Care Home Resource Pack

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Transforming health and care for Staffordshire & Stoke-on-Trent

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Recognising and responding to deterioration in your care home residents

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Recognising and responding to deterioration in your care home resident

An essential part of supporting any patient within a care home is ensuring they are safe and well and that any changes in their presentation is recognised early and responded too in a timely way. Within Staffordshire and Stoke-on-Trent we want to offer all care home patients and their carers the right tools and training to recognise any changes but more importantly the help and support that may be required as a result of these changes through health and social care services. We have worked with the West Midlands Academic Heath Science Network (WMAHSN) team and health and social care partners to provide care homes with a set of tools and pathways to respond to deterioration and more importantly get the right care at the right time for residents.

The approach that underpins managing deterioration is the PIER (Prevention, Identification, Escalation and Response) framework. This is a standardised approach that all health and social care sectors should be adopting. Deterioration can present in many ways and to allow carers and families to recognise these within our system we have agreed to use a set of tools that any care home can adopt and use to recognise small changes to more significant changes in residents. The tools can be adapted to use in all settings from residential to Nursing and support Elderly Mentally Infirm (EMI) placements. They are designed for any carer including families to use and will allow the care home teams the ability to make changes or seek support without delay

We recognise that not all care homes have the staff skilled around clinical management of patients so the tools are designed to allow carers to recognise the changes but then seek the help and support they require by using the pathways document of local care and support that sits alongside the tools.

As part of the continued support to care home residents and staff there has been training through WMAHSN in form of three Webinars and all of the links to these can be found in this pack alongside the links to the tools that will start you supporting your residents

The aim of the work is to allow for:

- Reduction of care home patients attending Emergency Departments and receiving care within their own home where clinically safe.
- Provide a of clear pathways around escalation when deterioration monitoring tools are utilised as a system approach – providing a level of consistent monitoring and accessibility of service provision for all patients across Staffordshire and Stoke-on-Trent.
- Provide training and support to all care homes around recognition of deterioration of residents via a series of Regional Webinars (also sharing of recorded links) and a localised training offer to support staff knowledge.
- Provide clear aligned Staffordshire and Stoke-on-Trent pathways and agreeing tools to enhance the levels of monitoring allows the care homes to seek support more rapidly to support patients but more importantly provides enhanced patient care and management.

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Community Rapid Intervention Service (CRIS)

The CRIS service provides a single viable alternative, via the Unscheduled Care Coordination Centre (UCCC) to ED that is able to respond rapidly to patients in the community with escalating, sub-acute healthcare needs.

The service is an integrated partnership between University Hospitals of North Midlands, Midlands Partnership NHS Foundation Trust, Staffordshire County Council and Stoke–on-Trent City Council (adult social care).

The Community Rapid Intervention Service (CRIS) combines senior hospital consultant decision–making skills with community health and social care admissions avoidance expertise.

CRIS provides rapid assessment, monitoring and treatment.

The aim of CRIS is to provide, through a single point of access (UCCC), a rapid response (within 2hrs) to patients with an escalating sub-acute healthcare need in their usual place of residency. Patents will be assessed, monitored and treated without the need to attend ED or be admitted to hospital. All patients will be reviewed before being discharged back to the care of their GP.

Who can refer?

Patients can be referred to CRIS by;

- GP
- Paramedics
- Care Homes
- Community Services
- 111
- Social care staff

Referral Pathway

The Service requires the referring clinician/care staff to have made a clinical assessment of the patient either in person, or by telephone (GP's only) on the day that the referral is made, and the patient is clinically safe to wait for 2hrs for a clinical response.

The types of conditions that might require a CRIS response to prevent an unnecessary hospital admission:

- All referrals from Care Homes
- Falls with no apparent injury
- Short term sub-acute illness e.g. infections
- Elderly frail patients at risk of unnecessary hospital admission
- Patients at End of Life

The CRIS will be unable to support with:

- Any patient with a clinical condition that precludes them from waiting 2 hours
- Any patient who has a non-urgent need and does not need a response within 2 hours
- Patients requiring core primary care
- Patients in mental health crisis
- Under 18's

Please contact the Unscheduled Care Coordination Centre

0300 123 0983

8am-8pm 7 days a week

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Information needed for a good referral to our service

- Patient Demographics – Date of Birth, Next of Kin, Contact Details age, etc…
- When they were last seen by their GP?
- What is their Past Medical History?
- Do they have a DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION (DNACPR) and/or ReSpect document?
- What medication are they taking?
- Do they have any End of Life medication in the home?
- What is wrong with them today?
- What are they normally like?
- Are there any soft sign changes? Refer to the soft signs STOP and WATCH tool page 65)
- What are their vital signs – blood pressure, pulse, temperature, respirations? For nursing homes please include a full set of observations RR Sats HR BP Temp and conscious level or the ACVPU score. Having completed the observation calculate a NEWS2 score and include a baseline NEWS2 score if available.
- What are their usual care needs?
- SBARD (Situation Background Assessment and Recommendation Decision) this is the tool staff should be using to escalate concerns and is mentioned on page 67.

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What the care homes can expect from the Community Rapid Intervention Service (CRIS)

- An open and honest assessment approach from our visiting clinicians
- Clinicians will be compassionate and caring in their attitude anda treatment of your residents
- Clinicians will have the courage to challenge situations sensitively, will prescribe medication appropriately, request bloods and samples as appropriate and report to GPs.
- Clinicians will be competent in their assessments and will acknowledge any limitations and will refer onto other Practitioners.
- Clinicians will communicate their findings with Care Homes, and offer advice to carers and nurses as required. The Clinician will send a report to the residents own GP to inform them of our visit
- We are committed to assisting your homes in the prevention of unnecessary admissions to hospital especially.

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What the Unscheduled Care Coordination Centre expects from care homes

- In the event that care homes need advice and support about a resident of concern we expect that care homes will refer to the escalation pathway on page 59 to ensure that the referral is escalated to the most appropriate service.
- We expect that on referral to the Unscheduled Care Coordination Centre the care homes will be able to inform the Unscheduled Care Coordination Centre if the resident has been reviewed by their own doctor.
- We expect that in the scenario that a resident has been deteriorating and has had multiple hospital admissions that the care home should have open discussions with residents/family and Doctors re: preferred place pf care and long term plans for residents, such as do residents/family members wish residents to be admitted to hospital or remain comfortable at home with available community treatments in the event that they were to deteriorate again.
- We expect that prior to the clinicians visit, the carers will have the patients care plan, medication record sheet, a recent urine sample or in exceptional circumstances a very wet continence pad, and the resident available in their room (if possible) so that the clinician can assess the resident promptly.
- If the clinician prescribes medication please ensure that there is a carer or family member who is able to collect the prescription. Your resident will need to commence on medication promptly in order to minimise further deterioration and avoid unnecessary hospital admission.
- If the care home is unable to administer or hold a stock of Homely Remedies such as paracetamol etc. We expect that you will inform the visiting Clinician and they can then prescribe individually for that resident.
- We expect that carers will closely observe residents for signs of deterioration (early soft signs of deterioration as advised in the Stop and Watch tool as used by all Stoke & Staffordshire Care Homes).
- We expect that carers will contact the Unscheduled Care Coordination Centre / 111 / 999 as instructed by the visiting clinician.
- We expect that care homes will be open and honest about the level of care they can provide and any limitations of the care they can provide to patients in order that your residents will receive the most appropriate care in the most appropriate place. Please inform clinicians if you think you are not able to maintain your resident in the home whilst receiving treatment.

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What is the potential harm to your resident from an unnecessary hospital admission?

- Residents with a diagnosis of Dementia or Alzheimer's can become more confused and their functionality (mobility/cognition) can irretrievably deteriorate.
- Residents are at risk of acquiring (catching) other hospital acquired infections (urine infections, chest infections, gastroenteritis (diarrhoea and vomiting/norovirus/c-diff)) whilst in the hospital environment.
- Whilst waiting to be assessed they may be at risk of acquiring pressure ulcers or of worsening pressure ulcers.
- Your carers know your residents well and are more likely to be able to encourage residents to eat and drink than nurses within the hospital environment, as your resident will be comfortable in your company, so the risk of dehydration and malnutrition could be less remaining at home than in hospital, as long as your resident is able to take nutrition orally.

ULTIMATELY IT IS THOUGHT THAT YOUR RESIDENTS ARE BEST LOOKED AFTER IN THEIR OWN HOME, WITH PEOPLE THEY KNOW AROUND THEM, UNLESS THEY ARE SO ACUTELY UNWELL THAT HOSPITAL ADMISSION IS THE ONLY OPTION.

THERE IS SOME EVIDENCE THAT 10 DAYS IN HOSPITAL IS THE EQUIVALENT OF 10 YEARS OF AGEING OF THE MUSCLES FOR AN OVER 80 PERSON.

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Frailty and the Soft Signs of Deterioration

Frailty

In medical terms "Frailty" is defined as a multi-dimensional condition that is considered to be a decline of physical health and cognitive reserves that leads to increased vulnerability. Those at risk have an increased possibility of poor nutrition, falls or hospital admission.

"Frailty is not an illness, but a syndrome that combines the effects of natural ageing with the outcomes of multiple long-term conditions, loss of fitness and reserves" (Lyndon 2014).

For care home residents/service users there are interventions that can slow decline and prevent crises by care home staff recognising the "Soft Signs" of Deterioration.

What are 'Soft Signs' of Deterioration?

- Soft signs are early indicators that the person you support might be coming unwell. This could be anything such as a change in physical presentation or behaviour or changes in mental state. They are the early indicators that someone may be becoming unwell
- Sometimes it can be obvious that someone is unwell, but at other times it might be much harder to spot.
- Often families and friends will pick up on the subtle changes in a person's behaviour, manner or appearance. These concerns should always be taken seriously, even if you think the person is fine.

It's important to understand what is normal for the person.

Examples of 'Soft Signs'

Soft Signs can be related to many things including:

Changes in physical presentations

- Increased breathlessness or chestiness
- Not passing much urine/ change in urine appearance / smell
- Being hot, cold or clammy to touch
- Being unsteady while walking
- Diarrhoea, vomiting, dehydration

Changes in behaviour or ability

- Changes to usual level of alertness / sleeping more or less
- New or increased confusion/ agitation /anxiety/ pain
- Change in usual drinking/diet habits
- Reduced mobility – 'off legs'
- Being very restless or hyperactive

Changes in mental state

- Having new or worse confusion
- Feeling more anxious or agitated
- Being more withdrawn than normal

OR just your own gut feeling that something is wrong or the resident has concerns

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Common Conditions

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Chest infections

Possible causes

- Bacteria or viral infection
- Coughing and Sneezing spread the illness
- Aspiration due to poor gag reflex allowing fluid or food to enter the lungs
- Poor Posture
- Smoking
- Some long term health conditions make people more at risk such as those with asthma, heart disease, diabetes, kidney disease, chronic obstructive pulmonary disease.
- Obesity
- Bed bound residents
- Consolidation (sputum becoming congested in the lungs)
- Immunocompromised residents such as those on chemotherapy.
- Over 65 years old.

Signs and symptoms of a Chest infection

- Temperature/ feels hot and shivery
- Uncontrollable shivering
- Nausea (feeling sick)
- Vomiting
- Chest pains
- Any increase confusion/disorientated or drowsy
- Any notable changes of colour to skin/lips/nails (cyanosis)
- Breathing faster than normal
- Persistent cough
- Bringing up thick yellow/green sputum
- Noisy breathing
- Fast heartbeat
- Poor appetite

Management of residents with Chest infection

- Give medication as prescribed (may be given antibiotics)
- Assist good posture as sitting upright can help the resident to bring up secretions
- Encourage deep breathing
- Observe any sputum production for any changes in colour and consistency
- Encourage fluids
- Infection control management use of tissues to Catch it Bin it Kill it and good hand washing for residents/staff/visitors
- Rest

Prevention

- Ensure visitors who have potential illness to not visit until well
- Ensure that residents who are eligible have their seasonal flu vaccination
- Strict hand washing by residents/staff/relatives
- Providing of clean tissues and receiver for disposal
- Early recognition of residents with any swallowing problems. Adhere to advice from the Speech and Language Team (SALT).
- Support quit smoking

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FACT SHEET

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What is Flu?

Flu is a highly contagious disease that is transmitted through the air in millions of tiny droplets from an infected persons nose or mouth. These droplets can survive for up to 24 hours and infect people of all ages who breathe in the droplets or touch a surface that the droplets have landed on and then a recipient touches that surface (indirect contact) and then infects' themselves on touching their eyes/mouth. It can lead to serious illnesses, such as pneumonia, particularly in the vulnerable and young. Tiredness symptoms can last for up to several weeks.

Flu symptoms can develop rapidly and will stop residents from completing their normal daily activities whilst a cold usually develops gradually and mainly affects the nose and throat and is usually fairly mild.

Signs and symptoms of Flu (any of these symptoms may be present):

- A high temperature of 38C or above
- Tiredness and weakness and feeling so exhausted and unwell that a resident has to stay in bed
- A headache
- Limb or joint pain
- Aching muscles
- A sore throat
- A dry chesty cough
- Cold like symptoms
- Diarrhoea or abdominal pains
- Reduced appetite
- Nausea and vomiting (gastric flu ie noro virus) actions as appropriate of results.

How to manage a Flu outbreak in your care home:

- Attempt to isolate residents if possible to prevent the spread of the outbreak
- Wash hands regularly with soap and water
- Use universal precautions, gloves/aprons when caring for an infected resident
- Increase the cleaning protocol of the home by regularly cleaning surfaces and door handles
- Encourage residents to cover their mouths with a tissues when sneezing or coughing
- Attempt to develop a "use it and bin it" policy for tissues
- Report an outbreak as per the Health Protection Agencies / Your Care Home Policies

Care of your resident with Flu:

- Allow residents to rest
- Keep them warm (be wary of high temperatures)
- Push fluids to avoid dehydration, light diet as tolerated
- Offer regular Paracetamol / Ibuprofen depending on the residents' allergies / intolerances. Ensure these are written up.

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Complications of Flu:

- Chest infection
- Pneumonia
- Sepsis from the above
- Dehydration
- Worsening of existing conditions such as Diabetes (raised blood sugars), COPD, Heart Failure, Chronic Kidney Disease

When to call Unscheduled Care Home Co-ordination Centre and (111 after 8PM to 8AM)

- Those residents who develop a cough, shortness of breath or who cough up blood
- Those residents who do not improve and are not eating or drinking

When to call 999:

- Residents with chest pain/severe breathing difficulties ie. cannot complete sentences/ become drowsy and not responsive

Finally a word on prevention:

- **Annual flu jab (not 100% effective as there are different strains of flu) however offers some protection to your residents).**

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Urinary Tract Infection (UTI's)

Possible causes of UTIs

- Reduced fluid intake (dehydration)
- Urinary and or Faecal Incontinence/ Poor hygiene
- Obstruction or blockage of the urinary tract such as kidney stones or in men enlarged prostrate.
- Weakened immunity such as residents who are receiving chemotherapy oral or Intravenous or taking certain rheumatology medication.
- Any condition which prevents your resident from emptying their bladder regularly such as constipation as the bladder is an excellent environment for bacteria to multiply if urine remains in the bladder too long.

Signs and symptons of UTI's

- Pain or burning sensation when urinating/ weeing (dysuria)
- Passing urine more often and may develop urinary incontinence
- Offensive cloudy urine or blood in urine
- Lower dull abdominal pain
- Dull ache in lower back, groin or side
- Feeling generally unwell
- High temperature of 38 centigrade or above or feels hot and shivery
- Uncontrollable shivering
- Nausea (feeling sick)
- Vomiting
- Diarrhoea

Signs and symptons of UTI's in Dementia

- Agitation or restlessness
- Difficulty concentrating
- Hallucinations or delusions
- Becoming unusually sleepy or withdrawn

Management of residents with UTI's

- Encourage residents to drink plenty of water to avoid dehydration and help clear bacteria from the urinary tract
- Residents need to go to the toilet as soon as they need to urinate rather than holding in
- Wipe front to back after using the toilet
- Wash genitals every day
- Cranberry Juice may help in the prevention of UTIs

UTI's can have more serious complications in certain residents including:

- Kidney disease
- Type 1 diabetes or type 2 diabetes
- Immunocompromised residents such as those on chemotherapy.
- Patients with kidney stones or a catheter.
- Over 65 years old.

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What's in a cup?

A fluid volume ready reckoner to help with fluid balance chart completion

200ml
Spouted Beaker Cup

150ml
Plastic Cup

1000ml
Water Jug

180ml
Plastic Cup

150ml
Tea Cup

200ml
Mug

150ml
Glass

160ml
Dysphagia Cup

200ml
Dysphagia Mug

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What's in a supplement?

A fluid volume ready reckoner to help with fluid balance chart completion

125ml
Ensure Compact

220ml
Ensure Plus Milkshake

220ml
Ensure Plus Juce

200ml
Ensure Twocal

240ml
Enshake

200ml
Ensure Plus Fibre

200ml
Vital 1.5kcal

30-40ml
Pro-Cal Shot

200ml
Fresubin Thickened Stage 1 or Stage 2

125g
Fresubin 2kcal Crème

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Gastroenteritis
(Diarrhoea and Vomiting) in adults

Possible causes of Gastroenteritis

- Norovirus (Commonly described as the "Winter Vomiting Bug")
- Food Poisoning
- Travel infections which may be passed onto residents
- Overuse of antibiotics (C-Difficile infection)

Signs and symptoms of a Gastroenteritis

- Repeated watery diarrhoea
- Vomiting
- Feeling sick
- Loss of appetite
- Cramp like stomach pains
- Aching limbs
- Headache
- Possibly a high temperature (feeling warm and sweaty)

Management of residents with Gastroenteritis

- Good infection control
- Isolate the resident from other residents to prevent spread
- Effective hand washing technique (7 steps hand washing technique)
- Ensure carers wear gloves and aprons when attending to affected resident (barrier nursing)
- Do not share commodes/toilets
- Ensure laundry is washed separately as per your internal Care Home protocols
- Offer regular cool fluids water preferably, but diluted juice and soup can be offered
- Residents may need oral rehydration solutions to replace salt, glucose and other important minerals via prescription from Nurse or GP
- If tolerated try light diet. Small meals often. Avoid fatty or spicy foods
- Please obtain stool sample to isolate type of infection
- If there is an infective cause of the diarrhoea it is not good practice to use an anti-diarrhoealmedication such as Loperamide

RESIDENTS REQUIRE URGENT REFERRAL TO THE UNSCHEDULED CARE COORDINATION CENTRE IF THEY ARE UNABLE TO KEEP DOWN ANY FLUIDS OR WHO ARE PASSING BLOOD OR MUCUS IN THEIR STOOL OR WHO ARE UNABLE TO STAND UP AND ARE BECOMING INCREASINGLY DROWSY OR AGITATED

Gastroenteritis can have more serious complications in certain residents including:

- Older persons
- Those residents with underlying health conditions including kidney problems, diabetes, heart failure (as they will most probably be taking watery tablets)
- Those residents who suffer from Crohns's disease or Ulcerative Colitis
- Those residents who have a weakened immune system such as those on chemotherapy and older residents

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Residents can easily become dehydrated

when they have Diarrhoea and Vomiting

Causes Of Dehydration:

- Diarrhoea and vomiting
- Not drinking enough fluid
- Excessive passing of urine
- Excessive sweating
- Hot weather and hot environments
- Increased risk of dehydration in diabetic residents due to high levels of glucose in the blood stream.

Signs and symptoms of mild dehydration can include:

- Thirst or a dry mouth
- Dark-coloured urine
- Dizziness and light headedness, particularly after standing up, which does not go away after a few seconds
- Feeling sick
- Lack of energy (lethargy)
- Headaches

Signs and symptoms of more severe dehydration can include:

- Weakness and apathy (a lack of emotion or enthusiasm)
- Muscle cramps
- Pinched face
- Sunken eyes
- Passing little or no urine in the previous eight hours
- Confusion or worsening confusion
- Rapid heartbeat/pulse
- Weak pulse
- A low level of consciousness

Management of residents with dehydration

- Offer regular clear fluids or diluted juice hourly regular sips are better than full glasses if residents are nauseous
- Oral rehydration solutions as previously stated can be used to replenish salts and fluid
- Maintain a fluid input and output chart. If resident uses pads describe the weight of filled pad ie: is pad as wet/heavy as normal.
- Observe colour of urine if resident has not passed urine in the last eight hours notify a clinician for advice
- Offer light diet
- If residents have signs and symptoms of severe dehydration which are complicated by not being able to keep fluids down and other illnesses such as crohn's disease they may need hospital admission for intravenous fluids.

Prevention of gastroenteritis and dehydration

- Good hand washing techniques
- Storing and cooking foods as per care home policy
- Informing visitors/relatives not to visit if they have gastroenteritis symptoms
- Isolating residents who develop gastroenteritis from other residents
- Offering regular fluids and increasing resident fluid intake in warm weather.

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Thorough fluid balance saves lives

- Monitor for symptoms and signs of dehydration
- Make sure you know what is expected fluid intake for your patient
- Make sure you know what is expected urine output for your patient

If the urine output has been less than 0.5ml/kg/h in the last 6 hours, ask for an urgent medical review!

Urine Colour Chart

Urine Colour	Possible Meaning
Clear	Good hydration, overhydration or mild dehydration
Pale Yellow	Good hydration or mild dehydration
Bright Yellow	Mild or moderate dehydration or taking vitamin supplemets
Orange, Amber	Moderate or severe dehydration
Tea-Coloured	Severe dehydration

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Cellulitis (red skin)

Mostly affects the legs, but can occur anywhere on the body

Possible causes

- Bacterial infection of the deeper layers of the skin and the underlying tissue.
- Can be caused more rarely by a fungal infection
- Infection enters through damaged or broken skin such as a cut, burn or bite.
- Leg ulceration
- Eczema
- Athletes foot
- Weak immune system
- Obesity
- Poorly controlled diabetes
- Having chickenpox or shingles
- Lymphoedema (fluid in limb)
- Previous cellulitis
- Circulatory problems

Signs and symptoms of Cellulitis

- Temperature above 38C (100.4F) or above/ feels hot and shivery
- Nausea (feeling sick)
- Vomiting
- Painful swelling and hot to touch area
- Any increase confusion/disorientated or drowsy
- Fast heartbeat
- Poor appetite
- Rapid breathing
- Blistering to the red area
- Dizziness
- Reduce urine output
- Looking pale
- Feeling cold, and clamminess to skin.
- Altered consciousness

Management of residents with Cellulitis

- Give medication as prescribed (cellulitis usually responds well to antibiotics these may be given orally or in some cases intravenously, severe cases may need hospital admission).
- Pain relief
- Encourage fluids
- Rest and elevation of limb with gentle movement of any affected joints

Complications

- Transfer across to signs and symptoms.
- Facial cellulitis
- Abscess formation
- Increase redness/swelling/pain
- Stomach upset or diarrhoea from antibiotics
- Septicaemia

Prevention

- Strict hand washing by residents/staff/relatives
- Well controlled blood glucose in diabetic patients
- Environment to prevent and trauma to skin
- Clothing not causing and restriction of movement
- Good skin care keeping skin well hydrated with use of moisturisers and fluid intake.
- Treating any breaks in the skin appropriately.
- Keeping nails short and clean (use of cotton gloves may be useful it residents are scratching area).

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Mental health information for care homes

Delirium

Signs and symptoms of delirium

- A disturbance of consciousness and a change in cognition
- Signs of infection e.g. coughing, strong smelling urine, fever
- A reduced ability to focus or concentrate
- Starts over a short period of time – acute
- A tendency to fluctuate, can be worse in the evenings
- Hypoactive form – withdrawn, sleepy, not interacting
- Hyperactive – restless, agitated
- Sleep disturbance
- Emotional disturbance

Risk factors for developing delirium

- Age
- Pre-existing cognitive impairment
- Previous episode of delirium
- Current severe physical illness
- Sensory impairment: hearing or visual

Prevent delirium by improving sensory environment

- Spectacles – available and clean
- Hearing aids – available and working
- Cognitive stimulation, appropriate reminiscence and activities (know your resident!)
- Regular but sensitive reorientation
- Routine and structure to the day
- Tell patients clearly what is happening and why before you touch them, speak slowly, use eye contact
- Encourage sleep – as quiet environment as possible, mobilise during the day
- Encourage family to bring in familiar objects and visit
- Low stimulus environment, limit noise and inappropriate television programmes and music

Management

- Refer to the Unscheduled Care Coordination Centre for further advice and information
- Going into hospital tends to make delirium much worse

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Dementia

The word 'dementia' describes a set of symptoms that may include problems with memory, thinking or reasoning, these three elements are known as cognition. Changes to cognition are often small to start with but for someone with dementia they have become severe enough to affect daily life, a person with dementia may also experience changes in their mood or behaviour.

There are some common symptoms of dementia but it is important to remember that everyone is unique. Two people with dementia are unlikely to experience the condition in exactly the same way and this may also depend on the type of dementia.

Alzheimer's disease

Alzheimer's disease is the most common cause of dementia. During the course of the disease, proteins build up in the brain to form structures called 'plaques' and 'tangles'. This leads to the loss of connections between nerve cells, and eventually to the death of nerve cells and loss of brain tissue. There is also a shortage of some important chemical messengers in the brain which help to transmit signals around the brain; this causes the signals to not be transmitted as effectively.

For most people with Alzheimer's the earliest symptoms are memory lapses and difficulty recalling recent events and learning new information. Someone with the disease will go on to develop problems with other aspects of thinking, reasoning, perception or communication.

Vascular dementia

Vascular dementia is the second most common type of dementia. Blood is normally delivered to the brain through a network of vessels called the vascular system, if this is damaged – so that the blood vessels leak or become blocked – then blood cannot reach the brain cells and they will eventually die. There are several different types of vascular dementia; they differ in the cause of the damage and the part of the brain that is affected and will have some symptoms in common and some symptoms that differ.

General symptoms of dementia

- Language – struggling to follow a conversation or repeating themselves
- Visuospatial skills – problems judging distance or seeing objects in three dimensions
- Concentrating, planning or organising – difficulties making decisions, solving problems or carrying out a sequence of tasks (such as getting dressed)
- Orientation – becoming confused or losing track of the day or date.

Behavioural and Psychological symptoms of dementia (BPSD)

When a person with dementia behaves differently, this is often mistakenly seen as simply another symptom of the condition; however, this is often not the case. The behaviour may have many causes such as mental and physical health, habits, personality, interactions with others and the environment. The possible causes of someone behaving out of character may be divided into biological (e.g. being in pain), psychological (e.g. perceiving a threat) or social (e.g. being bored).

When supporting a person with dementia who is behaving out of character it's important to see beyond the behaviour itself and think about what may be causing it. People with dementia have the same basic needs as everyone else, however, they may be less able to recognise their needs, know how to meet them, or communicate them.

Good quality ABC analysis (**A**ntecedent, **B**ehaviour, **C**onsequence) can help identify patterns, trends and triggers for BPSD.

BPSD can include:

- Behavioural changes – aggression, pacing, restlessness, disinhibition
- Mood disturbance – fluctuating moods, depression
- Psychotic symptoms – delusions or hallucinations
- Can occur in 50-80% of people with dementia

Consider reasons for out-of-character behaviour

- frustration – not understanding how others around the person are behaving, a sense of being out of control, or a feeling of not being listened to or understood
- an attempt to meet a need (e.g. removing clothing because they are too hot or walking around because they are bored or feel they need to be somewhere)
- communicating a need (e.g. shouting out because they need the toilet, are hungry, thirsty or uncomfortable)
- pain or discomfort, e.g. arthritic or dental pain
- a medical reason, e.g. constipation or the side effects of medication
- anxiety
- the environment - it may be too hot or too cold, over-stimulating or under-stimulating.

Reducing and managing out-of-character behaviour

- ensure continued social relationships
- encourage the person to engage in meaningful activities - for it to be meaningful you should know the person's likes and dislikes
- spend quality time with the person - perhaps chatting or sharing a task together
- develop a structured daily routine (other than the routine dictated by the care setting e.g. medication rounds and mealtimes)
- hand massage
- reduce unnecessary or inappropriate noise and clutter
- provide people with familiar personal items
- support the person to walk around the environment safely
- maintain a comfortable sleeping environment.
- divert the person away from potential conflict with others, if this is not possible without increasing distress consider diverting the other person instead
- distract the person with appropriate resources - familiar and soothing objects such as cuddly toys/dolls/photos or offer food and drink
- reminiscence - for it to be meaningful you should know the person's background and avoid recalling any distressing memories

Antipsychotic drugs can be prescribed to people with out of character behaviour. While these may be appropriate and helpful in some situations they can suppress behaviour without addressing the cause and may add to the person's confusion and increase their risks of falls and subsequent injuries. They should only be prescribed by a doctor or specialist nurse prescriber when absolutely necessary. Medical guidelines state they should only be used in the first instance if there is evidence of delusions or hallucinations and the person is severely distressed, or if there is a risk of harm to them or those around them. If antipsychotics are used, they should be regularly reviewed and monitored.

Sundowning and Sleep

Sometimes a person with dementia will exhibit an increase in certain behaviours in the late afternoon or early evening. For example, people may become more agitated, aggressive or confused. This is often referred to as 'Sundowning'. This pattern may continue for several months and often occurs in those in the moderate to severe stages of dementia.

Sundowning may be caused by:

- disturbance to the 24-hour 'body clock' that tells our bodies when to sleep, caused by the physical changes to the brain
- loss of routine at a previously busy time of day
- too little or disturbed sleep
- too little or too much light
- prescribed medication (e.g. for pain or discomfort) wearing off
- medications that worsen confusion and agitation
- excessive or disturbing noise

Dementia can affect people's sleep patterns. This is separate and different from normal age-related sleep difficulties. It can cause problems with the sleep-wake cycle and also interfere with the person's 'body clock'. Disturbed sleep can have a negative impact on a person's wellbeing (as well as that of their sleeping partner), so strategies to improve sleep will be beneficial.

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Depression

Most people feel low or down from time to time, but this is not the same as being depressed. Depression is a condition that lasts for longer periods. A number of feelings, such as sadness and hopelessness dominate a person's life and make it difficult for them to cope. People with depression may also experience physical symptoms, such as loss of energy and appetite changes. Physical symptoms of depression are more common in older people with the condition.

Depression is more common among people with dementia particularly those who have vascular dementia or Parkinson's disease dementia. Depression is often diagnosed in the early stages of dementia but it may come and go and may be present at any stage. Depression may also make behavioural changes worse in people with dementia, causing aggression, problems sleeping or refusal to eat.

Possible causes of depression and anxiety include

- traumatic or upsetting events – these can trigger high levels of anxiety that continue long after the event is over
- the effects of certain illnesses or the side-effects of medication
- lack of social support or social isolation – perhaps due to a change in environment or family not visiting
- loss and bereavement – of family, or staff or residents that they were close to
- lack of meaningful things to do, with feelings of boredom and aimlessness
- feeling stressed or worried over issues such as money, relationships or the future
- having a genetic predisposition to depression or anxiety

Possible Signs

- not wanting to do usual activities
- tearful
- isolating self
- not eating and drinking as well as usual
- voicing passive ideas of not wanting to be here anymore or active thoughts of wanting to kill themselves

Management

- Refer to own GP or Community Mental Health

www.alzheimers.org.uk
www.yhscn.nhs.uk/about/index

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What is the ReSPECT document and what does it mean?

The ReSPECT document stands for Recommended Summary Plan for Emergency Care and Treatment.

The ReSPECT process creates a summary of personalised recommendations for a person's clinical care in a future emergency in which they do not have capacity to make or express choices. Such emergencies may include death or cardiac arrest, but are not limited to those events. The process is intended to respect both patient preferences and clinical judgement. The agreed realistic clinical recommendations that are recorded include a recommendation on whether or not CPR should be attempted if the person's heart and breathing stop.

How does it work?

The plan is created through conversations between a person and one or more of the health professionals who are involved with their care. The plan should stay with the person and be available immediately to health and care professionals eg such as ambulance crews, out-of-hours doctors, care home staff faced with making immediate decisions in an emergency in which the person themselves has lost capacity to participate in making those decisions.

ReSPECT may be used across a range of health and care settings, including the person's own home, an ambulance, a care home, a hospice or a hospital. Professionals such as ambulance crews, out-of-hours doctors, care home staff and hospital staff will be better able to make immediate decisions about a person's emergency care and treatment if they have prompt access to agreed clinical recommendations on a ReSPECT form.

The following two pages contain an explanation of the form.

Personalised Care Support Planning (PCSP's)

Personalised care is a partnership approach document that helps people make informed decisions and choices about their health and wellbeing, working alongside clinical information who do not require a ReSpect document but will need a PCSP/Health Action plan. These are usually seen for example within Learning Disability Care Homes.

Please contact the Unscheduled Care Coordination Centre

0300 123 0983

8am-8pm 7 days a week

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ReSPECT **Recommended Summary Plan for Emergency Care and Treatment**

Full name
Date of birth
Address
NHS/CHI/Health and care number

1. This plan belongs to:

Preferred name
Date completed

The ReSPECT process starts with conversations between a person and a healthcare professional. The ReSPECT form is a clinical record of agreed recommendations. It is not a legally binding document.

2. Shared understanding of my health and current condition

Summary of relevant information for this plan including diagnoses and relevant personal circumstances:

Details of other relevant care planning documents and where to find them (e.g. Advance or Anticipatory Care Plan; Advance Decision to Refuse Treatment or Advance Directive; Emergency plan for the carer):

I have a legal welfare proxy in place (e.g. registered welfare attorney, person with parental responsibility) - if yes provide details in Section 8 ☐ **Yes** ☐ **No**

3. What matters to me in decisions about my treatment and care in an emergency

Living as long as possible matters most to me — **Quality of life and comfort matters most to me**

What I most value:	What I most fear / wish to avoid:

4. Clinical recommendations for emergency care and treatment

Prioritise extending life clinician signature	or	Balance extending life with comfort and valued outcomes clinician signature	or	Prioritise comfort clinician signature

Now provide clinical guidance on specific realistic interventions that may or may not be wanted or clinically appropriate (including being taken or admitted to hospital +/- receiving life support) and your reasoning for this guidance:

CPR attempts recommended Adult or child clinician signature	For modified CPR **Child only, as detailed above** clinician signature	CPR attempts **NOT** recommended Adult or child clinician signature

www.respectprocess.org.uk

ReSPECT Version 3.1 - DRAFT © Resuscitation Council UK

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5. Capacity for involvement in making this plan

Does the person have capacity to participate in making recommendations on this plan? ☐ Yes ☐ No Document the full capacity assessment in the clinical record.	If no, in what way does this person lack capacity? If the person lacks capacity a ReSPECT conversation must take place with the family and/or legal welfare proxy.

6. Involvement in making this plan

The clinician(s) signing this plan is/are confirming that (select A,B or C, OR complete section D below):

☐ **A** This person has the mental capacity to participate in making these recommendations. They have been fully involved in this plan.

☐ **B** This person does not have the mental capacity, even with support, to participate in making these recommendations. Their past and present views, where ascertainable, have been taken into account. The plan has been made, where applicable, in consultation with their legal proxy, or where no proxy, with relevant family members/friends.

☐ **C** This person is less than 18 years old (16 in Scotland) and (please select 1 or 2, and also 3 as applicable or explain in section D below):

- ☐ **1** They have sufficient maturity and understanding to participate in making this plan
- ☐ **2** They do not have sufficient maturity and understanding to participate in this plan. Their views, when known, have been taken into account.
- ☐ **3** Those holding parental responsibility have been fully involved in discussing and making this plan.

D If no other option has been selected, valid reasons must be stated here: (Document full explanation in the clinical record.)

7. Clinicians' signatures

Grade/speciality	Clinician name	GMC/NMC/HCPC no.	Signature	Date & time
Senior responsible clinician:				

8. Emergency contacts and those involved in discussing this plan

Name (tick if involved in planning)	Role and relationship	Emergency contact no.	Signature
Primary emergency contact: ☐			optional
☐			optional
☐			optional
☐			optional
☐			optional

9. Form reviewed (e.g. for change of care setting) and remains relevant

Review date	Grade/speciality	Clinician name	GMC/NMC/HCPC No.	Signature

If this page is on a separate sheet from the first page: **Name:** **DoB:** **ID number:**

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Tool Templates

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DO YOU NEED ADVICE or SUPPORT FOR A DETERIORATING CARE HOME RESIDENT?

Escalating → Clinical → Need

Social Care	Mental Health	Palliative / Hospice Services	Community Nursing Teams	GP	111	Crisis Rapid Response	999 - WMAS
			24 hours	8.30am – 6pm	24 hours	8am – 8pm	24 hours
Stoke-on-Trent Contact centre on **0800 561 0015** during office hours and **01782 234234** which is after 5pm or weekends Social Care Falls Responder Team: **01782 234545** **Staffordshire** For all Adult Social Care services: Monday to Friday, 9am to 5pm, except bank holidays **0300 111 8010** staffordshirecares@staffordshire.gov.uk **Out of hours** If you have a concern about the safety of a vulnerable adult and need to report it overnight, over a weekend or on a Bank Holiday, contact the Emergency Duty Service: **0345 604 2886**	**South Staffordshire** Mental Health Access Team on **0808 196 3002** 24/7 access.staffordshire@mpft.nhs.uk **North Staffordshire** Care Home Liaison Team: Planned care service providing mental health assessments in a care home setting **Monday to Friday 9am-5pm** (County) **0300 1230905 ext 6117** (City) **0300 1230893 ext 5162** If you have a care home resident that is currently involved with the Outreach Team and you have concerns about their mental health please contact: **01782 441689** 08:00 – 20:00 7 days a week. For OOH please contact the Crisis Team: **0800 032 8728 Option 1** Text: **07739 775202**	For Palliative Care advice call the PCCC – Palliative Care Coordination Centre on **0300 123 0989** 7 days a week 9am – 6pm Patients known to the service with an agreed plan can be seen by the District Nursing or CIS teams New EOL pts with no agreed care plan in place will need to be directed to the GP. Douglas Macmillan Hospice (North Staffs) **01782 344300** Katherine House (South West Staffs) **01785 254645** St Giles (South East Staffs) **0300 3309410** stgilesclinical@nhs.net Compton (South Staffs) **0300 323 0250** Treetops Hospice (East Staffs) **01335 344354**	If your resident is known to the community nursing service and you are concerned about a deteriorating condition or any other health concerns please contact the Local Access Point Urgent Nursing problems that will not wait until the next planned visit including; • Wound care • Continence and catheter problems • Skin Integrity • Palliative and End of life care Stoke on Trent, Newcastle, Moorlands **01782 831 110** Cannock and Seisdon **0300 123 9011** Burntwood Lichfield and Tamworth **0300 124 0347** Stafford **0300 124 0340** Burton on Trent **0300 323 0930** Community Learning Disability Health Team (North Staffordshire) - **0300 123 1152**	Contact your GP or your enhanced care home team for telephone advice, surgery appointments or home visits for; • Management of Long Term Conditions • General medical concerns • Treatment of medical needs • Ongoing medical or Psychiatric needs • New palliative patients Call 111 after 6pm, weekends and Bank Holidays for out of hours GP support and access to out of hours GP services	If you need medical help or support which is not a 999 emergency which may include; • Resident not appearing to be usual self • Breathing problems • Worsening confusion • Signs of infection • Falls with no signs of broken bones Also call **111** for advice if; • You think your resident needs to go to A & E • You don't know who to call • You need health information or reassurance of what to do next	If you need 2 hour clinical response for acutely unwell residents who require rapid interventions to avoid hospital attendance • Signs of infection • Reduced eating and drinking that day. • Resident does not appear their usual self that day. Call **UCCC** – Unscheduled Care Coordination Centre on **0300 123 0983** 7 days a week 8am – 8pm The UCCC provide urgent advice and access to the **CRIS** – Community Rapid Intervention Service 7 days a week 8am – 10pm	Call **999** in a medical or life threatening emergency such as; • Loss of consciousness • Severe chest pain or suspected heart attack • Choking • Fits • Severe breathing problems • Severe loss of blood • Serious accident • Suspected or obvious broken bones • Severe burns or scalds • Stroke • Serious head injury • Diabetic emergency

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Look Think Call

ALERT!

If you notice any of these signs or symptoms of a

CHANGE OF CONDITION

Please contact the Unscheduled Care Coordination Centre for advice.

0300 123 0983 daily 8:00am to 8:00pm

Inclusion Criteria

Off their food
Off their legs
Muddled
Won't cooperate
Breathless
Tummy ache
Sick
Complaining of pain
Upset

Person is not themselves today

LOOK

at your resident

THINK

do they meet the inclusion criteria

CALL 0300 123 0983

Inclusion Criteria

Crying
Washed Out
Can't sit up
Sleepy
Falling
Coughing
Smelly Urine
Feeble
Fidgety

Exclusions to this service

Acute Severe Chest Pain, New Severe Respiratory Distress, Falls with Acute Severe Head Injury, Falls with Bony Injury, Severe Abdominal Pain and Fits.

ABOVE WILL NEED 999

Clinical Frailty Scale*

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 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.

* 1. Canadian Study on Health & Aging, Revised 2008.
2. K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489-495.

DALHOUSIE UNIVERSITY
Inspiring Minds

Stop and Watch—Early Warning Tool

If you have identified a change while caring for or observing a resident, Date: ____/____/_____ Time:_____
please circle the letter, <u>underline the change</u> and notify the person in charge with a copy of this tool.

Name of resident:_____ Date of Birth____/____/_____ Room Number_____

S	**S**eems different to usual
T	**T**alks or communicates less
O	**O**xygen-increased requirement, breathless, chesty
P	**P**ain—new or worsening; Participates less in activities
A	**A**te less
N	**N**o bowel movement in 3 days; or diarrhoea
D	**D**rank less
W	**W**eight change
A	**A**gitated or more nervous than usual
T	**T**ired, weak, confused, drowsy
C	**C**hange in skin colour or condition, high temp, low temp, clammy, rash
H	**H**elp with walking, transferring or toileting more than usual, overall needs more help

Describe the change you noticed: _____

_____

_____

Carer Name:_____

Senior Nurse reported to: _____

Observations: RR_____ SATS_____ BP_____ Pulse_____ ACVPU_____ Temp_____

Senior Nurse Actions

Repeat observations and record NEWS2 score overleaf (if applicable)

Reported to (circle)**:** GP Rapid Response 111 999 not reported—Why?_____

_____

Used SBARD format (overleaf) **to communicate concerns :** Y / N

Date: _____/_____/_____ **Time** (am/pm)_____

Outcome: ☐ Phone advice

☐ Treatment given in home (circle) GP Rapid Response Ambulance

☐ Transfer to hospital

☐ Other_____

In line with their preferred place of treatment / death? (circle) Y / N (if N please advise below)

_____

Advance Care Plan: Y / N DNACPR/DNAR Y/N ReSPECT Form: Y / N (please circle as appropriate)

SBARD Communication Form

Before calling for help

Evaluate the resident: Complete relevant aspects of the SBARD form below
Review record: Recent progress notes, medications, other orders
Have relevant information available when reporting: (i.e. medical record, advance directives such as ReSPECT and other care limiting orders, allergies, medication list)

SITUATION Date: ____ /____ /_____ Time:_____

I am calling because I am worried about _____ Date of birth:____ /____ /_____

This started on ____ /____ /_____

Since this started it has got: Worse ☐ Better ☐ Stayed the same ☐

BACKGROUND

Medical Conditions _____

Other medical history (e.g. medical diagnosis of CHF, DM, COPD)

_____

_____

Frailty Status (if known)_____

Advance Care Plan: Y / N DNACPR/DNAR Y/N ReSPECT Form: Y / N (please circle as appropriate)

ASSESSMENT

Identify the change(s) from the Stop and Watch tool

_____

_____

Repeat Observations: RR_____ SATS_____ BP_____ Pulse_____ ACVPU_____ Temp_____

NEWS2 Score (if applicable):

RECOMMENDATION

Responding Service Notified:_____ Date____ /____ /_____ Time (am/pm)_____

Actions you were advised to take:

_____

_____

DECISION

_____

_____

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Resource Links

MiDoS for Care Homes in Staffordshire and Stoke-on-Trent (Updated September 2021) | Staffordshire Connects:
https://www.staffordshireconnects.info/kb5/staffordshire/directory/advice.page?id=c2-r0G5E0Kw

Register | Staffordshire Connects:
https://www.staffordshireconnects.info/kb5/staffordshire/directory/register.page

Course Bookings | Staffordshire Connects:
https://www.staffordshireconnects.info/kb5/staffordshire/directory/coursebookings.page?query=&start=21+October+2021&end=31+March+2022&type=&protected_only=0&e=results

Adult social care – information for providers | Care Quality Commission (cqc.org.uk):
https://www.cqc.org.uk/guidance-providers/adult-social-care

Sepsis – elearning for healthcare (e-lfh.org.uk):
https://www.e-lfh.org.uk/programmes/sepsis

COVID-19: Essential training (skillsforcare.org.uk)
https://www.skillsforcare.org.uk/About/News/COVID-19-Essential-