



# Acute care toolkit 16

## Acute medical care for people with a learning disability April 2022

### Who should read this resource?

All staff working in acute medical units will care for people with a learning disability who present acutely unwell to hospital.

These patients are vulnerable and may be unable to communicate their needs independently. The care provision for people with a learning disability is currently suboptimal, with increased mortality and morbidity. Constipation is a common cause of acute presentation and pneumonia is the leading cause of death.

The scope of this acute care toolkit is limited to the care of adults with a learning disability in acute hospitals, focusing on the acute admission phase. The principles can be applied to other phases of healthcare.

‘People with a learning disability die 20 years younger than their peers.’

### Key recommendations

- > Use primary care records / hospital alert system to help identify, on admission, all patients with a learning disability.
- > The clinical presentation of a person with a learning disability can be highly variable: multiple health conditions and polypharmacy are common at a young age, and people with a learning disability may die of common and preventable conditions. A specific focus on assessing and meeting the care needs of these patients is required.
- > Professional uncertainty when faced with complex patients is common, and seeking help is wise and advisable. Use the hospital learning disability team as a resource in guiding decisions around care.
- > Involve the person with a learning disability – and, where appropriate, their carers – in decision making as much as possible. Assess mental capacity for each decision.
- > The patient is entitled to reasonable individualised adjustments in communication and care.

### Background

#### Epidemiology

Learning disability or intellectual disability is defined as a ‘significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood with a lasting effect on development’.<sup>1</sup>

It is estimated that approximately 2% of the adult population has a learning disability.<sup>2</sup> The aetiology includes genetic and chromosomal conditions, antenatal and perinatal problems, and incidents in the early years of life, such as meningitis or trauma. Presentation is highly variable. On average, people with a learning disability have 11 different health conditions,<sup>3</sup> some of which are significantly more common than in the general population, for example epilepsy, dementia, mental illness, neurodevelopmental conditions and autism.

They might have sensory problems with vision and hearing, gait and postural problems, and difficulties with communication.

### Understanding risks associated with learning disability

The median age at death for people with a learning disability is 61 years; this is 20 years younger than that for the general population.<sup>4</sup> It is 10–20 years younger still in people from minority ethnic groups. Avoidable deaths are significantly more common in this population; for example, people with a learning disability may be eight times more likely to die from COVID-19 than the general population.<sup>5</sup> Additionally, some adults with a learning disability are more vulnerable to forms of abuse and might require safeguarding. Delayed assessment can contribute to poor outcomes.

## Key clinical challenges

‘50–90% of people with a learning disability have communication difficulties.’

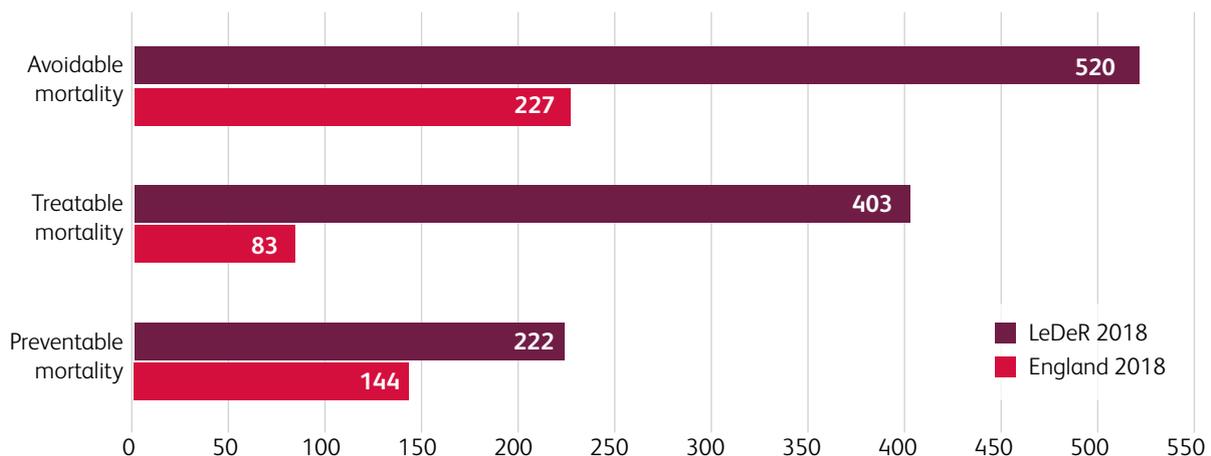
### Communication

Poor communication can lead to restricted access to public services, breach of human rights, lower quality of care and end-of-life support, as well as increased mortality. 50–90% of people with a learning disability have communication difficulties, ranging from mild limitations to being non-verbal (20%).<sup>7</sup> They also have an increased risk of hearing and vision disorders. Avoidable deaths stem in part from difficulties in communicating ‘soft signs’ (eg change in sleep or eating/drinking pattern) or changes in symptoms (such as pain), which can be indicative of acute illness.

### Behaviours of distress

Distressed or ‘challenging’ behaviour is often perceived and experienced as physical or verbal aggression, self-harming or socially unacceptable behaviours that have a negative impact on the person or those around them. These behaviours can

**Fig 1. Age-standardised avoidable, treatable and preventable mortality (per 100,000) for people with a learning disability and the general population.<sup>6</sup>**



The following definitions apply:

**Preventable mortality** – Causes of death that can be mainly avoided through effective public health and primary prevention interventions.

**Treatable mortality** – Causes of death that can be mainly avoided through timely and effective healthcare interventions, including secondary prevention and treatment.

**Avoidable mortality** – Causes of all deaths that are defined as preventable or treatable.

be a means of patients communicating physical illness. Triggers can include expressions of pain, anxiety, hunger, difficulty processing information, boredom, sensory differences or changes to routine.

Besides being distressing for the person and those around them, such expressions of distress can make their examination, investigations and treatment challenging. 'Diagnostic overshadowing' may occur when a healthcare professional assumes a certain behaviour to be part of the learning disability and not related to illness. It is therefore essential to consult family or carers who know the person well to aid interpretation.

**Patients may not be able to communicate their needs, but more than that, many will not even understand that they have needs. To use Holly as an example, yesterday she had to go to hospital for an X-ray on her leg as she was walking with a limp. If you ask her in a variety of ways if anything is wrong, she says no, but clearly something is. She will almost certainly refuse to let anyone look at it or touch it, and it will be tricky to get her to stand still for the X-ray. She also does not understand the repercussions if she doesn't get treated.'**

– Holly's mum

### Reasonable adjustments

Reasonable adjustments are a legal requirement and a way to ensure that every individual has equal access to health services. An adjustment is any action that reduces or alleviates a disadvantage. Services may need to provide more favourable support to disabled people in order to achieve the same outcomes. Reasonable adjustments are a statutory duty under the *Equality Act 2010*, which says that 'health and social care providers must make reasonable adjustments to remove any barriers – physical or otherwise – that could make it difficult for disabled people to use their services or prevent them from using them altogether. As far as possible, the effect of the adjustment should be to make services as accessible to disabled people as they are to other members of the public'. Under this act, public sector organisations, including the NHS, must make changes to their approach or service provision in order to ensure equitable care.

To consider reasonable adjustments for your patients, you can use the TEACH acronym to help you think this through:

#### T = time

Clinical assessments may need more time, which may mean factoring this into working plans, breaking it down into manageable yet effective components, scheduling with carers, or completing assessments outside standard times such as ward rounds.

#### E = environment

Consider noise, lighting, equipment such as bed height, personal belongings. Would a side room be appropriate?

#### A = attitude

Consider more open visiting or sharing caring duties in hospital. Consider less frequent monitoring of vital signs or laboratory tests, when the patient is stable.

#### C = communication

Use communication aids such as pictures, and ensure that communication is non-threatening and non-technical.

#### H = help

For example, ask for help from a learning disability team.

A reasonable adjustment flag can be added to the patient's electronic record, to alert staff to individual patient needs. This should be implemented in UK health systems.

Most importantly, ask the person with a learning disability and their carers what reasonable adjustments might help their care.

For more information on reasonable adjustment flags, see <https://digital.nhs.uk/services/reasonable-adjustment-flag>

For more information on reasonable adjustments, have a look at [Treat me well: Asking for reasonable adjustments](#) (YouTube)

### Communication of care

During admission, a clear written care plan based on the individual's needs relevant to this admission should be recorded. On transfer of care to the community, learning disability should be documented in hospital records and any written communication. There may have been a change in the patient's need – if so, their carers might need to do things differently, may need training etc. At discharge, information should be shared with GPs, care providers and learning disability specialists, and the patient's hospital passport might need to be updated, in consultation with the person and the people who know them well.

### Recommendations

- > Establish the patient's needs using their hospital passport, GP records, reasonable adjustment flag, health action plan, family and carers, and learning disability specialist nurses.
- > Use reasonable personalised adjustments, such as verbal and non-verbal communication tools, to enhance communication and understanding and minimise distressed behaviour.
- > Use the TEACH acronym to think through reasonable adjustments that might be applied.

**Table 1. Top tips for those caring for people with a learning disability**

<b>On admission</b>	<ol style="list-style-type: none"> <li>1 Get context: check the patient's summary care record, hospital passport, specific care plans and whether they have an attorney, deputy or guardian acting for them.</li> <li>2 Gather information from the person, family and carers, and the community or hospital learning disability team:                             <ol style="list-style-type: none"> <li>a check about previous problems, eg aspiration and constipation</li> <li>b establish what is usual and unusual for this patient</li> <li>c enquire about sensory or communication needs</li> <li>d ask about any existing supporting care plans, eg positive behaviour support plan.</li> </ol> </li> </ol>
<b>During admission</b>	<ol style="list-style-type: none"> <li>3 Remind yourself: despite trying, you may not be able to understand the individual patient, but need to be confident liaising with the family/carers who know them best and work together as a team.</li> <li>4 Involve the learning disability specialist liaison nurses, family and carers in daily care.</li> <li>5 Optimise communication:                             <ol style="list-style-type: none"> <li>a avoid distractions: choose a quiet room if you can</li> <li>b speak slowly in short sentences</li> <li>c ask the patient if they have pain, feel anxious, frustrated, tense or angry</li> <li>d describe <i>and</i> show the patient what you want them to do</li> <li>e consider breaks in longer communications.</li> </ol> </li> <li>6 Consider the patient's mental capacity, consent and best interests for all care and treatment decisions. When making best interest decisions, encourage the person to participate in decision making. Consider referring to an Independent Mental Capacity Advocate (IMCA) if no family/carer is available.</li> <li>7 Make required reasonable adjustments:                             <ol style="list-style-type: none"> <li>a consider communication aids, such as Makaton or pictures, and pain tools, for example the Abbey pain scale or <a href="http://booksbeyondwords.co.uk">booksbeyondwords.co.uk</a></li> <li>b consider relaxation therapies, graded exposure or, if the patient is severely agitated, oral sedation. Seek help from other specialties if required, eg anaesthetic colleagues may be able to help with vascular access.</li> </ol> </li> </ol>
<b>On discharge</b>	<ol style="list-style-type: none"> <li>8 Make sure that the patient's learning disability is documented on the hospital alert system (and GP register).</li> <li>9 Update and share care plans in a way that is understood by the person, family and their main carers and share with the GP.</li> </ol>

## Clinical presentations

**‘40% of deaths in people with a learning disability are due to pneumonia.’**

Hospitalisation is a challenging experience and people with a learning disability may have delayed presentation to acute medical services. This might be due to problems in communication with healthcare staff, poor access to information, a lack of reasonable adjustments, lack of compassion and respect, and/or discrimination. People with a learning disability experience worse patient safety outcomes and quality of care in hospital. It is therefore particularly important to obtain full sets of observations and to examine the patient carefully, even if this is challenging.

More than 70% of hospitalised patients with a learning disability have some form of dysphagia, which predisposes to aspiration and acute upper airways obstruction.<sup>8</sup> 40% of deaths in people with a learning disability are due to pneumonia.<sup>9</sup> Members of the multidisciplinary team, eg a dietician or speech therapist, should provide guidance as to the consistency and type of food that the patient can and cannot safely swallow.

Baseline physiology for people with a learning disability may differ from that of the general population, and checking vital signs to calculate a full National Early Warning Score (NEWS2) may provide objective comparison to the individual’s baseline vital signs. Incomplete NEWS2 measurements may need to trigger an escalation response at a lower threshold. If one physiological measure is not obtainable despite the equipment being used, this should trigger an immediate response. Common clinical presentations are listed in Table 2.

### Recommendations

- > Vital signs: check the patient’s normal range. Incomplete measures may trigger an escalation response at a lower threshold.
- > Look for non-specific symptoms or those that are unusual for the individual.
- > Beware of ‘diagnostic overshadowing’ by clinicians.

**Table 2. Features of acute presentations of people with a learning disability.**

<b>General illness</b>	<ul style="list-style-type: none"> <li>&gt; Consider: fatigue, reduced activity, withdrawal, sleepiness, decreased mobility, poor postural control and coordination, falls, uncontrolled diabetes.</li> <li>&gt; Baseline physiology may differ.</li> </ul>
<b>Cancer</b>	<ul style="list-style-type: none"> <li>&gt; May be unaware of lumps in their testicles or breasts, significant change in bowel habit, rectal bleeding, haematuria.</li> </ul>
<b>Dementia and delirium</b>	<ul style="list-style-type: none"> <li>&gt; Behavioural changes, reduced ability to perform activities of daily living, seizures.</li> </ul>
<b>Epilepsy</b>	<ul style="list-style-type: none"> <li>&gt; Assess the duration and frequency of seizures.</li> <li>&gt; Check whether there is any new cause of seizures, rather than assuming it to be ‘progression’.</li> </ul>
<b>Foreign bodies</b>	<ul style="list-style-type: none"> <li>&gt; Consider the presence of foreign bodies in the ear, mouth, upper gastrointestinal tract, rectum, vagina or urethra.</li> </ul>
<b>Gastrointestinal symptoms</b>	<ul style="list-style-type: none"> <li>&gt; Severe constipation, faecal impaction, ileus, bowel perforation, dysphagia, symptoms of gastro-oesophageal reflux disease.</li> </ul>
<b>Pain/distress</b>	<ul style="list-style-type: none"> <li>&gt; Poor appetite, change in sleep, change in behaviour eg aggression, rocking, shouting, pacing, or becoming quieter and withdrawn.</li> </ul>

### Managing medical problems in people with a learning disability

In the majority of cases, the medical treatment for people with a learning disability is the same as for the general population. 98% of people with a learning disability have multiple health conditions<sup>3</sup> and, as

a result, polypharmacy is common. Medications should be reviewed during the acute hospital admission, paying particular attention to drugs that worsen cognition, increase the risk of falls or cause constipation. Common side effects of treatments are summarised in Table 3.

**Table 3. Considerations for the treatment of common medical problems in people with a learning disability.**

Condition	Management considerations
<b>Constipation</b>	<ul style="list-style-type: none"> <li>&gt; Take a detailed toileting, exercise and fluid intake history.</li> <li>&gt; Constipation can be a side effect of some medicines, such as:                             <ul style="list-style-type: none"> <li>– anticonvulsants: gabapentin, phenytoin, pregabalin</li> <li>– antidepressants: tricyclic antidepressants eg amitriptyline, selective serotonin reuptake inhibitors eg sertraline</li> <li>– antipsychotics eg clozapine, risperidone</li> <li>– antiemetics: ondansetron, prochlorperazine</li> <li>– others eg opioids, non-steroidal anti-inflammatories, antimuscarinics.</li> </ul> </li> <li>&gt; This is not an exhaustive list and the pharmacist and available resources should be consulted for a full medication review.</li> </ul>
<b>Seizures</b>	<ul style="list-style-type: none"> <li>&gt; If you change a medication, balance the control of the epilepsy against the side effects and effect on quality of life.</li> </ul>
<b>Worsening cognition, increased risk of falls and delirium</b>	<ul style="list-style-type: none"> <li>&gt; Check for common causes of delirium.</li> <li>&gt; Consider side effects from:                             <ul style="list-style-type: none"> <li>– cardiovascular medicines eg beta-blockers, calcium channel blockers, furosemide, nitrates</li> <li>– antihistamines: H1 and H2 antagonists, including ranitidine</li> <li>– opioids and other analgesics, including non-steroidal anti-inflammatories eg ibuprofen, naproxen</li> <li>– benzodiazepines.</li> </ul> </li> <li>&gt; This is not an exhaustive list and the pharmacist and available resources should be consulted for a full medication review.</li> </ul>
<b>Dysphagia</b>	<ul style="list-style-type: none"> <li>&gt; For patients presenting with respiratory problems, consider a speech and language therapist assessment, with written instructions on discharge.</li> </ul>

### Recommendation

- > Review all medication that is known to worsen cognition and to increase the risk of falls, delirium and constipation.

## Medicolegal considerations

**‘Resuscitation decisions must never be made purely on the grounds that a person has a learning disability.’**

### Capacity assessment

People with a learning disability must be assumed to have capacity unless it is established that the person lacks capacity.<sup>10</sup> The principles of mental capacity legislation vary between the four nations of the UK, but apply to people with a learning disability in the same way as to the general population: capacity is time and decision specific. Making reasonable individualised adjustments might enhance capacity.<sup>11</sup>

If the patient is deemed not to have capacity for that decision, then delivering care should be made based on their best interests, considering previous documented decisions (eg advanced directive, hospital passport). It is important to involve the family/carer, speak to the court-appointed deputy if they have one and consider a referral to the IMCA. Legal advice may be necessary in certain cases. Common sense needs to apply to emergency situations and the duty of care. Careful documentation of this process is required to evidence that correct procedures have been followed using accessible resources for the patients and families, and to ensure that the medical team is providing care consistent with medicolegal guidance. Treatment should never be denied simply because someone has a learning disability.

### Escalation of care

Ultimately, decisions made by the clinical team must be based on their assessment as to whether the test or treatment in question is likely to improve a patient’s outcome. Clinicians are not obliged to administer a futile treatment and might have concerns about the ability of a patient to recover from a condition; however, the decisions to escalate care and DNACPR (do not attempt cardiopulmonary resuscitation) must never be made on the grounds that a person has a learning disability. The Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) can be used to guide discussion about personalised patient needs and wishes.<sup>12</sup> A framework for conversations for ethically complex care is recommended by the Royal College of Physicians.<sup>13</sup>

### Safeguarding

It is paramount that all professionals supporting the health and wellbeing of people with a learning disability consider the safety and welfare of the person, including any safeguarding concerns. In 2017–18, 14,655 adults with a learning disability were involved in section 42 safeguarding enquiries.<sup>14</sup> There have also been numerous high-profile safeguarding cases, where people with a learning disability have been exposed to unacceptable abuse. All health professionals have a responsibility to protect the wellbeing and human rights of the people they are providing care for, to enable them to live free from harm, abuse and neglect. This involves following national and local safeguarding and whistleblowing procedures.<sup>15</sup>

## Recommendations

- Every effort must be made to support people with a learning disability to make decisions around their health and care, and the information provided must be in a format that they can understand wherever possible.
- If a person with a learning disability is deemed not to have capacity, then a decision around escalation of care must be made in their best interests. Any decision about resuscitation must also be made in their best interests.

## Quality improvement

**‘Patients should be involved in the development of person-centred care pathways.’**

### Culture of care

Central to delivering good, effective care is organisational culture, focused on person-centred, safe and effective practice. There is a risk of unconscious bias, and practitioners need to take active steps to reduce this.

It is paramount that organisations work with patients, their families and carers in partnership to achieve good health outcomes. This should be both in the delivery of individual person-centred care, but also in the co-design of quality and service improvement and delivery of education and training.<sup>16</sup>

The learning disability improvement standards<sup>17</sup> and improvement tool for reducing deaths of people with a learning disability<sup>18</sup> help to develop safe and effective cultures of care for people with a learning disability, thus enabling good patient experience and patient outcomes. Some hospitals have developed an urgent care checklist / admission risk assessment for people with a learning disability.

## NICE guidance

“Learning disability” should be coded in discharge summaries.’

The National Institute for Health and Care Excellence (NICE) has issued a range of quality standards for people with a learning disability; quality statements 10 and 11 in Quality Standard 101 are relevant to hospital care.<sup>19</sup> People with a learning disability and ‘challenging’ behaviour should have a documented review each time that a restrictive intervention is used, and they should only receive antipsychotic medication as part of treatment that includes psychosocial interventions.

‘Learning disability’ should be coded in discharge summaries. NHS Digital has developed a ‘reasonable adjustment’ flag for electronic records. The use of a patient’s hospital passport, as well as contacting the patient’s usual care team (eg the community learning disability service), should be regarded as standard during a hospital admission.

### LeDeR reviews

LeDeR is the English national programme to review the deaths of people with a learning disability, with the aim of reducing health inequality, reducing the risk of avoidable death and improving their healthcare.

A LeDeR review examines areas of health and social care received by the person that are relevant to their health outcomes, looks for areas of improvement and shares best practice. These can be used to trigger local quality improvement workstreams.

## Recommendations

- > Monitor the usage of patients’ hospital passports as part of quality improvement.
- > Involve people with a learning disability and their carers as partners in the co-design of care.
- > Ensure adherence to clinical care pathways for people with a learning disability.
- > Ensure adherence to legislation to guide practice, for example application of the Mental Capacity Act.<sup>20</sup>
- > Use recommendations from local LeDeR reviews to trigger improvement projects.

## Education

The premature deaths of people with a learning disability have led to questions about the quality of training received by healthcare staff and their ability to care holistically for people with complex needs. Despite this, learning disability is not referenced in the training curriculum in many specialties, including acute medicine, but the principles of care can be linked to capabilities in the safeguarding of vulnerable people.

Training healthcare and social care professionals in the care of people with a learning disability is essential to provide the best outcomes for this group of patients, and requires excellent skills in communication with patients and their relatives.

## Recommendations

- > Consider the care of people with a learning disability as an important learning opportunity for trainees, supported by tailored workplace-based assessments and quality improvement projects.
- > Undertake learning through case review, including using structured judgement review as part of LeDeR,<sup>4</sup> following a patient death.
- > Share positive practice and stories as examples of good care, as well as learning identified to improve care.

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An Easy Read version of this toolkit, and a list of all those who contributed, are available at [www.rcp.ac.uk/act16](http://www.rcp.ac.uk/act16)

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