



Royal College *of*
Emergency Medicine

Learning Disabilities Toolkit

September 2024

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Introduction

“This is such an important resource with the potential to transform the emergency healthcare of people with learning disabilities. There is a general lack of awareness about people with learning disabilities in the UK, combined with a tendency to allow the learning disability label to cloud health professionals’ judgement and expertise. The large discrepancy in mortality rates among this group strongly speaks to this and emergency care is a space in which people need meticulous care and attention.

What has always struck me is how people with learning disabilities, their families and those close to them, have loving and often joyful relationships. The key to good healthcare is as simple as learning to recognise this and treating the person as human, and someone who matters deeply.”

Professor Sara Ryan, whose son Connor Sparrowhawk (who had a learning disability and epilepsy and was autistic) died in NHS care. An independent review concluded his death was preventable. Professor Ryan has campaigned not only for justice for her son, but for better medical care for all people with a learning disability.

There are approximately 1.5 million people with a learning disability in the UK – that’s 2.5% of the UK’s children and 2.16% of the UK’s adults, so every Emergency Department will regularly see patients with a learning disability¹. Many will have multiple comorbidities, so may attend relatively more frequently. People with a learning disability face huge barriers to accessing healthcare, with resultant health inequalities.

People with a learning disability die, on average, 20 years earlier than those without. They are twice as likely to die from an avoidable cause of death and up to five times more likely to die of something that should be treatable².

The NHS Long Term Plan³ made a commitment to address health inequalities, including those faced by people with a learning disability. There are many simple steps that emergency clinicians can take to help break down barriers to healthcare and minimise inequality. This resource toolkit aims to explain the main issues involved and guide readers the resources to support best care.

This video (right), featuring Sam and Gavin, two Experts by Experience, is a valuable insight into how an ED visit can feel to a person with a learning disability, and how we can improve their experience and their access to healthcare.

Read about a visit to ED by a young woman with Down syndrome:

[What a patient with a learning disability would like you to know | The BMJ](#)

When making reasonable adjustments for people with a learning disability and autistic people think

T.E.A.C.H.

Definitions

Learning Disability: “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 adulthood⁴”.

The degree of disability ranges from mild or moderate to severe and profound. There is no cure, although people can benefit from support in a variety of ways. Causes include genetic and chromosomal conditions, antenatal infections, hypoxic brain injury, neurodegenerative conditions and those that are idiopathic.

A learning disability can impact on someone’s ability to stay healthy as they may find it difficult to understand how to avoid risk or danger, how to follow a healthy lifestyle, how to seek help when they feel unwell, how to explain their symptoms, how to tolerate examinations and investigations, how to keep appointments and how to take medications. Depending on the cause of the learning disability, there may be additional risks of comorbidity and polypharmacy. There are also many external factors which also build barriers to healthcare, including the hospital environment, clinicians’ communication skills and diagnostic overshadowing, which will be described later.

Learning Difficulty: this is a difficulty with a specific area of learning, such as dyslexia, dyspraxia or ADHD. General intellect is not affected. People with a learning disability may also have one or more learning difficulties.

Autism: a lifelong developmental condition which affects how people communicate and interact with the world⁵. Each autistic person has their own challenges and strengths, which may include social communication difficulties, repetitive and restrictive behaviour, sensory processing difficulties, highly focused interests, anxiety and meltdowns or shutdowns. Autism is not a learning disability, although the two conditions may co-exist. There are around 700 000 autistic children and adults in the UK, about 1 in 100 of the population. Autistic people face their own barriers to healthcare⁶.

Although Autism is not a learning disability, many of the adjustments made to support those with a learning disability will also be beneficial to autistic patient due to the anxiety, sensory processing and communication challenges they can face.

More information can also be found here:
[Defining Learning Disability - Don't Forget the Bubbles](#)

Reasonable Adjustments

The Equality Act, 2010⁷, states that healthcare organisations and professionals need to make reasonable adjustments in order to enable people with disabilities (including learning disabilities) to access healthcare to the same standard as those without disabilities. In order to do this, we need to consider the challenges individuals might face, recognise the fact that each individual is exactly that – individual, and consider how we can reasonably minimise those challenges.

Alerts on electronic patient records, care plans, hospital passports, information from family and carers, and discussions with patients themselves can help to identify the reasonable adjustments which may need to be made.

Examples might include:

- Providing a quieter area to wait
- Providing ear defenders to help with auditory sensory overwhelm
- Accessible information – easy read posters, leaflets and signage
- Allowing for extra time during consultations
- Allowing family members or carers to stay with a patient
- Speaking clearly, avoiding medical jargon
- Using communication supports to aid with understanding
- Spending more time explaining procedures or interventions, demonstrating equipment or allowing a person to get used to the environment
- Offering topical anaesthetic creams prior to cannulation or venepuncture
- Local Community Acute or Emergency Medicine services may make it possible for some patients to have investigations or follow-up care at home/in their own environment

A mnemonic to remember some of the most commonly needed reasonable adjustments is TEACH:

T – Time: you may need to spend more time assessing your patient and enabling them to understand what is happening.

E – Environment: is there somewhere quiet for your patient to wait? Can you alter the environment to help them feel comfortable – removing equipment, silencing machinery or dimming lights?

A – Attitude: keep an open mind, avoid making assumptions about understanding or quality of life.

C – Communication: speak slowly and clearly, avoid jargon, look for non-verbal cues, consider communication tools.

H – Help: what help does your patient need? What help do you need? Would a family member, care plan, hospital passport or learning disability liaison nurse be helpful?

Whilst it is vitally important to not under-investigate and misdiagnose due to not wanting to cause distress, it is also important to carefully consider the risk and benefit of everything we do. In some situations, it may be appropriate to intervene less than we would for somebody who was not experiencing extreme distress or sensory overwhelm. An example of this may be a wound where cosmetic outcome is not a concern – it may be preferable to suture a wound to get the best possible outcome, but if the wound will heal with minimal intervention and will significantly reduce distress by doing so, this may be more appropriate. It may also make the patient's experience of a hospital visit more positive and make it easier if they need to attend in the future. This is obviously situation dependent and will need careful consideration and involvement of a senior decision maker.

Find out more about reasonable adjustments here:

[Reasonable adjustments make the biggest difference to people's health and wellbeing \(video\)](#)

[How I assess children with complex needs in the ED \(the TEACH mnemonic\) - Don't Forget the Bubbles \(dontforgetthebubbles.com\)](#)



For autistic patients: [Autistic SPACE: a novel framework for meeting the needs of autistic people in healthcare settings - PubMed \(nih.gov\)](#)

Reasonable Adjustments – The ED Pledge

You might like to write a pledge for your patients and ask your team to sign up to it. Examples are shown here:

THE ED PLEDGE

**Our Pledge for People With
Learning Disabilities**
Emergency Department | HUTH NHS Trust

WE PROMISE TO LISTEN TO YOU

**WE PROMISE TO LISTEN TO
YOUR PARENTS / CARERS**

**WE PROMISE TO TRY TO FIND YOU
SOMEWHERE QUIET TO WAIT, IF POSSIBLE**

**WE PROMISE TO FIND OUT HOW BEST TO
COMMUNICATE WITH YOU**

**WE PROMISE TO EXPLAIN WHAT
WE ARE DOING**

**WE PROMISE TO DO OUR BEST TO
HELP YOU FEEL SAFE**

**WE PROMISE TO DO OUR BEST TO
HELP YOU FEEL BETTER**


Hull University
Teaching Hospitals
NHS Trust

Our pledge for people with learning disabilities in the Emergency Department



We promise to:



Listen to you.



Listen to your grown ups.



Find you somewhere quiet to wait, if possible.



Find out how best to communicate with you.



Explain what we are doing.



Try to help you feel safe.



Try to help you feel better.

Communication

Communication is vital in all we do in the ED. It's worth remembering:

- Communication is not just verbal: consider your own non-verbal communication, along with that of your patient
- Communication is a two-way street: we must do our best to make ourselves understood, as well as trying to understand
- Communication and understanding are not always on the same level: someone may have excellent communication skills but find it difficult to understand, or they may not be able to communicate well, but understand everything that is said to them, about them or around them

People with a learning disability may face challenges with communication due to:

- Differences in understanding
- Associated hearing or vision problems (for example, people with Down syndrome often have comorbidities affecting the eyes and ears)
- Difficulties with auditory processing and short-term working memory
- Difficulties in speech sound production
- Social communication difficulties (commonly seen in autism too), including challenges in displaying or understanding non-verbal cues
- Environmental and social issues – noisy department, unfamiliar setting, differences in light and acoustics
- Anxiety

Some people can struggle with information processing. This can be helped by using simple terms, asking one question at a time and giving additional time for your patient to process what you have said and formulate a response (this can feel like an uncomfortable pause but is important in helping your patient to be able to give their response to a question or share their opinion). You may need to explain things more than once but remember that understanding can alleviate anxiety and also enable consent. Despite any pressure we are under to maximise our efficiency in the ED, it is a legal requirement to make reasonable adjustments for patients with a disability – this includes allowing more time to meet their needs.

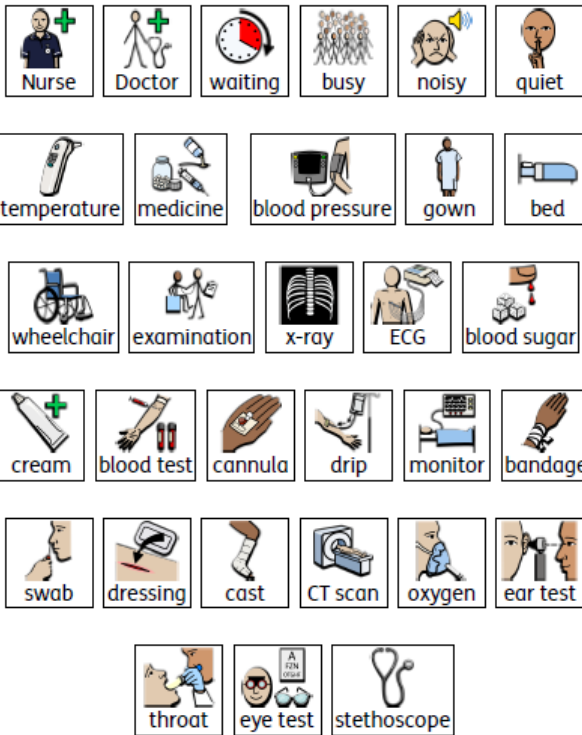
It is common for autistic people, particularly children, to interpret things literally. Consider the language you are using and avoid metaphors or idioms e.g. “it will be a piece of cake” or “the ball is in your court”. Autistic people are more likely to jump to the literal meaning of the phrase rather than the figurative meaning, which can be confusing, anxiety-inducing and minimise understanding. Trust is important and misunderstanding can lead to distress and distrust. For this reason, it can be better to use accurate, descriptive language when explaining a procedure (for example instead of saying “this won’t hurt”, it may be better to say “it might hurt a little bit when the needle touches your skin but then it will stop hurting quickly”). This will be person dependent and, as mentioned previously, is best gauged by the patient’s relative or carer, or by the patient themselves if they are able to communicate this.

For some patients, it may be enough to speak slowly, clearly and avoid jargon. Finding somewhere less noisy for your consultation can also help.

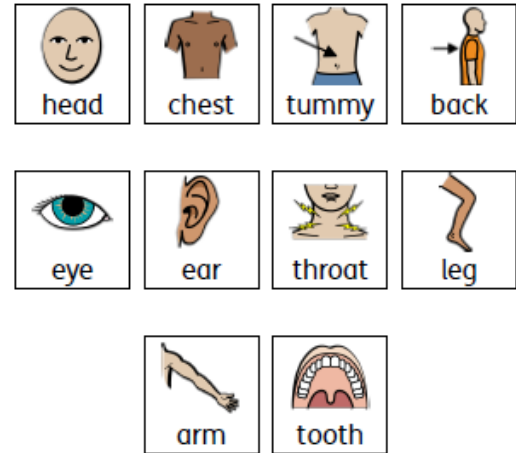
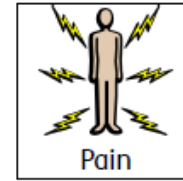
For others, we may need to support verbal communication with visual or other aids. These communication supports may include:

- Physical objects, e.g. demonstrating a saturation probe on yourself or the patient’s carer
- Pictures or photos
- Symbols – simple line-drawings which represent words, items or phrases. There are widely recognised forms of symbols such as those used by Makaton⁸, Picture Communication Symbols (PCS) and Widget⁹. Your patient may have their own symbol boards, books or app, for example

The Emergency Department



https://rcem.ac.uk/wp-content/uploads/2024/09/Communication_The_ED_v1.pdf



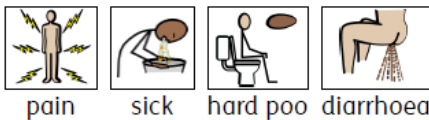
Created in WidgeOnline.com for RCEM

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https://rcem.ac.uk/wp-content/uploads/2024/09/Communication_Pain_v1.pdf



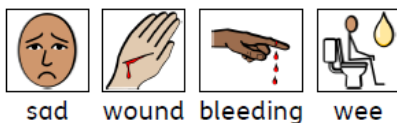
I feel ill



pain sick hard poo diarrhoea



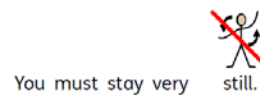
fever rash dizzy cough worried



sad wound bleeding wee

https://rcem.ac.uk/wp-content/uploads/2024/09/Communication_Symptoms_v1.pdf

Having an ECG





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https://rcem.ac.uk/wp-content/uploads/2024/09/Communication_ECG_v1.pdf


Having a blood test

You can have  cream or  cold spray.


After the  cream we must  wait.

The  spray is very  cold!

You can look at a  phone or  book


when we do the  blood test.



We will put a  tourniquet on your  arm.

It will feel  tight. You need to stay very


 still.

It will be  finished  soon.

You can have a  plaster afterwards.

The  blood tests will help us to  know

what is making you  ill, so we can



help you feel  better.


Having a cannula

You can have  cream or  cold spray.


After the  cream we must  wait.

The  spray is very  cold!



You can look at a  phone or  book


when we do the  cannula.

We will put a  tourniquet on your  arm.

It will feel  tight. You need to stay very


 still.



It will be  finished  soon.

You will have a  plastic straw in your

 arm.

You will have a  bandage or a  plaster.

We can give you  medicines through the

 cannula to make you feel  better.

https://rcem.ac.uk/wp-content/uploads/2024/09/Communication_Blood_Test_v1.pdf

https://rcem.ac.uk/wp-content/uploads/2024/09/Communication_Cannula_v1.pdf

Having an X-ray



An x-ray is a special picture that helps us



know what is happening inside you.



It does not hurt.



You must stay still when the picture is

taken.

https://rcem.ac.uk/wp-content/uploads/2024/09/Communication_Imaging_v1.pdf

Having a CT Scan



A CT scan is a special picture that helps us



know what is making you ill.



It does not hurt. It might be noisy.



You must lay very still.

https://rcem.ac.uk/wp-content/uploads/2024/09/Communication_Imaging_v1.pdf

Having an Ultrasound



An ultrasound helps us know what is



making you ill.



We will put some gel on your skin.



It does not hurt. It might be cold.



Then we will put the ultrasound on your skin.



You should try to stay still.



It will take a few minutes.

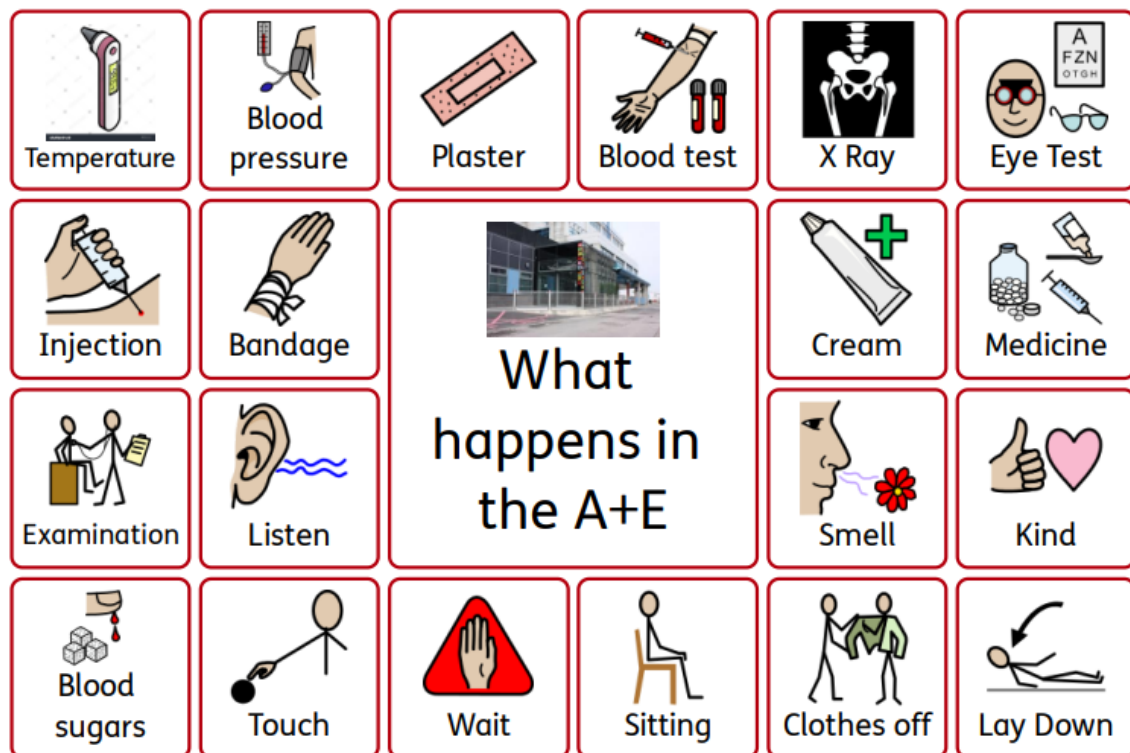


Then we will wipe the lotion away.

https://rcem.ac.uk/wp-content/uploads/2024/09/Communication_Imaging_v1.pdf

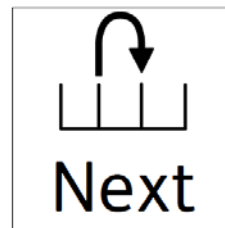
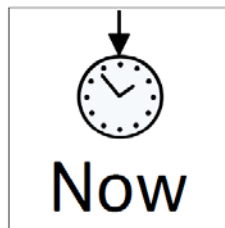
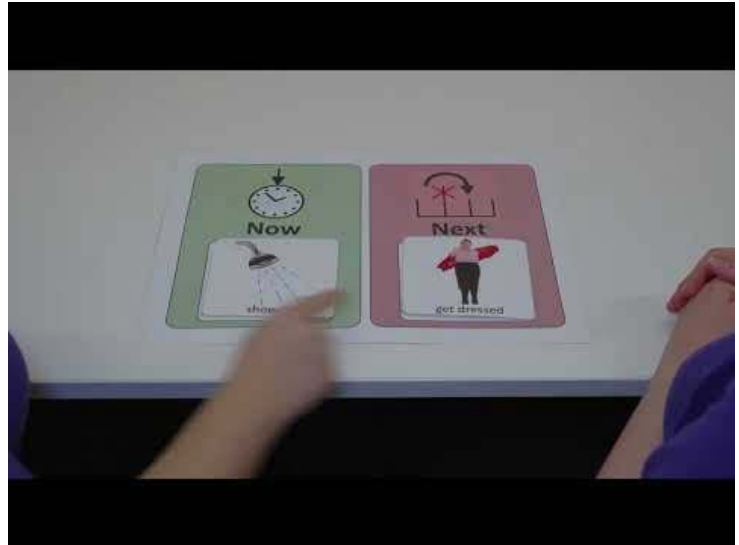
- Social stories¹⁰ – these are simple stories, usually with pictures or symbols, to describe things like a visit to the ED or having an x-ray
- Sign – your patient may use British Sign Language (BSL), but Makaton⁸ is more commonly used by patients with a learning disability. This is a simple tool which supports the spoken word, rather than a form of language itself. Key words are signed to give a visual representation. It's free to sign up to the Makaton website and access many resources, including healthcare signs and symbols: [Home \(makaton.org\)](http://Home(makaton.org))
- Electronic communication aids – these vary widely. If your patient uses one, make sure they can access it and keep it with them

Here's an example of a communication board:

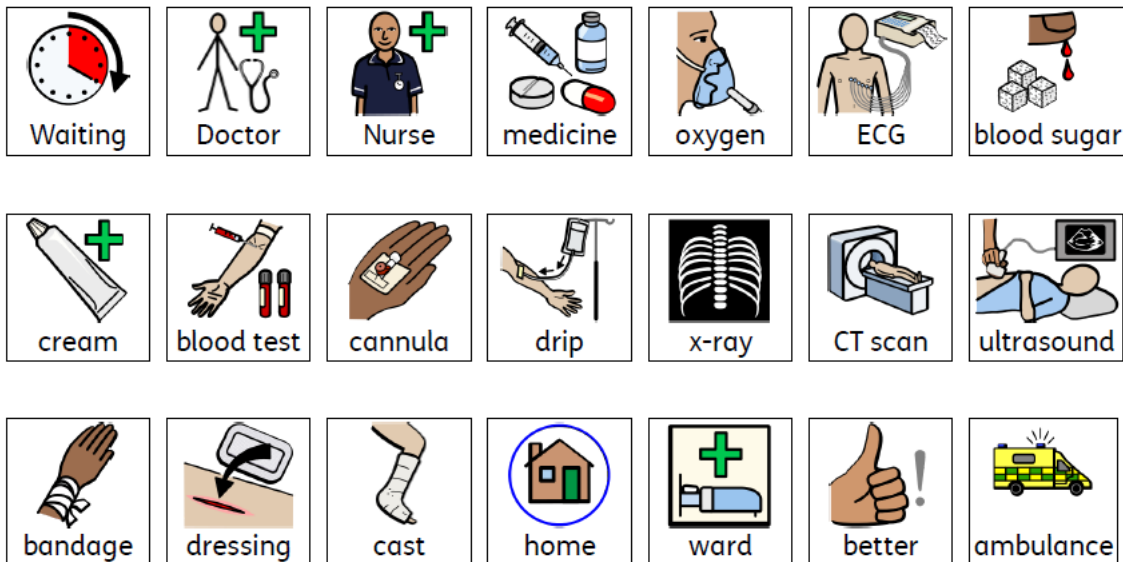


More on communication aids can be found here: [Types of AAC - Communication Matters](#)

Symbols and pictures can also be used in a “Now and Next” board, to show patients what will happen in the ED and what they are waiting for. Waiting is difficult for anyone, but even more of a challenge when there are difficulties with understanding or retaining information. Visual supports can help with this. More on Now and Next boards here (video, right).



Now and Next Symbols



Created In WidgitOnline

https://rcem.ac.uk/wp-content/uploads/2024/09/Now_and_Next_Board_v1.pdf
https://rcem.ac.uk/wp-content/uploads/2024/09/Now_and_Next_Symbols_v1.pdf

Any information given to patients, including that presented in text format (e.g. discharge advice leaflets), must meet Accessible Information Standards¹¹. Consider your patient information resources, departmental posters, and waiting boards or screens – do they meet these standards?

Text should be “Easy Read”. Some examples can be found here: [Easy Read | Translations \(nhsinform.scot\)](#)

More on accessible information can be found here: [Accessible communication formats - GOV.UK \(www.gov.uk\)](#)

Don't forget things like interpretation services for those who do not speak English as a first language, and hearing loops for those with hearing aids (plus make sure they have their hearing aid and it is switched on!).

Every patient is different and has different communication needs. You'll need to find out more about your patient, either from their family or carers, or from their hospital passport if they have one. Family and carers can also be very helpful in “translating” what your patient has to say, including through expressions, posture, noises and signs.

Mental Capacity

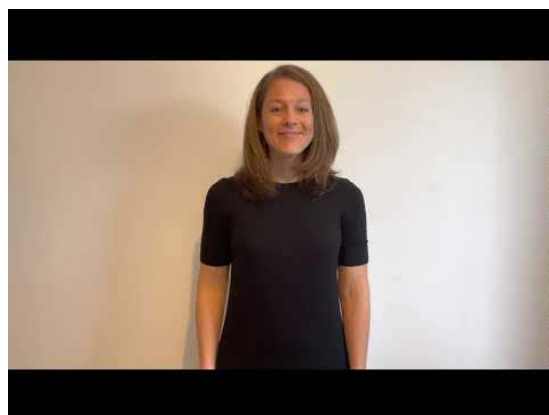
It is important to remember that, as per the Mental Capacity Act, 2005, capacity is decision-specific and can vary with time and situation. Don't assume that someone lacks capacity to make decisions regarding their health. The law says we must assume they have capacity until we are sure they don't, and that we must take all reasonable steps to enable someone to make their own decisions. For people with a learning disability, this will often mean giving information in an accessible format, explaining things in terms they can understand, using communication aids and, where possible, giving them time. It may be that the person is able to make some decisions, but not all decisions, particularly those that are more complex. If we are to make decisions for someone, those decisions must be in the person's best interests. To understand what that means for the individual patient in our care, we have to find out more about them, both from the patient themselves and from their family and carers. The person may have an appointed decision-maker (either someone with Lasting Power of Attorney, or a court-appointed Deputy). If not, and if there are no close family members or unpaid carers to support them it may be appropriate to ask for help from an IMCA (Independent Mental Capacity Advocate).

More information can be found here: https://rcem.ac.uk/wp-content/uploads/2021/10/RCEM_Mental_Capacity_Act_in_EM_Practice_Feb2017.pdf
<https://www.legislation.gov.uk/ukpga/2005/9/contents>

Some Potentially Useful Makaton Signs



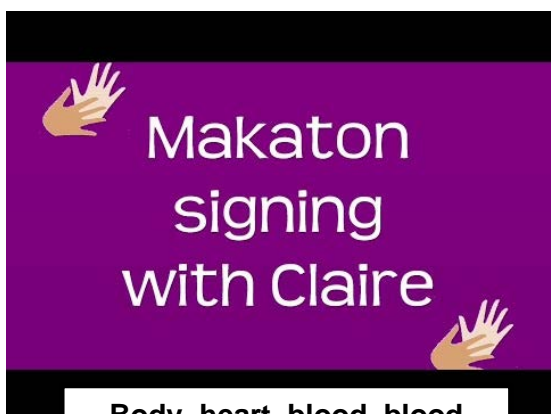
Doctor and Nurse



Hello



Please and Thank You



Body, heart, blood, blood test, ill/unwell, pain, headache, injection, medication, tablet, operation, x-ray, hospital, wheelchair, hearing impaired, hearing aid, visually impaired, glasses



Now and Next

Behaviours of Distress

This term describes a range of behaviours that may be displayed by people with severe learning disabilities when their needs are not being met. Other terms used to describe this include “challenging behaviours” and “behaviours that challenge”. “Behaviours of distress” reminds us that there is likely to be distress as the root cause and that the behaviour is a form of communication.

The formal definition, according to the Royal College of Psychiatrists is “Behaviour.... of such an intensity, frequency, or duration as to threaten the quality of life and/or the physical safety of the individual or others and....likely to lead to responses that are restrictive, aversive or result in exclusion.”

The behaviours may include:

- Self-injury
- Harming others
- Destructive behaviours: throwing or breaking things
- Ingesting or inserting objects
- Spitting
- Smearing
- Running away
- Removing clothes inappropriately

It can be tempting to assume that the behaviours seen are either normal for the person (a form of diagnostic overshadowing) or the result of an active choice made by the person to behave in this way.

It is important to remember that all behaviour is a form of communication and that telling the person to stop will not help or work.

Instead, we must try to work out the cause of the distress. This may be related to:

- Pain, nausea, hunger, thirst or other distressing symptoms
- Illness
- Injury
- Fear
- Medication – side-effects, overdose, withdrawal, interactions
- Toxins
- Sensory processing disorder (hyper- or hyposensitivity to sensations)
- Difficulties with hearing, vision, proprioception
- Environmental issues – noise, light, other people, smells
- Social issues – removal from home, being prevented from usual activities, difficulties with friends or family
- Mental health – anxiety, depression

A good collateral history, speaking to family and carers, and a full examination can help to identify most causes. Of course, examination will be difficult whilst the person is distressed, so may have to be deferred or completed in stages, depending on what the person can tolerate.

Meltdowns are very similar to behaviours of distress, although this term is used more commonly with regards to autistic patients. They are an intense response to an overwhelming situation. The overwhelm may be due to sensory overload, environmental stressors, social stressors, illness, injury or mental illness, for example. They can appear similar to temper tantrums, just as behaviours of distress can, but the person has no control over them.

Some people may respond to overwhelming distress by shutting down, instead – not interacting at all. **Shutdowns** and meltdowns are similar in cause, despite appearing very different to onlookers.

Low Arousal Approach

Often in Emergency Medicine, our approach to someone who is shouting and throwing things may be to call for extra staff (often security staff) and use either restraint or persuasion to stop the behaviour. This will not work for behaviours of distress or meltdowns. After ensuring that the person is safe (removing equipment or furniture which they may harm themselves with, for example), we may have better luck with a low arousal approach. That is to say, giving the person time and space to settle, preferably somewhere quiet and without harsh lighting.

Once they have settled, then we need to discover what they need, and aim to try to meet those needs.

More information can be found here: <https://www.rcemlearning.co.uk/foamed/behaviours-that-challenge/>

Family and Carers

Family and carers can be a valuable source of information. They know what your patient is like when they are well, so are often the first to notice when they are unwell (LeDeR²). They notice “soft signs” rather than clinical signs. They will know how to reassure your patient and what kind of things may make them feel more secure or more afraid. They also know how to communicate with your patient and may be able to “translate” changes in behaviour or posture, for example. It’s ok to ask how your patient might show you they are in pain, or whether they think your patient is comfortable. Videos and photos of your patient can also help to show how unwell they may be, by showing what they are like when they are well.

Consider asking a patient’s family or carers how the patient likes to be addressed, and also what helps the patient to feel more at ease. Do not assume that a patient does or does not want to be spoken to directly because they have a learning disability or are autistic. Likewise, some patients may prefer to not interact with a health professional directly and may feel more comfortable if you speak with their relative or carer. Distraction can help for some people, others may want to know exactly what is going on. There are often small things that can be done (e.g. avoiding direct eye contact/physical touch until it is absolutely necessary) that can make things easier for both the patient and clinicians.

It can help to involve the family or carer if there are small things to be carried out, for example applying EMLA or simple dressings. Some patients may be more comfortable having something done by someone well known to them and this can significantly minimise distress.

It’s ok to admit what you don’t know but show that you’re willing to listen and willing to learn.

“Please listen to us when we say something is not right, we can see the subtle changes in her health and behaviour that may not be apparent to the casual observer or even health professionals like yourselves.

Nieve, and others like her, cannot speak for themselves therefore as parents we have to ensure that we advocate for them in the strongest possible terms. We do not think we

are better than the team, nor are we full of our own self Importance, but we are simply trying to give a voice to our loved ones as they don't have one of their own."

Kristine Flint, mother to Nieve, who had complex needs and sadly died in 2024. Kristine and Nieve both worked hard to raise awareness about health inequalities and the importance of listening to families.

Family members may also appear anxious or frustrated. They may have had previous bad experiences and are likely to be used to having to fight for their loved one – in education, social care and health care.

Some family members, especially those in unpaid caring roles, may need extra support. Clearly this is not often in our power as ED clinicians to provide, but signposting to Primary Care, Social Care Services and local support groups can be a start and may help provide access to carer's assessments, respite care, sleep resources, family support and advocacy.

It's also worth bearing in mind that people with a learning disability, like those with other complex needs, are at an increased risk of abuse, in part due to the combination of increased family or carer stresses, isolation (e.g. away from family) and challenges with communication and understanding.

Hospital Passports

Hospital Passports are a document that can help you in your clinical assessment and management¹². Along with the usual medical history and allergies, they contain information about how to communicate with your patient, how they may show they are in pain, the things that will make them feel more comfortable and any sensory processing challenges they may face. Taking the time to read a hospital passport can save you time and energy later on.

Most Trusts now have their own local form of hospital passport which you should familiarise yourself with. Signpost to this if your patient does not already have one.

More about hospital passports can be found here:

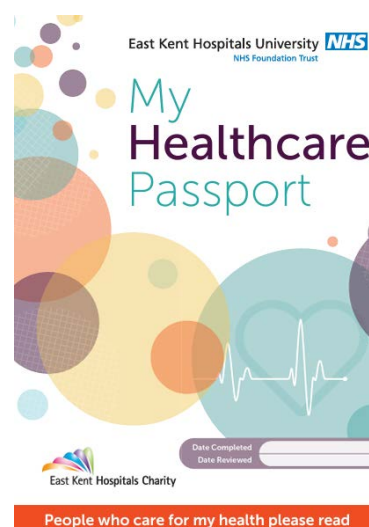
<https://dontforgetthebubbles.com/hospital-passports/>

Some examples can be found here:

<https://www.england.nhs.uk/6cs/wp-content/uploads/sites/25/2015/03/healthcare-passport.pdf>

<https://www.leedsth.nhs.uk/services/autism-and-learning-disability/the-hospital-passport/>

<https://www.mencap.org.uk/advice-and-support/health-coronavirus/health-guides>



Soft Signs

Soft Signs¹³ are the subtle changes that family or carers may pick up on that show them someone is unwell. It's important to take these seriously, particularly in people who may present atypically or in whom there may be challenges with clinical assessment.

Each individual patient will have their own soft signs, particular to them. For example, when they're ill one person may not be interested in their favourite TV programme, they may look more pale than usual and may be quieter than usual. Another person may not want to eat their favourite food or may be more restless than usual. Listening to why a family member is concerned is important.

There have been several attempts to put soft signs into clinically recognisable formats and to introduce them into hospital or care home practice. Some examples can be found here:

<https://rightdecisions.scot.nhs.uk/restore2/restore2-mini/#/restore2-mini-restore2-mini-recognise-early-soft-signs-take-observations-respond-escalate>

<https://www.hantsiowhealthandcare.org.uk/your-health/schemes-and-projects/restore2>

<https://thehealthinnovationnetwork.co.uk/wp-content/uploads/2020/05/Stop-and-Watch-poster.pdf>



This video explains Soft Signs a little more

Diagnostic Overshadowing

Diagnostic overshadowing is responsible for many missed or delayed diagnoses in patients with a learning disability and those who are autistic. This occurs when a clinician puts symptoms and signs down to a pre-existing diagnosis¹⁴.

For example, a man might appear agitated, restless, not able to engage in history taking, refusing to get undressed or to be examined. A clinician might assume this is “normal for them” and due to him having a learning disability, without finding out what the patient is like when well, and whether anything is causing him pain or distress.

A child with Down syndrome might appear floppy, disinterested and uncommunicative. It might be tempting to assume this is because they have Down syndrome, with hypotonia and developmental delay, without considering if this presentation is normal for them, and looking for other causes, such as infection or hypoglycaemia.

It's important to find out what your patient is like when they are well. This information can be gained from family or carers, or from documents such as hospital passports. Photos or videos can also show the difference between the patient when well and when unwell or in pain. Don't make assumptions. Watch out for non-verbal cues.

Actively consider alternative diagnoses – could the patient be in pain? Are they showing any signs of injury? Could there be an infection? Are they having an ischaemic event?

It's also worth considering the effect of the environment, altered routine and the distress of coming to the ED on the patient's behaviour and demeanour.

More on diagnostic overshadowing can be found here:

[Diagnostic Overshadowing: See Beyond the Diagnosis | Intellectual Disability and Health](#)

Pain

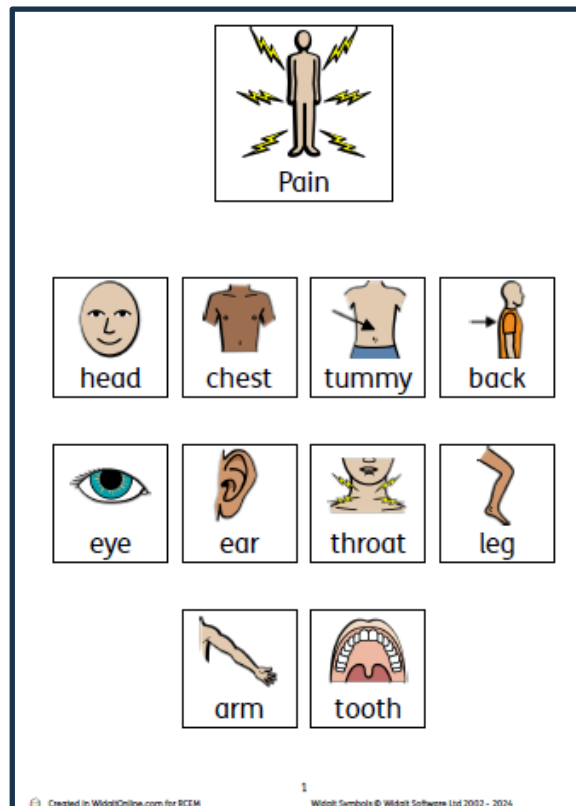
LeDeR² found that people with a learning disability were less likely to have their pain assessed appropriately and less likely to receive analgesia if they were found to be in pain.

It's important to consider non-verbal cues that someone might be in pain, including posture, facial expression and noises or sounds made. Family members or carers may be able to identify whether your patient is in pain. A hospital passport might also give you information about how your patient responds to pain.

Alternative pain scoring tools have been developed for use in patients who have a learning disability or communication difficulty.

For children, the FLACC¹⁵ scale can be useful. This looks at non-verbal cues such as facial expression, movement and activity, and crying and consolability. DisDAT¹⁶ and the Paediatric Pain Profile¹⁷ are more detailed but work on a similar basis. These latter two are best completed by family or carers in advance, to highlight the individual signs and symptoms that someone might show if they are in pain.

Supporting communication can also help to assess pain in patients with learning disability and/or communication difficulties. Simple steps include pointing to body parts or showing pictures or photos to support auditory information. Makaton signing⁹, the use of symbols¹⁰ and simple visual pain scales can also be helpful.



https://rcem.ac.uk/wp-content/uploads/2024/09/Communication_Pain_v1.pdf

Makaton sign for pain:
<https://www.youtube.com/watch?v=beT5xc3CBWo>

Sensory Processing

Sensory processing is the way our mind handles all the various sensations we receive every second of every day, so that we can evaluate and use that information without becoming overloaded or confused by it. Without it, or when there are differences in sensory processing, the amount of information received might become overwhelming and typically innocuous sensations might become very distressing or even painful.

Challenges with sensory processing are part of the diagnostic criteria for autistic spectrum conditions and are also very common in people with learning disability. The senses involved will vary from person to person, and there may be differences in processing in one area, or all eight senses (smell, vision, hearing, touch, taste, proprioception, vestibular system and interoception – sensations related to the physical condition of the body, e.g. hunger, thirst, pain, anxiety, tiredness).

Vestibular and proprioceptive processing differences can increase a patient's propensity to injury. As such, it is possible that patients with sensory processing differences will be seen in ED more frequently and it is important to know how to minimise the sensory overwhelm they may experience.

Problems with interoception can contribute to diagnostic difficulty; even if a patient is able to communicate well verbally it is possible that they are unable to differentiate between different bodily sensations and therefore may be unable to identify that they are in pain. Equally, interoceptive difficulties can contribute to patient distress over a long waiting period, as they may not recognise a specific feeling of hunger or thirst, for example, particularly when they are already overwhelmed.



This video helps to show what sensory overwhelm may feel like (watch with the sound turned up):

Now consider the ED: shouting, crying, screaming, laughing, monitors, alarms, phones, buzzers, bright lights, lots of people, strange equipment, BP cuffs, stethoscopes, needles ... and all whilst you're feeling unwell, in pain or distressed.

Where possible, a quieter area to wait can make a huge difference to someone with sensory processing challenges. In a busy ED this might not always be possible. Can you find somewhere with a closed door, or where it's less noisy or less bright? Can you remove equipment or turn off monitors? Ear defenders to loan out can also be a valuable resource and allow someone to be able to wait to be seen and managed, reducing health inequalities and improving outcomes.

Consider ways in which to reduce the sensory overwhelm that someone might experience during a clinical examination or intervention. Explain clearly what will happen (and use communication supports where appropriate). Demonstrate equipment and let your patient get used to it. Leave distressing procedures until the end of your assessment. Consider the use of analgesia, topical anaesthetics and sedation. Involve family and carers where possible.

Sensations can also be useful. They can help to calm and to distract. Autistic people often use sensations in this way – repetitive hand movements, for example. This is known as stimming. Sensations can also help to make people who are not autistic to feel more comfortable. Music, calming lighting, sensory equipment and fidget toys might all be useful.

Everyone is different and every sensory processing challenge is different. You'll need to find out what might make your patient feel more comfortable and what might make them feel distressed. Ask your patient, or ask family or carers, or look at their hospital passport or electronic patient record.

Early Warning Scores

LeDeR² found that people with a learning disability were less likely to have an early warning score such as NEWS2 calculated when unwell and, if it was abnormal, it was less likely to have been acted upon.

Reasons for not calculating the score include a fear of distressing a patient by recording a blood pressure or oxygen saturations, or a belief that the answer might be confusing or unhelpful. Reasons for not acting on a high score include a belief that the high score might be normal for the patient. In reality, a high score is unlikely to be normal for anyone. It is more likely that a falsely low score is calculated – people with neurological conditions causing their learning disability might not be able to mount a tachycardia or sustain an increased work of breathing when unwell. They may not become pyrexial in response to infection.

Early warning scores should be calculated as for anyone else. It may be, however, that it takes a bit more time and involves clear explanations about procedures such as blood pressure measurement, or demonstrations of equipment such as a thermometer or saturation probe. If a high score is calculated, it should be acted upon, again with reasonable adjustments as required.

Frailty

The Clinical Frailty Score evaluates patients based on their ability to perform activities of daily living. It does not take into account pre-existing disabilities and is not suitable for assessing frailty in people with learning disability^{18, 19}. It is important not to make assumptions about quality of life, nor to make decisions about resuscitation or ceilings of care without involving those who know your patient best or, ideally, your patient. 74% of people with a learning disability who died in 2022 had a DNACPR in place at the time of death. LeDeR reviewers judged this was correctly applied and followed 63% of the time². Of course, DNACPR decisions, and the conversations around them, are best considered by clinicians with a longer-term responsibility to the patient, preferably before they are required, in a setting such as the outpatient department, rather than the ED.

Some patients, depending on the cause of their learning disability, may develop conditions associated with ageing, at a younger age. For example, people with Down syndrome are more likely to develop Alzheimer's disease, with most affected individuals showing symptoms before the age of 65²⁰. Menopause in people with Down syndrome occurs about 5 years earlier than in the general population. These premature age-related changes increase the burden of health inequalities.

More about ageing and Down syndrome can be found here:

<https://www.downs-syndrome.org.uk/about-downs-syndrome/health-and-wellbeing/ageing-and-dementia/>

The Biggest Killers

The most common causes of death for people with a learning disability in 2022 were congenital malformations and chromosomal abnormalities, cancers, respiratory conditions (aspiration pneumonia, pneumonia, influenza), neurological conditions (complications of cerebral palsy, epilepsy), and circulatory disorders (ischaemic heart disease, stroke)².

Aspiration pneumonia

Risk factors for aspiration pneumonia include:

- Dysphagia
- Reflux
- Hypersalivation
- Poor oral health
- Poor posture
- Poor cough
- Immobility
- Constipation
- Epilepsy

This scenario from NHS England describes best care and inadequate care for a person with a learning disability who is a risk from aspiration pneumonia:

<https://www.england.nhs.uk/publication/rightcare-learning-disability-and-aspiration-pneumonia->

SUDEP

People with a learning disability are more likely to have epilepsy and that epilepsy is likely to be more difficult to control²¹. There is also an increased risk of SUDEP – sudden unexpected death in epilepsy. ED attendances may provide an opportunity to ensure that this vulnerable group are taking medications as prescribed, are attending follow up, have support and that family and carers are aware of seizure safety.

Constipation

People with a learning disability are more likely to be constipated due to a number of factors, including poor diet, reduced mobility, medication and comorbidities such as hypothyroidism or autonomic dysfunction²². It is also likely to be more difficult to treat, partly for the same reasons and partly due to difficulties in describing symptoms, diagnosis and following management plans. Diagnostic overshadowing is also an issue – symptoms may be wrongly attributed to the underlying condition (e.g. Down syndrome) rather than constipation, or conversely symptoms of serious abdominal pathology may be wrongly attributed to constipation. Constipation carried a large burden of morbidity but can also kill.

<https://www.inquest.org.uk/richard-handley-conclusion>

<https://www.inquest.org.uk/sally-lewis-inquest>

NHS England has produced resources to support the management of constipation in people with a learning disability:

<https://www.england.nhs.uk/publication/constipation-resources-for-people-with-a-learning-disability/>

Intra-abdominal Pathology and Emergency Surgery

Patients with a learning disability, particularly those on anti-psychotic medications, those with constipation and those with sensory processing differences, may have physical signs of intra-abdominal pathology which are difficult to elicit. Not only are they being higher risk from surgical causes of illness, but also from anaesthesia and surgical complications. This is recognised by the Royal College of Anaesthetists and was highlighted in the National Emergency Laparotomy Audit²³. They advise that appropriate care and support be provided throughout the patient's hospital admission, including liaison with a learning disability nurse and an understanding of the Mental Capacity Act²⁴.

Suggestions for your ED – Resources and Equipment

This is a list of suggested resources and equipment that might be useful in your department

- A quiet area or room for waiting and/or clinical assessment for those with sensory processing challenges
- Ear defenders to lend to patients (available from most DIY stores from about £3 per pair)
- Wipe-clean bean bag chairs might be an option for seating in a quieter area of the department or sensory room (to satisfy sensory differences)
- Dimmer switches in clinical rooms or quieter waiting areas, or the facility to turn off some lights
- Charging sockets and free Wi-Fi
- Tablets with headphones to help calm and distract
- A set of fidget or sensory “toys” to lend to patients (available from <https://www.starlight.org.uk/> or from toy retailers)
- Makaton healthcare cards (or attach them into lanyards) – download for free from <https://makaton.assetbank-server.com/assetbank-makaton/action/viewAsset?id=3918&index=0&total=20&view=viewSearchItem> after signing up to a free account
- Communication boards – with symbols, to help support verbal/auditory communication (either laminate to wipe clean, or use single use paper sheets) – [See communications boards in the toolkit here](#), and download the individual communication boards using the links below;
 - https://rcem.ac.uk/wp-content/uploads/2024/09/Communication_The_ED_v1.pdf
 - https://rcem.ac.uk/wp-content/uploads/2024/09/Communication_Imaging_v1.pdf
 - https://rcem.ac.uk/wp-content/uploads/2024/09/Communication_Blood_Test_v1.pdf
 - https://rcem.ac.uk/wp-content/uploads/2024/09/Communication_Cannula_v1.pdf
 - https://rcem.ac.uk/wp-content/uploads/2024/09/Communication_ECG_v1.pdf
- Now and Next boards – with symbols, photos or pictures to attach either with tape, if using paper, or Velcro if laminating. [This can be seen in the Toolkit here](#), and download the individual communication boards using the links below;
 - https://rcem.ac.uk/wp-content/uploads/2024/09/Now_and_Next_Board_v1.pdf
 - https://rcem.ac.uk/wp-content/uploads/2024/09/Now_and_Next_Symbols_v1.pdf
- Simple visual pain scales with pictures of body parts, e.g. can be bought from the following sites; [See communications boards in the toolkit here](#), and download the individual communication boards using the links below;

- https://rcem.ac.uk/wp-content/uploads/2024/09/Communication_Pain_v1.pdf
- Hospital passports – blank copies of your Trust’s hospital passport to give to families or carers to complete and bring in next time
- ED Pledge – to remind your team about reasonable adjustments and let your patients know what they can expect
- Down syndrome Top Tips poster: https://www.downs-syndrome.org.uk/wp-content/uploads/2020/05/DS-infographic_TopTipsTriagingTreating.pdf
- Consider toileting facilities for those with disabilities, including those who may be wheelchair users and those who may be ambulatory but need carers to support them <https://www.changing-places.org/>
- Images of the department online, including a video walk-through, to enable people to familiarise themselves with the environment (with a note to say it may be busier and noisier at times!)

Departmental Recommendations

- Patients with a learning disability should be prioritised for clinical assessment within their triage category (if used)
- All patients with a learning disability presenting with anything other than a minor injury should have a full set of vital signs performed and a NEWS2 score calculated
- Staff should actively request to see hospital passport if available and be clear about a patient’s risk of aspiration before providing food or drink
- Avoid front-loading bloods, arrange early clinician assessment instead
- As well as taking the time to explain about taking blood when required, consider using local anaesthetic creams or distraction techniques
- Patients with a learning disability presenting with abdominal pain should be an indication for discussion with and/or review by a senior doctor
- Ensure patient and carers are kept informed of management plans whilst in the ED with regular updates
- ED pharmacists should be encouraged to undertake a medicines review to identify potential ‘over medication’
- For patients with a learning disability who are likely to remain in the ED beyond 4hrs, consider commencing a stool chart
- Do not use the Clinical Frailty Score to assess patients with a learning disability
- For patients with a learning disability who are being discharged, consider discussion with a senior doctor
- Learning disability should never be an indication for DNACPR/RESPECT form
- In the event of a patient with a learning disability dying in the ED, ensure a mortality review is carried out and ensure the case is reported nationally (<https://leder.nhs.uk/report>)
- EDs should have an identified member of staff who is a link with the hospital learning disability team
- Staff should undertake training which focuses on the needs of patients with a learning disability in the ED

FOAMed and eLearning Resources

- <https://www.rcemlearning.co.uk/foamed/learning-disabilities-in-the-ed/>

- <https://www.rcemlearning.co.uk/foamed/autism-spectrum-condition-in-the-ed/>
- <https://www.rcemlearning.co.uk/foamed/public-health-in-the-emergency-department-series-3/>
- <https://www.rcemlearning.co.uk/foamed/health-inequalities-in-the-ed/>
- <https://www.rcemlearning.co.uk/foamed/syndrome-emergency-physicians/>
- <https://www.rcemlearning.co.uk/foamed/behaviours-that-challenge/>
- <https://dontforgetthebubbles.com/defining-learning-disability/>
- <https://dontforgetthebubbles.com/hospital-passports/>
- <https://dontforgetthebubbles.com/step-it-up-communicating-with-neurodivergent-patients/>
- <https://dontforgetthebubbles.com/communicating-clearly/>
- <https://dontforgetthebubbles.com/how-to-assess-children-with-complex-needs-in-the-ed/>
- <https://www.e-lfh.org.uk/programmes/the-oliver-mcgowan-mandatory-training-on-learning-disability-and-autism/>
- <https://doi.org/10.12968/hmed.2023.0357> Lee A, Herrieven E, Harrower N. Health inequalities for people with learning disabilities: why it matters and what emergency physicians need to know. British Journal of Hospital Medicine Feb 2024 85:2
- https://rcem.ac.uk/wp-content/uploads/2021/10/RCEM_Mental_Capacity_Act_in_EM_Practice_Feb2017.pdf
- <https://www.legislation.gov.uk/ukpga/2005/9/contents>

Authors

Dr Liz Herrieven, Consultant in Emergency Medicine, Sheffield Children's Hospital

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Endorsements

None

Review

Usually within three years or sooner if important information becomes available.

Declaration of Interests

The author is a member of the steering group for the Down Syndrome Medical Interest Group and works as a volunteer for the Down's Syndrome Association and is also a member of a NCEPOD study advisor group looking at acute medical illness in patients with learning disability. They also have a daughter who is autistic and has Down Syndrome.

Disclaimers

The College recognises that patients, their situations, Emergency Departments and staff all vary. This guideline cannot cover all possible scenarios. The ultimate responsibility for the interpretation and application of this guideline, the use of current information and a patient's overall care and wellbeing resides with the treating clinician.

Research Recommendations

None

Audit standards

See Departmental Recommendations section

Key words for search

Emergency medicine, emergency department, learning disability, learning difficulty, autism, autistic, communication, soft signs, diagnostic overshadowing, Makaton, health inequalities, reasonable adjustments, Equality Act, Mental Capacity Act, MCA, Accessible Information Standards, hospital passport, sensory processing.

Introduction



RCEM
Royal College
of Emergency
Medicine

The Royal College of Emergency Medicine
54 Ayres Street
London
SE1 1EU

Tel: +44 (0)20 7400 1999
Fax: +44 (0)20 7067 1267

www.rcem.ac.uk

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