact details:

The local primary health facilitator is:
Name:
Contact details:

The Acute Liaison Nurse is:
Name:
Contact details:

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THE BASICS

This document contains all the information you should need to allow you to support people with learning disabilities on a day-to-day basis, to help them to improve and maintain their health. We do not think health should be seen as something separate, something we think about when we have time or when someone is ill. We should be more proactive than that. We should use every day routines to observe people’s health and wellbeing, to ensure we are doing everything we can to support them.

For instance, when you are at the cinema with someone, observe how they are when they are eating or drinking or walking... are their behaviours different? Or when you are supporting someone to have a bath, discreetly observe to see if there is any bruising, swelling or a difference in their body. Everyday observations can tell so much and save people pain and discomfort in the long term. However, please don’t forget that people’s privacy and dignity are paramount.

The greatest factor is to have staff who are knowledgeable to understand and support people and maintain a good relationship with them.
Introduction

In this section
7 The importance of good healthcare
8 How to use this toolkit
Did you know?

50% of people with a learning disability have poor eyesight
The importance of good healthcare

People with a learning disability can have poorer health and are more likely to have a lower life expectancy than the general population (Mencap 2004).

In 2007, after Mencap received complaints from families about the support and treatment that their relatives with a learning disability had received in NHS support, Mencap produced a report. It was called Death by indifference and concentrated on six individuals with a learning disability who had all died while under NHS acute hospital support.

In 2009 the ombudsman’s enquiry into these deaths released its findings in a report entitled The Six Lives. The report highlighted several failings of NHS hospitals when treating people with a learning disability including institutional discrimination.

Five years later, in 2012, Mencap released a progress report called Death by indifference with the subtitle 74 deaths and counting. This report continued to raise concerns that the NHS too often fails to provide the most basic nursing support such as nutrition, hydration and pain relief and is denying people with a learning disability dignity and respect.

How Turning Point staff can make a difference

If people do not have good healthcare their lives can be significantly impaired. At Turning Point we want to give staff as much relevant, up-to-date information as we can so that they can give the best support possible to the individuals they care for. People with learning disabilities have many different health issues, but if we get better and quicker at noticing the signs of ill health in all areas, we will improve people’s life chances and help them to lead a long and fulfilled life.

We also want to improve the knowledge, skills, competence and confidence of staff in advocating and monitoring the healthcare needs of people with a learning disability when accessing all healthcare services.

We know that making sure our support staff have a good understanding of basic health needs will make a difference to people’s health and wellbeing.

The greatest support we can give, is to provide staff who are knowledgeable and understanding and maintain a good relationship with the people they support.
How to use this toolkit

This toolkit will help you to recognise the signs and symptoms of potential ill health more readily, in order to get support when necessary, and in a timely manner. You will not be expected to make diagnoses but it will help you to have a better understanding of health concerns.

If in doubt always seek professional guidance.

This toolkit is divided into six sections. The first four of these will be relevant for all carers, and you should read these to gain an understanding of how best to look after the people in your support.

The later sections that deal with particular illnesses or conditions and might not be relevant to the individuals you are working with at the moment. This toolkit is meant to be used as and when required.

We have not included information about first aid as you will undertake regular first aid training.
Essential information

In this section
11 Understanding consent and capacity
12 Primary health support services
14 Mental wellbeing
17 Hospital Support
18 Advanced Support Planning
19 Resuscitation
Did you know?

35% of people with a learning disability are obese compared with 22% in the general population.
Understanding consent and capacity

Consent is being asked if you agree to something.

Capacity is whether you can understand the choice you need to make.

The Mental Capacity Act 2005 states that everyone over the age of 18 can make their own decisions unless we find out that they can’t.

Many people we support may find making decisions difficult but we need to support them to understand their choices by:

• Taking the time to explain.
• Using easy-to-read leaflets, pictures and videos.
• Visiting hospitals or clinics.
• Getting help from others who know them well, to explain things.
• Supporting them to use different ways of communicating.

Before we say that they cannot make a decision, we need to consider that:

• No one can be stopped from making a decision just because someone else thinks it is wrong or a bad decision (unless they are detained under the Mental Health Act)
• No one can assume that the person cannot make a decision just because they have a disability.
• No one can assume that the person cannot make more complicated decisions.
• No one can assume that the person has not been able to make decisions in the past.
• No one can make a ‘blanket decision’ to say someone lacks capacity – each decision should be looked at individually.

To be able to consent a person:

X Must be able to understand the information about the choice.
X Must be able to remember the information in order to make the choice.
X Must be able to use the information to think about what is best for them.
X Must be able to communicate their choice to others.

Where we know individuals cannot understand their choice (that they lack capacity), the law says other people may make that choice for them through a best interest meeting.

The person’s relative or advocate should be invited to the best interest meeting but cannot make the choice for them on their own.

Where the person has no relative or advocate, or it is a complex decision, an Independent Mental Capacity Assessor (IMCA) should be used.

If the person is detained under the Mental Health Act an IMHA (Independent Mental Health Assessor) should be used.
An IMCA should always be involved where the person’s choice is about a serious medical treatment or changing where they live.

At the best interest meeting the people involved need to work out what is in the person’s best interests and:

- Ensure that they listen to the person and that they have asked the people who know the person well what they think the person would want.
- Ensure that the person is involved in the meeting.
- Ensure that the decision is the least restrictive option for the person.

Turning Point offer a range of training and support options for staff to help navigate through the Mental Capacity Act.

All staff should complete the e-learning module and face-to-face MCA training which is included in the following training:

- Person centred approaches
- An introduction to learning disabilities
- Support planning

If you are supporting someone through the process of capacity assessments and best interest assessments there is a face-to-face training session available to give you further practical help and guidance – ask your line manager for more details.

Primary health support services

What is it?

Primary healthcare provides the first point of contact within the healthcare system. In the NHS, the main source of primary healthcare is general practice.

The aim is to provide an easily accessible route to support, whatever the patient’s problem.

Primary healthcare is based on caring for the person rather than a specific disease. This means that professionals working in primary support deal with a broad range of physical, psychological and social problems, rather than being a specialist in any one particular disease area.

Primary healthcare involves:

- Providing treatment for common illnesses
- The management of long term illnesses such as diabetes and heart disease
- The prevention of future ill-health through giving advice and self help guides
- Immunisation and screening programs
Primary health facilitator

The primary health facilitator works with health workers in the community (doctors, nurses, surgery staff) to make it easier for people with a learning disability to get the right healthcare. This is normally a learning disability nurse who has gone into a primary support role. Unfortunately not everywhere has these. Find your local one and put their details at the front of this guide.

Health Action Plans

Health Action Plans (HAPs) are individual health plans written for people with learning disabilities.

Their purpose is to identify health actions that will make a positive difference to the health and wellbeing of the individual.

Health Action Plans should record information which is important and useful to the individual and to those supporting them in managing their health and any long term conditions that they might have.

Health Action Plans can vary in design, content and style. Most local health authorities have their own version of agreed HAPs but all generally follow a similar format for example:

- Personal information
- Visiting the doctor
- Important information about their health
- Medication
- Immunisations
- Family history
- Health and lifestyle
- For men/women
- People who support me
- Contact details

Health Action Plans need to be reviewed at least every six months to ensure that all the information recorded is accurate and up to date.
Mental wellbeing

Background
Mental wellbeing is about feeling good about yourself and being able to cope with everyday life and when things go wrong.

Conditions such as depression, anxiety and challenging behaviour might affect a person’s mental wellbeing.

Depression is a word used to describe lots of different upset feelings, sad thoughts and difficult moods.

Depression can be caused by:

• Life events such as a traumatic incident or accident
• Loss of a person or possession such as moving house
• The person being unable to express their anger
• Some physical conditions can cause depression, such as:
  - Conditions affecting the brain and nervous system
  - Hormonal problems, especially thyroid and parathyroid problems
  - Symptoms relating to the menstrual cycle or the menopause
  - Low blood sugar
  - Sleep problems
• Depression can be a side effect of a lot of different medicines

What to look out for
If someone shows five or more of the following symptoms, it could be depression:

Changes in the way they feel:

• Low-spirited for much of the time, every day
• Restless and agitated
• Easily tearful
• Unusually irritable or impatient
• Finds no pleasure in life or things they usually enjoy

Changes in behaviour:

• Not doing activities they usually enjoy
• Avoiding social events they usually enjoy
• Avoiding the company of others previously enjoyed
Changes to the way they think:
• Difficulty remembering things that previously could remember
• Finding it hard to concentrate or make decisions that they were previously able to make

Physical symptoms:
• Difficulty sleeping
• Sleeping much more than usual
• Feeling tired and having no energy
• Loss of appetite, and losing weight
• Eating a lot more than usual and putting on weight
• Physical aches and pains with no obvious physical cause
• Moving very slowly
• Using more tobacco, alcohol or other drugs than usual

Anxiety
People who are depressed often get anxious too. Common symptoms include:
• Headaches
• Aching muscles
• Sweating
• Dizziness
• Difficulty sleeping
• Lack of concentration
• Panic attacks

Actions to take
• Make a referral to a medical professional. A simple blood test may possibly be able to rule out a physical health condition being the cause.
• Talk to others about your concerns, someone who knows the person well.
• Gather all the information, signs and symptoms you’ve noticed, that a medical professional might need.
• Keep the individual informed and supported throughout the process.
• Talking to and being listened to by someone who shows an understanding and cares can help the person feel better.
**Ongoing monitoring**

- Keep a written record of your concerns (times, dates).
- Ensure healthy eating and that they maintain an appropriate dietary intake.
- Encourage exercise, and participation in activities that will help the person to feel better about themselves.
- Monitor the person’s physical appearance and personal hygiene.
- Monitor any other identified physical health conditions.
- Monitor the effects of prescribed medication. Most anti-depressant medication takes two to four weeks before it starts to work.

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**Assessing mood**

There are lots of different types of mood charts that can be used for a variety of observations.

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**Useful websites**

[www.easyhealth.org.uk](http://www.easyhealth.org.uk)
[www.turning-point.co.uk/mental-health/self-directed-support](http://www.turning-point.co.uk/mental-health/self-directed-support)
Hospital support

Many people will experience healthcare and support inside an acute hospital during their lifetime. People with learning disabilities often face issues in accessing prompt support and when they do get admitted, the healthcare and support isn’t always what you or I would expect. Here are some of the issues that have already been identified that you should look out for:

• Poor communication.
• Expecting staff or family carers to agree procedures without best interest meetings
• Lack of support for eating and taking medication
• Lack of confidence with healthcare staff in working with people with learning disabilities
• Expectation that staff or family carers will do all the support for them
• Not seeing past the person’s learning disability
• Not being given the tests others would expect

In order to combat this we have to be strong and either empower the individual to speak up for themselves or ensure they have a strong voice in other ways (independent advocacy or us speaking up for them). Many times we will want to be in the hospital to support people but sometimes this is not possible. A robust discussion needs to take place with the hospital staff around who is doing what and the different roles and responsibilities. For instance, we should not be administering medication when they are in hospital but we can support the individual during meal times.

Passports

Hospital passports were developed as a quick reference guide for acute hospital staff to ensure they knew the basics about the individual.

Everybody you support should have a hospital passport. This passport may look different in different areas as many community learning disability teams issue them to providers and there will be regional variations. Make sure the person you support has one and it is regularly updated and you all know where it is. It is important that when someone is admitted that this passport is taken with them and shown to the hospital staff. Make sure you have a copy of it as you don’t always get them back.

Acute Liaison Nurses

Acute Liaison Nurses were introduced into acute hospitals to facilitate better understanding, access and care and support of people with learning disabilities into the acute hospital. They tend to be qualified learning disability nurses with experience of working in both community and hospital provision. They are not present in all acute hospitals. Find out if your local hospital has one and put their details at the front of the book.

If your hospital has one then they are a good person to contact to support you with the admission. If things are not going as expected they will also be good to facilitate dialogue with the hospital staff.
Advanced support planning

An End of Life Plan can be put in place for someone who is dying or if a person just wants to plan in advance for their end of life. Planning ahead will avoid staff having to sit down with the family and person themselves at a time which is going to be already confusing and frightening, to go through things which could have been dealt with previously. It enables the individual and families to receive the support they wish.

Remember:

• Each person has the right to be treated with dignity and respect.
• A person with a learning disability has the right to the same treatment as someone without and to be treated and cared for in the same way as everyone else.
• Discussions may focus on the person remaining at home, care home, hospice or have hospice support where they live.
• Preparation for a death makes all the difference for family, close friends and the person themselves.

Planning is really important here are some tips:

• Decide on a time and place to meet that is sensitive to the discussion.
• Involve the family and the person themselves and complete an End of Life Plan together.
• Ensure that the individual understands everything that is being discussed.

This should be placed in their file and reviewed regularly.

• The plan will require regular reviewing,
• Best interest meetings may need to be had for incidents such as if the person then becomes terminally ill and if things such as DNR’s are going to be put in place or if treatments are going to commence or change.
• Pain relief and symptom control will need to be discussed and plans put in place which are regularly reviewed.

Your local authority may be able to provide staff with a range of services and equipment to help a person remain at home. This may include items such as home adaptations i.e. hand rails, raised toilet seats, commodes etc.

🔗 Useful websites

www.nhs.uk – end of life support
www.mencap.org.uk – end of life support
**Resuscitation**

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) refers to not making efforts to restart breathing or the heart in cases of respiratory or cardiac arrest. It does not refer to any other interventions, treatments or care such as fluid replacement, feeding, antibiotics etc.

**Who can put a DNACPR in place?**

A DNACPR decision is made by the most senior clinician responsible for an individual’s support in their current healthcare setting as defined by local policy and arrangements. In an acute setting the most senior responsible clinician would usually be a consultant, a GP in a community setting and in some cases a senior nurse in palliative support services. It is important that you and the individuals you support can identify the most senior clinician involved in their support.

**How are DNACPRs recorded?**

A DNACPR decision is recorded on a specific DNACPR form by the most senior responsible clinician. DNACPR forms are slightly different in different areas across the UK. A DNACPR form applies only to one specific treatment that relates to a specific event – not to attempt CPR following cardiac arrest. A DNACPR form is not a legal document and can be overruled but the clinician will need to justify this. DNACPR forms should be accurate and easily identified to help health professionals make a quick judgement when an arrest occurs. In hospital the DNACPR form is usually held at the front of the clinical record. In an individual’s home the form should be kept at the front of their personal folders. The original DNACPR form must be used, never copies.

**How long do they last?**

DNACPR decisions should not be ‘indefinite.’ DNACPRs should be reviewed regularly to reflect any changes in an individual’s condition and wishes. It is important DNACPR decisions are communicated and transferred when an individual changes support settings. It is common for a DNACPR decision to be suspended temporarily (such as during transfer or surgery). If a DNACPR is cancelled the DNACPR form must have “cancelled” or “invalid” across the form.

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**Cardiopulmonary Resuscitation (CPR)** – Emergency treatment that supports the circulation of blood and/or air in the event of a respiratory or cardiac arrest.

**Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)** – A written decision to withhold CPR in the event of a future arrest.

**Advanced Decision to Refuse Treatment (ADRT)** – A verbal or written legally binding refusal of specific future treatment by an adult with capacity regarding their future care should they lose capacity.

**IMCA** – Independent Mental Capacity Advocate.
Routine checks and observations

In this section
23 Routine checks and observations
Did you know?

More than 40% of people with a learning disability have a problem with their hearing.
**Routine checks and observations**

There are many common things to look out for when assisting people with their daily needs. Several can be done discretely and will act as preventative measures. With people who are more independent, it is not always possible or desirable to monitor them discretely. Below are some prompts you can ask yourself during specific activities.

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<th>Possible causes:</th>
<th>Further action:</th>
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<td>A refusal to eat or drink</td>
<td>Diarrhoea or vomiting</td>
<td>Refer to page 84, dysphagia</td>
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<td>Signs of pain when eating</td>
<td>Tummy ache</td>
<td>Keep a food diary chart and weight chart if ongoing</td>
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<tr>
<td>Difficulties feeding themselves, shaking of hands, look of confusion when presented with a meal</td>
<td>Sore mouth</td>
<td>Refer a support plan to your manager and consider:</td>
</tr>
<tr>
<td>Coughing when eating or drinking</td>
<td>Dysphagia</td>
<td>• Referral to GP if diarrhoea is for a prolonged period of more than one day</td>
</tr>
<tr>
<td>Difficulties when swallowing</td>
<td></td>
<td>• Referral to dietician to discuss strategies for dealing with eating and drinking difficulties</td>
</tr>
<tr>
<td>Changes in eating habits</td>
<td></td>
<td>• Referral to speech and language therapy for help with dysphagia symptoms and help with positioning when eating</td>
</tr>
<tr>
<td>Change in weight</td>
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<td>Regurgitation, smell of acid or vomiting</td>
<td>Acid reflux</td>
<td>Refer to page 70, GORD (gastro oesophageal reflux disease)</td>
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<td>Indigestion</td>
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<td>Sounds of wheezing or chestiness</td>
<td>Asthma/COPD</td>
<td>Refer to page 80, Chronic Obstructive Pulmonary Disease</td>
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<td>Chest infection</td>
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<td>Use inhalers if prescribed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Refer to GP if chest infection suspected</td>
</tr>
<tr>
<td>What to look for:</td>
<td>Possible causes:</td>
<td>Further action:</td>
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<tr>
<td><strong>Bath time or personal support</strong></td>
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<td></td>
</tr>
<tr>
<td><strong>Eyes:</strong> Discharge or weepiness Cloudy covering</td>
<td>Eye infection Worsening vision Cataracts</td>
<td>Refer to page 41, How to look after your eyes, for further information Refer to GP if suspected eye infection Refer to optician if vision worsens or if cataracts is suspected</td>
</tr>
<tr>
<td><strong>Ears:</strong> Has hearing changed? Do ears appear blocked with wax or have an offensive odour coming from them?</td>
<td>Ear canal blocked with wax Ear infection</td>
<td>Refer to page 46, How to look after your ears, for further information Treat with pain relief, if prescribed or ask for appropriate pain relief to be prescribed Refer to GP if not clearing up within 48 hours</td>
</tr>
<tr>
<td><strong>Mouth:</strong> White areas on tongue or at the back of the throat Discomfort when brushing teeth Bleeding gums when brushing teeth</td>
<td>Oral Thrush Gum disease/toothache</td>
<td>Refer to page 68, recognise and manage thrush If you suspect thrush tell your line manager who can speak to a pharmacist for over-the-counter medication Refer to page 43, How to look after your teeth Refer to dentist if required</td>
</tr>
<tr>
<td><strong>Skin:</strong> Reddened or raised areas of skin, bruising or reddened areas possibly due to pressure? New moles that have appeared or old ones that have changed in size, colour or texture Dry areas Scratches</td>
<td>Pressure sores Suspicious moles Dry skin</td>
<td>Refer to page 88, tissue viability, and follow protocol for dealing with pressure sores Moles that have changed should be checked by a GP Refer to pharmacist for advice on emollients</td>
</tr>
<tr>
<td><strong>Feet and nails:</strong> Thickened areas of skin, cracked skin, corns or verrucas Thickened nails or nails that have split or look ingrowing (redness to the sides, warmth, pus, tenderness)</td>
<td>Ingrown toenail Infected areas Corns Verrucas</td>
<td>Refer to page 48, how to look after your feet Refer to podiatry if treatment required If infection suspected – refer to GP for antibiotic cover</td>
</tr>
<tr>
<td>What to look for:</td>
<td>Possible causes:</td>
<td>Further action:</td>
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<tr>
<td><strong>When using the toilet</strong></td>
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<tr>
<td>Take a look at the urine, is it dark?</td>
<td>If urine is dark, it could be a sign of dehydration</td>
<td>Encourage more fluid intake. (Use a fluid chart if appropriate)</td>
</tr>
<tr>
<td>Does it smell offensive?</td>
<td>Offensive smelling urine could indicate an infection</td>
<td>Refer to GP if infection suspected</td>
</tr>
<tr>
<td>Is the person straining when using the toilet?</td>
<td>Constipation Side effect of some medications If the stool isn’t hard, this could indicate a gastro-intestinal bleed</td>
<td>For constipation, refer to page 62, Intestinal Problems Give appropriate dietary advice If gastro-intestinal bleed suspected, refer to GP ASAP</td>
</tr>
<tr>
<td>Does the stool look hard or black in colour?</td>
<td></td>
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</tr>
<tr>
<td>Is the stool very loose and offensive smelling?</td>
<td>Diarrhoea</td>
<td>Refer to page 62, Intestinal Problems for diarrhoea. Refer to GP if persistent/not improving</td>
</tr>
<tr>
<td>Is there any blood on the paper after wiping?</td>
<td>If coming from the back passage, could be haemorrhoid or other more significant problem Unexplained vaginal bleeding (i.e. not menstrual) If blood suspected from bladder, could indicate a urinary tract infection or more significant problem</td>
<td>Refer to page 62, Intestinal problems Refer to GP to check causes of unexpected bleeding</td>
</tr>
<tr>
<td><strong>Night time</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficulty in getting to sleep?</td>
<td>Too many stimulants late at night (caffeine/nicotine/alcohol) Poor sleep hygiene (eg. not sticking to routine, sleeping more in the day) Stress and worry Sores, skin issues</td>
<td>Refer to support plan or line manager for advice Ensure good sleep hygiene Use calming techniques Check skin</td>
</tr>
<tr>
<td>A difference in the sleep pattern?</td>
<td></td>
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<tr>
<td>Difficulty in getting comfortable?</td>
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How to guides

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31  How to weigh someone
33  How to look after teeth
34  How to obtain a urine sample
35  How to administer a spacer device
Did you know?

Six out of 10 people with a learning disability need glasses.
How to take a temperature

Background

The definition of temperature is ‘the level of heat natural to a living being’.

Although a normal temperature is around 35.5-37°C, everybody is different. It depends on:

• The person
• Their age
• What they have been doing
• The time of day
• Which part of the body you take the temperature from

Many people with multiple disabilities have a lower body temperature.

It is important that a baseline temperature is taken for each person and documented in their Health Action Plans, so that differences can be acted upon e.g. a high temperature.

Take an individual’s temperature on three different occasions in order to establish the baseline.

Always record on which part of the body you took the individual’s temperature.

Equipment and method

There are several different types of thermometer available. The procurement team has a list of suppliers or they can be purchased from a pharmacy. The two most common are:

1. Digital thermometer
2. Tympanic (ear) thermometer

Digital

These can be used to take a temperature from somebody’s mouth (not suitable for somebody who might bite on the thermometer) or from under their armpit.

When taking somebody’s temperature under the arm, place it directly against the skin of the armpit, making sure the silver tip touches the skin, and hold the arm gently against the body. Read the manufacturer’s instructions to find out how long to leave the thermometer in place. Document the result in their support plan.

Read the instructions for keeping the thermometer clean and to prevent cross contamination.

Ear

These are quick and easy to use but can be expensive. To use it:

1. Apply disposable cap to thermometer.
2. Hold outer ear out slightly.
3. Insert thermometer to sit just inside ear canal.
4. Thermometer will beep when complete.
Ensure that you have enough disposable caps, as they must be disposed of after each use. Also ensure that you have spare batteries.

If in doubt read the manufacturer’s instructions on how to place the thermometer in the ear and how long the reading will take. The result may not be accurate if it is not placed correctly in the ear.

**Forehead**

You can buy thermometer strips from the chemist which are a lot less invasive, but are not very accurate. You can also buy infra-red thermometers which mean people do not need to be touched. These are used in hospitals.

**When is it needed?**

Take somebody’s temperature if they:

- Are looking pale or flushed
- Show a loss of appetite
- Show a change in their behaviour or communication
- Are saying or indicating that they do not feel well
- Are appearing clammy or sweating

**Actions to take**

- Check that the environment is correct, for instance it is not too hot or the individual hasn’t got too many layers of clothes on.
- Take the temperature and record it in the Health Action Plan. If the temperature is higher than 38.5°C, administer pain relief as prescribed and re-test temperature 30 minutes after to check effectiveness of pain relief.
- Contact GP if temperature remains raised for 24hrs.

**Ongoing monitoring**

- Keep an eye on the person to ensure their temperature comes down.

**Useful websites**

www.nhs.uk – NHS Choices
How to weigh someone

Background

It is very important to ensure when you are weighing someone that it is done correctly. Everyone’s ideal weight will vary and will depend on things such as height, age and health issues.

A graph of body mass index as a function of body mass and body height is shown. The dashed lines represent subdivisions within a major class. For instance the underweight classification is further divided into severe, moderate, and mild subclasses.

A record should be kept in the Health Action Plan of a person’s weight each time it is done and this can be used as a reference for other professionals as to how their health is doing.
When is it needed?

- You should decide how often a person requires weighing depending on each individual circumstances, i.e. daily, weekly or monthly.
- If someone’s clothes are becoming too tight or too loose this may be an indication of a change in weight.
- Sometimes people may not want to be weighed. In this instance, you need to observe for signs such as a change in their appetite which may be leading to weight loss or gain, or a change to their clothing fit.

Equipment and method

Ideally the same weighing scales should be used each time. Try to weigh at the same time of day and always either with or without their shoes.

Weighing someone in a wheelchair:

1. Use wheelchair scales.
2. Explain to the person what is going to happen.
3. Ensure the person is settled and still to gain an accurate reading.
4. Set the scales to zero.
5. Clear accessible space around the scales to be able to get the wheelchair onto the scales.
6. Weigh the wheelchair empty first on each occasion as sometimes cushions etc can add weight to the chair.
7. Weigh the person sitting in the wheelchair and then subtract empty chair total from full chair total to get the total weight.

Weighing someone on free standing scales:

1. Explain to the person what is going to happen.
2. Place the scales in the position of the person’s choice. Try not to move the scales if possible as this affects calibration and upsets the accuracy.
3. Ensure scales are set to zero.
4. Assist the person to step up onto the scales.
5. Ask the person to stand independently on the scales without holding onto anything as doing so will affect the reading.
6. Make a record of the weight on appropriate documentation.

Actions to take

If the person’s weight has changed by +/- 10%, or you’re unable to weigh them but have concerns, then you need to contact the dietician.

Ongoing monitoring

People should be weighed according to their support plans. This may be daily, weekly or monthly depending on each individual’s circumstances.
How to look after teeth

Background
Teeth are covered in a hard outer coating called enamel. Every day a thin film of bacteria called dental plaque builds up. This bacterium produces acids which start to damage the enamel. Over time the acids can cause a hole and this is called a cavity. When the plaque builds up along and under the gum line, this causes gum disease.

When is it needed
All individuals should be supported in cleaning their teeth at least twice a day. Brushing should also be encouraged an hour after meals.

Equipment and method
People should use a small brush and fluoride toothpaste and be encouraged to use the correct technique for tooth-brushing:

- **X** Brush using small circular strokes, and short back and forth strokes.
- **X** Brush gently and carefully along the gum line.
- **X** Brushing should last two minutes.
- **X** Clean a tongue by brushing with a soft toothbrush. Some pharmacies sell a special plastic tongue scraper.
- **X** They should change their toothbrush every 3-4 months (sooner if it is wearing out) and use an antiseptic mouthwash if possible.

Actions to take
Advise people on good oral health including:

- **X** Cut down on sugary foods and drinks.
- **X** Only drink alcohol in moderation.
- **X** Cut down on smoking.

Ongoing monitoring
Make sure people have a dental check-up at least once a year.
How to obtain a urine sample

ℹ️ Background

A urine test is a really good way of finding out what is going on in your body. Because urine carries the waste from your blood a test can help diagnose a huge variety of conditions. These range from a minor urine infection, to diabetes, kidney disease or tumours.

⏰ When is it needed

If the person is going to see the nurse practitioner or GP, it is advisable to obtain a urine sample prior to the appointment, this reduces stress and pressure on the individual at the surgery.

📝 Equipment and method

If possible, request a sample bottle and bed pan from the surgery. If you’re unable to do this then collect sample in a clean sealable container. You will need to check if your local hospital accepts samples in containers other than sterile urine containers – lots of hospitals now refuse them due to contamination.

If the person is incontinent and wears incontinence pads, a urine collection pack can be used to draw a sample of urine from the pad. These are usually made up of two collection pads, a 5ml syringe and a urine specimen container. Contact your local continence service or GP surgery for advice on how to obtain and use these.

Samples must not have been in contact with faeces.
How to administer a spacer device

Background

Spacers may be prescribed by a GP for people who are unable to use an inhaler in the correct way, either because they struggle to get a good seal around the inhaler with their lips or when they find it difficult to co-ordinate their breathing.

Using a spacer ensures more medication reaches the lungs.

When is it needed?

This will depend on the individual and whether their ability to take the inhaler varies. Most people prescribed a spacer will use this each time they use the inhaler.

Equipment and method

To administer the spacer device:

• Shake the inhaler before firing each puff.
• If the dose is more than one puff, then do one puff at a time.
• The user should start breathing in from the mouthpiece as soon as possible after the puff is fired.
• They should hold their breath for a few moments after breathing in.
• Make sure they breathe in and out a few times before firing the next puff.
• Check that the valve opens and closes with each breath.
• Hold the spacer slightly tilted with the inhaler end uppermost to help the valve open and close easily.
• Static charge can build up on the inside of the plastic chamber. This can attract particles of the drug and reduce the output when the spacer is used. To prevent this, wash the plastic spacer as directed by the manufacturer’s instructions. This is usually before first use, and then once a month with washing up liquid and water. Let it air dry without rinsing or wiping.
Introduction

Focus on

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Did you know?

One in three people we support has a sight problem.
**Weight**

**Background**

Obesity is a complex public health issue that affects quality of life for both children and adults.

Weight loss as a symptom is any loss of weight that you cannot explain, was not planned or worked for through increased diet control and exercise.

We know that people with a learning disability are more likely than the general population to be either underweight or overweight.

People with profound and multiple learning disabilities are often underweight because of poor feeding and swallowing, while others may be overweight because they aren’t getting the support they need to make healthy diet and lifestyle choices.

In some cases, learning disabilities are associated with other conditions that make being overweight more likely, such as Down’s Syndrome, which also affects a person’s height, or Prader-Willi syndrome, which causes an insatiable appetite. These factors can make weight management particularly challenging.

**Causes of weight gain:**

- Poor diet
- Lack of exercise
- Side effects of medications
- Thyroid problem
- Kidney or heart failure
- An increase in muscle through exercising
- Hormonal
- Genetic
- Pregnancy
- Menopause

**Causes of weight loss:**

- Poor diet / malnutrition
- Thyroid problem
- Depression
- Painful mouth sores
- Poor dental care
- Heart disease
- Chronic diarrhoea or other digestive disorders
- Loss of appetite
- Eating disorders such as anorexia nervosa or bulimia
- Poor swallowing / dysphagia
- Incorrect environment around meal times
What to look out for

Weight loss symptoms related to the digestive system include:

- Abdominal bloating or abdominal pain
- Bad breath, dry mouth or mouth ulcers
- Chronic constipation or diarrhoea
- Bowel motions which are pale or foul smelling
- Loose or painful teeth, sore gums or tongue
- Loss of appetite
- Nausea and vomiting which may or may not be intentional
- Puffy cheeks from swollen salivary glands
- Alternating binging and purging
- Depression
- Poor memory or concentration
- Excessive use of laxatives or diet pills
- Obsessive-compulsive behaviours

Weight gain symptoms related to different body systems including:

- Abnormal menstrual cycle
- Constipation
- Difficulty breathing or shortness of breath
- Fatigue or lethargy
- Swelling in the face, abdomen or extremities
- Temperature sensitivity (especially to cold)

Actions to take

- Try to understand the root cause of the issue. Is it something as simple as poor dental care leading to a sore mouth, is it their swallowing or is there an underlying health issue? Is it poor diet?
- Look out for any kind of change to a person's appetite and their dietary intake. Make sure they are empowered with good dietary knowledge which will help them to make an informed choice.
- Be aware of healthy options and snacks. It is important that we don't force poor eating habits onto others.
- Be aware of services available such as dieticians or the speech and language therapy service who can assess any issues around swallowing, food textures etc, or the mental health services who can assess to see if there are any underlying mental health issues.

Ongoing monitoring

If there are concerns about a person’s weight, the body mass index chart (see page 31) is always useful to refer to as a guideline. This should only be used as a guideline and medical professionals should be involved to ensure there are no underlying issues.

Useful websites

http://www.nhs.uk/Change4Life/Pages/healthy-eating-tips.aspx
www.nhs.uk/weightloss
http://www.locallyhealthy.co.uk/wellbeing
www.pwsa.co.uk
www.downs-syndrome.org.uk

The nearest set of wheelchair scales are here:

Contact name:

Contact details:
Eyes

Background

According to SeeAbility, the people that we support are particularly prone to having eye problems, yet not many people have regular eye checks.

Unidentified sight problems lead to a reduced quality of life, sight loss which could have been prevented, and increased dependency.

As well as visual difficulties people may experience eye infections which can be very painful but easily treated, and cataracts which can be effectively treated.

What to look out for

The abnormal appearance of a person’s eye:

- The whites of the eyes appear red, blood shot or sore
- The white of the eye appears yellow
- Frequent eye infections or sticky eyes with discharge
- Watery eyes or dry eyes
- Frequent cysts or styes on the eyelids
- Eyes which constantly flicker or move up and down
- Eyes which look milky, you may not be able to see the iris (colour) of the eye or pupil clearly
- Eyes which appear to bulge
- Eyes which seem scarred or damaged
- Ingrowing eyelashes
- Partially closed or drooping eyelids
- One eye turning in or out, squinting

Observing changes in people’s behaviour or actions:

- If the person feeds themselves and they start to go to one side of the plate there may be an issue
- Frequent touching of the eyes, rubbing or poking
- Gazing into the light, lamps etc
- Avoiding bright light
- Unusual head positioning
- Unusual head movements e.g. frequent shaking
- Covering one eye, constant blinking
- Starts to knock things over, bumps/walks into things
- Difficulty in judging distances
- Startled by sudden noises
- Feels their way around
- Confusion, disorientation, cannot cope with changes in the environment
- Frustration, anger
- Sees some colours better than others
- Does not make eye contact
- Increased falls
- There might be an increase in challenging behaviour
**Actions to take**

- Discharge from the eye indicates an eye infection and the individual needs to see a GP to be prescribed an ointment to be applied to the eye. The eye would need bathing to remove the discharge. Eye infections can be very contagious and good personal hygiene must be in place.
- Follow instructions if using eye baths or droppers.

**How to bathe an eye**

- Use cool boiled water or sterile water.
- Ensure that the water is not warm or too cold.
- Using a clean cotton pad wipe carefully from the inside of the eye out and then dispose of the pad.
- Use a fresh pad for each eye and dispose of it each time to prevent the spread of any infection.
- Pat dry and then wash the towel.
- Bathe four times daily.
- If no better within 48 hours, the person should see a GP.

**Ongoing monitoring**

- If somebody is prone to regular eye infections they should have a support plan in place, identifying the symptoms, and action to be taken.
- If somebody is diagnosed with a condition, find out about how to support them from the optician and put a support plan in place. e.g. Somebody with tunnel vision being approached from the front and not the side, having things placed directly in front of them, etc.
- Everybody should go for an eye check-up at least every two years. People should be registered with a local optician. Opticians are able to check the health of eyes, even without people being able to verbally communicate.
- There are opticians who will perform home visits if the person is housebound.
- The optician may refer directly, or refer back to the persons GP if a referral to hospital is needed.
- A best interest meeting may be needed if more invasive action is called for.

**Useful websites**

- [www.seeability.org](http://www.seeability.org) – has lots of easy read fact sheets about supporting people to go to the opticians, and explaining some of the more common types of visual problems.
- [www.outsideclinic.co.uk](http://www.outsideclinic.co.uk)
- [http://www.nhs.uk/NHSEngland/AboutNHSservices/opticians/Pages/NHSopticians.aspx](http://www.nhs.uk/NHSEngland/AboutNHSservices/opticians/Pages/NHSopticians.aspx)
**Teeth**

**Background**

Statistics show that people with learning disabilities frequently experience inferior healthcare – unfortunately with oral care this results in a higher incident of dental decay and gum disease than in the general population.

Good oral health is essential for speech, communication, enjoyment of food, good nutrition, social interaction and can improve self-esteem and dignity. If people have poor oral hygiene, the fact that their teeth may be discoloured, even black, with bleeding gums and offensive breath may make them feel uncomfortable in a social setting. Other people may also respond negatively to people with these issues, and it may cause isolation.

Reasons for poor oral care are given as ‘consent issues’, e.g. Joe doesn’t like his teeth being brushed, in which case The Mental Capacity Act 2005, and best interest meetings should be in place. Another reason is a lack of knowledge and skills among carers.

### All about dentures

- Dentures should always be handled very carefully to ensure that the plastic and clasps do not get damaged or bent.
- Dentures should always be removed after eating and rinsed under water to remove food debris and other loose particles.
- Use a soft brush to clean the tongue and palate.
- Dentures should be brushed daily using a proper dental cleaner and soft brush.
- Dentures should be soaked overnight as most types need to be kept moist to keep their shape. Special tubs can be purchased (and named if necessary) and then the dentures soaked in water or a special dental soaking solution that can be purchased from supermarkets or chemists. The dentist can give more information.
- The solution or water should be changed daily.
- The dentures should always be rinsed prior to putting them back in.
- The dentist will advise on how often to have the dentures professionally checked and professionally cleaned.

The dentist can help to ensure a proper fit to prevent slippage and discomfort. Loose dentures can cause irritation, sores and infection, so it is really important that any signs of change or discomfort are checked as soon as possible. Changes such as loss of weight or weight gain can affect the fit of dentures.
What to look out for

- Toothache
- Poor appetite, pain while eating and drinking
- Bleeding gums
- Staining/ discoloration
- Bad breath
- Sensitivity to hot, cold, sweet drinks and food

In addition, it’s worth being aware of the following conditions:

- **Rotten teeth**
  When teeth have become rotten, they are usually discoloured and may become loose. These need removing as soon as possible.

- **No Teeth**
  Sometimes people may have had all their teeth removed, but cannot manage dentures. However everybody should be given the choice and there should be no assumptions that they would not be able to cope with dentures.

  If they have no teeth it is still important to clean the tongue and gums twice a day, with a small soft brush. It is also important to still have regular dental checks, to ensure that the general health of the mouth is checked.

- **Dry mouths**
  This is when somebody does not have enough saliva to keep their mouth wet. This makes it hard to eat, swallow, taste and even speak. This can cause tooth decay and mouth infections.

  This can be quite common as a side effect of medication; it can also be when people breathe through their mouths rather than their noses. This might also be why some people like to have lots of drinks.

Actions to take

- Offer pain relief according to individual's protocol.
- Bleeding gums indicate that brushing needs to be continued.
- Urgent referral to the dentist if there is acute pain.
- Dentists sometimes prescribe gel or mouth wash which can be used as a temporary measure for reducing plaque.
**Ongoing monitoring**

- Ensure that support plans are in place, being carried out and reviewed regularly.
- Ensure that regular dental appointments are being accessed and attended (ideally every six months). People should have check-ups from a dentist even if they have dentures or no teeth.
- If the person is uncomfortable going to the dentist, a referral can be made to the Community Dental Services (information can be found at [www.nhs.uk](http://www.nhs.uk)) so that everybody has a dental check-up, ideally every six months.

**Useful websites**

[http://www.easyhealth.org.uk/listing/teeth-%28leaflets%29](http://www.easyhealth.org.uk/listing/teeth-%28leaflets%29)
Ears

Background

Approximately 40% of adults with a learning disability experience moderate to severe hearing loss. It is particularly common among people with Down’s Syndrome. As with the general population it is more likely and more severe as people age.

An early diagnosis is vital as hearing loss can have a significant impact on their learning disability.

Ear wax is normal and is present to protect the ear canal. You should not put items into the ear, e.g. cotton buds to try and clear it out as this can make matters worse.

Ear infections can cause temporary hearing loss and can be very painful. The pain can vary between sharp, dull or burning and be constant or come and go. One or both ears can be affected.

The ear is made up of three parts; the outer, the middle and the inner. It is possible to identify where the infection may be.

What to look out for

Infection

Signs of pain or earache, redness to outer ear or swelling to the side of the face, a discharge which may be blood stained or smelly, deafness, dizziness, loss of balance, noises (tinnitus), vomiting and diarrhoea.

• Individuals may hit or pull their ear.
• People may have loss of appetite or vomiting.
• Trouble sleeping due to the pain.
• Popping, ringing or tenderness.
• Discharge from the ear.

Hearing loss

This can be gradual and not immediately noticed:

• Not understanding what somebody has said.
• Not responding when being spoken to.
• Not responding to the doorbell or telephone.
• Having music or the TV turned up high.
• Constant rubbing of the ear.
• Appearing irritable, tired or stressed.
• “Jumping” when suddenly aware that somebody is near.
• Loss of sound localisation, i.e. the ability to tell where sounds are coming from. This has safety implications, e.g. being able to tell which direction traffic is coming from.
Actions to take

• Call a doctor immediately if there is a severe injury to the ear.

• If somebody appears in pain administer pain relief as per individual’s protocol. If this is still needed after 48 hours contact the GP for advice.

• The GP may prescribe antibiotics or eardrops.

• Apparent hearing loss should be referred to the GP as soon as possible.

Ongoing monitoring

• If somebody has repeated ear infections, there should be a support plan in place, identifying the signs and action to be taken.

• If somebody has an ear infection offer regular pain relief, keep the ear warm and dry e.g. don’t go swimming or out in the cold.

Useful Websites

www.actiononhearingloss.org.uk
www.sense.org.uk
www.hald.org.uk
Feet

**Background**

It is extremely important that people are supported with the hygiene of their feet, in order to check for issues such as fungal infections, e.g. athlete’s foot, or painful conditions such as bunions.

If somebody is immobile and not weight bearing, it is still as important to check the health of their feet.

When supporting people with the hygiene of their feet it is really important to ensure that the area between the toes is washed and dried thoroughly, as these are areas in which infections can develop.

Prompt people to change their socks daily, for hygiene reasons.

If the individual has diabetes, foot care is even more important and the individual should have a support plan and be seen regularly by a chiropodist.

**What to look out for**

- Signs of changes in someone’s mobility, e.g. if they become unsteady or complain of pain.
- A bad odour when taking off shoes. Offer support on hygiene.
- Look for any unusual marks, calluses or bumps. Ill fitting shoes can cause bunions, corns or pressure areas.

**Athlete’s Foot** – an itchy red rash in the spaces between toes. The skin may become scaly, flaky and dry. This can be treated with anti fungal medication, in tablet, cream, spray, liquid or powder form. If untreated it can spread to the toe nails.

**Verrucas** – these are warts that develop on the soles of feet. They appear as small rough lumps and can be very painful. They are very infectious, but can take weeks or months to appear.
**Bunions** – this is a bony deformity of the joint at the base of the big toe. It is evident from the big toe leaning in the direction of the other toes. It is not known what causes bunions, but it can be linked to family history, and badly fitting shoes makes it worse. A referral to the GP is necessary if it seems to be a problem or is causing pain.

**Ingrowing toenail** – this develops when the sides of the toenail grow into the surrounding skin. The nail pierces the skin which then becomes red, swollen and tender. The big toe is the most likely to be affected. This can be caused by incorrectly cut toenails, tight fitting shoes, socks or tights, nail infections, natural shape of the nail, injury, excessive sweating or poor foot hygiene. Pain relief can be given, apply good foot hygiene, and refer to podiatry. The GP should be contacted if the skin is very red with pus as antibiotics could be required.

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**Action to take**

- Refer to podiatry, chiropody or GP depending on what you observe.
- Twice daily foot hygiene.
- Check people’s toenails to ensure that they are kept short and healthy, and that there is no infection in the nail. Toe nails should always be cut straight across and not shaped.

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**Ongoing monitoring**

- If there is an ongoing problem, a support plan should be in place.

**Useful websites**

http://www.nhs.uk/Livewell/Foothealth/Pages/Foothealthhome.aspx
Managing pain

Background
For people with a learning disability, difficulty in managing pain can often be magnified as a result of additional communication issues.

Everyone feels pain. People who have a learning disability are no exception to this. Sometimes it is just not interpreted correctly. All too often people think it is part of someone’s learning disability. It is important not to jump to conclusions and ensure that a process of assessment is carried out.

If someone is displaying particular behaviours don’t necessarily think ‘behaviour’, think, ‘are they in pain?’

What to look out for
There could be several signs or symptoms to pain:

- A change to someone’s sleep pattern
- Change in their behaviour – increased agitation
- Change to appetite
  - Change to their sleep pattern – maybe an increase or decrease in sleep:
- Change to mobility and balance
- Confusion
- Change to their vocalisation
- Change to how a person uses or holds their body
- Distended or swollen stomach
  - Some common causes of pain:
  - Poor dental hygiene
  - Injury from a suspected fall
- Headache
- Menstruation pain
- Infection
- Fracture
  - Musculoskeletal problem such as arthritis or a sprain
- Depression and anxiety may cause people to feel pain more
- Nerve pain
- Pain from reflux
- Constipation or diarrhoea
- Side effects of medication
**Actions to take**

- Communicate with the individual in a way they understand – use their passport (see page 17). Take appropriate action depending on the response.

- Observe for any kind of change to the person which may be out of character for them. Use the process of elimination to help build up a picture.

- Use a disability distress assessment tool to assess the level of pain.

- Give pain relief if appropriate, seek GP appointment or call the manager on call for advice.

- Seek immediate medical advice if there are concerns that the pain is more serious and there may be something underlying which requires medical attention.

**Wong-Baker FACES® Pain Rating Scale**

- 0: No Hurt
- 2: Hurts Little Bit
- 4: Hurts Little More
- 6: Hurts Even More
- 8: Hurts Whole Lot
- 10: Hurts Worst

**Ongoing monitoring**

- Pain management support plan needs to be reviewed every six months or more regularly if required.

- Medication review must be undertaken on an annual basis, or more frequently if there are concerns.

- It is also important to remember that some people will not be able to communicate clearly when they are in pain and your assessment will only be able to be done through close observation and through knowing a person well.

**Useful websites**

- [www.wongbakerfaces.org](http://www.wongbakerfaces.org)
- [www.rcn.org.uk](http://www.rcn.org.uk)
**Choking**

### Background

Some of the people we support might be more prone to choking due to physical disabilities and posture. It is a higher risk if the individual has dysphagia which is not supported correctly.

It is important that the individuals we support are assessed for the risk of choking and support plans are developed to minimise the risk.

Effective observation at meal times is essential if there is a risk of choking however this needs to be done in a way that is not over bearing to the individual.

Some of the individuals we support maybe at risk of choking due to the following:

- Will eat walking around
- Will overload the mouth
- May swallow without chewing
- Will accept or put any item into their mouth
- May have issues around eating with others
- May eat food too quickly so they can move on to the next activity

Communication is also a key factor, as the individuals within the service rely on staff to support them with shopping, menu planning and preparing meals and drinks. If an individual suffers from anxiety this can also increase the risk.

### What to look out for

- An individual who is choking may instinctively grab at their throat and begin to panic. However, sometimes they can just sit quietly and not alert anyone. It is important to observe individuals who are at risk especially when eating and drinking.

- Foreign bodies can cause either mild or severe airway obstruction.

- Signs of a mild obstruction are that the individual is able to speak, cough and breathe normally, they can still respond to questions, are able to take a breath before coughing and are fully responsive.

- Signs of a severe obstruction are that the individual cannot speak (if they could normally), are unable to breathe, breathing sounds wheezy, attempts at coughing are silent, decreasing levels of consciousness, cyanosis (turning blue).
Actions to take

Take immediate action, checking mouth for obvious obstructions.

• Carry out basic First Aid. This should be provided as mandatory training.
• If basic First Aid is not successful dial 999.

Ongoing monitoring

• Adhere to support plans and risk assessments at all times.

Useful websites

www.sja.org.uk/sja/support-us/the-difference/five-ways-to-be-the-difference/choking.aspx
Understanding…

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Did you know?

People with a learning disability have much higher rates of stomach disorders.
Urinary tract infection (UTI)

Background

Urinary tract infections (UTIs) are very common. They can be painful and uncomfortable, but they usually pass within a few days or can be easily treated with a course of antibiotics.

They are more common in women than men (although men can still get them), they are also more likely in people who:
- Wear incontinence pads
- Have a catheter
- Have pre-existing health issues such as diabetes
- A weakened immune system
- Are pregnant
- Are over 65 years old

People who are prone to getting UTIs regularly should have this written in a support plan – including signs and symptoms and what to do to diagnose and treat.

There are two types of UTI; each have different symptoms and treatment.

What to look out for

Lower UTI:
- Confusion
- New occurrence of incontinence
- Cloudy urine, or with "bits" in it
- Needing to urinate more often during the day, night or both
- Pain or discomfort when urinating – look at pain section (page 50) for signs of pain
- Pain in stomach
- A feeling of tenderness around pelvis
- An urgent need to go to the toilet, increase in accidents as holding the urine becomes difficult
- Urine smells unusually unpleasant
- Back pain
- Blood in urine
- A general sense of feeling unwell
- Delirium – There are different types of delirium and symptoms can include agitation or restlessness, increased difficulty with concentrating, hallucinations or delusions, or becoming unusually sleepy or withdrawn.
Upper UTI:
• A high temperature (fever), this is generally above 38°C however this should be based on what is normal for the individual
• Confusion
• Uncontrollable shivering
• Nausea
• Vomiting
• Diarrhoea
• Pain in side, back or groin, often worse when urinating
• Any infection might cause someone to have more seizures

Actions to take
Seek GP advice straight away if it is thought that a UTI is causing:
• Unmanageable pain
• Self-injurious behaviour
• Blood in urine
• Confusion, delirium
• Increase in seizures
• Poor urine output
• Any signs and symptoms of upper UTI

Or if it is catheter related:
• Treatment such as antibiotics or further input from hospital may be needed.
Otherwise try:
• Offer a minimum of six to eight glasses of fluid such as water or weak, diluted juice.
• Give pain relief if thought to be in pain or if they have a high temperature.
• Do not use non-steroidal anti-inflammatory drugs (NSAID’s) such as ibuprofen and naproxen – these can increase risk of damage to the kidneys.
• If pain becomes unmanageable or symptoms last longer than two days refer to GP or nurse practitioner.
• Obtain a urine sample (see page 34) to take to GP or nurse practitioner to be tested.
Understanding…

What colour should urine be?

Use this colour chart when observing a person’s urine to give an indication of whether they need to be offered more drinks.

Ongoing monitoring

If someone is at higher risk of UTI, or are displaying possible signs of UTIs on a regular basis discuss with the GP ways to monitor this such as a routine test on a regular basis.

Give advice on how to prevent UTIs:

- Drink more water
- Go to the toilet as soon as the need arises rather than hold it in
- Wipe from front to back
- Drinking cranberry juice might help (do NOT do this if taking warfarin)
- Treat constipation
- Use condoms that don’t have a spermicidal lubricant on them and empty bladder after sex

Useful websites

www.patient.co.uk/doctor/Urinary-Tract-Infection-in-Adults#
Chest infection / pneumonia

**Background**

- Chest infections are common, especially during the autumn and winter or after a cold or flu.
- Pneumonia is inflammation (swelling) of the tissue in one or both lungs. The most common cause is an infection caused by bacteria called Streptococcus Pneumonia.
- People with a learning disability who have modified diets are at high risk of recurrent chest infections and pneumonia.
- People with profound and multiple learning disabilities are susceptible to pneumonia due to a number of reasons aspiration, poor positioning, physical disabilities and immobility.
- Those at risk are babies or very young children, elderly people, people who smoke, people with a weakened immune system and people with other health conditions, such as heart conditions, kidney/liver conditions and a lowered immune system, caused by flu, asthma, chemotherapy or HIV and Aids.
- Communication is also a key factor as individuals rely on carers to support them with their health needs and accessing health services therefore staff need to act on their observations.
- Staff need to be aware that modified diets and fluids recommended to prevent or reduce the risk of aspiration due to dysphagia and prevent or reduce the risk of chest infections/pneumonia must be adhered to at all times both in the services and out in public areas.

**What to look out for**

- A chesty cough, breathing difficulties and chest pain. It is also common to get a high temperature.
- There are two types of chest infections acute bronchitis and pneumonia. Acute means that the infection is short lived, a one-off illness.
- Common signs and symptoms of pneumonia are a cough which can be dry or may produce phlegm, fever and difficulty breathing which may become rapid and shallow; sufferers may feel breathless even when resting.
- The symptoms of pneumonia can develop over 24-48 hours or may come on more slowly over several days.
- The other signs and symptoms are feeling generally unwell, sweating and shivering, loss of appetite and pain in the chest.
- Less common are coughing up blood, headaches, fatigue, nausea, vomiting, wheezing, pain in joints, muscles and feeling confused.
**Actions to take**

- Contact the GP. They will do tests and might suggest a chest X-ray or further tests to confirm the diagnosis.
- Mild pneumonia can be treated at home with antibiotics, rest and fluids.
- Severe pneumonia might be treated in hospital.
- Complications can be respiratory failure, lung abscesses and blood poisoning (septicaemia).
- Keep observing for improvement or worsening of the condition and take appropriate action.

**Ongoing monitoring**

- Prevention of pneumonia can be treated with a pneumonia and flu jab.
- Regular health checks.
- For the individuals we support, it is essential to have robust support plans and risk assessments in place and an up-to-date health action plan.

**Useful websites**

[www.pamis.org.uk](http://www.pamis.org.uk)
**Intestinal problems – constipation and diarrhoea**

### The Bristol Stool Chart

This chart helps us understand bowel movements:

- **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
- **Type 6** – Fluffy pieces with ragged edges, a mushy stool
- **Type 7** – Watery, no solid pieces. Entirely Liquid

If someone is having issues with their bowel motions the Bristol Stool Chart is a good tool to use to monitor a person’s motions. Making note of a type of stool and its size is good information to then hand over to other professionals such as a GP or continence nurse.

- **Type 1–2** indicate constipation;
- **Type 3–4** are ideal stools as they are easier to pass, and;
- **Type 5–7** may indicate diarrhoea and urgency.

### Background

Normal bowel habits vary from person to person. Some adults normally go to the toilet more than once a day, whereas it’s normal for others to go only every three to four days.

Problems are either constipation or diarrhoea.

Causes of constipation can be:

- Psychological and behavioural – being upset can make your bowel slow down or speed up. Ignoring the natural urge to open bowels can cause long term changes in how muscles work
- Not eating enough fruit, vegetables and cereals (fibre)
- A change in routine/lifestyle
- Having limited privacy when using the toilet, or being rushed
- Immobility or lack of exercise
- Not drinking enough fluids
- Anxiety or depression
- Psychiatric problems, such as those brought on by sexual abuse, violence or trauma
- Related to medication
- Related to underlying health conditions
Monitoring is useful if someone is prescribed laxatives as it will allow a good evaluation of the drug when it comes to be reviewed with the GP.

If constipation is left untreated it can cause faecal impaction, this is potentially fatal. It is where dried, hard stools collect in the rectum and anus. Once there is faecal impaction, it is very unlikely that a person will be able to get rid of the stools naturally.

Faecal impaction worsens constipation because it makes it harder for stools and waste products to pass out of the anus as the path is obstructed.

Faecal impaction can lead to the following issues:

- Swelling of the rectum
- Losing sensation in and around the anus
- Faecal incontinence, an uncontrollable leakage of soft or liquid stools
- Bleeding from the anus
- Rectal prolapse, when part of the lower intestine falls out of place and comes out from the anus
- Pain

If there is thought to be no issue with constipation or any other bowel related illness then there would be no need to keep taking note of a person’s bowel motions unless it was suggested by a GP.

Diarrhoea is passing looser or more frequent stools than is normal for somebody.

It affects most people from time to time and is usually nothing to worry about.

Causes can be a bowel infection or gastroenteritis caused by:

- A virus – such as norovirus or rotavirus
- Bacteria – which is often found in contaminated food
- A parasite

In adults, bouts of diarrhoea can sometimes be the result of anxiety or drinking too much coffee or alcohol. Diarrhoea can also be a side effect of certain types of medication.

What to look out for

**Constipation**

Doctors define constipation the following ways:

- Opening bowels less than three times a week
- Needing to strain to open your bowels on more than a quarter of occasions
- Passing a hard or pellet like stool on more than a quarter of occasions
- Stools may be dry, hard and lumpy, abnormally large or abnormally small
Constipation can cause:

- Stomach ache and cramps
- Feeling bloated
- Feeling nauseous
- Loss of appetite
- Lack of energy
- Feeling irritable, angry or unhappy
- Abdominal pain and discomfort - look at pain section for signs of this
- Soiling clothes
- Generally feeling unwell
- Small liquid stools may be a sign of fluid passing around the stool; this does not necessarily mean the bowel is empty

Other health issues related to constipation:

- Haemorrhoids
- Losing sensation in and around anus
- Bleeding from anus
- Rectal prolapse
- Increase in seizures

The severity of constipation can also vary. Many people only experience constipation for a short time, but for others, constipation can be a long term condition that causes pain and discomfort and affects their quality of life.

**Diarrhoea**

As well as diarrhoea, people may have other symptoms such as:

- A fever
- Severe stomach cramps
- Nausea, vomiting and a loss of appetite

Diarrhoea usually lasts between two to four days. If diarrhoea is severe or prolonged it may cause dehydration. In adults, symptoms of dehydration include:

- Tiredness and a lack of energy
- Loss of appetite
- Nausea
- Feeling lightheaded
- Dizziness, particularly when standing up
- Dry tongue or lips
• Sunken eyes
• Muscle cramps
• Rapid heartbeat

In adults, diarrhoea that lasts more than a few weeks may be a sign of a more serious condition, such as bowel cancer, Crohn’s disease or irritable bowel syndrome (IBS).

It could also be a side effect of medication, most commonly antibiotics.

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**Actions to take**

**Constipation**

Seek GP advice straight away if you think that constipation is causing:

• Unmanageable pain
• Self-injurious behaviour
• Poor diet/fluid intake
• Other health related issues (see above)
• No bowel motion has been noted for four or more days

Otherwise try:

• Offer plenty of fluids; try water, prune juice, fresh orange.
• Increase fibre intake.
• If not too uncomfortable and if possible promote movement such as going for a walk.
• Give pain relief if needed – but make sure this is not codeine based which worsens constipation.
• Look at possible causes (see page 62) it may be that a change in medication may be needed or if reoccurring and cannot be controlled by diet or fluids a laxative may need to be prescribed.

**Diarrhoea**

A GP should be contacted if someone has:

• Diarrhoea and they have recently been in hospital
• Recently been treated with antibiotics
• Diarrhoea that has blood in it
• Diarrhoea and persistent vomiting
• Unexplained weight loss
• Bleeding from their rectum (back passage)
• Passed a large amount of very watery diarrhoea – they may be at risk of dehydration
• Diarrhoea at night that is disturbing sleep.
• Diarrhoea that lasts longer than a week (it usually passes within two to four days).
• If someone has persistent diarrhoea, they should visit their GP so the doctor can try to establish a cause. This is particularly important if they have blood or pus in their faeces.

Someone should also see the GP if they feel particularly unwell when they have diarrhoea.

**Ongoing monitoring**

**Constipation**

There are four key things that help to prevent constipation.

1. **Fibre**
   
   Inform the service user of the benefits of eating a balanced diet that includes some of the following:
   
   • Fruit
   • Vegetables
   • Wholegrain rice
   • Wholewheat pasta
   • Wholemeal bread
   • Seeds
   • Nuts
   • Oats
   
   Eating more fibre will keep bowel movements regular because it helps food pass through the digestive system more easily.
   
   When increasing fibre intake, it is important to increase it gradually. A sudden increase may cause bloating, wind and stomach cramps.

2. **Fluids**
   
   Make sure that service users are offered plenty of fluids to avoid dehydration (at least two litres/daily) and steadily increase fluid intake when exercising or when it is hot. Try to encourage them to cut back on the amount of caffeine, alcohol and fizzy drinks that are consumed.

3. **Toilet habits**
   
   Make sure individuals never ignore the urge to go to the toilet. Ignoring the urge can significantly increase chances of having constipation. The best time to pass stools is first thing in the morning, or about 30 minutes after a meal.
   
   When using the toilet, make sure individuals have enough time and privacy to pass stools comfortably.

4. **Exercise**
   
   Keeping mobile and active will greatly reduce the risk of getting constipation. Ideally, do at least 150 minutes of physical activity every week.
Prevention of diarrhoea:

To prevent diarrhoea caused by infection, you should take steps to prevent the infection spreading. For example, make sure you help people to:

- Wash their hands thoroughly after going to the toilet and before eating or preparing food.
- Clean the toilet, including the handle and the seat, with disinfectant after each bout of diarrhoea.
- Avoid sharing towels, flannels, cutlery or utensils with other household members.
- Stay at home until at least 48 hours after the last episode of diarrhoea.

Useful websites

www.nhs.uk/Conditions/Constipation/Pages/Introduction.aspx
www.patient.co.uk/health/constipation-in-adults-leaflet
Thrush

Background
Thrush is a yeast infection that can affect various parts of the body, most commonly the mouth, vagina, penis and skin.

Thrush is a common side effect of some antibiotics and steroids.

If someone has a poor immune system. For example, if they have HIV/AIDS, or are having chemotherapy, or have certain types of serious blood disorder.

People who have diabetes are more prone to thrush.

In most cases, thrush is not contagious.

What to look out for

Oral thrush

- Sore, white patches (plaques) in the mouth that can be wiped off.
- A painful, burning sensation on the tongue.
- An unpleasant taste in the mouth that can be bitter or salty.
- Redness and soreness on the inside of the mouth and throat.
- Cracks at the corners of the mouth.
- Difficulty swallowing – observe for changes in eating and drinking.

Vaginal thrush

Typical symptoms include:

- Itching and soreness around the entrance of the vagina.
- Pain during sex.
- A stinging sensation when urinating.
- Vaginal discharge, although this isn’t always present; the discharge is usually odourless and it can be thin and watery or thick and white like cottage cheese.
Severe symptoms could be:

- A red and swollen vagina and vulva
- Cracked skin around the entrance of the vagina
- Sores in the surrounding area – this is rare, but it may indicate the presence of another fungal condition or the virus that causes genital herpes.

**Thrush in men**

- In men it usually affects the head of the penis causing inflammation
- A smelly lumpy discharge
- Pain while passing urine

**Skin**

- Areas of skin that are moist or sweaty are ideal environments for thrush to thrive. Therefore, the common sites affected are in the folds of skin in the groin, armpits, and under large breasts.
- Nappy rash is sometimes due to thrush.
- Obese people may develop thrush between folds of skin. It can also affect skin between fingers and toes, and the corners of the mouth.

**Actions to take**

Seek advice from the pharmacist as there are over the counter medications to treat thrush in men and women. If you are unsure, consult with a GP or nurse practitioner to give a diagnosis and prescribe the most appropriate course of treatment.

**Ongoing monitoring**

If someone takes antibiotics regularly and often gets thrush due to this, it might be worth talking to the GP about prescribing treatment as a precaution. This should then be written up in a support plan.

**Useful websites**

[www.nhs.uk/Conditions/Thrush/Pages/Symptoms.aspx](http://www.nhs.uk/Conditions/Thrush/Pages/Symptoms.aspx)
Gastro-oesophageal reflux disease (GORD)

Background

Gastro-oesophageal reflux disease (GORD) is sometimes described as heartburn or indigestion, a burning sensation in the chest, just behind the breastbone.

GORD is a very common digestive condition. It is estimated that 48% of people with a learning disability will have GORD. This is significantly higher than the general population. As this condition is frequently overlooked, particularly in those unable to communicate their pain easily, the number of people experiencing GORD could be much higher.

Most cases of GORD are caused by a problem with the lower oesophageal sphincter muscle (LOS). This is a valve that opens to let food down into the stomach and then closes to prevent acid leaking back up into the oesophagus, in cases of GORD this muscle becomes weakened.

People who are pregnant or who have a hiatus hernia are also prone to GORD.

What to look out for

Common symptoms include:

- Heartburn – burning chest pain or discomfort that occurs after eating
- An unpleasant sour taste in the mouth, caused by stomach acid coming back up into the mouth
- Dysphagia – pain and difficulty swallowing
- Burping

Less common symptoms include:

- Feeling sick
- Persistent cough, often worse at night
- Chest pain
- Wheezing
- Tooth decay
- Laryngitis (inflammation of the larynx), which causes throat pain and hoarseness

Also if someone has asthma and GORD, asthma symptoms may worsen as a result of stomach acid irritating the airway.
**Actions to take**

There are many risk factors that are related to lifestyle choices which someone may be able to change to reduce the effects of GORD:

- **Being overweight or obese** – this can place an increased pressure on the stomach, which can in turn weaken the LOS.
- **Having a diet high in fatty foods** – the stomach takes longer to dispose of stomach acids after digesting a fatty meal.
- **Consuming tobacco, alcohol, coffee or chocolate** – in some cases this may relax the LOS.
- **For people who are feeling the effects of GORD a couple of times a month** the above lifestyle changes should be offered before going to the GP.

However, if someone’s behaviour is being affected due to this or if someone is suffering on a regular basis then contact the GP for advice.

The GP may refer someone for further tests to ensure it is definitely GORD and to enable them to prescribe the correct medication or propose another form of treatment.

**Ongoing monitoring**

- Observe for any signs of pain especially after eating and drinking.
- Observe for any reluctance to eat or drink.
- Observe for any changes in behaviour.

**Useful websites**

- [www.nhs.uk/conditions/gastroesophageal-reflux-disease](http://www.nhs.uk/conditions/gastroesophageal-reflux-disease)
- [www.patient.co.uk/health/acid-reflux-and-oesophagitis](http://www.patient.co.uk/health/acid-reflux-and-oesophagitis)
Heart disease

Background

Research from the Royal College of Nursing shows that coronary heart disease is the second highest cause of death for people with a learning disability and that people with a learning disability tend to exercise less and are more likely to develop hypertension and obesity, all of which are risk factors for ischaemic heart disease.

People with Down’s Syndrome are at higher risk of congenital heart problems.

Healthy lifestyle, healthy heart

Lifestyle can have a big effect on heart health. People should be encouraged to:

- Stop smoking
- Lose weight
- Keep active
- Eat a healthy, well balanced diet
- Reduce blood pressure
- Reduce cholesterol

What to look out for

Heart attack

The most common heart attack symptom in men and women is chest pain or discomfort. However, only half of women who have heart attacks have chest pain.

Women are more likely than men to report back or neck pain, indigestion, heartburn, nausea (feeling sick to the stomach), vomiting, extreme fatigue (tiredness), or problems breathing.

Heart attacks can also cause upper body discomfort in one or both arms, the back, neck, jaw, or upper part of the stomach. Other heart attack symptoms are light-headedness and dizziness, which occur more often in women than men.

Men are more likely than women to break out in a cold sweat and to report pain in the left arm during a heart attack.

Heart failure

Heart failure is when your heart can’t pump enough blood to meet your body’s needs. Heart failure doesn’t mean that your heart has stopped or is about to stop working. It means that your heart can’t cope with the demands of everyday activities.

Heart failure causes shortness of breath and fatigue that tends to increase with physical exertion. Heart failure can also cause swelling in the feet, ankles, legs, abdomen and veins in the neck.
Arrhythmia

An arrhythmia is a problem with the rate or rhythm of the heartbeat. During an arrhythmia, the heart can beat too fast, too slow, with an irregular rhythm, or with palpitations which is a fluttering or thumping feeling or skipped beats in the chest.

Angina

Angina is a pain that comes from the heart. It is usually caused by a narrowing of the coronary arteries, which causes a reduction in blood supply to parts of the muscle.

Symptoms can include a pain in the chest, arms, jaw or neck or a stomach ache. There can also be discomfort or tightness across the front of the chest, often felt on exertion.

Sufferers take an anti-anginal medication daily and can also have a Glycerin Trinitrate medicine in the form of tablets or spray that can be used when angina pain develops and that the sufferer should always carry with them.

People with angina have a higher than average risk of having a heart attack.

Actions to take

If someone is describing any of the symptoms above call 999 immediately.

In the case of angina attack, use a glyceryl trinitrate (GTN) spray as prescribed. Repeat after ten minutes. If the person is still in pain, call 999.

Ongoing monitoring

- For people born with Down’s Syndrome, because of the link between this and heart disease, tests should be carried out from birth.
- The person may need to attend regular appointments and check-ups.
- The person may need regular review of medications if they’re on any.
- If someone has a history of heart disease in their family they should be checked regularly.
- Always remember prevention is better than cure so a healthy diet and regular exercise may keep it at bay.

Useful websites

www.bhf.org.uk/heart-health/conditions
Diabetes

Background

Diabetes is caused by having a high amount of glucose (a type of sugar) in the blood. Normally a hormone called insulin controls the amount of sugar in the blood. Food that we eat is broken down and goes into the blood. The insulin then helps to move the sugar out of the blood and into the cells. It is then broken down and made into energy. In diabetes the body is not able to fully use the sugar in the blood.

There are two types of diabetes:

- **Type 1 diabetes** – where the person no longer produces any insulin.
- **Type 2 diabetes** – where the person does not produce enough insulin and/or the body is unable to use the insulin efficiently.

Type 1 diabetics need to inject insulin several times a day

Type 2 diabetics use a combination of diet, exercise and medication to control their diabetes.

A healthy well-balanced diet and exercise is important for both type 1 and type 2 diabetes.

What to look out for

In type 1 diabetes, the signs and symptoms come on quite quickly and the person can rapidly become ill. These symptoms include:

- Excessive thirst
- Weight loss (significant)
- Passing urine more frequently
- Thrush
- Eye problems
- Vomiting, confusion and generally unwell

Type 2 diabetes is much more gradual and is often detected as part of routine screening. Its symptoms can include:

- Increased thirst
- Passing urine more frequently
- Thrush
- Blurred vision
- Sores to the feet
- Unusual feelings in lower limbs, particularly the toes
Hypoglycaemia (Hypo) Low Blood Sugar
Type 1 diabetics and some type 2 diabetics (depending on medication) may experience low blood sugars. This is where the blood sugar falls below four (normal levels are between four and 10).

A hypo can be caused by:
• Too much insulin/medication
• Missed meals or snacks
• More than usual amount of exercise
• Alcohol

The signs and symptoms include dizziness, seeing flashing lights, confusion and clumsiness.

Those at risk of hypo's should always carry some quick acting sugar with them. They should also have some identification on them.

Hyperglycaemia (Hyper) High Blood Sugar
This occurs when the sugar levels in the blood are too high and can be a result of:
• Being unwell
• Infection
• Eating too much
• Not taking medication correctly, or not at all
• Poor control (Long Term)

Actions to take
Onset of diabetes
It is important to find out as soon as possible if a person has diabetes so that treatments can begin. If you notice any of the above symptoms:
• Seek an appointment with the GP or nurse
• Take a urine sample to the appointment (see page 34). If the urine sample detects sugar a blood sample will also be required to confirm diabetes.

Treatment for hypoglycaemic attacks
It is important to act quickly. Ensure the person gets sugar in a quick acting form such as full sugar coke, Lucozade or glucose tablets. This needs to be followed up with some carbohydrate to keep the blood sugar stable for example toast, a sandwich or cereal.

If a hypo is not brought under control it can lead to confusion, slurred speech and collapse.

If this happens call 999.
**Treatment for Hyperglycaemia (Hyper)**

- Monitor the blood sugar every one to two hours.
- If the person is vomiting – seek help as soon as possible.
- If blood sugars are over 18, and the patient is unwell, contact the GP straight away.
  
  If the person is well:
  - Check the amount of insulin being taken is correct.
  - Check dietary intake – is there anything with a lot of sugar in that they are eating.
  - Have they stopped exercising.
  - If continual increased blood sugars for two weeks or more, contact the nurse for further advice.

**Ongoing monitoring**

The GP surgery will undertake regular tests on all diabetics.

You will need to regularly check the person’s blood sugar levels. This may need to be done up to four or more times a day depending on advice given by the diabetes team.

Record the results in order to establish a person’s normal pattern and to be able to detect and prevent a potential hyper/hypo episode.

All diabetics need to:

- Monitor their daily food intake. A dietician will advise and help to work out an appropriate food plan.
- Exercise regularly as exercise lowers the blood sugar level.
- Try to cut down or stop smoking.

**Eye care**

- Annual eye tests should be maintained.
- Diabetics are prone to the blood vessels in the eye becoming damaged. This is called Retinopathy and if untreated can lead to blindness.

**Diabetics and foot care**

- Diabetics are more likely to have problems with their feet. Foot ulcers and infections can result from minor cuts and grazes.
- Ensure nails are kept short and feet are washed daily in warm water.
- Ensure feet are checked daily for cuts and grazes that do not heal and check for swelling and any skin that feels hot to touch.
- All diabetics with a learning disability should have their feet assessed by a nurse annually. Some might need regular visits to the podiatrist or chiropodist.
Useful websites

www.easyhealth.org.uk
www.diabetes.org.uk
# Asthma

## Background

Asthma is a common condition that affects the airways. It is caused by inflammation of the airways. The inflammation irritates the muscles around the airway which causes them to narrow.

What makes symptoms worse:

- Infection
- Smoking
- Cigarette fumes
- Chemicals
- Pollens
- Mould
- Exercise
- Some types of bedding/pillows
- Emotional upset
- Allergies to animals
- House dust mites
- Some types of food

Most people are treated with inhalers. Inhalers are devices that hold medication that a person takes by breathing in. This allows the medication to go directly into the airway.

The two types of inhalers are known as:

- Relievers
- Preventers

A reliever inhaler is used to ease symptoms. These inhalers widen the airways. They can be used several times a day. However, if a person needs to use a reliever more than three times per week, they may need a preventer inhaler too.

A preventer inhaler is taken every day to prevent symptoms from developing. They contain steroids which work by reducing the inflammation in the airways.

There are many different types of inhaler devices and a GP should prescribe the best one for the patient’s needs depending on their learning disability.

## What to look out for

- Frequent cough, especially at night
- Chest tightening or pressure
- Loss of breath easily or shortness of breath
- Feeling very tired or weak when exercising
- Wheezing (noise made when breathing out) or coughing after exercise

Some people with asthma may have long periods without any symptoms, interrupted by a sudden increase of symptoms asthma attacks. Some may only have asthma during exercise or it may be triggered by temperature change or viral infection.

## Actions to take

If someone doesn’t have a diagnosis of asthma however present with one or more of the signs/symptoms, refer to the GP.

Anyone diagnosed with asthma should have a plan in place recommended by their GP regarding use of an inhaler/medication and this should be reviewed regularly in clinic.

Exacerbations can be caused by many things and treatment will depend on symptoms and severity. Steroid tablets, antibiotics and an increase in usual inhalers may be advised.

Asthma can be serious. If a person is unable to talk in full sentences, feels tight chested, and develops a blue tinge to the lips, then call 999.
Ongoing monitoring

Asthma sufferers should attend an annual review with an asthma nurse. They should also have the flu vaccination each year. They need to use their inhalers as prescribed.

Useful websites

For more detailed information and a video demonstration on how to use the different types of inhaler: http://www.asthma.org.uk/advice-inhalers-treatment-medicines

Also www.asthma.org.uk

Types of inhaler

The standard MDI inhaler (Metered Dose Inhaler)

The MDI inhaler contains a pressurised inactive gas that propels a dose of drug in each ‘puff’. Each dose is released by pressing the top of the inhaler. This type of inhaler is quick to use, small, and convenient to carry. It needs good co-ordination to press the canister, and breathe in fully at the same time.

Many people do not use it to its best effect. Common errors include: not shaking the inhaler before using it; inhaling too sharply or at the wrong time; not holding your breath long enough after breathing in the contents.

Breath-activated inhalers

Breath-activated inhalers don’t require you to press a canister on top, instead, you trigger a dose by breathing in at the mouthpiece. Accuhalers, clickhalers, easyhalers, novolizers, turbobhalers, diskhalers and twisthalers are all breath-activated dry powder inhalers. You need to breathe in fairly hard to get the powder into your lungs.

Spacer devices

Spacer devices are used with metered dose inhalers to deliver medication in an easier way. The spacer between the inhaler and the mouth holds the drug like a reservoir when the inhaler is pressed. A valve at the mouth end ensures that the drug is kept within the spacer until you breathe in. When you breathe out, the valve closes. You don't need to have good co-ordination to use a spacer device.

A facemask can be fitted on to some types of spacers, instead of a mouthpiece. This is sometimes done for young children and babies who can then use the inhaler simply by breathing in and out normally through the mask.
Chronic Obstructive Pulmonary Disease (COPD)

Background
COPD is a term for people with chronic bronchitis, emphysema or both. With COPD, the airflow to the lung is restricted. It is usually caused by smoking, which causes the lining of the airways to become inflamed and damaged. In COPD there is permanent damage to the airways. It tends to affect those over the age of 40 and is more common in men than in women.

What to look out for
• Cough
• Breathlessness
• Purulent sputum (when a cough produces yellow or green mucus)
• Chest infections
• Weight loss
• Tiredness

Actions to take
• The person should stop smoking – this is most important.
• Use inhalers (relievers/preventers) and medication as prescribed. Some sufferers might be issued with a "rescue pack" of specific medication to deal with flare ups.
• Use home oxygen – for those with severe symptoms or end-stage COPD.

Ongoing monitoring
Sufferers should have an annual COPD review with the respiratory nurses.
They should receive a flu jab annually and a pneumonia vaccination.
They should be encouraged to adopt a healthy lifestyle with no smoking and regular exercise.

Useful websites
www.blf.org.uk
Epilepsy

Background
Electrical activity is happening in our brain all the time. An epileptic seizure occurs when there is a sudden burst of intense electrical activity. This causes a temporary disruption to the way the brain normally works, meaning that the brain's messages get mixed up.

The brain is responsible for all functions of the body. What is experienced during a seizure will depend on where in the brain the epileptic activity begins, and how widely and rapidly it spreads. There may be a disturbance of consciousness, behaviour, emotion, motor function or sensation.

For this reason there are many different types of seizure, and each person will experience epilepsy in a way that is unique to them.

Causes of epilepsy
There are a variety of reasons why epilepsy occurs, some examples are:

• Brain damage caused by a difficult birth
• A severe blow to the head
• A stroke
• An infection of the brain such as meningitis
• A tumour
• Neurodegenerative diseases, such as Alzheimer's
• Drugs and alcohol, such as binge alcohol drinking, alcohol withdrawal
• In approximately six out of 10 sufferers the cause is unknown

SUDEP
Sudden unexpected death in epilepsy is the most common cause of death directly related to epilepsy.

It is defined as sudden, unexpected, non-traumatic, non-drowning death in an individual with epilepsy, witnessed or unwitnessed in which the post mortem examination does not reveal an anatomical or toxicological cause for death.

Information should be given to all individuals with epilepsy, and carers about the small but definite risk of SUDEP. It appears to occur most commonly during sleep, and more often affects younger people.

Status epilepticus
This is when a seizure lasts more than 30 minutes, or when a person has a series of seizures and does not regain consciousness in between. This is classed as a medical emergency.
What to look out for

Auras

Some people have a distinctive feeling or warning sign that a seizure is going to occur. These are simple partial seizures. They vary from person to person, but can include a strange taste or smell, a feeling of déjà vu, a sense of fear or anxiety, a feeling that the outside world suddenly becomes dreamlike. This warning cannot prevent a seizure from occurring, but it can give the individual the chance to warn the people around them, and get into a safe position.

Types of seizures

Seizures are classified into partial (where only a small part of the brain is affected), generalised (where most or all of the brain is affected) and unclassified.

Partial seizures

There are two types, simple partial and complex partial:

• **Simple partial** – the muscles in arms, legs and face may become stiff, with twitching on one side.

• **Complex partial** – strange and random bodily behaviour, smacking lips, rubbing hands, moving arms around, chewing or swallowing.

Generalised

In most cases people will be completely unconscious. The most common seizure is a tonic clonic seizure, and this is the seizure most people identify with epilepsy:

• **Tonic clonic seizure** – this is in two stages, the person becomes stiff, and then the arms and legs start to twitch.

• **Absence Seizures** – individual appears “vacant” for a few seconds.

• **Myoclonic jerks** – arms, legs and upper body twitch for a fraction of a second.

• **Clonic Seizures** – as Myoclonic but lasting for longer.

• **Atonic Seizures** – all the muscles relax, so a person may fall to the ground.

• **Tonic Seizures** – muscles become stiff rather than relax, and people may fall.

Some people may become incontinent during a seizure.

Actions to take

• If it is a first seizure, an ambulance should be called

• An ambulance should also be called if it lasts for more than five minutes, or the individual does not fully regain consciousness.

• The individual should be reassured, and if possible put into a position where they cannot hurt themselves.

• Once the seizure is over the person should again be reassured and kept safe until they are fully conscious. People may be embarrassed, particularly if they have become incontinent.
### Ongoing monitoring

- If the individual has a history of epilepsy, there should be an epilepsy management plan in place, describing the type of seizure usually experienced, the usual length, and what interventions such as medication may be required.

- All staff supporting an individual with epilepsy should have up-to-date epilepsy training, and medication training if rescue medication is required.

- All seizures should be recorded on the individual's epilepsy chart, the type, time, duration, and recovery, plus any intervention required.

- These charts should be reviewed on a regular basis with the epilepsy specialist. The frequency will depend on the individual, but should be at least once a year.

- Medication should be given as prescribed, and reviewed with the GP for side effects.

- Bloods should be taken at least once a year to check for therapeutic levels, depending on the medication the person is taking.

### Useful websites

- [www.epilepsy.org.uk](http://www.epilepsy.org.uk)
- [www.epilepsysociety.org.uk](http://www.epilepsysociety.org.uk)
Dysphagia

Background

The medical term for swallowing difficulties is dysphagia.

There are two types of dysphagia. Oropharyngeal or high dysphagia which are swallowing difficulties caused by problems with the mouth or throat and oesophageal or low dysphagia which are swallowing difficulties caused by problems with the oesophagus.

Some individuals with dysphagia have problems swallowing certain foods and liquids, while others cannot swallow at all.

Neurological causes are:

• Stroke
• Parkinson’s disease
• Dementia
• Motor neurone disease
• Brain tumours

Congenital (something you are born with) and developmental (affected by the way you develop) causes are:

• Learning disabilities
• Cerebral palsy
• Cleft palate

What to look out for

• Coughing and choking during meals
• Difficulty with mealtimes and refusing food
• Gagging with certain food consistencies
• Gurgling noises in the throat or the voice
• The inability to cope with lumps
• Wheezing episodes following fluids
• Repeated chest infections
• Bringing food and fluids back up, sometimes through the nose
• A sensation that food is stuck in the throat or chest
Actions to take

- Make an appointment with the GP who may request further assessments.
- A referral may need to be made to the speech and language therapist or the dietician who will assess for dysphagia and recommend a modified diet or fluids that are appropriate for the individual.
- Some of the tests are diagnostic gastroscopy, barium swallow, video fluoroscopy, manometer and 24 hour PH study.
- A nutritional assessment may also be requested.

Ongoing monitoring

- If there is a diagnosis of dysphagia then a modified diet and fluids will be identified. The assessment will then need to be followed at all times. Examples of modified diets are ‘fork mashed’ and ‘easy chew’ which are a soft diet and a pureed diet. Examples of modified fluids are syrup, custard and semi-solid consistency. Thickener will be prescribed so that the required consistency can be given. This is added to food and fluids to create the right consistency.
- Support plans and risk assessments should be completed to support the individual and the carers.
- Meals need to be planned which adhere to the assessment.
- It is important to constantly monitor the individual’s weight and any issues and concerns raised and actioned.
- If the individual cannot manage a pureed diet and semi-solid fluids then a reassessment is needed as the next stage may be a peg feed or nasal gastric tube.

Useful websites

www.nhs.uk/conditions/dysphagia/pages/definition.aspx
Oxygen therapy

Background

People may need oxygen therapy for a number of reasons e.g. lung cancer, heart disease, pulmonary hypertension, asthma, or injury. In non-nursing homes oxygen therapy must only be used after assessment by a doctor and following a prescription which must indicate the type of delivery, rate of oxygen flow and duration of treatment.

Depending on the amount and frequency of therapy prescribed the person might have either an oxygen cylinder, which is a cylinder full of oxygen, or an oxygen concentrator, which purifies air to produce oxygen. The concentrator needs to be plugged in to the mains to work.

Oxygen can be given using either a mask or a nasal cannula. The person’s prescription will tell you which to use.

Make sure you understand how to use the oxygen delivery system that has been prescribed. If you are not sure ask someone who knows or ring the ‘on call’ for advice.

Anyone who is prescribed oxygen must have a support plan describing in detail when and why they need it, how to administer it to them and when to stop.

What to look out for

Oxygen therapy is when oxygen is prescribed to help somebody who is having difficulty breathing. This could be as a result of lung cancer, heart disease, pulmonary hypertension, asthma or injury.

If a person is having difficulty breathing check the following:

Appearance

• Laboured shallow breathing
• Check general colour of their lips/face
• Colour of nails, are they changing colour from pink to blue?
• Does the person appear alert, orientated, exhausted, confused, anxious or unresponsive?
• Are there any non-verbal expressions of pain, for example, grimaces, facial distortion, lip biting?
• Is there any evidence of facial flushing or cyanosis (blue/grey tinge to the skin)?
• Finger clubbing

Posture

• Does the person adopt an erect, slouched or crouched-forward posture?
• Does the posture suggest any localised areas of pain?
• Does the person’s posture indicate whether he or she is anxious or afraid?
• Does the person suffer from breathlessness when lying down?
Physical symptoms

- Is the person unable to complete a full sentence or is breathlessness only experienced on exertion?
- Does the person make grunting sounds while breathing?
- Is there an increase in chest size, coughing or increased respiratory secretion?

If any of these things are present then the person may be having difficulty breathing.

Actions to take

- If this is the first time the person has had difficulty breathing call 999 and ask for an ambulance. Do not administer oxygen if it has not been prescribed for the person.
- If the person is prescribed oxygen therapy, check their support plan and MAR sheet for instructions specific to them. These must include the rate of oxygen flow, delivery system and duration of use.
- Administer oxygen as per the person’s guidelines and prescription.
- Record what has happened in the person’s notes.

Ongoing monitoring

- Regular GP or consultant’s appointments.
- Regular monitoring of the underlying illness.
- Oxygen cylinders/machines will need weekly in-house checking and will need to be checked by the providing company on a regular basis.
- Should also include specialist respiratory nurse

Useful websites

www.blf.org.uk/Page/Oxygen
Tissue viability

Background

Everybody has at some point in their life experienced the feeling of a pressure injury. Sit in the cinema for two hours, and you may become uncomfortable and begin to wriggle. Imagine being somebody who cannot move and you will understand how important repositioning is. The literal meaning of tissue viability is preservation of the tissue, and ensuring that damage to the skin does not occur.

Damage to the skin is known as a pressure ulcer or sore. This is an area of flesh or tissue that is squeezed between a hard surface and a bony prominence. As the flesh is squeezed, the blood cannot reach the tissues and this causes a pressure injury (not broken, but painful and red). Eventually the tissues will die and turn black – this is a pressure ulcer.

People who are unable to get out of bed are at risk of developing pressure ulcers on their:

- Shoulders or shoulder blades
- Elbows
- Back of the head
- Rims of the ears
- Ankles, heels or toes
- Spine
- Tail bone (the small bone at the bottom of your spine)

Wheelchair users, or those who sit in a chair for most of the day, are at risk of developing pressure ulcers on:

- Their buttocks
- The back of their arms and legs
- The back of their hip bone

People are more at risk of pressure ulcers if they have:

- Reduced mobility or immobility
- Sensory impairment
- Acute illness
- Low level of consciousness
- A history of skin damage
- Malnutrition
- Additional health issues such as diabetes or obesity, or if they are old

Pressure ulcers are graded due to their severity. The most common system is the EPUAP (European Pressure Ulcer Advisory Panel) where the higher the number, the more severe is the injury to the skin and underlying tissue (see what to look out for page 90).

These injuries are easily avoided with appropriate support.
What to look out for

• **Grade 1** – This is the most superficial type. The affected area of skin becomes discoloured and becomes red on pale skin, and purple or blue in people with darker skin. The skin remains intact but may hurt or itch. It may feel either warm and spongy or hard.

• **Grade 2** – some of the outer surface of the skin (the epidermis) or the deeper layer of skin (the dermis) is damaged leading to skin loss. The ulcer looks like an open wound or blister.

• **Grade 3** – skin loss occurs through the entire thickness of the skin. The underlying tissue is also damaged. The underlying muscle and bone are not damaged. The ulcer appears as a deep cavity like wound.

• **Grade 4** – This is the most severe. The skin is severely damaged and the surrounding tissue begins to die. The underlying muscles and bone may also be damaged.

There is a high risk with a grade 4 of developing a life threatening infection.

Actions to take

• Repositioning – make sure that individuals at risk have regular changes to their position. If a pressure area has already developed, regularly (at least every two hours) changing the position avoids putting further pressure onto the affected area and gives the wound the best chance of healing.

• A major contributor to pressure sores is shearing. This occurs when pressure and friction combine. An example of this is when a person slides across a bed and the skin folds over on itself. It is extremely important when moving somebody to make sure that their whole body is supported, and that nothing is left ‘dragging’.

• Contact the GP who will liaise with the district nurse. Treatment will depend on the severity of the pressure area.

• District nurse and/or occupational therapist may access specialist equipment such as mattresses, pillows.

• All pressure ulcers graded as two and above must be reported to the local community health team.

• **A CQC notification under regulation 18, outcome 20 of essential standards of quality and safety must be made for all pressure ulcers graded 3 and above.**

• Risk assessments and support plans are reviewed and in place.

Ongoing monitoring

• Repositioning as above.

• Equipment – selecting appropriate equipment, such as mattresses and cushions. Again these should be sourced through the district nurse or OT.

• Nutrition – Eating a healthy, balanced diet that contains an adequate amount of protein and a good variety of vitamins and minerals can help prevent skin damage and speed up the healing process.

• Regular reviews of risk assessment.

Useful websites

www.judy-waterlow.co.uk  www.nice.org.uk  www.ihi.org
Men’s health

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94 Testicular lumps or swelling
96 Prostate cancer
Did you know?

People with a learning disability are 54 times more likely to die before the age of 50 than the general population.
Evidence suggests fewer men go to the GP, dentists or ask the pharmacist for advice and information than women. The result being that men are more likely to end up in hospital because they delay for so long.

They are more likely to:

• Try to “tough out” illness.
• Give priority to work commitments over treatment and rest.
• Fear the consequences of illness and disease.
• Be embarrassed at having to discuss symptoms in general and have examinations.
• Have a self-image that encourages them to deny illness – illness equals weakness.

They are less likely than women to:

• Be prepared to discuss their health.
• Realise doctors are also there for prevention and can discuss age appropriate screening.
• Have an established relationship with a doctor or nurse, as many women are used to going for regular smear tests and contraception.

Men may also lack awareness regarding health issues. For example, high cholesterol levels or high blood pressure may have no symptoms, but can lead to a stroke. Similarly, raised blood sugars may not be noticeable but can be a sign of diabetes.

This means that we need to be observant when delivering support and supportive when assisting them to access healthcare professionals.

It should also be explained that when carrying out personal hygiene (if they are able to do this themselves) this is a good time to check for signs of certain issues.
Testicular lumps or swelling

Background
The testicles are part of the male reproductive system. They produce sperm and testosterone (male sex hormone). The testicles sit inside a loose sac of skin known as the scrotum, which hangs down behind the penis.

Testicular lumps and swellings can have many different causes. In rare cases, they can be a sign of testicular cancer. However, most lumps are not related to cancer.

What to look out for
A lump or swelling on one or both testicles.

Severe pain in the testicle and other symptoms that could include:
- Swelling of the scrotum
- Nausea (feeling sick)
- Vomiting
- Abdominal (tummy) pain
- A low grade fever
- A frequent need to urinate

These might indicate testicular torsion.

Actions to take
Pain relief to be offered where needed.

For testicular torsion (the cord that supplies the testicles with blood becoming severely twisted), dial 999 and make sure the sufferer is taken to hospital.

For other lumps and swellings, make an appointment with the GP who will ask whether the person has:
- Felt any pain – and if so, where it was, how severe it was and how long it lasted for.
- Any other symptoms, such as pain when they urinate (which is a sign of a urinary tract infection) or any discharge from the urethra (the tube that carries urine from the bladder).
- A history of trauma, such as a sports injury to the groin.

The GP will also physically examine the testicles.

If the GP cannot confirm a diagnosis from the examination, an ultrasound scan might be needed. This uses high-frequency sound waves to create an image of the inside of the body.

In some cases a patient may be referred to urology.

If there are issues regarding informed consent a best interest meeting might be needed.
Ongoing monitoring

- Make regular observations where possible and be aware of any changes.
- Encourage people to seek information from their GP regarding how to check themselves for any testicular lumps.

Useful websites

www.nhs.uk/Conditions/Testicular-lumps-benign/Pages/Introduction.aspx
www.macmillan.org.uk/Cancerinformation/Cancertypes/Testes/Testicularcancer.aspx
www.cancerresearchuk.org/cancer-help/type/testicular-cancer/
Prostate cancer

Background

The prostate is a small gland in the pelvis found only in men. About the size of a walnut, it is located between the penis and the bladder. It surrounds the urethra, the tube that carries urine from the bladder to the penis.

The main function of the prostate is to help in the production of semen. It produces a thick white fluid that is mixed with the sperm produced by the testicles, to create semen.

Common health issues relating to the prostate include it becoming enlarged, and prostate cancer.

What to look out for

The symptoms of prostate enlargement are caused by the enlarged prostate placing pressure on the bladder and urethra (which carries urine from the bladder to the penis).

This can affect urination in the following ways:

- Making it difficult to start urinating.
- Weaken the flow of urine, or cause "stopping and starting".
- The need to strain to pass urine.
- The need to frequently urinate.
- Cause someone to wake up frequently during the night to urinate.
- Cause a sudden urge to urinate, which can result in incontinence if unable to find a toilet quickly enough.
- Cause inability to empty the bladder fully.
- Cause blood in the urine (haematuria).
- In late stages, prostate enlargement can cause urine retention and other complications like bladder stones, bladder infections and damage to the kidneys.
Actions to take

Pain relief to be offered where needed.

All symptoms could also apply to someone who has prostate cancer, therefore it is important to get checked by a GP as soon as possible.

There is no single test for prostate cancer, so the GP will discuss the pros and cons of the various tests to try to avoid unnecessary anxiety.

The doctor is likely to:

• Ask for a urine sample to check for infection.
• Take a blood sample to test the level of prostate-specific antigen (PSA).
• Examine the prostate (digital rectal examination).

There is a chance that some individuals will need to complete a consent form prior to bloods being taken and a manual examination.

Ongoing monitoring

• Continual observations for any of the above signs and symptoms.

Useful websites

http://prostatecanceruk.org/
http://www.macmillan.org.uk/Cancerinformation/Cancertypes/Prostate/Prostatecancer.aspx
http://www.cancerresearchuk.org/cancer-help/type/prostate-cancer/
Women’s health

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Did you know?

Coronary heart disease is the second most common cause of death for people with a learning disability at 14-20%
Screening and health surveillance

It is very important that women are aware of and are receiving their routine health checks, such as cervical screening test (also known as a smear test, see box) and mammogram. These screenings are used to detect any changes or abnormalities to the body which may not necessarily at the time be cancer but may lead onto or develop into a cancer.

A woman's age or previous medical and family history will depend on how often they will receive these routine screenings.

CERVICAL SCREENING

Women are invited for routine cervical screening every three years between the ages of 25-50, and every five years between the ages of 51-65.

A cervical screening test is currently the most effective way to screen for cervical cancer. This is a way of preventing cervical cancer by detecting and treating pre-cancerous cell changes. If left untreated, these abnormal cells could develop into cervical cancer. There are circumstances where a screening test may not be the right thing to do. If a woman has such severe learning disabilities and no language, then she is unlikely to be able to give consent to having the test. This can make it very difficult for the people caring for her to make a decision about what is best for her. Under these circumstances, we would suggest that you ask each woman's GP for advice.
Breast screening

Background

Breast cancer is the most common cancer in the UK. Most women who get breast cancer are over 50, but younger women, and in rare cases, men, can also get breast cancer.

The exact causes of breast cancer are not fully understood, but many factors increase its likelihood, including age and a family history of breast cancer.

Women who have a higher-than-average risk of developing breast cancer may be offered screening and genetic testing for the condition.

The NHS Breast Screening Programme is aimed at women aged 50 to 70. If someone is registered with a GP they will automatically be invited for screening. The check takes place at a special clinic or mobile breast screening unit.

Abnormalities with the breast tissue may develop before this age or in-between screenings therefore it is important for women to get to know what is normal for their breasts so any changes can be detected and reported to a GP early.

What to look out for

The first symptom of breast cancer most women notice is a lump or an area of thickened tissue in their breast. Most lumps (90%) are not cancerous, but it is always best to have them checked by a doctor.

In order for changes to be picked up as soon as possible, it is important to be breast aware. Where possible encourage those in your support to get to know what is normal for them. For instance, breasts may look or feel different at different times of the month. This will make it much easier to spot potential problems.

You’re looking out for the following:

• A lump or area of thickened tissue in either breast.
• A change in the size or shape of one or both breasts.
• Discharge from either nipple (which may be streaked with blood).
• A lump or swelling in either armpit.
• Dimpling on the skin on the breasts.
• A rash on or around the nipple.
• A change in the appearance of the nipple, such as becoming sunken into the breast (inverted).
• Pain in either breasts or armpits not related to a period.
**Actions to take**

If there are any of the above symptoms make an appointment with the GP as soon as possible. The GP will carry out an examination and, if they think the symptoms need further assessment, make a referral to a specialist breast cancer clinic.

**Ongoing monitoring**

- **Lump** – may not be seen, but might be felt
- **Skin texture e.g. dimpling/ puckering**
- **Appearance or direction of nipple**
- **Nipple discharge**
- **Rash or crusting**

Where possible individuals should be encouraged to look out for changes themselves and to feel their own breasts to check what is normal and how lumps need to be checked. Most of the other indicators can be observed by staff during personal support.

Where possible, make an effort to find out someone's family medical history, as this could show an increased risk which would warrant them undergoing screening.

**Useful websites**

- [www.breastcancercare.org.uk/breast-cancer-information/breast-awareness](http://www.breastcancercare.org.uk/breast-cancer-information/breast-awareness)
- [www.macmillan.org.uk/Home.aspx](http://www.macmillan.org.uk/Home.aspx)
Menstruation (periods)

Background

Menstruation is a woman’s monthly bleeding, commonly known as periods. When someone menstruates, the body sheds the lining of the womb. Menstrual blood flows from the uterus through the small opening in the cervix and passes out of the body through the vagina.

When periods come regularly, this is called the menstrual cycle. Having regular menstrual cycles is a sign that important parts of the body are working normally. The menstrual cycle provides important body chemicals, called hormones, to keep healthy. It also prepares the body for pregnancy each month. A cycle is counted from the first day of one period to the first day of the next period. The average menstrual cycle is 28 days long. For the first few years after menstruation begins, longer cycles are common. A woman’s cycle tends to shorten and become more regular with age. Most of the time, periods will be in the range of 21 to 35 days apart.

The rise and fall of levels of hormones during the month control the menstrual cycle.

During a period, the thickened uterine lining and extra blood is shed through the vagina. Each period may not be the same every month. It may also be different than other women’s periods. Periods can be light, moderate, or heavy in terms of how much blood comes out of the vagina. This is called menstrual flow. The length of the period also varies. Most periods last from three to five days. But, anywhere from two to seven days is normal.

What to look out for

What kinds of problems do women have with their periods? Women can have a range of problems with their periods, including pain, heavy bleeding, and skipped periods.

Amenorrhea

The lack of a menstrual period. This term is used to describe the absence of a period in:

• Young women who haven’t started menstruating by age 15.
• Women and girls who haven’t had a period for 90 days, even if they haven’t been menstruating for long.

Causes can include:

• Pregnancy
• Breastfeeding
• Extreme weight loss
• Eating disorders
• Excessive exercising
• Stress
• Serious medical conditions in need of treatment

Menstruating regularly means that important parts of the body are working normally. In some cases, not having menstrual periods can mean that the ovaries have stopped producing normal amounts of oestrogen. Missing these hormones can have important effects on overall health. Hormonal problems, such as those caused by polycystic ovary syndrome (PCOS) or serious problems with the reproductive organs, may be involved. It’s important to talk to a doctor if this is the case.
Dysmenorrhea

Painful periods, including severe cramps. Most teenagers with dysmenorrhea do not have a serious disease, even though the cramps can be severe. In older women, the pain is sometimes caused by a disease or condition such as uterine fibroids or endometriosis.

For some women, using a heating pad or taking a warm bath helps ease their cramps. Ibuprofen and paracetamol over-the-counter pain relief is usually sufficient to control period pains.

If these don't relieve the pain, advice should be obtained from a doctor. Treatment depends upon what's causing the problem and how severe it is.

Abnormal uterine bleeding — vaginal bleeding that’s different from normal menstrual periods. It includes:

- Bleeding between periods
- Bleeding after sex
- Spotting anytime in the menstrual cycle
- Bleeding heavier or for more days than normal
- Bleeding after menopause

Abnormal bleeding can have many causes. A doctor may start by checking for problems that are most common in someone’s age group. Some of them are not serious and are easy to treat. Others can be more serious. Treatment for abnormal bleeding depends on the cause.

In both teens and women nearing menopause, hormonal changes can cause long periods along with irregular cycles. Even if the cause is hormonal changes, they may be able to get treatment. Keep in mind that these changes can occur with other serious health problems, such as uterine fibroids, polyps, or even cancer. See a GP if someone has any abnormal bleeding.

Actions to take

Contact a GP if:

- Menstruation has not started by the age of 15.
- Someone has not started menstruating within three years after breast growth began, or if breasts haven’t started to grow by age 13.
- Someone’s period suddenly stops for more than 90 days.
- Periods become very irregular after having had regular, monthly cycles. However if the person is over the age of 50, this could be symptomatic of the menopause.
- Someone’s period occurs more often than every 21 days or less often than every 35 days, if this is not normal for them.
- Someone is bleeding for more than 10 days.
- The bleeding is heavier than usual or using more than one pad or tampon every one to two hours.
- There is bleeding between periods.
- Someone has severe pain during their period.
- Someone suddenly gets a fever and feels sick after using tampons.
**Ongoing monitoring**

It’s useful to have a general knowledge of an individual’s ‘normal’ monthly cycle, if any changes are noticed then a menstrual cycle chart could be commenced to further monitor cycles. This will provide more information for a GP.

If someone is displaying severe signs of pain and usual pain relief does not work also refer them to their GP.

**Useful websites**

www.nhs.uk/chq/Pages/984.aspx?CategoryId=60&SubCategoryId=182

http://www.patient.co.uk/health/vaginal-discharge-and-vaginal-bleeding
Menopause

Background
The menopause, also known as the ‘change of life’ is the end of menstruation. This means a woman’s ovaries stop producing an egg every four weeks. She will no longer have a monthly period or be able to have children.

In the UK, the average age for a woman to reach the menopause is 52 years of age, although women can experience the menopause in their 30s or 40s. If a woman experiences the menopause when she is under 45 years of age, it is known as a premature menopause.

Menstruation (monthly periods) can sometimes stop suddenly when you reach the menopause. However, it is more likely that your periods will become less frequent, with longer intervals in between each one before they stop altogether.

What to look out for
The menopause is caused by a change in the balance of the body’s sex hormones. In the lead up to the menopause oestrogen levels decrease, which causes the ovaries to stop producing an egg each month (ovulation). Oestrogen is the female sex hormone that regulates a woman’s periods.

The fall in oestrogen also causes both physical and emotional symptoms including:

- Hot flushes and night sweats
- Loss of libido (sexual desire)
- Vaginal dryness and pain, itching or discomfort during sex
- Palpitations (changes in heart rate)
- Headaches
- Mood changes, such as depression, anxiety or tiredness
- Sleeping problems, such as insomnia
- Urinary tract infections

Actions to take
Speak to the GP to make sure the symptoms which someone is experiencing are definitely caused by the menopause.

Although there is no definitive test to diagnose the menopause, a blood test to measure the level of follicle-stimulating hormone (FSH) may sometimes be recommended.

Ensure that the menopause is explained to the individual concerned and that what they may be feeling is normal.

Medication may not be necessary if someone has reached the menopause and there are no severe symptoms.

Many women are able to ease their menopausal symptoms by making simple changes to their lifestyle and diet.
For some people the menopause might cause new behaviours (such as someone taking their clothes off, which could be because they are having hot flushes) or an increase in challenging or self-injurious behaviour (possibly due to changes in someone’s mood). If this is the case, follow the advice on page 107, then if it continues discuss with the GP or psychiatrist.

Hormone replacement therapy (HRT) is effective in treating a number of the most common menopausal symptoms, including hot flushes and night sweats, vaginal symptoms and urinary tract infections, such as cystitis.

In the long-term, HRT can also reduce the risk of osteoporosis (weak and brittle bones) and combined HRT can reduce your risk of developing bowel cancer, however it can be linked to an increased risk of developing breast cancer.

As well as HRT, antidepressants can be prescribed to stabilise someone’s mood, and vaginal lubricants to ease vaginal dryness.

Coping with the menopause

To improve hot flushes and night sweats:
• Take regular exercise
• Wear light clothing
• Keep bedroom cool at night
• Try to reduce stress levels
• Avoid potential triggers, such as spicy food, caffeine, smoking and alcohol

To improve sleep problems:
• Avoid exercising late in the day
• Go to bed at the same time every night

To improve mood changes:
• Get plenty of rest
• Take regular exercise
• Try relaxation therapies, such as yoga or tai chi
Ongoing monitoring

If someone is taking HRT, they will need to return to their GP for a follow-up review three months after starting the treatment and once a year after that. At the three month review the GP will:

- Make sure symptoms are under control.
- Ask about any side effects and bleeding patterns.
- Check blood pressure and weight.

At the annual review the GP will:

- Review the type of HRT they are taking and make any necessary changes.
- Discuss breast self-examination.
- Remind them about the benefits and risks of HRT.

If they are using non-HRT treatments, they will need to return to the GP for a review at least once a year. If the symptoms have stopped after one or two years of treatment, the GP may suggest they stop treatment.

It is useful to monitor symptoms, side effects and weight so the GP can see the records.

Useful websites

www.nhs.uk/Conditions/Menopause/Pages/Introduction.aspx
http://www.easyhealth.org.uk/listing/menopause-(leaflets)
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