NHS
Surrey and Sussex

STOP ▸ LOOK ▸ CARE

Adults



Supporting you to deliver great care for adults

This booklet is the property of:

If found, please contact:

Other important contact details:

- Home Manager/Owner:
- Community Matron:
- GP:
- Health Protection Team:

UKHSA Surrey and Sussex HPT (South East)
County Hall North, Chart Way
Horsham
West Sussex
RH12 1XA

Telephone: 0344 225 3861
Including out of hours for health professionals requesting urgent advice
Email: SE.AcuteResponse@ukhsa.gov.uk

Local Policy/SOP location:

Local escalation process:

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Supporting you to deliver great care

This booklet is designed for Care Workers, Carers, Support Workers, Personal Assistants, Shared Lives workers and family members who support people with clinical needs. It can also be used as a reference guide to increase awareness of issues of concern and encourage a referral if concerns are identified.

Care Workers / Carers are in the ideal position to identify changes in a person's condition by monitoring them and/or recognising any deterioration in a person's wellbeing. For the purposes of the publication, we will use the term carers throughout.

This booklet highlights:

- Why different aspects of observation and care are important?
- What to look for?
- What action to take?

Always consider in your actions:

Communication | Mental Capacity Act | Reasonable Adjustments | Observations/ Statistics | SBARD

Use of Tools:

In Sussex, we highly encourage using **Restore 2** for monitoring individuals under your care and supplemented with other tools specific to the individual's condition or risk assessment.

The actions are colour coded like a traffic light system providing a **STOP LOOK CARE** approach:

- **GREEN - ACTION: Continue to support and monitor using appropriate tools, give advice/ signpost to information and document observations.**
- **ORANGE - ACTION: follow local escalation, provide close monitoring, additional support, intervene within your scope and document.**
- **RED - ACTION: Seek further support from other services using SBARD tool, closely monitor and provide intervention. Document.**

Refer to page 4 for, 'Are you concerned about a person?

REMEMBER: Always **DOCUMENT** observations, actions or interventions, including advice given.

We have taken every care to create content for this booklet and ensure it is accurate. However, the material is intended to only provide general information and is not intended to be regarded as a substitute for medical advice, which you would normally receive from your GP or any other healthcare professional.

If you are concerned about a person's health, please follow your local escalation process, contact the appropriate healthcare services (e.g. NHS 111) or encourage the person to seek medical help themselves.

Are you concerned about a person?

***Please check Anticipatory Care Planning, if a person has one, before ringing**



Adult Social Care

Consideration of personal social care needs and eligibility as outlined in the Care Act (2014)

Help to source appropriate services to help support the cared for person.

West Sussex County Council Adult Social Care, CarePoint: 01243 642121

East Sussex Adult Social Care: 0345 6080191

Brighton & Hove Council, Adult Social Care, Access Point: 01273 295555

Surrey County Council, Adult Social Care: 0300 200 1005

For other useful contacts, see dedicated Adult Safeguarding and Learning Disability pages.



Local Community Pharmacy

Advise, recognise and treat common illnesses

- Minor skin conditions
- Coughs and colds
- Bruises, sunburn and minor burns
- Constipation and piles
- Hay fever
- Aches and pains, including earaches, headaches, migraines and back pain
- Vomiting, heartburn, indigestion, diarrhoea and threadworm
- Period pain
- Head lice
- Conjunctivitis
- Nappy rash and teething
- Warts and verruca



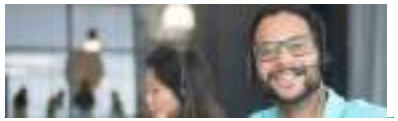
GP/ Paramedic Practitioners / Nurse Practitioners

Available on telephone advice during surgery hours and surgery appointments

- General medical concerns
- Medication concerns
- On-going medical/ psychiatric problems
- GP Out of Hours

Mon-Fri 6:30pm-8am

Weekends and Bank Holidays - call NHS 111



NHS 111

Medical help that is not for a 999 emergency, which could include:

- Unwell person (not normal to person)
- Breathing problems
- Worsening confusion Worsening pain
- Need health information

Note: Where known to ECHO, Hospice or MacMillan – please contact these services first.

For medication issues, please contact your community pharmacy before contacting the above services.



999

For life-threatening emergencies, 24 hours

- Signs of a heart attack; Chest pain
- Choking
- Fitting (new or prolonged)
- Severe breathing problems
- Sudden swelling of lips, mouth, throat or tongue - Anaphylaxis
- Signs of a stroke
- Sudden confusion (delirium)
- Unconscious
- Severe loss of blood
- Diabetic emergency (Hypoglycaemia with other symptoms such as drowsiness, or Hyperglycaemia with increased thirst and urination)
- Head injury – on anticoagulant medication

SBARD tool

When action is needed or if you need to contact a health professional, use this chart to help you remember all the important information to tell them:

S Situation	• I am a carer (Name, say if you are a registered professional) working for (Organisation). • I am calling about (Name, DOB) • I am calling because I am concerned that / unsure about / need advice NEWS score if available • What happened? • How are they? • NEWS score if available
B Background	• Their normal condition is (e.g. alert / drowsy / confused / abilities / usual activities of daily living / level of learning disability) • How has this changed? • Their relevant history includes (e.g. asthma, dementia, ischaemic heart disease) Current medications include (e.g. x, y, z)
A Assessment	• I have found that they are (e.g. struggling to breathe / walk / has pain / has injured / confused) Vital signs if equipment available (e.g. blood sugar, temperature, blood pressure, pulse) I think the problem is / may be • **OR** I don't know what's wrong but I'm really worried
R Recommended	• I now need your assistance • I would like you to visit the person (when is it urgent or routine?) I would like your advice as to what to do next / in the meantime
D Decision	• We have agreed that the following decisions were made and the following action(s) that will now be taken • I will record the decision and action in the service users/patients record or communication sheet Record decision and action where appropriate

SBAR was developed for healthcare by Dr M Leonard and colleagues from Kaiser Permanente in Colorado, USA

First Aid and Resuscitation

It is of utmost importance that carers familiarise themselves in advance with the Advance Care Plan and Legal Directives of the individual/s under their care.

Resuscitation Council UK - Lifesaver, collection of interactive film on resuscitation skills.

1. Before initiating resuscitation or escalation:

Check for documented treatment decisions, including:

- ReSPECT form or,
- DNACPR / DNAR / DNR orders **(does NOT apply to choking unless specified)**
- Advance Decision to Refuse Treatment (ADRT)
- Advance Statements or Directives

Ensure the document is:

- Valid and applicable to the current situation
- Accessible (paper copy, electronic record, care plan folder, bracelet/identifier)

Understand that:

- A **DNACPR applies only to CPR**, not to other first aid or comfort measures
- ADRTs are **legally binding** if valid and applicable

When in doubt and documentation is not immediately available, act in the person's **best interests** while seeking clarification as soon as possible.

See dedicated Mental Capacity Act and for Advance Care Plan / ReSPECT pages for further information.

2. Act Within the **Scope of First Aid and Duty of Care**

- Provide **immediate, proportionate, and appropriate care** until the person recovers, or responsibility is transferred to a more qualified healthcare professional
- Do not exceed your training or competence.

3. Ensure **Personal and Scene Safety**

4. Maintain competence, **be up to date with accredited training**.

5. Familiarise yourself in advance with the **location and use** of the nearest equipment, e.g.:

  - Emergency kit
  - Medication – also check if person is carrying medication (e.g. Adrenaline self-injector or Epi-pen,
  - Automatic External Defibrillator (AED)
  - Face shield or pocket mask
  - Clean gloves (protect carers and can be used to cover wound to protect from infection
  - Bandage and splints

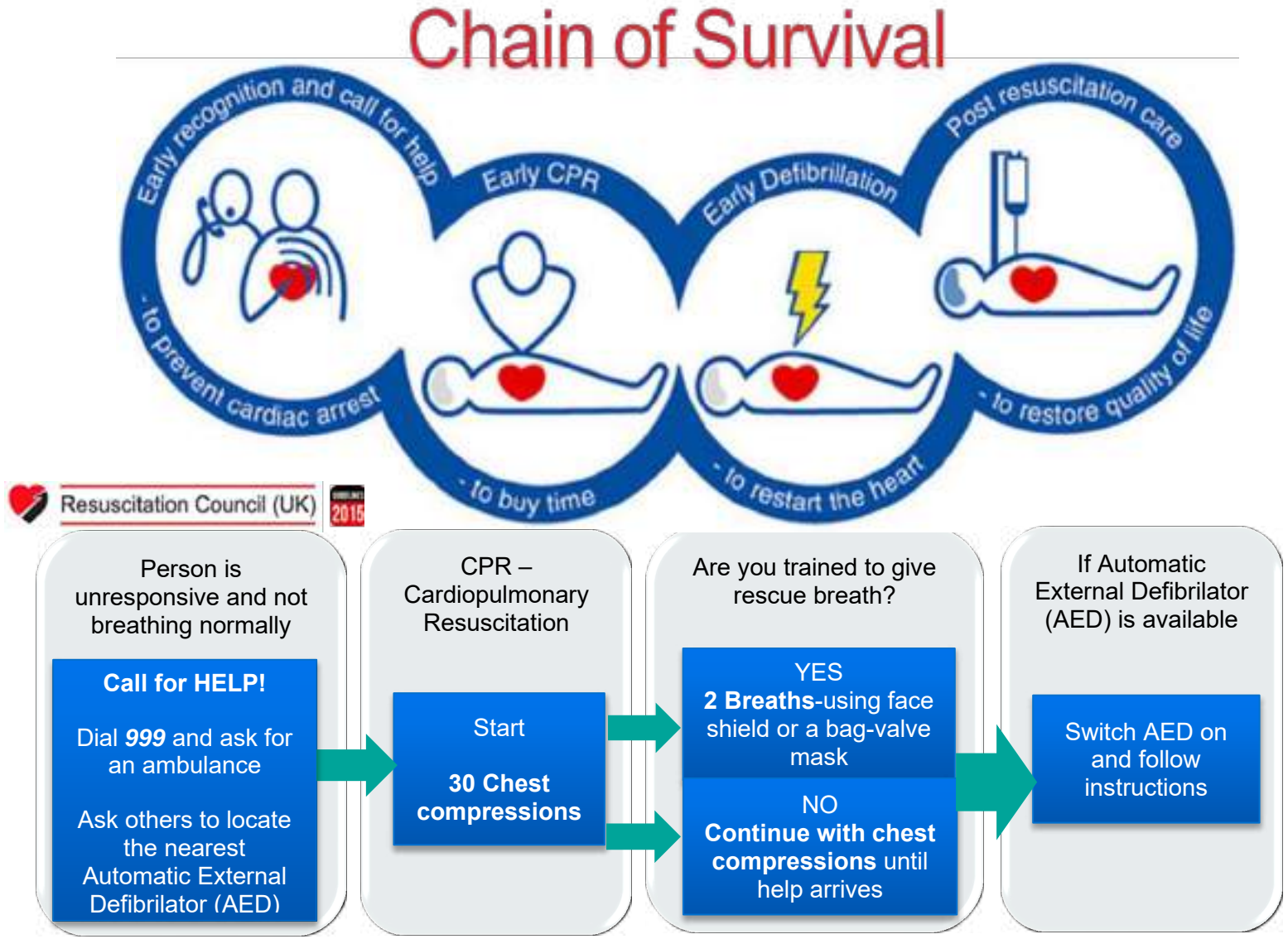
6. Prioritise **Early Recognition** and **Timely Escalation**

7. **Call or shout for HELP!** Promptly. Dial **999** when required.

8. Deliver Care with **Dignity, Compassion, and Respect**

- Reassure the person and explain what you are doing where possible.
- Respect privacy and cultural or personal preferences.
- If death is expected and documented, focus on **comfort, dignity, and support**, not futile intervention.

Adult Basic Life Support (ABLS) (1/2)



More information can be found in: [Resuscitation Council UK]

Adult Basic Life Support (ABLS) (2/2)

- Before initiating resuscitation, ensure that there is not a decision regarding ‘Do Not Attempt Cardiopulmonary Resuscitation (DNA CPR)’ in the person’s Advanced Care Plan (ACP). See dedicated page for ACP.
- Emergency plans must consider the person’s physical ability and presentation to receive CPR. This would include the management of wheelchairs in an emergency.
- Be up to date with your **ABLS training.**
- Familiarise yourself **in advance** with the location of the nearest Automatic External Defibrillator (AED).
- Rescuers who have not been trained to give rescue breaths using a face shield or pocket mask should do compression-only CPR as this can still help save a life.
- Rescuers who have been trained **should** perform chest compressions **and** rescue breaths, as this can provide additional benefit for children and those who have sustained a cardiac arrest due to not being able to breathe e.g. airway obstruction, choking, drowning and depressed respiratory drive.



Choking

The following information is for choking in adults. There is separate advice on how to stop a child from choking.

Mild choking – Encourage to cough. If coughing doesn't work, start back blows. Airway is only partly blocked, the person will usually be able to speak, cry, cough or breathe.

Severe choking – Start back blows. The person won't be able to speak, cry, cough or breathe, and without help they'll eventually become unconscious.



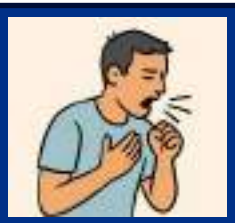
Guidance on Choking

British Red Cross:
Choking: First aid steps and key action

What if the person has a Do Not Attempt CPR (DNACPR) order?

Unless it is written that they do not want CPR even if choking, **start CPR**. A DNACPR recommendation does not apply unless it clearly includes choking.

Choking (continuation)



Step 1:
Encourage coughing



Step 2: Bend them forward and give up to 5 back blows



Step 3: If they are still choking, give up to 5 abdominal thrusts



Step 4: If they are still choking, **call 999**



Step 5: If they become unconscious, call 999 and start chest compressions

How to do back blows
To help an adult or child over 1 year old:

1. Stand behind the person and slightly to one side. Support their chest with 1 hand. Lean the person forward so the object blocking their airway will come out of their mouth, rather than moving further down.
2. Give up to 5 sharp blows between the person's shoulder blades with the heel of your hand (the heel is between the palm of your hand and your wrist).
3. Check if the blockage has cleared.

Do not give abdominal thrusts to babies under 1 year old or to pregnant women.

To perform abdominal thrusts on a person who is severely choking:

1. Stand behind the person who is choking.
2. Place your arms around their waist and bend them well forward.
3. Clench 1 fist and place it just above the person's belly button.
4. Place your other hand on top of your fist and pull sharply inwards and upwards.
5. Repeat this up to 5 times.
6. The aim is to get the obstruction out with each chest thrust, rather than necessarily doing all 5.

If the person's airway is still blocked after trying back blows and abdominal thrusts:

1. Call 999 and ask for an ambulance. Tell the 999 operator that the person is choking.
2. Continue with the cycles of 5 back blows and 5 abdominal thrusts until help arrives.

The person choking should always be seen by a healthcare professional afterwards to check for any injuries or small pieces of the obstruction that remain.

Epilepsy

Epilepsy is a common condition that affects the brain and causes seizures.

There are different types of epileptic seizures. How a seizure affects one person might be different from how it affects someone else.

If you support someone with epilepsy, ensure that you are familiar with the person's seizures and epilepsy guidance/care plan, and have the appropriate knowledge and training required.

If you care for someone with epilepsy, the things you do to support them may include:

- Keeping them safe during a seizure
- Calling for medical help, or giving first aid or emergency medication
- Staying with them or seeing them home safely after a seizure
- Noting any pattern or trigger to their seizures, which may help if they don't recall their seizures
- Helping with their routine of taking anti-seizure medication (ASM)
- Going with them to appointments, helping to take notes, or providing descriptions of seizures to the person with epilepsy and/or their doctor
- Acting as a representative or advocate for the person, with their doctors or others involved in their care
- Joining in with leisure activities that might pose a safety risk if they were to have a seizure, such as swimming
- Providing transport if necessary
- Helping them to adapt their home or lifestyle to provide a safe living environment.

The person's seizures are what is normal for them. They are well controlled and they are in good health.

▶ **Ensure Advanced or Treatment Care Plan is current and familiarise the management around 'Epilepsy at End of Life'** when people are less able / refuse to take or are no longer able to take oral medications, equally those affected by a cognitive condition such as Advanced Dementia.

▶ **Continue to monitor and document observations.**

Ensure the person is appropriately supported during and after the seizure. Ensure all seizure details are recorded. Check that there are no underlying health issues, such as infection.

▶ **Monitor closely during a seizure.**

▶ **Seek urgent GP/medical support if a person's seizures are not what is normal for them. Support during and after seizure episode.**

▶ **Call 999 for an ambulance if someone:**

- is having a seizure for the first time
- has a seizure that lasts more than five minutes
- has lots of seizures in a row
- has breathing problems or has seriously injured themselves

More epilepsy information can be found on the Epilepsy Society website: **epilepsysociety.org.uk**

SUDEP and Seizure Safety Checklist Register for the checklist here: **sudep.org/checklist**

The SUDEP and Seizure Safety Checklist is a risk factors checklist based around a person with epilepsy (PWE), demographics, seizure, physical, psychological and lifestyle issues.

Recognising a deteriorating person (continuation)

A ‘deteriorating person’ is someone whose condition is worsening from their normal baseline that increases their risk of harm and of a worsening outcome (e.g. organ failure or death). Early identification, escalation and intervention are crucial to prevent serious adverse events and avoidable deaths.

Key elements in recognising a deteriorating person:

Shifting from Baseline

Establish what is normal for the person in your care.

Physiological Changes

Worsening vital signs or observations (NEWS2 tool) are key indicators.

If you don't perform physiological observations, please use "Soft Signs".

"Soft Signs"

Subtle changes in breathing, behaviour and habits, mood, sleep, appetite, mobility, urination or defecation can be identified before significant physiological changes occur. (see next page for guidance).

Person/Family/Friends Concerns

Any reported concerns should be taken seriously and acted upon as people closest to the person in care may be the first to notice changes that could be an early sign of deterioration.

Person in care should be asked, at least daily, how they are feeling and if they are getting better or worse, and this information should be acted on in a structured way.

Continuous assessment, both visually and audibly, of people being cared for is a really important skill. Check what is normal for this person and if they have any changes in the areas listed on the **deteriorating person monitoring tool**, ask more probing questions, escalate and document changes.



Recognising a deteriorating person (continuation)

Symptoms match their documented baseline or what is normal for them and are managed according to clinician's instructions, including for any pre-existing conditions.

Check that an Anticipatory Care Planning is in place

▶ **Document observations and continue to monitor.**

If changes in symptoms are an expected deterioration, and a plan is in place,

- Ensure the person is appropriately supported during and after episodes and details are recorded.
- Check that there are no underlying health issues, such as infection.

▶ **Follow plan, closely monitor, support and document.**

▶ **Seek urgent senior and GP/111 support if a person's symptoms are not what is normal and expected for them:**

- Any new symptoms – Also, check actions on **NHS Conditions A-Z**
- Any change or increase in severity of symptoms
- Abnormal observations

Call 999 for NEW ONSET of:

- Stroke (facial/arm weakness, speech problems)
- Central chest pain / Heart attack / Cardiac arrest
- Severe breathlessness

**See page 5 for other conditions or dedicated 'Are You Concerned About a Person' page*

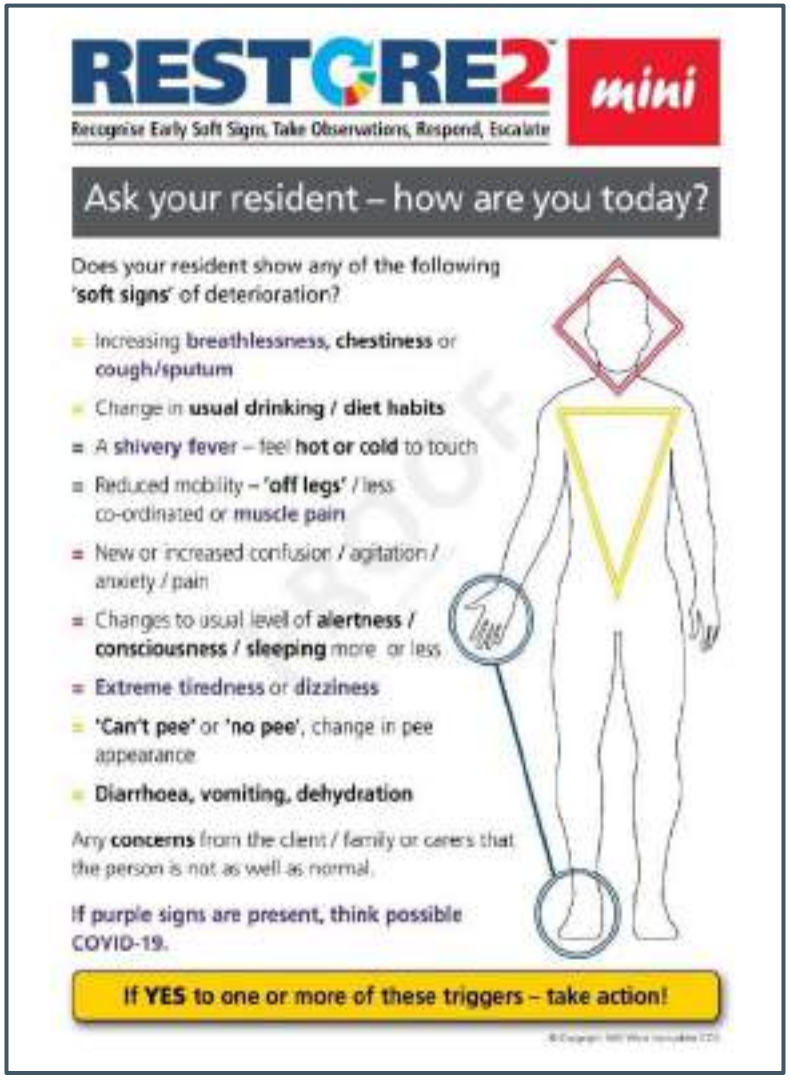
Training is available at: E-learning for healthcare: Recognising and managing deterioration

Video compilation: NHSE Managing Deterioration using NEWS

Restore 2 Tools

Recognise Early Soft Signs, Take Observations, Respond, Escalate

In Sussex, we highly recommend using Restore 2 Tool. This is a physical deterioration and escalation tool for care/nursing homes developed by Hampshire and Isle of Wight ICB and is free to use to all health and care settings. It combines recognising soft signs of deterioration (including sepsis) with formal physiological observation and a National Early Warning Score (NEWS2) to determine person's level of unwellness/illness.



If you answer **YES** to any of these triggers, your resident is at risk of deterioration.
If purple signs are present, think possible COVID-19

RECOGNISE SOFT SIGNS OF POSSIBLE DETERIORATION → **TAKE COMPLETE SET OF OBS AND CALCULATE NEWS** → **ESCALATE USING ESCALATION TOOL AND SBARD**



Restore2 Mini is a condensed version – ideal for introducing care and residential homes that are *currently unable to measure vital signs*. It is designed to act as a steppingstone to the *adoption of the full Restore2 tool*. It's also recommended to keep by the telephone /computer to support staff to communicate effectively.

Training and resources plus the full Restore2 and Restore2 Mini are available to download via this QR code or link:

Restore 2 official website

GREEN ACTION – Carry on as normal: monitor & document

ORANGE - ACTION – Closely monitor and provide additional support

RED - ACTION - Seek further support and advice

SEPSIS on Sepsis Trust

Sepsis is a life-threatening condition where the body has an extreme reaction to an infection. Sepsis can happen very quickly and lead to shock, multiple organ failure and death especially if not recognised early and treated promptly.

Document is available to download: [SEPSIS Trust Community Toolkits +16]

How do I spot sepsis?

Sepsis can initially look like other illnesses like flu or gastroenteritis and can be difficult to spot.

There is no one sign, and symptoms can present differently in adults and children.

[A Public Sepsis Assessment Tool] – is available to help assess the risk of sepsis, endorsed by The UK Sepsis Trust.



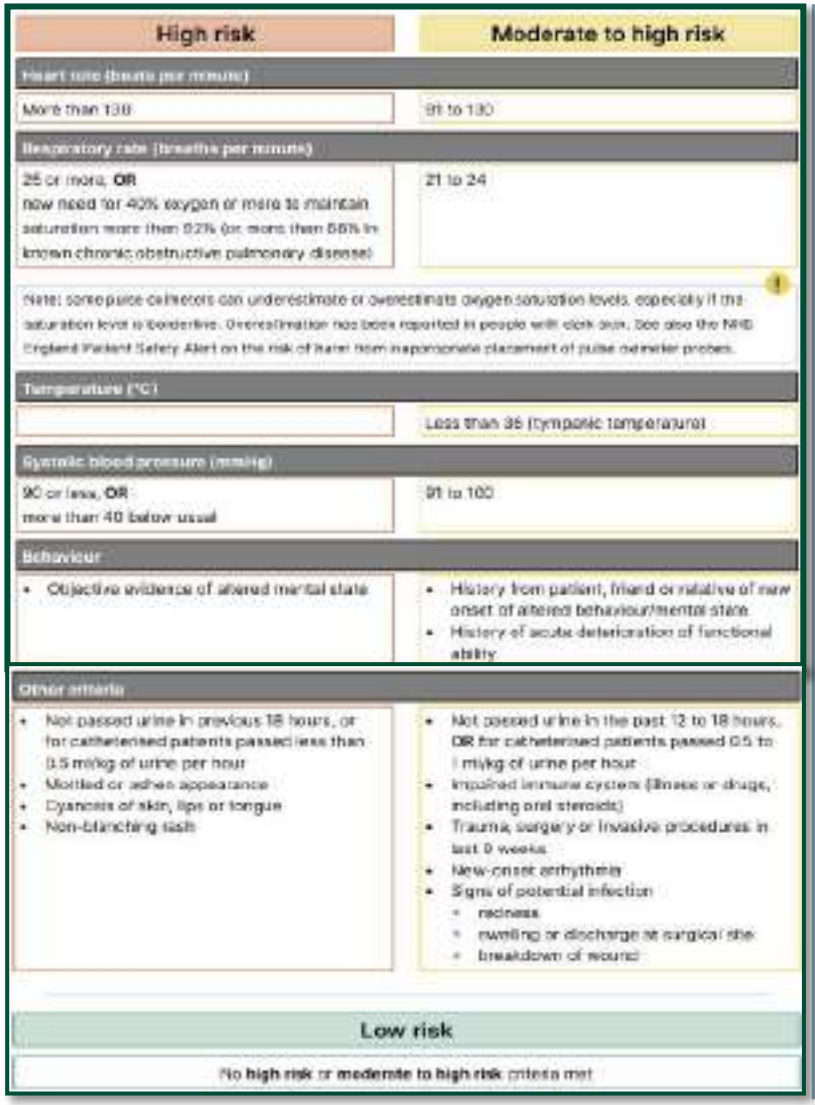


NICE NG253 Guidance on Suspected Sepsis

Evaluation Risk and Management for +16 (not pregnant) in the Community

Includes trauma, surgery or invasive procedures in the last 6 weeks on assessment for Moderate – High risk suspicion of sepsis

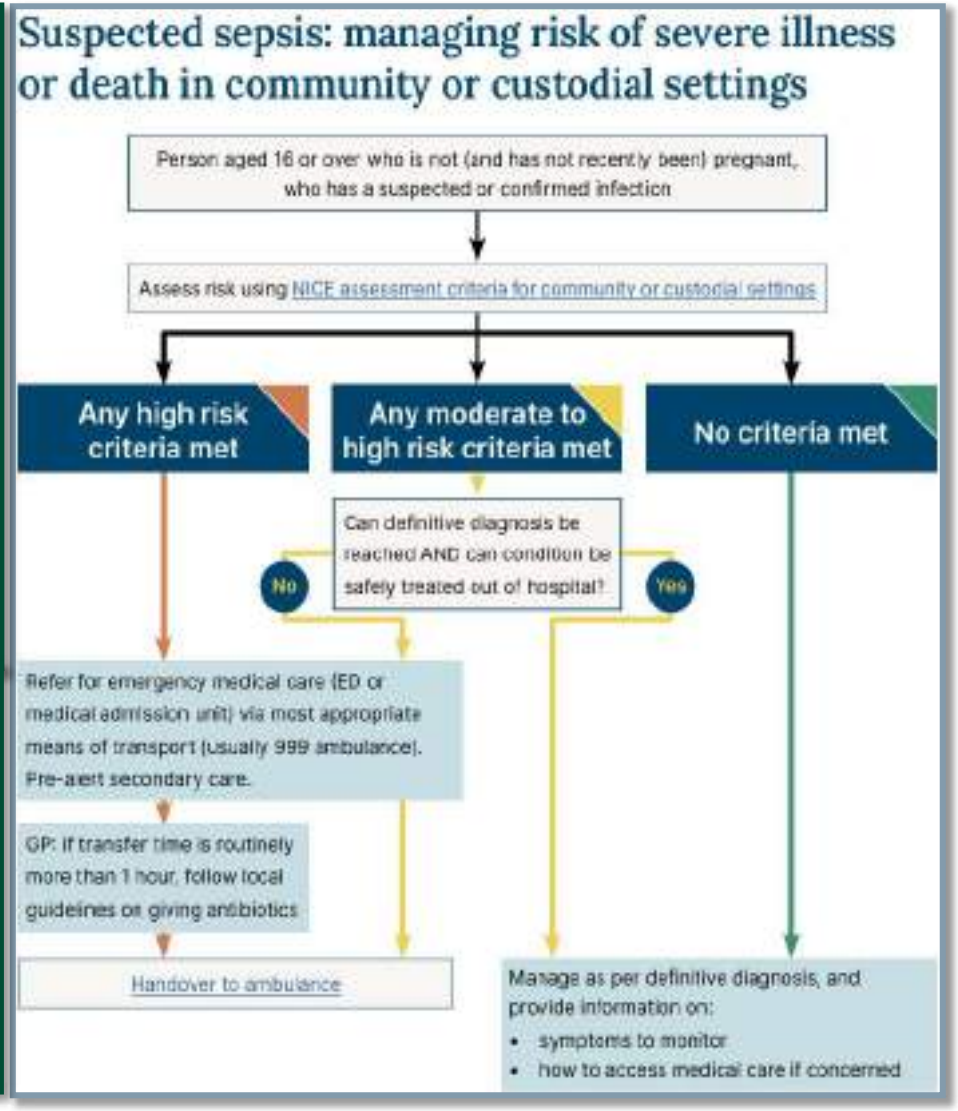
Documents available to download:
[NICE NG253 Guidance]



High risk	Moderate to high risk
Heart rate (beats per minute)	
More than 130	91 to 130
Respiratory rate (breaths per minute)	
25 or more, **OR** new need for 40% oxygen or more to maintain saturation more than 92% (or more than 88% in known chronic obstructive pulmonary disease)	21 to 24
Note: some pulse oximeters can underestimate or overestimate oxygen saturation levels, especially if the saturation level is borderline. Overestimation has been reported in people with dark skin. See also the NHS England Patient Safety Alert on the risk of harm from inappropriate placement of pulse oximeter probes.	
Temperature (°C)	
	Less than 36 (tympanic temperature)
Systolic blood pressure (mmHg)	
90 or less, **OR** more than 40 below usual	91 to 100
Behaviour	
• Objective evidence of altered mental state	• History from patient, friend or relative of new onset of altered behaviour/mental state • History of acute deterioration of functional ability
Other criteria	

• Not passed urine in previous 18 hours, or for catheterised patients passed less than 0.5 ml/kg of urine per hour
• Mottled or ashen appearance
• Cyanosis of skin, lips or tongue
• Non-blanching rash
	• Not passed urine in the past 12 to 18 hours, **OR** for catheterised patients passed 0.5 to 1 ml/kg of urine per hour
	• Impaired immune system (illness or drugs, including oral steroids)
	• Trauma, surgery or invasive procedures in last 6 weeks
	• New-onset arrhythmia
	• Signs of potential infection
	  ◦ redness
	  ◦ swelling or discharge at surgical site
	  ◦ breakdown of wound

Low risk	
No **high risk** or **moderate to high risk** criteria met	



Frailty

Frailty is a complex clinical syndrome that affects primarily older adults but can also impact people with multiple health conditions and disability. It involves physical, cognitive, and psychosocial factors that require a holistic approach to address effectively.

Two Models of Frailty

Phenotype – defines frailty by the presence of three or more features – unintentional weight loss, weak grip strength, slow gait speed, self-reported exhaustion, and low physical activity.

Cumulative Deficit (Rockwood): defines frailty as a cumulative measure of disease, symptoms and disability. (see next page)

Frailty increases a person's vulnerability, where minor events like a fall or mild infection can cause serious health decline.

Frailty syndromes where clinical assessment may be required:

- **Falls** – collapse, legs giving way
- **Immobility** – sudden change in mobility
- **Delirium** – sudden change in levels of confusion
- **Incontinence** – change or worsening in continence
- **Medication** – change or increase in side effects

Supportive and Palliative Care Indicators Tool for healthcare professionals

Supporting self-care/prevention of frailty deterioration include:

- Maintaining physical activity can improve strength and balance.
- Eating a healthy diet and drinking enough fluids can help minimise the impact of frailty. Carers should check how much fluid people have had, particularly those dependent for support.
- Please see dedication Living Healthy and Living Well page for more health guidance.
- Raise Advance Care Planning (ACP) with individual. Please see dedication ACP page of the booklet.

Person fit and active, independent with most activities of daily living, washing, dressing, provision of food

▶ **Document observations and continue to monitor**

Person less fit and active, requires some support with activities of daily living, monitor and support in a person-centred way

▶ **Document as this enables better detection of increased frailty**

Change in person's level of independence; appears frailer or presenting with a frailty syndrome.

▶ **Seek urgent support and advice from GP or Community Nurse, intervene and document.**

Symptoms of frailty can have a simple explanation sometimes, but it's best to have the person reviewed if you are concerned about a change in their level of frailty.

Rockwood Clinical Frailty Scale

It is a toolkit to measure how frail someone is and can be used to monitor any deterioration.



1. **Very Fit** – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.



2. **Well** – People who have no active disease symptoms but are less fit than category 1. Often, they exercise or are very active occasionally, e.g. seasonally.



3. **Managing Well** – People whose medical problems are well controlled but are not regularly active beyond routine walking.



4. **Vulnerable** – While not dependent on others for daily help, often symptoms limit activities. A common complaint is being “slowed up”, and/or being tired during the day.



5. **Mildly Frail** – These people often have more evident slowing and need help in high order Instrumental Activities of Daily Living Scale (IADLs) (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.



6. **Moderately Frail** – People need help with all outside activities and with keeping house. Inside, they often have problems with stairs and need help with bathing and might need minimal assistance (cuing, standby) with dressing.



7. **Severely Frail** – Completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months)



8. **Very Severely Frail** – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.



9. **Terminally Ill** – Approaching the end of life. This category applies to people with a life expectancy. <6 months, who are not otherwise evidently frail.

Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia**, they cannot do personal care without help.

Rockwood et al 2005 K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005; 173:489-495.
© 2007-2009. Version 1.2. All rights reserved. Geriatric Medicine Research, Dalhousie University, Halifax, Canada.

Pain

Pain is a personal, individual and subjective experience that can greatly affect daily life, limiting movement and reducing quality of life. It can cause both physical discomfort and emotional distress. Recognising pain and communicating concerns to healthcare professionals is essential to reduce this distress.

Different types of pain:

- **Acute pain** – often starts suddenly and likely short-term. Infection, broken bone or after an operation
- **Chronic pain** – lasts longer than 3 months (commonly used clinical threshold)
- **Referred pain** – pain perceived at a site distant from the actual source
- **Phantom pain** – perceived where a body part is no longer present
- **Breakthrough pain** – often happens in between regular, scheduled painkillers
- **Total pain** includes the emotional, social and spiritual factors that affect a person's pain experience

Pain - NHS

Pain Assessment / Recognition:

- Carers need to take into consideration the **person's ability to express** their pain.
- It may be difficult for some vulnerable people to articulate their pain, for example those with learning disability, dementia, stroke or Parkinson's disease.
- Pain symptom manifests itself in many ways and carers should be able to recognise **verbal and non-verbal signs** (facial expressions and body language). **Changes in behaviour** may indicate pain.
- The most important element of assessment of pain is that it is a **functional assessment**.

This means that we assess the person's pain on appropriate activity e.g. when they are mobilising or if confined to bed when giving care. Always assess pain before giving pain relief and again about 1 hour later to check that it has had effect.

When the person has pain mainly on mobility/turning give pain relief about 1 hour prior to doing the activity.

Pain (continuation)

No verbal / non-verbal cues for pains. The individual appears settled and comfortable.

- Continue using pain monitoring tool, document observations and advice given.
- Teach pain relief techniques (e.g. deep breathing), assess need and availability of a pain relief medication in the event that the person may need them.

Person is verbalising or showing non-verbal signs of pain (in distress or discomfort).

- Ensure the person is appropriately supported during and after the episode.
- If appropriate, teach pain relief techniques and give pain relief medication.
- Ensure assessment and observation details are recorded. Check that there are no underlying health issues, such as infection.

Seek urgent GP or NHS 111 medical support if,

- Pain is not well controlled, please have the pain assessment data to hand, what pain relief is currently given and its effects as well as any side effects and discuss with the medical team.
- A person has chronic pain with a suspected musculoskeletal cause, speak to their GP and consider referral for a physiotherapy assessment.

Examples of Pain Assessment Tools

That intended to help identify distress cues in individuals who have severely limited communication. Use the same pain assessment tool within your organisation so that when you communicate your observations it is easily understood.

Wong – Baker FACES Pain Rating Scale Used from 3+, facilitating communication and improving assessment so pain management can be addressed.

Abbey Pain Scale is an NHS-utilized observational tool designed to assess pain in individuals with severe cognitive impairment or dementia who cannot communicate verbally. It measures pain across six areas—vocalisation, facial expression, body language, behavioral change, physiological, and physical changes—scoring from 0 to 18 to indicate pain severity (0-2: No Pain, 3-7: Mild, 8-13: Moderate, 14+: Severe).



Bolton Pain Assessment Scale

Developed by Bolton NHS Foundation Trust, the aim of the project was to identify and implement a pain assessment tool sensitive to the cognitively impaired patient.

DisDAT Assessment Tool

Short for Distress and Discomfort Assessment Tool was developed by St. Oswald's Hospice.

- Designed to describe an individual's usual content cues, thus enabling distress cues to be identified more clearly.
- Give carers confidence in the observation skills by documenting what many carers have done instinctively for many years thus providing record against which subtle changes can be compared.
- Once distress has been identified the usual clinical decisions have to be made by healthcare professionals.

Respiratory – Breathing

There are a number of different respiratory problems which can affect people, these include:

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Fibrosis

People with respiratory problems may require extra time, support, and patience with their activities of daily living, particularly activities which may cause them to become breathless.

Breathlessness can increase anxiety and confusion in some people, so being calm and understanding can help.

People may use inhalers, nebulisers and / or oxygen to support their breathing.

- Correct inhaler and nebuliser use can prevent exacerbations, which can potentially cause admissions to hospital.
- People should be using their oxygen and nebuliser as per their prescription, this should be written in their yellow folder in the oxygen section. If in doubt phone and check with respiratory team or GP.
- Nebuliser maintenance as per manufacturer's instructions is essential, otherwise they can lead to complications.
- Ask the GP or respiratory services about **referral to the Virtual Ward, or remote monitoring** to enable them to **get better at home,** and **avoid hospital admissions** when possible.

People will generally know what is normal for them. People can present as anxious, and more confused if breathless.

Breathing is within normal rate and depth for person.

Normal rate for a healthy adult is 12-20 breaths per minute.

Blood oxygen saturation is what is normal for person (should be established by clinician).

- **Encourage deep breathing and relaxation exercises.**
- **Continue with support, monitor and document observations.**

Know how to support persons with inhaler /nebuliser / oxygen if they require this, ensuring this is in line with their respiratory care plan.

- **Support and signpost to resources. See next page.**
- **Continue to monitor and document observations.**

Breathing is abnormal for person, above 20 or below 10 breaths per minute, appears breathless, they could have blue lips /nails.

- **Support with positioning to open airway and deep breathing technique.**
- **Administer rescue medicine if prescribed (e.g. reliever inhaler for asthma, EpiPen for severe allergic reaction or COPD rescue packs, etc.)**
- **Seek urgent medical support from GP or NHS 111, intervene and document.**
- **Consider calling 999 or got to A&E if severely breathless or breathless with chest pain.**

Pulseoxi

Blood oxygen saturation levels - tells us how well the person is breathing by checking how much oxygen is in the blood.

Target oxygen saturation:

- **94-98% For someone who's healthy**
- 88-92% Chronic hyperapnic respiratory failure, mostly seen in people with acute exacerbation of COPD, **should only be used the direction of a qualified clinician.**

[NHS: How to use a pulse oximeter at home]



Inhaler Technique

There are many different types of inhalers, below are some examples of how to use the main ones.

Asthma & Lung UK have videos which demonstrate how to use each type, these can be found on their website

asthma.org.uk/advice/inhalers-medicines-treatments/using-inhalers

Advice on how a person should use their inhalers

'Press and breathe' Metered Dose Inhalers (pMDIs) are often called 'puffers'.



- Shake the MDI inhaler, breathe out gently, then put the mouthpiece in your mouth and wrap your lips around it.
- Breathe in SLOW AND STEADY, press the canister down to release the medicine and continue to inhale deeply.
- Remove the inhaler from your mouth and hold your breath for up.
  to 10 seconds before breathing out slowly.
- Repeat process for second doses.

MDIs should be used with spacers. Spacers collect the medicine inside them, so you don't have to worry about pressing the inhaler and breathing in at exactly the same time. This makes these inhalers easier to use and more effective.

Encourage the person to 'Breathe in hard' Dry Powder Inhalers

(DPIs) release medicine in a very fine powder form instead of a spray



Accuhaler

- When they breathe in through the mouthpiece, they need to breathe in quite QUICK and DEEP to get the powder into their lungs.

Examples of DPIs include Accuhalers, Clickhalers, Easyhalers, Handihalers, Turbohalers, Diskhalers, Genuair and Twisthalers.

Breathe in normally 'breath actuated' inhalers are usually given to people who have difficulty using a standard 'puffer.'



- These inhalers are activated by your breath, so when you breathe in SLOW and STEADY through the mouthpiece, it releases the medicine in a fine spray form.
- With this inhaler you don't have to push the canister to release a dose. Autohaler and Easi-breathe are examples of breath actuated MDIs.

People should be encouraged to rinse their mouths or have a drink after using inhalers as this can reduce the incidence of oral thrush.

Supporting use of a spacer

Improper inhaler technique is associated with poor control of disease.

- The use of a spacer helps to overcome the problem of pressing the inhaler and coordinating breathing in.
- Using a spacer allows the user to press the inhaler first and then take a breath, as the medicine will stay in the spacer until it is inhaled.
- Using a spacer also reduces the risk of oral thrush as more medicine reaches the lungs and less medicine hits the back of the throat and is swallowed.



People with COPD sometimes can find it difficult to take in a deep breath. Using a spacer means the inhaler can be pressed and then the user can put their lips around the spacer and then just breathe normally for 5 breaths.

Spacers are single patient use only.

- Person competent and able to use inhaler correctly.
- Symptoms are effectively managed.
- **Document observation and continue to monitor**

- Person requires some support to use inhaler or nebuliser correctly
- **Seek further support from Community Pharmacist, Practice Nurse, GP, Respiratory Team for advice, closely monitor and document**

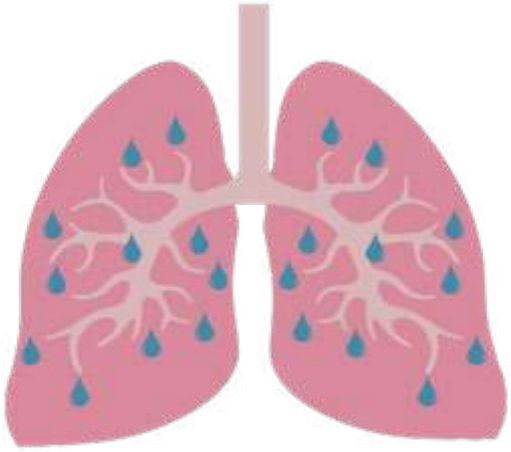
- Person unable to use inhaler and has no support in place to help them using their inhaler.
- Symptoms persist or worsening after medication.
- Requiring increasing dose to manage symptoms.
- **Seek medical support, GP or 111, provide advice on day identified and document**
- **Consider calling 999 if severely breathless.**

Important advice about cleaning a spacer

- Spacers should be cleaned regularly – at least once a month.
- They should be washed in warm soapy water using a mild detergent without rinsing.
- Leave parts to dry at room temperature
- DO NOT rub the inside of the spacer with a cloth as this causes static electricity. The static electricity attracts the medicine to the sides of the spacer and sticks there and reduces the amount available to be inhaled in the lungs.

Community Acquired Pneumonia (CAP)

The risk of community-acquired pneumonia (CAP) is significantly higher for people with older age or people with more complex health needs, with a rising incidence and higher mortality rates than in healthy young adults. Risk factors include age itself, alongside chronic conditions like COPD, heart failure, and diabetes, as well as lifestyle factors like smoking and poor nutrition.



Diagnosis and management of CAP (British Thoracic Society)

What is Pneumonia?

Pneumonia is inflammation of the lungs caused by an infection.

Causes:

Pneumonia can be caused by a bacterial or viral infection

Common signs of pneumonia:

Symptoms of pneumonia can start suddenly or gradually over a few days.

- a cough – with or without yellow or green mucus (phlegm)
- shortness of breath
- a high temperature
- chest pain
- an aching body
- appearing very tired
- loss of appetite
- wheezing
- appearing confused
- change in alertness
- altered behaviours
- Other soft signs personal to the individual

Prevention and Management of Community Acquired Pneumonia (CAP)

Prevention strategies involve vaccination, and prompt treatment of atypical symptoms such as confusion or delirium is crucial for early diagnosis and better outcomes.

Some of the risk factors can be treated and it is important to identify them and then refer to the GP for help.

Risk factors for CAP:

- Age over 65
- Smoking
- History of chest infections
- Difficulty clearing secretions from chest (chronic cough/ audible crackles and wheeze)
- Eating and drinking difficulties (coughing when eating/difficulty chewing - aspiration risk)
- Reflux (heartburn/burping/ vomiting)
- Excessive saliva (difficulty controlling saliva/drooling/gurgling voice)
- Poor oral health (difficulty cleaning teeth/evidence of tooth decay)
- Epilepsy (frequent seizures and aspiration risk)
- Sleep disordered breathing (loud snoring/excessive daytime sleepiness/morning headaches)
- Reduced mobility/lack of physical activity
- Other lung conditions (e.g. asthma/ COPD)
- Being underweight or overweight
- Effects of medication (saliva production and breathing)
- Long term condition (e.g. diabetes/renal disease/immunosuppression)

No risk factors identified and no respiratory signs & symptoms

- **Ensure that person is up to date with vaccination (e.g. Flu, Pneumococcal, Shingles, RSV and Covid vaccines).**
- **Continue to support, monitor and document observations.**

If you identify one or more of the risk factors.

If person is not up to date with vaccinations.

- **Book with GP due vaccinations.**
- **Intervene/support person where you can (e.g. activities of daily living), seek medical or GP and other services for support as appropriate.**
- **Document intervention and advice given. Continue to monitor.**

If you notice signs of developing infection/pneumonia or recognise early soft signs. Take observations, complete SBARD. Respond and escalate.

- **Seek urgent medical support from the GP or 111, intervene and document.**

Consider dialing 999, use SBARD tool

- struggling to breathe – choking, gasping and unable to speak
- pale, blue or blotchy skin, lips or tongue
- sudden onset of new or worsening confusion

Fluids

In climates, such as the UK, it is recommended we drink about six to eight glasses of fluid every day, to stop us from getting dehydrated.

Sometimes a person may be on a restricted fluid intake due to a health condition, but all others should be encouraged to drink the recommended amount.

If thickened fluids have been recommended by Speech and Language Therapy, please ensure all fluids are thickened to the correct consistency.

Record the daily intake of fluids if a person is at risk of dehydration (which would include those on thickened fluids) or is dependent on full support.

If fluid charts are used, please ensure fluid levels are totaled at the end of each day. If total is less or more than recommended amount, escalate and take action as per the person's care plan.

There are a range of foodstuffs that are rich in fluid and can be offered to help with fluid intake, including:



- Custard
- Jelly
- Ice-cream
- Yoghurt
- Soup
- Fruit and vegetables
- Gravies and sauces

People with restricted fluid intake (e.g. renal failure) will need to follow medical advice on fluid intake. Intake and output should also be closely monitored and recorded.

Person drinks the recommended eight glasses of fluid daily and independently

▶ **Document observations and continue to monitor.**

Person drinks only five cups daily

▶ **Monitoring amount may require some additional support and encouragement to drink. Community Pharmacy may be able to support. Refer if concerned.**

Person drinks two cups or less daily, with signs of dehydration

▶ **Seek urgent medical support from GP or 111, intervene and document.**

Based on NHS England advice and the Eatwell guide, drink six to eight glasses of fluid a day.

nhs.uk/live-well/eat-well/water-drinks-nutrition

Dehydration

Dehydration occurs when our bodies don't have enough water.

Water helps to lubricate the joints and eyes, aids digestion, flushes out wastes and toxins, and keeps the skin healthy.

Dehydration can directly contribute to:

- Increased risk of Urinary Tract Infections (UTIs)
- Feeling lightheaded which might cause the person to fall
- Confusion and irritability
- Constipation and seizures

Who is at risk of dehydration?

- As we get older, our sense of thirst becomes less reliable.
- Older people may be anxious about drinking due to continence issues
- People with certain diseases have increased water requirements, e.g. fever, diarrhoea, vomiting, kidney stones
- When the weather is hot, and in homes with high central heating, people will lose more fluid through sweating,
- People with oral discomfort and or swallowing difficulties
- Use of medications such as diuretics and laxatives can increase fluid losses

Signs dehydration?

- Feeling thirsty; dry mouth, lips and tongue; sunken eyes
- Feeling dizzy, lightheaded or tiredness; changes in mental health
- Only passing small amounts of urine and urinating infrequently
- Dark coloured, strong-smelling urine (but remember that some medications and foods will alter the colour and smell of urine)

Poor fluid intake is one of the most common causes of dehydration in adults, often influenced by factors such as mobility limitations

No signs of dehydration. Person is eating and drinking well.

▶ **Document observation and continue to monitor.**

If person is at risk of dehydration, ensure the person is supported with hydration and monitored closely. Check that medications are appropriate (e.g. diuretics and laxatives).

▶ **Monitor closely for signs of dehydration and document observations and actions.**

▶ **Encourage fluids and seek urgent medical support (call the GP or NHS 111) if someone is:**

- feeling unusually tired
- new or increasingly confused and disorientated
- feel dizzy when standing up and it does not go away
- have dark yellow pee or peeing less than normal

Consider dialing 999, use SBARD tool and document.

- Person is not passing urine for 8 hours, lethargic, breathe quickly, weak/rapid pulse, fits (seizures) or altered level of consciousness.

Hydrate To Feel Great is a project that aims to help people over 65 to reduce their risk of getting a Urinary Tract Infection (UTI) by improving hydration. This includes 'My Hydration Plan' which, is a 4-week drink diary to help record and monitor how much the older person drink.

NHS advice on link: Hydrate to Feel Great

NHS advice on link: Dehydration

Urinary Tract Infection (UTI)

Urinary tract infections (UTIs) affect your urinary tract, including your bladder (cystitis), urethra (urethritis) or kidneys (kidney infection). UTIs may be treated with antibiotics, but they're not always needed.

Urine dipsticks should **NOT** be used to diagnose UTIs for people over 65; instead, diagnosis should be based on symptoms of infection, which include 2 or more listed below.

Urine sample for culture testing should be obtained where possible.

Common signs of a UTI

- pain or burning sensation when passing urine (dysuria)
- needing to pee more often than usual
- needing to pee more often than usual during the night (nocturia)
- needing to pee suddenly or more urgently than usual
- urine that looks cloudy
- new incontinence
- blood in urine
- lower tummy pain or pain in your back, just under the ribs
- a high temperature, or feeling hot or cold, and shivery
- a very low temperature below 36°C
- feeling tired or weak
- Can't pee' or 'no pee'

Symptoms in older, frail people or people with a urinary catheter may also include:

- changes in behaviour, such as acting agitated or confused (delirium) or not wanting to take part in usual activities
- leaking pee (wetting themselves or incontinence) that is worse than usual
- new shivering or shaking (rigors)

If UTI is suspected

▶ **Seek medical support from GP or 111 and document observations and actions**

Gov.UK:
Diagnosis of urinary tract infections: quick reference tools for healthcare professionals in primary care

NHS advice on link:
Urinary Tract Infections

Urinary Catheters and Catheter Associated UTI

Urinary Catheters increase the risk of UTI

The longer a catheter is used, the greater the risk of infection and usually needs to be treated with antibiotics. This is why it's important that catheters are **inserted correctly, maintained properly,** and **only used for as long as necessary**.

There are some things you can try to help prevent a urinary tract infection (UTI) happening or prevent it from returning.

- Keep adequately hydrated (drink 6-8 glasses of fluid per day)
- Encourage regular bladder emptying
- Mobilise as much as able
- Wipe from front to back after toileting
- Keep the genital area clean and dry
- Wash the skin around the vagina with water before and after sex
- Pee as soon as possible after sex
- Promptly change nappies or incontinence pads if they are soiled
- Wear cotton underwear

Living with catheter – Minimising risks of infection/complication

- Wash the skin in the area where the catheter enters your body with mild soap and water twice a day and after every bowel action.
- Wash your hands with soap and warm water before and after touching your catheter equipment
- Make sure you stay well hydrated – you should aim to drink enough fluids so that your urine stays a pale colour
- Avoid constipation – staying hydrated can help with this, as can eating high-fibre foods, such as fruit and vegetables and wholegrain foods
- Avoid having kinks or bends in the catheter and make sure any urine collection bags are always kept below the level of your bladder

NHS advice on link:
Urinary Catheters

NHS advice on link:
Living with Urinary Catheters

Catheter Care

It is recommended that all carers who support people with a catheter, should undertake some sort of formal training, but here is some advice.

HOW TO CHANGE A LEG BAG

- Always wash your hands with soap and water first and dry hands well and wear gloves and apron
- Empty the existing leg bag as you usually would, remembering to close outlet tap
- Remove existing leg bag
- Remove cap from new leg bag and quickly attach to catheter
- Ensure the outlet tap is closed
- Leg drainage bag will need to be changed according to manufacturer's instructions, usually every 7 days unless there is a problem sooner
- Wash hands with soap and water and dry hands well

CATHETER CLEANSING

- Cleansing around the catheter is recommended twice daily and following any bowel action. Use a disposable cloth with mild soapy water
- Catheters should be cleaned by wiping away from where the catheter enters the body. In females, ensure you wipe front to back only. This is to reduce the risk of infection
- Any discharge from around the catheter should be noted and observed. The frequency of cleansing may need to also be increased.

If you feel you need further advice or support, please contact the community bladder and bowel service:

Sussex Community Foundation NHS Trust: Bladder and Bowel Service for Brighton and Hove and West Sussex

East Sussex Healthcare NHS Trust Community Bladder and Bowel Advisory service – East Sussex Healthcare NHS Trust

Urine Continence Care: Urine light in colour, continent

Catheter Care: Flowing clear urine light in colour

No signs or symptoms of UTI

Continue to support, monitor and document observation and advice given.

Urine Continence Care Urine: dark or cloudy – encourage fluids.

Long term urinary incontinence, support with appropriate continence aids and appliances or pads.

Catheter Care: Cloudy with sediment - Encourage fluids monitor

No signs or symptoms of UTI

- **Support with hydration, increase monitoring frequency and monitor for signs of infection, document observations and interventions, including advice given.**
- **In addition to Catheter Care: refer on to Community Nurses.**

Signs of infection or symptoms of UTI.
Significantly dehydrated or unable to take oral fluids and medicine.
Pregnant. Have a higher risk of complications. Have recurrent catheter-associated UTIs. Have bacteria resistant to oral antibiotics.

Urine Continence Care: New urinary incontinent

Catheter Care: Severe or ongoing bladder spasm (lower tummy or pelvis), catheter is blocked, urine is leaking, there is pus, blood or dark urine, indwelling catheter has fallen out, and you do not know how to replace it.

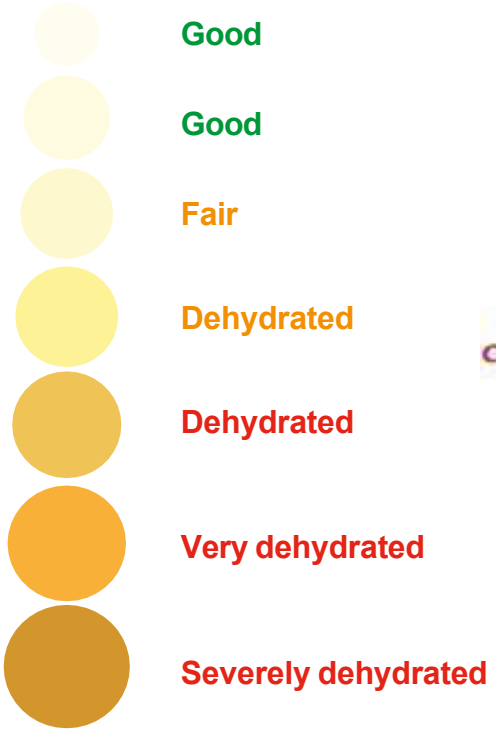
- **Seek urgent support from GP or Community Nurses, intervene and document**

If sepsis is suspected or any signs or symptoms of a more serious illness or condition,

- **Call 999 or go to A&E**

Preventing UTIs by recognising signs of dehydration

Complications of UTI are not normally common but can be serious for people in older age group and can lead to kidney failure or sepsis. Complications can affect people with pre-existing health problems, such as Diabetes or weakened immune system. A sudden change in behaviour is one of the best indicators of a UTI in older people.





Be aware that some medications can change urine colour, so it is important look for symptoms of dehydration too.

If urine colour either of the first 2 colours on urine colour chart, with no symptoms of dehydration

▶ **Continue to support with hydration, monitor and document observations.**

If urine colour matches either of the middle colours (3 and 4) on the urine colour chart, and person is starting to show symptoms of dehydration but is still able to drink, offer more fluid to drink. Keep a fluid chart so you can observe fluid intake. If someone is struggling to drink fluids consider foods with a higher fluid content such as ice lollies, cucumber, jelly and melon.

▶ **Encourage fluids. Closely monitor fluid intake and output. Community Pharmacy may be able to support. Refer if concerned.**

If urine colour matches the last 3 colours on the urine colour chart (5,6,7), and the person is showing symptoms of dehydration, the person needs to be encouraged to drink more fluids. Keep a strict fluid chart, document fluid intake and urine output.

▶ **Seek urgent medical support with GP or NHS 111, intervene and document.**

Consider dialing 999, use SBARD tool

Person is not passing urine for 8 hours, lethargic, breathe quickly, weak/rapid pulse, fits (seizures) or altered level of consciousness.

Nutrition – Healthy Eating

A good diet is important for maintaining general good health.

If a person is underweight or overweight, they may benefit from altering their diet.

Follow individual advice given by their doctor or other healthcare worker if applicable.

'The Eatwell Guide' shows the food groups, and the proportions in which we should eat them, to create a balanced diet when we are a healthy weight or overweight.



Body Mass Index (BMI) is a widely used, simple, and rapid measurement used to assess if an adult is a healthy weight for their height.

< 18.5: Underweight range

18.5 to 24.9: Healthy weight range

25 to 29.9: Overweight range

30 or above: Obese range

Being very overweight can cause problems, such as:

- Breathlessness / Difficulty with physical activity
- Swollen legs
- Feeling very tired a lot of the time
- Joint and back pain
- And can increase the risk of heart disease, type 2 diabetes, some types of cancer and stroke.

To help reduce weight use smaller portion sizes, avoid high energy snacks (e.g.: crisps, cakes, biscuits, fizzy drinks) and increase intake of fruit and vegetables

Healthy weight (nhs.uk)

Food Facts (The Association of UK Dietitians)

Nutrition - Unintentionally losing weight / Malnutrition

Having malnutrition can be serious for some people and can increase their risk of health problems, e.g.:

- Bone fractures if they fall
- Pressure damage
- Weakened immune system with increased risk of infections
- Increased risk of vitamin and mineral deficiencies

If someone is underweight and/or their appetite has decreased, it is important to try and increase the amount of energy and protein in their diet using nourishing food and drink, which includes micronutrients, protein and energy from fat.

You may be asked to record a person's daily intake if there are concerns about dietary intake. Make sure you record what is eaten AND the amount eaten.

NHS Sussex Health & Care **Boost your nutrition leaflet** gives practical advice on how to improve diet if the individual has a small appetite, struggling to eat and drink or are losing weight without meaning to.

Key recommendations are to:

- **Eat "little and often"**
- **Fortify your food and drink**
- **Have nourishing drinks in between meals**

  If the person cannot chew well, soft or pureed food may be preferred.

NICE recommends the use of **The Malnutrition Universal Screening Tool (MUST),** developed by the British Association for Parenteral and Enteral Nutrition, to identify people who may be at nutritional risk or potentially at risk, and who may benefit from appropriate nutritional intervention.

The 'MUST' calculator can be used to establish nutritional risk using either objective measurements to obtain a score and a risk category or subjective criteria to estimate a risk category but not a score.

If you are concerned about the person's nutritional status, specifically regarding unintentional weight loss, being underweight, being overweight, or concerned with their diet,

- **Provide personalised support, continue to monitor and document observations and interventions.**
- **Contact their GP, NHS 111 or their Primary Care Network.**

The clinician should be able to assess for any underlying medical conditions and/or refer you to appropriate services.

Eating Disorder – is a mental health condition where a person use the control of food to cope with feelings and other situations. Unhealthy eating behaviours can affect nutrition by disrupting the body's ability to obtain, absorb, and utilise essential nutrients.

Healthcare professionals may be able to refer individuals diagnosed with an eating disorder requiring support to Sussex Eating Disorder service.

Swallowing

As we age, and as we approach the end of our life, there are natural changes to the way we swallow. Some conditions can also cause swallowing difficulties (also known as “dysphagia”) including, stroke, cerebral palsy, dementia and other neurological disorders, profound learning disability, head and neck cancer and respiratory illnesses.

Some signs and symptoms of swallowing difficulties include:

- Wet or ‘gurgly’ breathing and/or voice during or after
- eating or drinking
- Food, drink or saliva spilling from the mouth
- Difficulty biting and chewing
- A feeling of food sticking in the throat
- Discomfort during eating/drinking
- Holding food in the mouth
- Coughing during or after eating/drinking
- Choking (airway blocked by food and not able to breathe)
- Recurrent chest infections
- Unintentional weight loss
- Shortness of breath after eating or drinking



Swallowing difficulties may impact on the amount of food and drink that people can manage.

This can lead to malnutrition, dehydration and reduced quality of life. In some cases, dysphagia can be life-threatening, causing:

Choking – food lodged in the airway may prevent breathing and immediate action must be taken. In cases of unconscious choking, CPR should be carried out even if the person has a DNACPR recommendation in place, *unless* this expressly includes choking. See dedicated page for Choking.

Aspiration – food and/or fluids, including saliva, entering the airway/lungs.

Silent aspiration – when there is no audible sign of food/fluid entering the lungs (e.g. no coughing). This should be considered in the case of recurrent unexplained chest infections.

Pneumonia - Some people may be able to tolerate some aspiration at times, but it can result in chest infections, including pneumonia, which can seriously affect the person’s health.

People who have associated risk factors may be more vulnerable to aspiration pneumonia. These risk factors may include:

- not being mobile
- poor oral health
- being dependent on others for assistance with eating/drinking
- having a feeding tube

When people are dying – it is common for people to experience difficulties swallowing but this rarely requires a specialist referral. At this stage it is important to try to make the person comfortable, perhaps offering tastes of favourite foods/drinks, and to help ensure their mouth is moist and comfortable.

Swallowing Management

Being able to eat and drink safely is fundamental to maintaining health and wellbeing.

Simple changes can often make a big difference. Carers are in an ideal position to identify symptoms of difficulties with eating and drinking and to use first-line safer-swallowing strategies (next page) to help improve comfort and safety.

People with mild/low-risk swallowing difficulties can usually be managed by front-line staff who have had training. People with complex difficulties will require a specialist assessment of swallowing by a speech & language therapist.

If the first-line swallowing strategies are not helpful or you are concerned that a person is at risk of harm from their swallowing difficulties, refer to speech and language therapy.



Some people may benefit from texture-modified diet and/or drinks as described in the International Dysphagia Diet Standardisation Initiative (www.IDDSI.org) descriptors.

If the person has a **Swallowing Management Plan**, this will have been carefully created to best meet their needs. It is important to follow this and raise concerns if you become aware of problems.

What to do if someone doesn't want to follow the Swallowing Management Plan:

- Explain why the recommendations have been made
- Discuss with your supervisor and ensure that the speech and language therapy team are contacted for further advice/support.

Person can swallow with no identified problems

▶ **Document observations and continue to monitor.**

Person has symptoms of swallowing difficulties but there are no concerns about choking / chest infection / dehydration / weight loss.

▶ **Trained front-line staff create swallowing management plan**

Person may be managing mild swallowing difficulties by using first-line safer swallowing strategies.

Person may have been assessed by a speech and language therapist and specialist recommendations are in place.

▶ **All staff support, closely monitor and document any changes**

First-line safer swallowing strategies or swallowing management plan are not helpful. Person has new difficulties and you are concerned about risk (e.g. chest infection/malnutrition/dehydration/choking/reduced quality of life)

▶ **Document and escalate to senior support:**

▶ **If person is unwell or is likely nearing the end of their life, contact GP, Care Home Matron or NHS 111**

▶ **If person is not likely nearing the end of their life, refer to speech and language therapy**

First-Line Safer Swallowing Strategies

(For mild swallowing difficulties / when awaiting specialist assessment)

- If the person is sufficiently alert to eat and drink, trial the following strategies.
- If the symptoms improve, the person will likely not need referral for specialist speech and language therapy assessment.
- Close monitoring will be important. Document your observations.
- If the person has capacity, discuss avoiding foods that have been difficult to swallow.
- **If the person is not sufficiently alert to eat and drink DO NOT give them food or drink and consider whether they are unwell and need a health care professional, contact the GP or NHS 111.**

Positioning	• Try to make sure the person is sitting as upright as possible • Encourage them to keep their head in a neutral position, or with the chin slightly tucked down • If necessary, reduce distractions in the environment (e.g. consider turning off the television)
Mouthful size	• Small sips are generally safer than large mouthfuls • Support the person to have one sip at a time, not continuous drinking • Try a smaller spoon for food
Equipment	• Avoid using cups/bottles that require head-tipping (e.g. lidded beakers, medicine cups, sports bottles, tall/narrow cups) • Wide-brimmed open cups or nose cut-out cups (Kapi/nosey cups) help encourage a neutral head position • Trial whether a drinking straw may help
Support	• Support the person to be as independent as possible, prompting them to take small mouthfuls of food /sips of drinks if necessary • If required provide partial- or full assistance • Allow plenty of time between mouthfuls • Ensure that no food remains in the mouth after meals, support with mouth care if required

My eating and drinking matters

Back to basics: care for people who have difficulties with eating and drinking

Swallowing Awareness Day – Have your cake...but can you eat it?

1 BE POSITIVE

You can help me by:
- Giving me time
- Encouraging me to be independent
- Talking to me about what I am having and how I am doing

2 KNOW ME WELL

- Listen to me
- Give me a choice
- Know how I communicate
- Know what I like and dislike
- Know what is safe for me
- Know what equipment I need

3 MY MOUTH NEEDS CARE

Please check that:
- My lips are pink and moist
- My mouth and teeth are clean
- I don't have ulcers or mouth infection
- My teeth are in good condition
- My dentures fit

4 MY ENVIRONMENT MATTERS

You can help me by:
- Checking I am relaxed and comfortable
- Checking I am not distracted
- Helping me to concentrate
- Sitting at the same level as me
- Giving me your whole attention

5 GET ME READY TO EAT AND DRINK

You can help me by:
- Checking I am awake and alert
- Checking I am sitting upright
- Checking I am ready to eat or drink

6 KEEP ME SAFE

You can help me by:
- Discouraging chat during the meal
- Ensuring I remain sitting upright for half an hour after the meal

Alert a healthcare professional if there is a change in:
- Coughing or choking
- Voice sounds wet or gurgly
- Breathing changes
- Food stays in the mouth when meal is finished



Giving Voice | Speech and Language Therapy awareness days

If you have concerns with any of the above please seek advice from my Speech and Language Therapy team

Royal College of Speech & Language Therapists

my-eating-and-drinking-matters.pdf

▶ GREEN ACTION – Carry on as normal: monitor & document ▶ ORANGE - ACTION – Closely monitor and provide additional support ▶ RED - ACTION - Seek further support and advice

Oral Health and Mouth Care

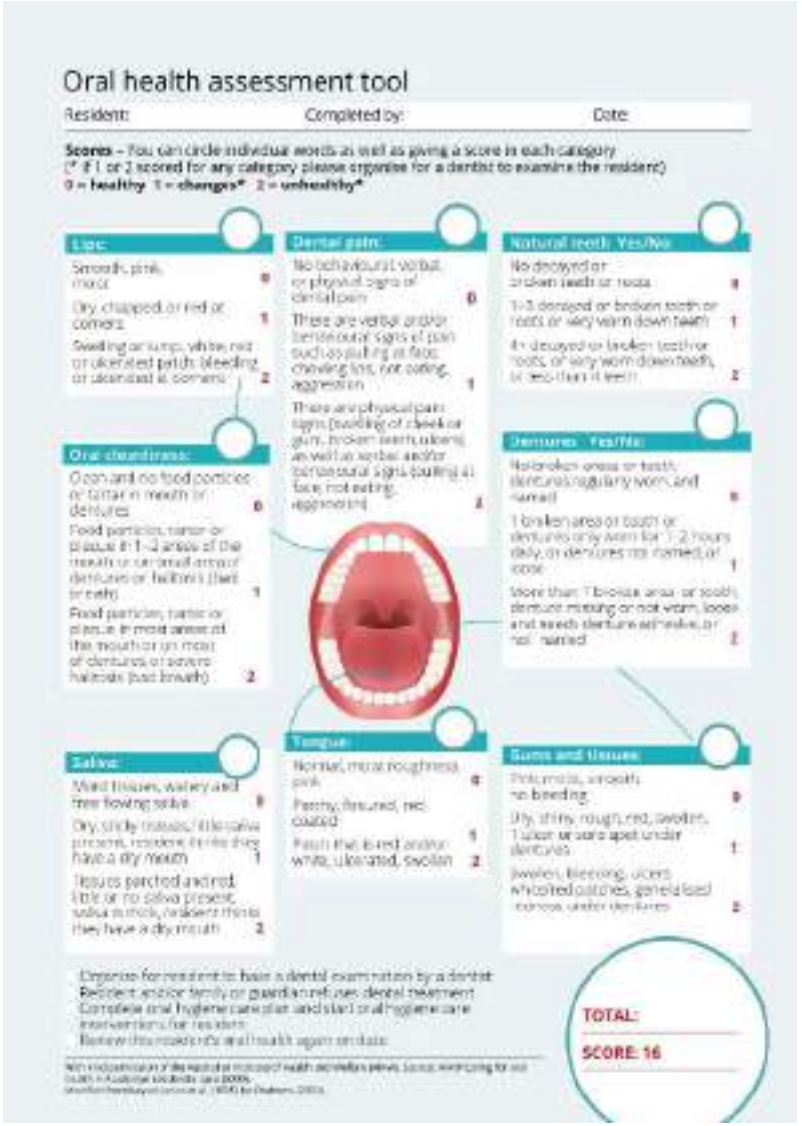
Mouth care is an essential aspect of care in all settings and should be considered part of daily routine person's care. Assessment and intervention should be instigated early to optimise comfort and prevent more serious problems and treatment complications.

Gum disease and poor oral health may increase the risk of all kinds of other health complications, including:

- Lack of appetite
- Heart disease
- Malnutrition
- Pneumonia

Assessment and Mouth Care Plans

1. Assess the mouth care needs of person being cared as soon as possible, regardless of the length or purpose of their stay. Consider using the oral health assessment tool for this guideline. Where family and friends are involved in ongoing care, consider involving them in the initial assessment, with permission, if it will help carers understand their usual oral hygiene routine.
2. Make an appointment for the person to see a dental practitioner, visiting a dentist is advised once a year unless the dentist suggests an alternative.
3. Record the results of the assessment and the appointment in the individualised care plan.
4. Review and update mouth care needs in their individualised care plans as their mouth care needs change.



Oral Health assessment tool available in:
NHS Oral health: A quick guide for care home

Guidance on Supporting Mouth Care

- Explain how you are going to support the person, as some people can feel anxious. You must ensure that you have consent before attempting assisted toothbrushing and that you have noted this and a summary of the care provided in the person's care plan.
- Encouraging persons to look in the mirror whilst being supported will enable them to see what is happening. It can be easier for the carer to stand slightly behind, or to the side, when supporting persons with oral health care
- Some people's gums may bleed when brushing, this is a sign that their gums are unhealthy. The only way to improve gum condition is to gently brush the bacteria away. **Refer to a dentist.**
- Teeth should be brushed in a circular motion, with the brush at a 45 degree angle with a small amount 'pea sized' toothpaste.
- Ensure dentures placed in a labelled denture pot when not being worn especially on admission to hospital, as these can go missing
- Loss of dentures may cause great distress and can be expensive and time consuming
- Ensure the person is comfortable and ensure that you are not rushed
- Remember you may not be able to support brushing the person's whole mouth in one go
- Encourage the person to spit out after brushing and not to rinse. Try to avoid eating or drinking for twenty minutes after brushing.
- It is better to leave a little toothpaste residue in the mouth to maintain fluoride concentration levels
- Support persons with false teeth to clean them daily
- Dentures should be removed at night and soaked in plain water
- Support the person twice a day to clean their teeth
- Replace the tooth brush every three months or sooner if required
- The frequency and amount of sugary food and drink should be reduced and where possible, kept to mealtimes
- Ensure when the person's dentures are removed, they do not have any residual food left in their mouth, clean the soft tissues of the mouth with the toothbrush
- Dentures which do not fit well can affect eating, drinking and speaking and can be uncomfortable
- Frequent oral health care is important for those who are unable to take any food or drink orally. It is important to minimise oral bacteria that might be aspirated, as well as optimising oral comfort



dentalhealth.org/caring-for-my-teeth

NICE Guidance on Oral Health for Adults

Daily Mouth Care

- Ensure carers offer oral care twice daily. This involves providing daily support to meet their mouth care needs and preferences, as set out in their personal care plan after their assessment. This should be aligned with the advice in the Public Health England delivering better oral health toolkit, including:

  - ✓ brushing natural teeth at least twice a day using a pea size amount of fluoride toothpaste
  - ✓ providing daily oral care for full or partial dentures
  - ✓ using their choice of cleaning products for dentures if possible
  - ✓ using their choice of toothbrush, either manual or electric/battery powered
  - ✓ daily use of mouth care products prescribed by dental clinicians
  - ✓ daily use of any over-the-counter products preferred by **the person under your care, if possible, such as particular mouth rinses or** toothpastes; if they use sugar-free gum, consider gum containing xylitol.

- Ensure care staff know which member of staff they can ask for advice about getting prescribed mouth care products or helping someone to use them.

- Ensure care staff know how to recognise and respond to changes in a person's mouth care needs.

- Ensure care staff know how to respond if a person does not want daily mouth care or to have their dentures removed (see NICE's information on making decisions about your care).



Mouth is healthy, clean and moist

▶ **Document observation and continue to monitor.**

Mouth is dry, food and bits remain around teeth

▶ **Assess and plan regular effective mouth care for all.**

▶ **Intervene/support person with mouth care and explain the importance of mouth care.**

▶ **Monitor response to interventions and document.**

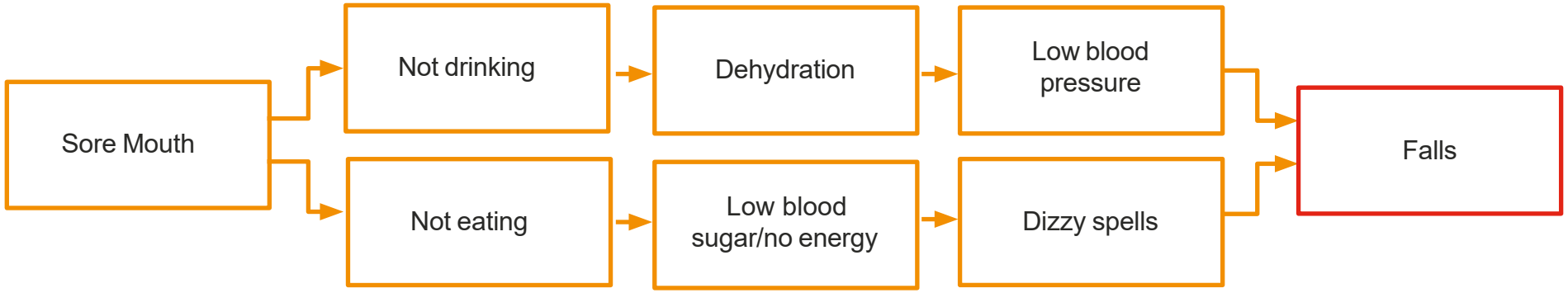
Mouth is inflamed, dry and sore or ulcerated

▶ **Seek additional support on day identified from GP, or their own Dentist, intervene and document.**

Further advice on:
Oral Health Foundation: Caring for teeth and gums

Case Study: Sore Mouth to Falls

Remember that different conditions or different aspects of poor health can impact on another area of the body.



Example:

Eileen lives in supported living with three peers. Staff are available throughout the day and night. Some of the staff have supported her for many years and know her really well.

- **ACTION: Eileen has been to the dentist and is eating and drinking well**

Eileen has a severe learning disability and shows you what she wants by taking you to it. She particularly loves tea. She also has a severe scoliosis which over years has resulted in her developing chest problems.

- **ACTION: Eileen is not requesting her usual tea and is drinking less. Start recording what she is drinking.**

Eileen eats a good diet but has recently lost some weight. When Eileen is in pain she may pull at her hair. She has recently taken longer to open her bowels and sustained a fractured wrist due to a fall.

- **ACTION: Eileen is holding her mouth and appears lethargic. You look in her mouth and spot a tooth that is moving. You book an emergency dental appointment.**

Skin

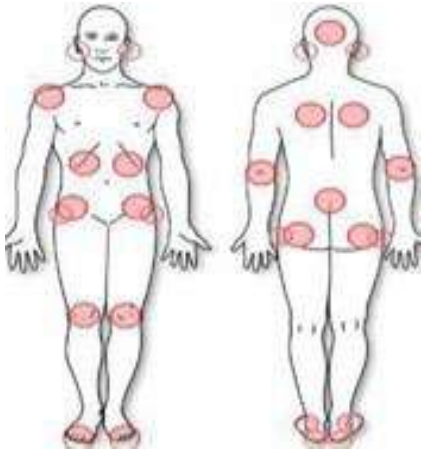
Pressure ulcers (pressure sores or bed sores) are areas of damage to your skin and the tissue underneath. You have a higher chance of getting them if you have difficulty moving.

Pressure ulcers usually form on bony parts of the body, such as the heels, elbows, hips and tailbone.

Maintaining good skin condition is really important; pressure ulcers can have a huge impact on person's wellbeing, causing pain, distress etc.

Carers are ideally situated to monitor a person's skin condition; the parts of the body that are at higher risk of developing pressure ulcers are:

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



Wheelchair users are at risk of developing a pressure ulcer on:

- Buttocks (area most at risk is the sitting bone or ischial tuberosity)
- The back of arms and legs
- The back of the hip bone

Assess Risk: Holistic assessment:

Use of validated tool to support clinical judgements.

Skin Assessment, Skin Care & Care Plan: Regular observation and inspection of the skin is important to detect skin conditions early on to enable prompt treatment and minimizing potential complications - Does their skin have redness, rashes, sores or lesions?

- Non-blanchable erythema may present as colour changes or discolouration, particularly in darker skin tones or types.

Individualised care plan – outcome or assessment; strategise the need for pressure relief and devices; their mobility and ability to reposition themselves; other comorbidities and patient preference.

Surface Ensure the patient is on an appropriate surface (e.g., specialized mattress or cushion) to redistribute pressure.

Keep Moving: Encourage person to move or change position every 2-3 hours. If they are unable to reposition themselves, offer help to do so, using appropriate equipment if needed. Document the frequency of repositioning required.

Incontinence & Increased Moisture: Has the person that you are caring for become incontinent? Keep the skin clean and dry.

Nutrition & Hydration: Assess nutritional and fluid intake with validated tools & take action where necessary. Reduced intake increases the risk of pressure damage.

Giving Information: Communicate effectively & provide accurate supporting information to patients, carers and Multi-Disciplinary Team.

Pressure Ulcers (Pressure Sores)

If you see discoloured skin that **does not turn white when pressure is placed on it** or any of the signs below, the person could be starting to develop a pressure ulcer.

▶ **Consider completing an SBARD and seek further advice and support**

At the start of a pressure ulcer, you may see:

Skin that appears discoloured

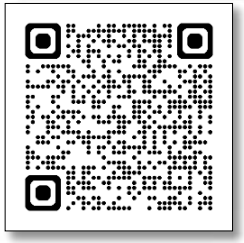
- It is red in people with paler skin
- It is purple or blue in people with darker skin
- The skin is intact, but it may hurt or itch (Be aware of how the person you are supporting may communicate this, especially if they may be non-verbal)
- It may feel either warm and spongy, or hard Person complains of pain to the area (How does this person experience/ show/ communicate pain?)



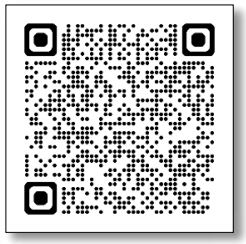
NHS Conditions: Pressure ulcers (pressure sores)



EPAUP: Pressure Ulcer Guideline



NICE Guidance: Pressure ulcers prevention and management



Pressure Ulcer Classification Tool - Scottish Adaptation of the European Pressure Ulcer Advisory Panel

Skin intact and good colour

▶ **Follow individualised care plan, skin-care guidance on previous page and links below. Continue to monitor and document.**

Skin is painful, swollen, discoloured (for a short time only and returns to normal quickly) or sweaty. If the person has reduced mobility or is unwell or has very thin skin or poor nutrition / hydration, they are at increased risk of pressure damage – permanent / temporary

▶ **Review and update individualised care plan. Ensure that care plan is being followed. Closely monitor and document observations and interventions.**

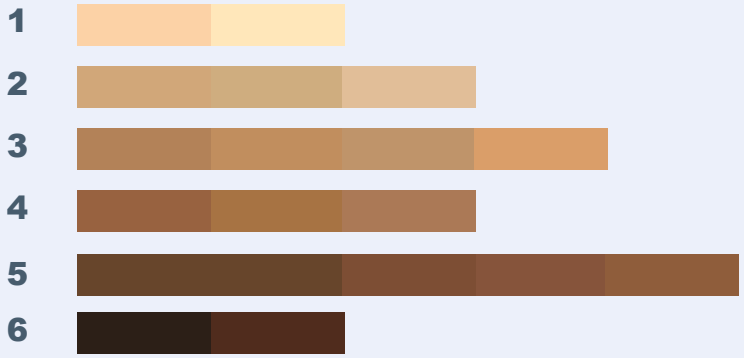
▶ **Seek urgent support from GP or NHS 111, or Community Nurse if known to them, intervene and document**

- signs of pressure ulcer
- hot, swollen or red skin – it can look blue or purple on brown or black skin
- pus coming out of the ulcer
- a high temperature
- severe pain or pain that's getting worse

Skin Tone Tool

The skin tone tool (Ho and Robinson, 2015) is a validated skin tone classification tool. Using this tool, skin tone can be selected that most closely matches the patient's inside upper arm. The skin tone tool is a simple way of assessing skin tone and can be used across care settings. The tool encompasses more options other than light and dark generalisations so it is more useful. It is worth noting that skin tone may differ across different areas of the body.

If you see something unusual or not right about the person's skin – React and Seek support



By determining a person's skin tone, it can be easier to recognise and monitor for any changes.

When assessing the skin for changes, compare similar anatomical locations (e.g., Heels)

Supporting and encouraging a person with regular changes of position is important to prevent and maintain good skin condition. They may need prompting to do this, assisting or need your help. How often to reposition either in bed or in a chair / wheelchair is based on person assessments. Ask if you are not sure.

If the person has pressure-relieving equipment, check it - if you have any concerns, contact the equipment store where it was delivered from. Equipment should be regularly serviced. Remember persons with Alternating (Air) Mattresses still need regular repositioning.

Wounds International: Pressure Ulcers and Skin Tone Made Easy, September 2023

Society of Tissue Viability: Assessing skin on patients with darker skin tones in relation to Pressure Ulcer Prevention, November 2021

NHS digital service manual: Skin symptoms – Medical sources for symptoms on black and brown skin

Skin excoriation tool

ONLY use products listed on Sussex Wound Care Formulary

	**Healthy Skin** No evidence of tissue damage, no erythema (redness).	• Promote good skin care • Discuss risk of moisture damage • Cleanse skin using a pH balanced soap & water • Consider a barrier cream	**Continue to support, monitor and document observation and advice given.**
	**Mild Excoriation** Erythema (redness) no broken skin. No moisture lesions but area may be uncomfortable to clean and apply creams.	• Promote good skin care • Cleanse skin using a pH balanced soap & plain water • Use prescribed barrier cream: **Medi Derma-S** -Apply thin layer every 12 hours. Allow to absorb.	**Consider the cause:** • Review continence assessment. • If erythema is diffuse and satellite lesions present, consider fungal infection and treat accordingly. • Consider allergy or contact dermatitis. • **Seek additional support from GP or NHS 111, or Community Nurse (if known to them) and document**
	**Moderate Excoriation** Extensive erythema with diffuse broken skin and moisture lesions. Moderate exudate and may bleed on contact. Painful to clean and apply cream.	• Promote good skin care • Cleanse with plain water ONLY • Use prescribed barrier film: **Medi Derma-S.** Apply once every 48 hours. Allow to absorb. Do not rub vigorously.	**Consider the cause:** • Review continence assessment and pad absorbency, • Fungal infection or allergy • **Seek *urgent* support from GP or NHS 111, or Community Nurse (if known to them), intervene and document**
	**Severe Excoriation** More than 50% broken skin and moisture lesions. Bleeds easily. Extremely painful on movement, passing urine or faeces, when cleaned and creams applied or exposed to air.	• Promote good skin care • Gently clean with soap substitute or skin cleanser. • Pat dry as much as possible. • Use prescribed barrier film: **Derma Pro.** Apply a liberal layer to the excoriated skin after each episode of incontinence or as directed by a healthcare professional. Allow to absorb. Avoid rubbing the skin.	**Consider the cause:** • Review continence assessment and pad absorbency, • Fungal infection or allergy • **Seek urgent support from GP or NHS 111, or Community Nurse (if known to them), intervene and document**

Continence - Urine

(please also see page xx)

Problems with continence both bladder (urine) and bowels (faeces) are relatively common; however, embarrassment can often cause people to not ask for help.

Carers are again in a perfect position to support and refer people on for help and advice.

- People generally go to the toilet to pass urine four to seven times in a day.

However, some people may develop incontinence; some of the common signs that indicate people may need to have a proper continence assessment include:

The colour of urine can indicate dehydration; however, some foods and medicines can also cause urine to become discoloured.

If the person is drinking the recommended six to eight glasses per day and urine appears an unusual colour or darker, please monitor and seek advice if necessary.

If urinary tract infection (UTI) is suspected, please refer to the "UTI" and Urinary Catheter section of this booklet.

NHS Conditions: Urinary incontinence

Common Signs that indicate people may require some additional support	
Stress Incontinence	**Urge Incontinence**
Leaking when exercising	Described as having a sudden urge to pass urine and often described as unable to get to the toilet in time
Leaking small amounts of urine when sneezing	Going to the toilet frequently, either during the day or overnight
Leaking small amounts of urine when laughing	
Leaking urine when lifting heavy objects	

Continence - Bowels

Different people have different bowel habits

- Most people have a bowel movement more than 3 times a week and pass good textured faeces (not too hard or soft) without straining.
- Since it can be hard to state what is normal and what is abnormal, some health professionals use a scale to classify the type of stool passed.

An ideal stool should be type 3 or 4, and, depending on the normal bowel habits of the person, should be passed every one to three days without straining.

If stools are very dark (black) or very pale encourage the person to speak with their GP. Some medication can change the colour of stools, this can be discussed with a pharmacist.

People with increased risk of constipation which can even lead to death due to the following risk factors:

- Poor diet
- Poor hydration
- A lack of exercise/reduced opportunity for exercise
- A lack of knowledge and/or reporting
- A lack of health promotion and available accessible information
- Medications such as anti-psychotic and seizure prevention drugs
- Poor mobility
- Postural issues and neurological disorders in those with profound and multiple disabilities
- Learning disabilities

Bristol Stool Chart

Type 1		Separate hard lumps, like nuts (hard to pass)
Type 2		Sausage-shaped but lumpy
Type 3		Like a sausage but with cracks on the surface
Type 4		Like a sausage or snake, smooth and soft
Type 5		Soft blobs with clear-cut edges
Type 6		Fluffy pieces with ragged edges, a mush stool
Type7		Watery, no solid pieces. Entirely Liquid

Continence

People may require additional support and personal care due to incontinence issues with their bowels for example, people may be incontinent of faeces or have a stoma bag.

The colour of stools can vary; however, if someone has very dark stools (black) it may be related to medication (iron) or something more serious.

Ensure care plans document any medication that may affect the colour of stools.

Every person prescribed a regular laxative should have a bowel management plan to include the recording of bowel movements using Bristol Stool Chart as guide.

Continence Pads

- Continence pads should be stored out of bright light and in a damp free environment – not in the bathroom
- People's skin should be clean and dry before support with pad application
- Only use a pea sized amount of barrier / cream should be used as more may interfere with absorbency (unless advised otherwise by a professional)
- Pads should be opened for a minute or two prior to application to allow pad to expand – but not shaken.
- Pad should be folded in half and inserted from the front to back, this prevents faeces coming to the front if a stool is passed during application



Bristol Stool Chart by Bladder & Bowel Community, provide free resources to help those who are living with conditions that affect the bladder or bowel.

Bowels normal for person and discomfort is not noted.

Person is not losing weight unintentionally.

▶ **Continue to support, monitor and document.**

3-day rule: If a person has not had a bowel movement in the past 3 days, consider the possibility they may be constipated

▶ **Follow their personalized constipation management plan**

Change in bowel habit, constipation without discomfort, make a routine referral to GP.

▶ **Consider cause, and support with hydration and change in diet as appropriate.**

▶ **Closely monitor and support person with continence care if needed.**

Stools are very dark (black) or very pale,

▶ **If likely due to medication – Speak with a pharmacist**

▶ **If cause is unknown, presence of discomfort and weight loss, or there is a concern – Seek urgent support from GP or NHS 111**

Sudden onset of diarrhoea with abdominal discomfort

▶ **Seek urgent support from GP or NHS 111 as person might have an infection.**

▶ **Review if person had antibiotics in the previous 3 months and report to the GP for possible Clostridiodes difficile (C.diff) infection.**

Mobility and Falls

Mobility and prevention of falls is fundamental in supporting people to retain their confidence and independence.

Falls can have a significant effect on people's health and wellbeing

Keeping people mobile can reduce the incidence of

- Infections
- Pressure damage

It is important that people seek early intervention from specialists to maintain mobility.

Exercise guidelines and workouts - NHS have advice on exercises for older people, which can be undertaken in the home - including exercising when seated and exercises to improve balance, flexibility and strength.

Age UK gives advice on how you can prevent a fall, how to make fall-proof a home and what you can do if you are worried.

Age UK advice line: 0800 678 1602, 8am to 7pm every day

Encouraging people to increase their strength and balance through exercises will help maintain mobility and reduce the risk of falls. Consider introducing the "Get up and Go Booklet" and signposting to local exercise groups.

Mobility - Independently mobile with or without aids.

Falls Risk - No history of falls or near misses, good mobility, good mental health status and good confidence

- **Continue to support, monitor and document observation.**

Falls Guidance - NICE

Mobility - Needs assistance beyond their usual level

Falls Risk - If the answer is yes to any of the 3 questions below,

1. **History of falls and near misses** - Has the person fallen in the last year?
2. **Unsteady** - Do they have problems with their strength and balance when walking?
3. **Reduce in confidence** - Do they have a fear of falling?

- **Increase monitoring, support and document.**
- **Consider further advice and support from GP, or Community Nurse/Physiotherapist and Community Falls Prevention Team.**

Mobility - Can no longer move independently when could before

Falls Risk - New/acute falls causing injury, may be in pain or unwell, new/acute problems with balance and co-ordination (also consider effects of dementia and medications)

- **Seek urgent support from GP or NHS 111 and document.**

  Keep them comfortable and warm. Carefully help them get up if they can, but do not try to lift them yourself.
- **Consider 999 if fallen and injured (head, back neck or hip) or cannot get up, support and document.**

Falls - NHS

Falls prevention

[Fall prevention for the elderly | Age UK]

[RoSPA's Safety Advice- Preventing falls in later life: Safety tips for older adults] produced series of practical videos on falls prevention.

Environmental	☑ Keep rooms well lit. Consider brighter bulbs in risky areas such as stairways and bathrooms. Low energy light bulbs are useful in reducing bills, but they take a minute or two to warm up. ☑ Remove clutter, trailing wires and frayed carpet. ☑ Keep floors dry and mop up spillages straight away. ☑ Remove rugs and mats or ensure they are tacked down. Consider non-slip mats in a bath or shower. ☑ Ensure easy access to commode or toilet (ensure appropriate clothing to ease independence). ☑ Ensure nightlight is available or keeping a torch by the bed. ☑ Advise not to rush. ☑ Make sure cats or dogs have bright collars or bells to help prevent tripping over them. ☑ Consider assessment from an Occupational Therapist or a Community Falls Prevention Team. ☑ Make sure there is suitable equipment (e.g. low-profile bed, raised toilet seats and grab rails around the house) if needed ☑ Request social service for a home assessment: Home adaptations - Social care and support guide - NHS
Impaired Sight and hearing	☑ Support those who wear glasses to keep them on or have them close by, ensure they are kept clean, in good condition and they can see out of them, it fits properly and are the right prescription ☑ If vision seems to be deteriorating, check they have had a recent eye test. If not, refer to optician. ☑ Advise annual eye tests. Some services are able to visit people at home when they are not able to go out. ☑ Rails on stairs or grab rails around the home in a contrasting colour to the walls can be easier to see. ☑ Equipment such as toilet seats and walking aids can also come in different colours ☑ Is hearing reduced? Check hearing aids are clean and working. Consider the need for a hearing test.
Mobility and Balance	☑ Stay active - Support clients to move regularly throughout the day using any recommended equipment. ☑ Walking aids such as walking sticks or zimmer frames can help with stability and balance. Make sure they are always in reach and in good working order. Regularly check the rubber end (ferrule) is not worn down. New ones can be purchased. ☑ Promote physical activity and mobility. Encourage participation in tailored exercise routines that focus on improving strength, balance, and flexibility, as well as walking and dancing, as these can significantly reduce the risk of falls. ☑ If unsteadiness is new – seek support from physiotherapist, Community nurse or GP.

Falls Prevention (continuation)

Feet, footwear and clothing	☑ Check condition of feet, check for pain, problematic bunions or toenails – may need to see a podiatrist ☑ Check footwear is suitable, fits well, is in good condition, do not slip off, have a good grip and supports the ankle ☑ Ensure shoes have non-slip soles ☑ Ensure clothing allows the person to move their legs and feet freely. Encourage people not to wear clothes that are too tight or too loose-fitting, trailing clothes that might trip them up ☑ Footwear to have Velcro or laces, so shoes can be adjusted if feet swell
Illnesses and medication	☑ If known to have low blood pressure when standing (Postural Hypotension), advise to stand for 10-12 seconds. ☑ If complaining of dizziness, ensure eating and drinking adequately, may need to seek support from Community Nurse, GP or Pharmacist ☑ Ensure proper management of medications, including regular reviews of side effects and interactions that might contribute to dizziness or instability. ☑ Medications may cause imbalance, be aware if on 4 or more medications or started new medication; including medication bought over the counter or online from a pharmacy, supermarket, or health food shop, herbal or alternative medicine or recreational drugs – seek support from pharmacist ☑ If you are taking several medicines, or you have a long-term condition, or you are an older person, a health professional – for example, your GP, practice nurse or a pharmacist may arrange a meeting with you to discuss whether you are getting the best from your medicines. ☑ Over 65 years should have an annual medication review.
Hydration and Nutrition	☑ Promote a healthy diet and sufficient hydration, as nutritional deficiencies and dehydration can significantly contribute to weakness, constipation, lack of energy, low blood pressure and therefore an increased risk of falls. See “Nutrition” and “Fluids” section in this booklet. ☑ Look after your bone health – eat food containing calcium, and make sure you get enough vitamin D

Diabetes

It is important that people with diabetes receive regular check- ups to help manage their condition. Supporting people to keep their blood glucose, blood pressure and blood fat levels under control will greatly help to reduce the risk of developing complications in diabetes.

People who take insulin may be offered Continuous Glucose Monitoring – please speak to your healthcare team.

The short-term complications can include

Low-blood sugar (Hypoglycaemia) signs and symptoms:

- Feeling hungry, shaky, tired, dizzy, anxious, irritable or confused, sudden change in mood, pale, sweating, reduced or lack of concentration, possibly blurred vision, tingling lips or heart palpitations.

Severe hypoglycemia symptoms:

- Seizures or fit or become unconscious

High-blood sugar (Hyperglycaemia) signs and symptoms:

- Feeling thirsty, dry mouth, blurry vision, feeling very tired, weak, headaches, passing urine more than usual, possible abdominal pain, nausea, reduced or lack of concentration, losing weight without trying.

The long-term complications can include problems with:

- Vision – eye screening every 1 to 2 years
- Heart attack and stroke (cardiovascular disease)
- Kidney problems (nephropathy)
- Nerve damage and foot problems – diabetes can cause damage to nerves (peripheral neuropathy)
- Gum disease
- Sexual dysfunction

NHS Conditions: Diabetes

NHSE Diabetes Prevention Programme

No diagnosis of diabetes – follow health lifestyle, eat varied diet and exercise regularly

- **Continue to support, monitor and document observation.**

Person identified as at risk for developing type 2 diabetes.

Diagnosed with non-diabetic hyperglycemia or diabetes that is well controlled. Ensure the person has received structured lifestyle education.

- **Continue to support, monitor and document observation.**
- **Refer on if concerned to the GP or Practice Nurse**
- **Consider referral to NHSE Diabetes Prevention Programme,** helps people who are at risk of developing type 2 diabetes.

Person has Type 2 Diabetes and needs support in managing condition.

- **Consider signposting to SCFT Type 2 Diabetes Education programme**

Suspecting diabetes or symptoms of diabetes on an undiagnosed person. Diagnosed with diabetes – poorly managed, presenting unwell or with hypoglycaemic (low – blood sugars) / hyperglycaemic (high- blood sugars) episodes.

- **Follow treatment plan or treat as per NHS Low blood sugar (hypoglycaemia)**
- **Seek urgent support from the diabetes team the person is under, GP, Practice Nurse or Community Nurse, support/intervene and document.**
- **Consider calling 999**
  - Sudden onset of confusion; loss of consciousness or unresponsive

Diabetic Foot Care

Foot Care is particularly important, as people with diabetes can have reduced feeling and sensation or abnormal feelings in the feet (Peripheral Neuropathy).

People with Diabetes can also have a reduced blood supply to the feet due to narrowing of the arteries in the legs (Peripheral Arterial Disease).

Legs

Carers who support people with diabetes should check their feet on a regular basis when supporting them with personal care.

Refer on if any concerns, for example red areas, inflammation, or blisters, corns / callus or open areas.



Diabetes UK: How to look after your feet

NICE Guidance: Recommendations | Diabetic foot problems: prevention and management

Here are some top tips for the promotion of good foot care:

- Check feet daily for redness, swelling, pain or hard skin – monitor for changes and escalate if concerned
- Good control of blood sugar level can prevent foot problems or help heal open wounds
- Keep feet clean, wash and dry thoroughly daily and dry well particularly in between the toes
- Always ensure shoes / slippers fit well
- Explain importance to client of never walking barefoot, especially outdoors
- Cut or file toenails regularly. If the person is unable to see or reach their feet or have no carer / family to help with nail care then a referral to a Podiatrist could be arranged. Ensure corns or hard skin are treated by a podiatrist if gentle filing and emollient cream do not control the hard skin
- If there are any changes in sensation or feeling to the feet, ensure you report this to your health professional
- Make sure they attend their annual diabetic review with their GP or Practice Nurse as a foot check should be performed every year

Medication

Medicines need to be stored appropriately and safely so that the products are not:

- Damaged due to incorrect storage (e.g. heat or not refrigerated when this is required)
- Mixed up with other people's medicines
- Stolen
- Posing a risk to anyone else (e.g. children and vulnerable adults)

Remember the 'Eight Rights'

1. **Right person:** Confirm identity and check allergies.
2. **Right medicine**: Match the medicine label with the Medication Administration Record (MAR).
3. **Right dose**: Confirm the correct dose and formulation.
4. **Right route:** Confirm how the medicine should be given.
5. **Right time:** Check timing and spacing of doses.
6. **Right to decline:** Ask if the person is willing to take the medicine or a best-interest decision has been made where applicable.
7. **Right Information about the medication:** So that the person understands what the medication is for, how to take it, possible side effects and any precautions.
8. **Right Documentation:** Signing the MAR, recording refusals, omitted doses and reasons.

Classifications of Medicines

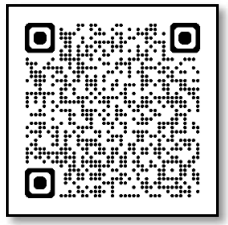
GSL (General Sales List) – can be sold without a prescription from retail outlets under conditions.

P (Pharmacy) – supplied in a pharmacy under supervision of a pharmacist.

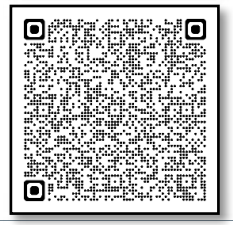
POM (Prescription Only Medicines) – only supplied on prescription from authorised prescribers.

CD (Controlled Drugs) are a subset of medicines legally controlled under the Misuse of Drugs Regulations and have specific storage and record-keeping requirements; they are all POMs but with additional controls.

Homely remedies are medicines used to treat a minor ailment e.g. pain relief or indigestion. They are purchased over the counter and kept as stock in a care home to give people access to medicines that would commonly be available in any household. They do not need to be prescribed but a policy of how to administer these safely should be provided by your organisation.



Sussex Health & Care: Medicines optimisation for care homes **(MOCH)** under "Self-care Toolkit" tab, shares SCFT's guidance on Homely Remedies and in supporting people to access self-care medications.



West Sussex County Council Medication Policy made an overview on Homely remedy on Section 14.19 to 14.24.

Medication (continuation)

Medication Reconciliation (or medicine reconciliation)

This is a structured safety process used to ensure that a person's Medication Administration Record (MAR) is accurate, complete and up to date, particularly at points of transition such as admission to hospital, transfer between services, or entry into a care home. This involves:

1. **Collecting an accurate medication history**
   - All prescribed and non-prescribed medicines and herbal or complementary products including dose, route and frequency
   - Allergies and sensitivities
2. **Using at least two independent sources**
   - GP medication list / repeat prescription record
   - Person's own medication (labelled boxes/blister packs)
   - Community pharmacy records
   - Hospital discharge summary
   - Summary Care Records
   - Care or family confirmation (where appropriate)
3. **Checking for differences and resolving discrepancies**
   - Missing medicines
   - Incorrect doses
   - Stopped medicines still listed
   - Changed frequencies
   - Duplications

   Any discrepancies must be clarified with the prescriber before updating the MAR chart.

Medication Reviews

Medication reviews must be undertaken at least annually as part of an Annual Health Check but can also be undertaken by Primary Care Network and Medicines optimisation in care homes (MOCH) pharmacists.

Supporting Medication Administration

Carers must be trained and competent for the level of support they provide determined in Care plans and risk assessments.

- **Level 1 – Assist** (Prompt, Pass, Prepare under supervision, Open but not give)
- **Level 2 – Administer** (Prepare unsupervised, Give, Apply)
- **Level 3 – Administer by special techniques** (Rectal or Vaginal medicines, PEG, RIG, Injections, Nebuliser, Oxygen canister changing, Buccal Midazolam)

Ask a pharmacist for advice if you have a medication related query, they are usually best placed to respond to queries.

Tip: Write the telephone number of the patient's community pharmacy on the Medication chart or care plan along with the GP surgery in case of any queries.

NICE Guidance: Managing medicines for adults receiving social care in the community also includes guidance on "Managing medicine in care homes" and Home care – delivering personal care and practical support to older people living in their own homes.

Medication (continuation)

Medicines may be administered by carers or care workers provided the medicine has been prescribed by an appropriate practitioner, the individual has given consent (or a best-interest decision has been made where applicable), and the carer is acting within their role, training, and organisational medicines policy. In regulated care settings, carers must be trained, assessed as competent, and follow local procedures.

Principles for Carers Who Support Medication

- Always read the instructions on the medicine packaging,
- Always read the instructions on the medicine packaging, pharmacy label, MAR chart, or dosette box before administration.
- Medicines must be given exactly as prescribed, including dose, timing, and route.
- Instructions on how and when medicines should be given must be clear. If anything is unclear or inconsistent, seek clarification from a pharmacist, GP, nurse, or prescriber before administering.
- Medicines should be given at the recommended time of day and with regard to food requirements (before food, with food, or on an empty stomach), as incorrect timing may reduce effectiveness or increase side effects.
- Follow your employing organisation's medicines policy, which defines:
  - → What level of support you may provide
  - → Which medicines you may administer
  - → What training and competency assessment is required
- Never administer medicines outside your level of competence or contrary to local policy. Seek additional support.

STOMP: Stopping Over Medication of People with a Learning Disability and Autistic People aimed at reducing the inappropriate prescribing of psychotropic medicines for people with a learning disability and autistic people.

Person is assessed as competent and able to take their medicines safely.

- ▶ **Continue to monitor and document.**

Person requires support with medicines.

- ▶ **Provide assistance in a person-centred manner, promoting independence where possible.**
- ▶ **Support may include prompting, preparation, or administration, depending on assessed need.**
- ▶ **Monitor and document.**

Problems identified with taking medicines.

- ▶ **Seek urgent support from a pharmacist, GP, Practice Nurse or Community Nurse on the day the issue is identified.**
- ▶ **Do not alter medicines (e.g. crushing tablets) unless this has been authorised and documented.**
- ▶ **Continue to monitor, document the issue, advice received, and actions taken in the care record and MAR chart as appropriate.**

Read more about STOMP in Stop Look Care 2024 handbook is available for supporting delivery of great care for people with a learning disability.

What is a learning disability?

The Department of Health's 2001 on a 'New strategy for learning disability in the 21st century', stated that a learning disability included the presence of:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence),
- a reduced ability to cope independently (impaired social functioning), and
- which started before adulthood, with a lasting effect on development

…meaning that learning disabilities can make everyday life more challenging, and that support might be needed in order for the person to live with as much independence and choice as possible.

However, they do not define the person.

Learning disability is a protected characteristic under the Equality Act 2010 and services need to ensure that they provide reasonably reasonable adjustment combined with anticipatory duty for people with a learning disability to best meet their needs.

NHS England » Reasonable adjustments

A learning disability should not be confused with:

- **Learning Difficulty** – is more easily described as 'a type of special educational need, where adjustments and targeted support can usually mitigate the difficulty, and which does not affect general intellectual function.' E.g. dyslexia, dyspraxia.
- **Mental Health diagnosis** – this can be temporary and fluctuate and doesn't necessarily interfere with cognitive function.
- **Autistic Spectrum Disorders** – although autistic people may also have a learning disability.
- **Acquired brain injury acquired after age 18** – is a type of brain damage with multiple different effects. An acquired brain injury before the age of 18 will result in a learning disability.

Learning Disability Resources

The NHS Sussex ICB produced a specific Stop, Look & Care booklet to support carers and people with learning disabilities.

Use the link: Stop Look Care 2024 - Supporting you to deliver great care for people with a learning disability



Read more about available support here:

Sussex Health and Care: **Support for people with a learning disability**

NHS **LeDeR - Resource Bank**

Normal presentation no concerns identified, support in a personalised way.

- **Continue to monitor and document observations.**
- Ensure reasonable adjustments are in place.
- Ensure annual health check from the age of 14 is attended once a year.

Additional support needs identified.

- **Support, continue to monitor and document observation and intervention.**
- Ensure that reasonable adjustments are current and relevant.
- Refer to **SLC 2024** for further support

Concerns or person has unmet needs.

- **Support, continue to monitor and document observation and intervention.**
- **Refer to SLC 2024 for further support**
- **Seek support from healthcare professionals:**

Person is showing some changes in their presentation, behaviour or function – liaise / inform the GP.

The GP, social worker or community learning disability health team should be able to provide information about advice and support services in your area, including NHS services, social services, charities and voluntary organisations.

Learning disabilities (adult): Sussex Partnership NHS Foundation Trust

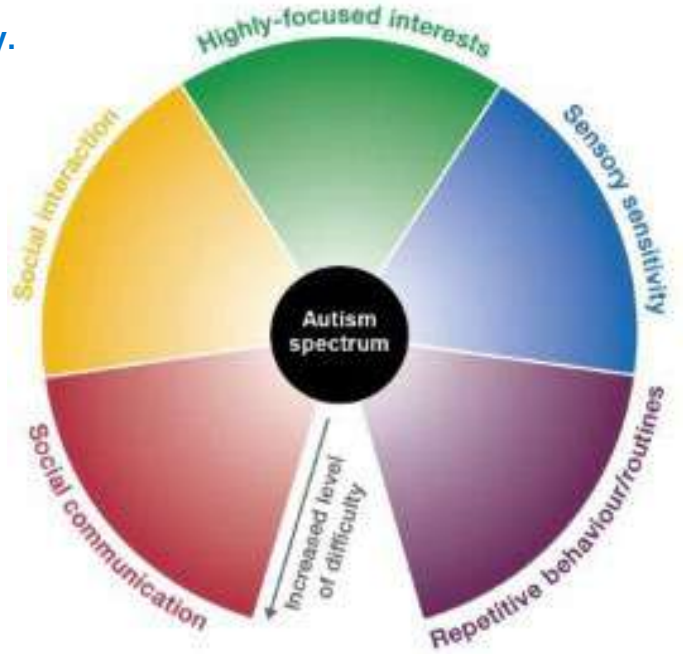
Autism spectrum condition (ASC)

Not all autistic people have a learning disability.

Autism is a lifelong neurodevelopment condition that influences how people experience and interact with the world. It is a lifelong neurodivergence and disability.

It also affects how people make sense of the world around them. People with a learning disability are more likely to have autism (20-30%, compared to 1% of general population).

Autistic people may have difficulties in areas specified within the infographic (see right); the level of difficulty in each section may vary.



Signs of autism in adults - NHS

- Common signs of autism in adults include:
- finding it hard to understand what others are thinking or feeling
- getting very anxious about social situations
- finding it hard to make friends or preferring to be on your own
- seeming blunt, rude or not interested in others without meaning to
- finding it hard to say how you feel
- taking things very literally – for example, you may not understand sarcasm or phrases like "break a leg"
- having the same routine every day and getting very anxious if it change

See a GP or healthcare professional to be referred to an autism assessment.
Where to get autism support - NHS

More information
More information about autism and ASC can be found here:

National Autistic Society website
www.autism.org.uk

NHS Sussex Partnership website
www.sussexpartnership.nhs

Mental Health and Wellbeing

Mental health (MH) disorder typically involves:

- Disturbances in how a person thinks, their mood, or behaviour
- Difficulty coping with everyday life and functioning
- Distress and/or significant impairment in relationships, work, education or social participation

Risk factors for poor Mental Health:

- Certain factors may increase an individual's vulnerability to mental health difficulties, including:
- Lifelong or long-term health conditions
- Limited social networks or isolation
- Communication difficulties
- Sensory processing difficulties
- Low income or financial insecurity
- Limited coping strategies
- Lack of meaningful activities, education, or employment

Carers play a vital role in supporting mental health by:

- Recognise early signs of mental distress and raise concerns or signposting individuals to appropriate support services.
- Using personalised, person-centred approaches
- Empowering individuals to maintain choice, control, and independence
- Being aware that their own attitudes, communication style, and behaviour can have a positive or negative impact on the person they support

Some individuals may be unable to recognise or communicate how they are feeling. In such cases, they rely on carers to actively observe changes in their behaviour, mood, or routine and to promote positive mental wellbeing.

It is important to:

- Give individuals time and space to express their thoughts and feelings where possible
- Encourage an active, inclusive, and enabled lifestyle
- Proactively reduce avoidable stressors or sources of distress
- Take concerns seriously and act promptly

Common mental health conditions include (not an exhaustive list):

- **Psychosis (e.g. schizophrenia or bipolar disorder):** May result in confusion and acute distress, due to hallucinations, delusions and lack of self-awareness or profound lethargy
- **Depression:** May cause persistent change in mood, changes in personality and problems with sleeping, changes in appetite and difficulties in relationships.
- **Anxiety:** Can lead to sleep problems, heart palpitations, dry mouth, panic or feeling of fear, and physical symptoms such as cold or sweaty hands and feet.
- **Personality Disorder**: May affect a person's ability to cope with everyday life, manage relationships and regulate emotions effectively.

Mental Health Support Services in Sussex

Early detection of concerns about mental health is important to ensure that people are supported in the correct way.

Signs of a Mental Health Crisis

Emotional and Psychological Signs

- Intense distress, panic, or overwhelming anxiety
- Extreme mood changes, agitation, or emotional withdrawal
- Feelings of hopelessness, despair, or worthlessness
- Expressions of paranoia, fear, or feeling out of control
- Talking about death, self-harm, or suicide

Behavioural Signs

- Sudden changes in behaviour or routine
- Aggression, hostility, or uncharacteristic risk-taking
- Social withdrawal or refusal to engage
- Neglect of personal care, nutrition, or hydration
- Giving away possessions or making final arrangements

Cognitive and Perceptual Signs

- Confusion, disorientation, or inability to concentrate
- Hallucinations (seeing or hearing things others do not)
- Delusions or strongly held false beliefs
- Poor decision-making or loss of insight

Physical Signs

- Significant sleep disturbance (insomnia or excessive sleeping)
- Physical symptoms of anxiety (e.g. palpitations, shaking)
- Unexplained physical complaints linked to anxiety or distress

Don't Brush It Under the Carpet - suicide prevention campaign tailored for older adults provides guidance, resources, and support for older adults, as well as those caring for or working with them. It brings together practical advice, risk awareness, and access to help services to support mental wellbeing and prevent suicide in later life.

If your life – or someone else's life – is in immediate danger,

▶ **Call 999 or go to A&E now for immediate help.**

If you are concerned and would like to know what support is available, please Ctrl + click images to follow the link below:



Bereaved by Suicide Support Services in Sussex

Cruse's Bereaved by Suicide Sussex service offers free, confidential support for people affected by suicide across Sussex, helping them navigate the complex and often overwhelming grief that can follow such a loss. It provides a range of tailored support and guidance, recognising that bereavement after suicide can be especially painful and difficult to process.

Email sussexbereavedbysuicide@cruse.org.uk or
Call 07376 616628

Trauma-Informed Practice

The “Three Es” definition of Trauma:

Trauma happens when someone **Experiences** something deeply upsetting, harmful, or life-threatening.

This could be one **Event**, several events over time, or ongoing difficult circumstances.

These experiences can have long-lasting **Effects** on a person’s physical and mental health, relationships, emotions, and sense of safety or identity.

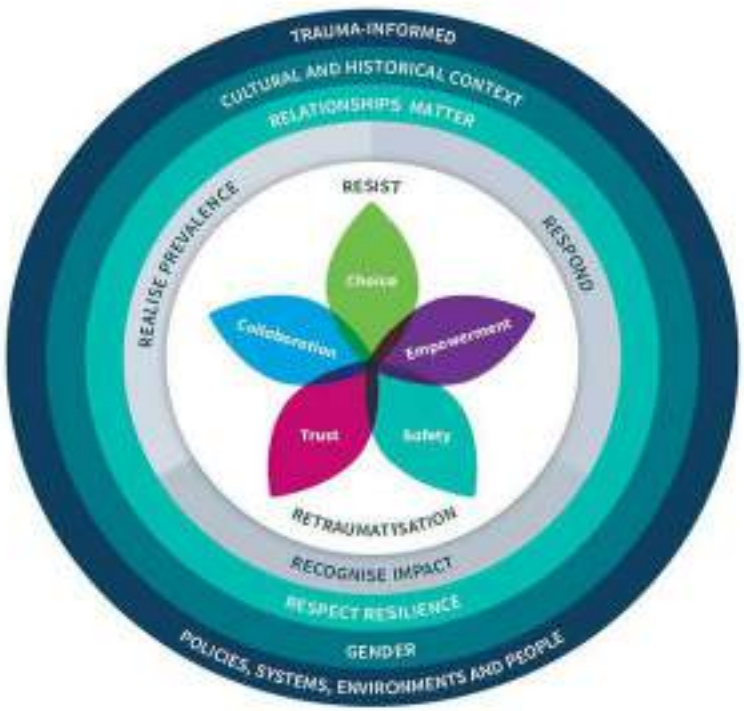
Trauma-Informed Practice (TIP) is an approach that recognises the widespread impact of trauma and understands potential paths for recovery. It emphasises **physical**, **emotional**, and **psychological safety** for everyone and seeks to create environments where people **feel safe**, **supported**, and **empowered**.

TIP is based on key principles: safety, trustworthiness, choice, collaboration, and empowerment.

TIP aims to **recognising the signs of trauma**, **avoiding re-traumatisation**, and **responding with compassion** as well as the importance of viewing someone through the lens of their cultural and historical background.

Sussex Health & Care: Trauma Informed Framework Call to Action is to embed Trauma-informed practice across Sussex.

TIP is not a specific intervention, but a cultural shift in how services are delivered – valuing relationships, co-production, and equity. It is relevant across all sectors, helping build resilience and improve long-term outcomes



Legislation that is relevant to carers:

Citizens Advice - Human rights Act 1998 protects the basic rights and freedom that belong to every person in the UK.

NHS - Mental Health Act (easy read) is the main piece of legislation that covers the assessment, treatment and rights of people with a mental health disorder.

The UK's data protection legislation controls how personal information is used by organisations, including businesses and government departments.

Dementia

Dementia is an umbrella term for a number of conditions that affect thinking skills, such as memory, language, object perception, attention and the ability to plan and organise.

The most common types of dementia are Alzheimer's Disease, Vascular Dementia, Lewy Body Dementia, Fronto- Temporal Dementia and dementia in Parkinson's Disease.

Dementia is a progressive illness so an early diagnosis of dementia can help planning for the future, including conversations around Lasting Power of Attorney and end of life wishes whilst the person still has capacity. In some cases, an early diagnosis of dementia can improve access to certain types of medication, which may support the person.

A person-centred and personalised approach is needed for all people with dementia. The approach needs to change as this develops for each person.

People can live well with dementia. If persons are showing signs of distress, then they may have physical or mental health issues that can be managed.

Distressed behaviour — including behaviours that may be described as challenging — are frequently expressions of unmet need that may relate to: Comfort, Attachment, Inclusion, Occupation and Identity. Adopting a Positive Behaviour Support approach can help consider and proactively address these needs.

Normal presentation no concerns identified, support in a personalised way.

- **Continue to monitor and document observations.**
- Ensure advance care plan is in place and current.
- Baseline measures of skills and abilities can be taken at this stage, by community learning disability teams and can be checked against if there are concerns in the future.

Dementia - NHS

Person has a diagnosis of dementia: support in a personalised way and follow care plan.

- **Support, continue to monitor and document observation and intervention.**

Person is showing some changes in their presentation, behaviour or function – liaise / inform the GP or mental health team if known

The GP, social worker or dementia specialist should be able to provide information about advice and support services in your area, including NHS services, social services, charities and voluntary organisations.

To speak to a specialist dementia nurse about any aspect of dementia, please call the free Dementia UK Helpline on 0800 888 6678.

Sudden or serious change in presentation: urgently contact the GP surgery or mental health team if known to document concerns

- **Seek urgent support from GP or mental health team if known to the team**

Delirium

Delirium is an acute disturbance of mental function characterised by:

- A sudden change in attention, awareness, and cognition – over hours or days.
- May fluctuate throughout the day, often worsening in the evening or at night.
- Commonly seen in people who are physically unwell, particularly older adults or those with serious medical conditions.
- Common and serious condition; however, it is often reversible if the underlying cause is identified and treated promptly.
- Frequently misdiagnosed as dementia, although the two conditions are clinically distinct.

Symptoms of Delirium

Individuals may experience one or more of the following changes:

- Disorganised or rambling speech and impaired thinking
- Sudden changes in behaviour or personality
- Disturbed sleep–wake cycles, including nighttime agitation or daytime drowsiness
- Rapid and unpredictable mood changes
- Hallucinations (seeing or hearing things that are not present)
- Delusions or paranoid beliefs

Hypoactive Delirium - reduced alertness, lethargy, withdrawal, and slowed movements or speech. Individuals may appear quiet, sleepy, or depressed. This subtype is commonly overlooked or misdiagnosed as depression or fatigue, despite being associated with poorer outcomes if untreated.

Hyperactive Delirium - increased alertness, restlessness, agitation, and sometimes aggressive behaviour. Individuals may experience hallucinations or delusions (e.g. believing others intend to harm them).

Mixed Delirium - individuals alternate between hypoactive and hyperactive delirium symptoms over the course of the day.

Individual is well, normal presentation no concerns identified, support in a personalised way.

- **Continue to support, monitor and document observations.**
- Undertake Delirium risk assessment.

NICE Guidance: Delirium

Person is unwell and your risk assessment is showing that individual is prone to developing delirium. Treatment and care plan for underlying conditions are in place.

- **Support, increase monitoring frequency and document observation and intervention.**

Person has gradually become more forgetful or confused.

You are concerned or worried.

- **Seek NHS111 or GP support.**

Person suddenly becomes confused. Consider Acute Deterioration, infection and Sepsis.

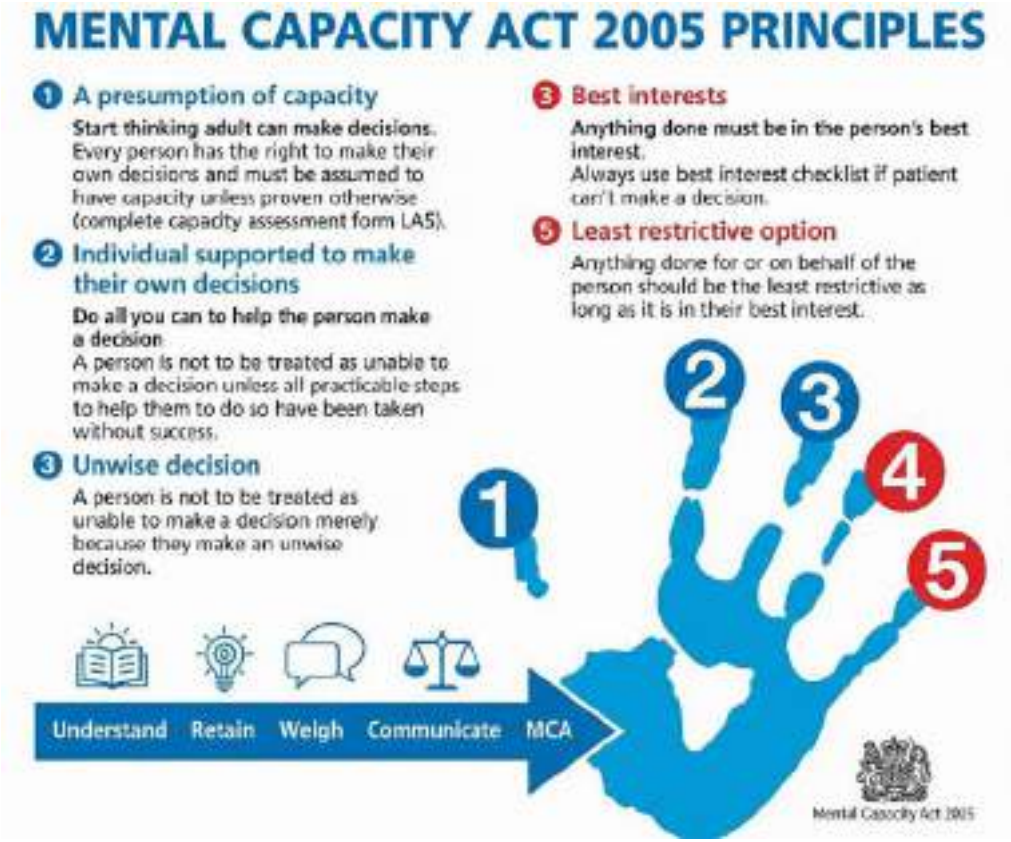
- **Go to A&E or call 999.**

Mental Capacity

What is mental capacity?

- Mental capacity is the ability to make an informed decision
- It can vary over time.
- It can vary depending on the decision to be made
- Physical conditions and the environment can affect a person's ability to make a decision.

The Mental Capacity Act is designed to protect and empower individuals who may lack the mental capacity to make their own decisions about their care and treatment.



Relevant Legislation for Carers

NHS: Mental Capacity Act - Social care and support guide

West Sussex Mental Capacity Act summary guidance | Summary guidance | Safeguarding Adults Board

Mental Capacity (continuation)

Person has capacity to make their own decision.

- **Continue to regularly assess person's mental capacity and document observations.**
- Ensure advance care plan has the up-to-date contact details of next of kin.

Person has fluctuating capacity or is unable to make some decisions

- **Support them to make decisions when they do have capacity through all practicable means.**
  - Providing information in an accessible format (using plain language, visual aids, pictures, familiar objects or written summaries)
  - Allowing sufficient time
  - Choosing the right time and environment
  - Breaking information into smaller parts
  - Involving trusted people
  - Explaining consequences clearly
  - Supporting communication (using interpreters, sign language and communication aid)
- **Seek support from speech and language therapist where needed.**

Person lacks the mental capacity to make serious decisions—such as managing their finances, deciding where to live, or consenting to medical treatment—despite all practicable support having been provided and exhausted.

- **Follow advance care plan.**
- **Contact the appropriate decision maker and support them to assessment capacity and make a best interest decision.**
- **Organise a Best Interest meeting (next page).**

Mental Capacity - Best Interest

The Mental Capacity Act 2005 (MCA) sets out a checklist of factors to be considered when making a best interest's decision.

Best interests are not just medical best interests. You must consider the person's welfare in the widest possible sense, and consider the individual's broader wishes and feelings, and values and beliefs.

Once you decide that a best interest decision is required, remember - The best interests assessment process will depend upon what is reasonable, practical, and appropriate in each case.

Best Interest Checklist

- Take all reasonable steps to permit and encourage the person to participate or to improve their ability to participate in the decision.
- Take account of the person's past and present wishes, feelings, values and beliefs where those are known or can be reasonably ascertained.
- The fact that a person lacks capacity does not automatically mean that their views can be excluded or discounted in the decision-making process. The person lacking capacity should participate as fully as is possible in any decision affecting them.
- Those involved in caring for the person, or interested in his or her welfare, must be consulted about their views on the person's best interests, and the person's past and present wishes, feelings, beliefs and values. Ensuring they have all the information in their preferred format to help them participate as much as possible is essential.
- Ensure you have a proportionate approach to decision–making and the least restrictive intervention



Mental Capacity - Best Interest (continuation)

Who is responsible for making the best interests decision under the MCA 2005?

Responsibility for best interests decisions lies with those involved in the person's care. Best interests decision-making is a shared responsibility and should follow a **multi-disciplinary approach**, ensuring that relevant professionals involved in the person's care are consulted, in order to take a **holistic and informed approach**. This ensures that the person's wishes, feelings, values, and overall circumstances are properly considered.

A **multi-disciplinary approach** should be taken wherever appropriate, with input from professionals who can reasonably contribute to the decision.

Where the decision relates to **medical treatment**, the **doctor or healthcare professional** responsible for proposing and delivering that treatment is the formal decision-maker under the Act. They must, however, follow the best interests checklist and consult with relevant individuals as required by the Mental Capacity Act.

Advance decisions to refuse treatment (ADRTs) Sometimes a person will have made a valid and applicable advance decision to refuse treatment (ADRT), which applies in the person's clinical situation. Here the person has already decided to decline a certain treatment and that decision must be respected, as if it were a person with capacity making it.	**Lasting power of attorney (LPA)** Some people have made a lasting power of attorney (LPA) appointing a health and welfare attorney. Where a person has the appropriate powers (including, in the context of decisions about life-sustaining treatment, the power to consent to or refuse such treatment), and the LPA has been registered with the Office of the Public Guardian (OPG), the health and welfare attorney is the lawful decision-maker.
Court-appointed deputies In some cases, the Court of Protection may have appointed a deputy to make welfare and healthcare decisions for someone who lacks capacity. The decision to appoint (and who to appoint) is to be taken in the best interests of the person, taking into account their wishes and feelings, and also the principle that the appointment of a deputy is not necessarily less restrictive of a person's rights and freedoms than the normal decision-making process of the MCA.	**Independent Mental Capacity Advocate (IMCA)** provides independent safeguards for people who lack capacity and, at the time the decision needs to be made, have no-one else to support or to represent them.

Remember - The MCA established the **Court of Protection** to make a decision or to appoint a decision-maker on someone's behalf in cases where there is no other way of resolving a matter affecting a person who lacks capacity.
This may arise because there is disagreement.

Advance Care Planning (ACP)

Advance care planning means **thinking ahead**, having **conversations with healthcare team** and **writing down wishes about the care the person would like in future**. Planning ahead can help make sure their wishes are followed, in case they become too unwell to make or communicate decisions themselves.

It helps make sure that **their choices are known, respected and followed** by healthcare professionals and family members**.**

Who it's for

- Anyone over **18 years old,** can start advance care planning at any stage in life and is something that can be reviewed and updated.
- It is particularly important for people who are at risk of deterioration, are frail or have long-term conditions.

Easy Steps to start on Advance Care Planning

1. For the individual to think what matters to them
   - **What matters to them** (values, beliefs, quality of life)
   - **Care they would or would not want** (for example, life-sustaining treatment)
   - **Where they would prefer to be cared for** (home, hospital, hospice)
   - **Who they want to speak for them** if they can't make decisions
2. Talk with people who matter - with family, carers, and healthcare professionals
3. Record their wishes
4. Keep copies and keep it updated
5. Share with relevant people – family or trusted friends, GP or clinicians involved in your care

Important to know

- The individual can **change or cancel** your plan at any time

Different tools used in ACP

- ReSPECT process and form is recommended in Sussex as it replaces traditional DNACPR decisions (which focus only on CPR) because it covers all emergency treatments.
- **Advance Statement**
  Explains the person's wishes, values, and preferences. Not legally binding, but doctors must consider it.
- **Advance Decision to Refuse Treatment (ADRT)**
  A legal document that lets the person refuse specific treatments in certain situations.
- **Lasting Power of Attorney (Health and Welfare)**
  Lets someone they trust make health decisions for them if they lose capacity.

Sussex Health & Care: End of life care provides carers with information to support someone who may need an **Advance Care Planning** conversation or who may be nearing the end of life.

It also includes guidance on **palliative care: anticipatory medicines, community and hospice support**, **out-of-hours support**, and other useful **resources for carers**.

Marie Curie Charity also produced free resources for individuals and carers. Link: Advance care planning - Gold Standard Framework

ReSPECT Plan

Recommended Summary Plan for Emergency Care and Treatment Plan

ReSPECT is the recommended advance care planning tool across Sussex. It is developed by the Resuscitation Council UK. It is a structured planning process and personalised emergency care plan.

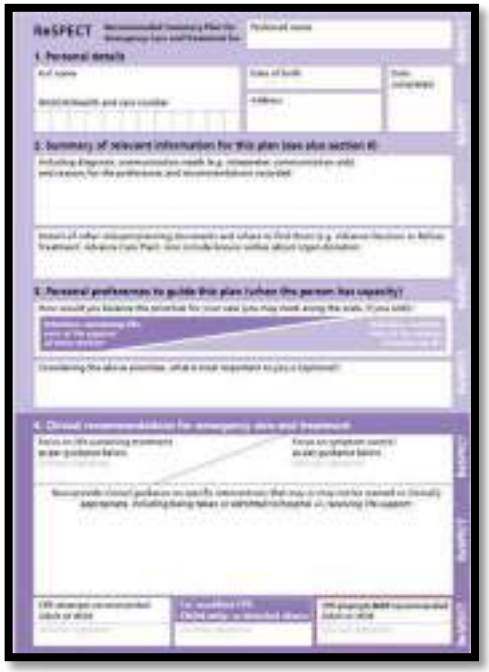
It helps people and their healthcare professionals think ahead and agree on which treatments *may* or *may not* be appropriate in the future emergency when someone cannot make or communicate decisions themselves.

Key points:

- **ReSPECT can replace traditional DNACPR decisions** (which focus only on CPR) because it covers *all* emergency treatments.
- **Keep it current** by regularly reviewing and updating the ReSPECT form.
- **ReSPECT is person-centred:** it focuses on what matters to *the person* rather than only clinical decisions.

  It asks:
  - *What treatments you would want considered,*
  - *What treatments you would not want, and*
  - *What treatments would not work or might cause harm in your situation.*
- **It supports shared decision-making:** their preferences and clinical judgment together shape the recommended plan.
- **It is not legally binding:** healthcare professionals use it to guide emergency decisions, but final clinical decisions are made based on the person's plan and best practice.

Resuscitation Council UK



Free resources available on the website: [ReSPECT | Resuscitation Council UK]

- **Free downloadable forms**
- **Video resources** for patient and carers
- **E-learning courses** for healthcare professionals

Also, visit link: [ReSPECT for healthcare professionals.]

If your organization wish to adopt ReSPECT, you will have to contact [info@respectprocess.org.uk].

Resource in other language is also available in: [ReSPECT resources | Resuscitation Council UK]. (Arabic, Chinese, Gujarati, Polish, Punjabi, Urdu and Turkish)

End of life care – caring for dying people

Everyone should be able to die as comfortably as possible.

Recognising that a person is dying usually involves careful clinical decision-making, including acknowledgement that there are no reversible causes remaining, appropriate documentation, and clear communication to allow a natural death. This may include completion of a **ReSPECT form** (includes instructions on Do Not Attempt Cardiopulmonary Resuscitation if applicable).
See the “Advance Care Planning” section of this booklet, alongside open conversations with the dying person and those important to them, including carers.

Once this is agreed, the focus of care can shift from life-sustaining, often invasive treatments to prioritising comfort, wellbeing, dignity, and respect for the person’s wishes. Although it can be difficult to be certain that someone is dying, acknowledging the possibility allows the whole care team to work together to establish appropriate goals of care.

Death is not always easy to talk about, despite being a universal experience. Research shows that most people are aware when they are dying and prefer to talk about it when given the opportunity. In contrast, families and loved ones often experience regret when these conversations do not take place openly.

The national framework to support caring for dying people is called the **Ambitions for Palliative and End of Life Care**



“I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s).”

NICE Guidance: Care of dying adults in the last days of life

NHS Sussex launched the **Respecting Faith and Culture in End of Life Care** handbook for health and care staff to help colleagues provide truly personalised end of life care. Download the resource below.

End of life care (continuation)

Though every death is different, there are some common symptoms to review regularly

1. Pain
2. Breathlessness
3. Nausea/Vomiting
4. Anxiety and Delirium
5. Secretions

Ensuring there is a multidisciplinary plan for each of these symptoms including rapid access to relevant medications is essential and requires liaison with medical and pharmacy teams. Seek support from the community nursing team or your local hospice.

Care after death should be considered as part of advanced care planning.

Don't forget bladder, bowel, oral and skin needs

5 Priorities to deliver best care for a dying person

Each step helps us to create a personalised plan of care for the person and those important to them.

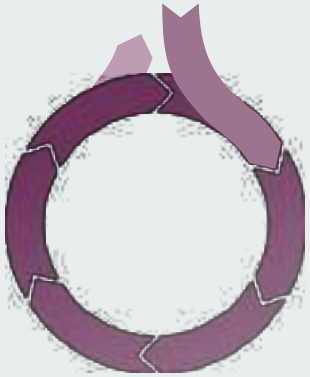
1. Recognise
The possibility that a person may die within the next few days or hours is recognized and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.

2. Communicate
Sensitive communication takes place between staff and the dying person, and those identified as important to them.

3. Involve
The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants

4. Support
The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.

5. Plan & do
An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.



Bereavement Support

Losing someone can be very difficult. It can impact everyone, families, friends, other residents and staff members.

Bereavement is highly individualized. It affects everyone in different ways. There's no right or wrong way to feel.

An individual will probably go through all stages of Grief, but they won't necessarily move smoothly from one to the next. Their grief might feel chaotic and out of control, but these feelings will eventually become less intense. Give them time.

If you feel that you or the person requires bereavement support, you can speak to your GP or local hospice or national Cruse helpline on 0808 808 1677.

Stages of Grief:

Denial - shock and numbness.
Denial helps regulate overwhelming affect in the acute phase of loss. It is typically temporary but can resurface at triggering moments (e.g., anniversaries)

Anger – irritable or rage; blames oneself or others; resentment
Anger often masks vulnerability—hurt, fear, helplessness. It can provide a sense of agency in a situation defined by powerlessness.

Bargaining – "what if" scenario; "If only I had…" rumination; replaying events to find alternative outcomes; making promises to a higher power; guilt-driven thinking

Depression - overwhelming sadness or despair; withdrawal from social interaction; tiredness or exhaustion.
Confrontation with reality of loss.

Acceptance - acknowledgment that the loss is real; ability to remember without overwhelming distress; gradual re-engagement with life

Easy Read Bereavement Resources and Support:

- Macmillan - Grief and loss when someone dies
- Macmillan - How you may feel when someone dies

Sussex Health & Care: End of life care - list of hospices in Sussex

East Sussex County Council: Bereavement Support

Brighton & Hove City Council: Bereavement support resources

West Sussex County Council: What to do when someone dies

Bereaved by Suicide Services from Sussex Community NHS Foundation Trust offers specialist counselling and support for individuals affected by suicide. It provides compassionate, tailored help to people coping with loss, aiming to improve emotional wellbeing during bereavement.

Email - sussexbereavedbysuicide@cruse.org.uk
Call - 07376 616628

Live Healthy and Live Well

NHS guidance for adults on staying healthy, taking part in screening, keeping your heart healthy, and accessing reasonable adjustments in healthcare.

1. Staying Healthy for Longer

Encourage adults to take simple steps to stay healthy and independent for longer. This includes eating well, staying physically active, avoiding smoking, limiting alcohol, and looking after your mental wellbeing.

6 -week course Living Well Programme

NHS Healthy Living

Better Health

Age UK Charity

2. NHS Screening Programmes for Adults

The NHS offers free screening to adults to help detect certain conditions early, before symptoms appear. You will usually receive an invitation when you are eligible.
Adult screening programmes include:

- **Cervical screening** (women aged 25–64)
- **Breast screening** (women aged 50–70, with some over 70)
- **Bowel cancer screening** (adults aged 50–74)

3. Keeping Your Heart Healthy

Adults aged **40–74** are eligible for a free NHS Health Check every five years. This checks your risk of heart disease, stroke, diabetes, kidney disease, and some forms of dementia.
The Health Check includes:

- Blood pressure
- Cholesterol
- Weight and lifestyle questions

4. Reasonable Adjustments in Healthcare

If you are an adult with a disability, learning disability, sensory impairment, or other additional needs, the NHS must make **reasonable adjustments** so you can access healthcare safely and comfortably.
Examples include:

- Longer appointments
- Easy-read or large-print information
- Quiet waiting areas
- Communication support or interpreters

Tell your GP or healthcare provider about your needs so adjustments can be recorded and provided.

5. Supporting Good Health Checklist

Use this checklist to help manage your health:

- Registered with a GP
- Attending adult screening when invited
- NHS Health Check completed (if aged 40–74)
- Vaccinations up to date
- Long-term conditions reviewed regularly
- Reasonable adjustments requested if needed

If you are unsure or have concerns, speak to your GP or practice nurse.



Adult Social Care

Adult social care is a broad term that refers to support provided by a wide range of agencies and persons to help those in need to maintain their independence and well-being.

Some people will have social care needs which they need paid and professional support to meet. These needs should be assessed under the Care Act 2014 by the Local Authority.

The Care Act 2014 is the law that sets out how adult social care in England should be provided. It requires local authorities to make sure that people who live in their areas: receive services that prevent their care needs from becoming more serious or delay the impact of their needs. For example, day centres, respite services, shared lives schemes, supported living houses, residential and nursing care homes.



Also, there are lots of places in the community that can help a person meet their social care needs. Here are some ideas below.

- Family and friends
- National charities
- Local charities
- Care agencies
- Church groups
- Community groups
- Cleaning services
- Meals on Wheels
- Dial a Ride
- Local council for telecare
- Carers support services

Who is a Carer?

A carer is a person of any age who provides unpaid care and support to a family member, friend or neighbour who is disabled, has an illness or long-term condition, or who needs extra help as they grow older.

Information about support for carers can be accessed via www.sussex.ics.nhs.uk/professional-guidance/carers/support-for-carers/

Adult Social Care (continuation)

Sometimes people are not able to manage their own social care needs or require additional professional support from a Social Care Worker.

A Social Care assessment can be completed by your local Social Care Team who will consider the following factors in relation to eligibility:

- The adult's needs for care and support arise from or are related to a physical or mental impairment or illness and are not caused by other circumstantial factors.
- As a result of the adult's needs, the adult is unable to achieve two or more of the outcomes specified in the Care Act (2014); examples include unable to manage personal care, nutritional needs or accessing the community.
- As a consequence of being unable to achieve these outcomes, there is, or there is likely to be, a significant impact on the adult's wellbeing.

Everyone is entitled to a Social Care Assessment or a Carer's Assessment, as outlined in the Care Act (2014).

The Care Act also gives carers the right to receive support from their local authority if they have eligible needs

If you feel an adult social care assessment or a carers assessment would be of benefit, please contact your local authority.

The person is independent and has no appearance of needs.

▶ **Continue to monitor and document.**

Person has social care needs entirely met through their support networks.

Person is having social care difficulties that cannot be managed by family or friends.

Person can access support from various community sources listed overleaf.

Consider whether a social care assessment / carers assessment would be of benefit.

▶ **Support, closely monitor, document and escalate to local Social Care Team if appropriate.**

Person is unable to meet their own social care needs and/or there is a high risk of Carer burnout

▶ **Contact the local Social Care Team to request an Adult Social Care Assessment**

Adult Safeguarding

What is adult safeguarding?

- Protecting an adult's right to live in safety, free from abuse or neglect
- Promoting the wellbeing of the adult
- Showing regard for the adult's views, wishes, beliefs and feelings when deciding on action
- Providing support and interventions for adults who have experienced or are experiencing abuse

Please consider the needs of any children who maybe in the household or have contact with the adult you are concerned about
Link to child Pan Sussex Safeguarding policy and procedures:
[Sussex Safeguarding and Child Protection Policy and Procedures Resource]

You must raise a safeguarding concern if you are working with an adult who:

- Has care and support needs, and
- Is experiencing, or is at risk of, abuse or neglect, and
- Is unable to protect themselves because of their care and support needs



Additional protocols and guidance | Sussex Safeguarding Adults Policy and Procedures

Types of Abuse & Neglect (ten categories)

1. **Neglect**
   Ongoing failure to meet someone's basic physical or emotional needs.
2. **Self-neglect:**
   When a person's own behaviour puts their health, safety, or wellbeing at risk.
3. **Physical Abuse**
   Causing or threatening physical harm.
4. **Sexual Abuse**
   Involving someone in sexual activity without consent.
5. **Psychological / Emotional Abuse**
   Ongoing emotional harm.
6. **Financial & Material Abuse**
   Misuse of someone's money or property.
7. **Organisational Abuse**
   Poor care or neglect within a service or institution due to how it operates.
8. **Discriminatory Abuse**
   Abuse based on personal characteristics — age, disability, gender identity, race, religion, sexuality, etc., including harassment or exclusion.
9. **Modern Slavery**
   Exploitation such as forced labour, human trafficking, domestic servitude, or being held in conditions of slavery or servitude.
10. **Domestic Abuse**
    Abuse by someone in a close relationship — physical, sexual, psychological, financial, or emotional, including controlling/ coercive behaviour and honour-based violence.



Types of Abuse & Neglect - Brighton SAB

Adult Safeguarding (continuation)



Report adult safeguarding concerns to Brighton & Hove Access Point

Call: 01273 295 555 – 9am to 5pm, Monday to Friday (outside these hours, calls will be answered by Carelink Plus)

Email: hascsafeguardinghub@brighton-hove.gov.uk

Or report your concern online:

brighton-hove.gov.uk/adult-social-care/report-safeguarding-concern

▶ **In an emergency, always call 999**



Report adult safeguarding concerns to East Sussex Health and Social Care Connect (HSCC)

Call: 0345 60 80 191 - 8am to 8pm every day

Out of Hours: 0345 60 80 191 (select option 2 to connect to the Emergency Duty Service.)

Or report your concern online:

adultsocialcare.eastsussex.gov.uk/web/portal/pages/presafeguardingpage

▶ **In an emergency, always call 999**



Report adult safeguarding concerns to the West Sussex Carepoint

Call: 01243 642121 – 9am to 5pm, Monday to Friday and Out of Hours

Email: socialcare@westsussex.gov.uk

Or report your concern online:

westsussex.gov.uk/social-care-and-health/social-care-support/adults/raise-a-concern-about-an-adult

▶ **In an emergency, always call 999**

Acknowledgment

The Stop Look Care booklet was originally developed and published in 2016 by registered nurses Carol Hards and Helen Rignall.

The Stop Look Care book won a Nursing Times Award in 2018.

The book has gained national recognition and the Stop Look Care model and book has been adopted in several areas across the country.

Stop, Look & Care booklet was reviewed and updated in 2026 by registered nurse Danielle Jover at NHS Sussex ICB.

We would like to thank the many NHS, Social Care and Provider organisations and specialist professionals in supporting the review of this booklet.

Making health and care information accessible

We are committed to following the NHS Accessible Information Standard. If you require this in a different format or a larger print size, please contact us:

- Email: sysxicb.contactus@nhs.net
- Media enquiries: sysxicb.surreyandsussex.media@nhs.net