

A Focus on

# Learning Disabilities and Autism



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Care

# Why are learning disabilities and autism important topics?

People who have learning disabilities and autism may need special consideration to ensure that they receive care and treatment which meets their specific needs and maintains their safety while they are patients in our care at ELHT.

The National Patient Safety Agency (2004) concluded that patients with learning disabilities are particularly vulnerable when in acute hospital settings leading to varying degrees of harm as a result.

**“People with a learning disability, autism or both often have poorer physical and mental health than other people. We know that we need to understand why so that we can make a difference to people’s lives”.** (NHS England, 2018)

People who have learning disabilities and autism often have a number of complex needs. These may include impairments in functional skills, communication and additional sensory impairments. In addition they may also have multiple disabilities or complex health problems and are therefore more likely to use health services (including acute hospital services) on a regular and frequent basis.

## How will I know if my patient has a learning disability?

Family, carers or the patients themselves may tell you that they have a learning disability. It may also be documented on the electronic patient systems or in the case notes that the patient is known to have a learning disability. This can sometimes be confused with learning difficulties so you may need to confirm this diagnosis.

You may notice however that the person:

- Has difficulty understanding and retaining new or complex information
- Will require that you use simple language and explain things that may be unfamiliar
- May rely on others to meet some or all of their basic needs or to maintain their safety
- Has difficulty following instructions
- Has difficulty understanding abstract concepts such as time or directions
- Repeats phrases in conversation without expanding on the content

Learning disability and autism do co-exist but can also be mutually exclusive.





# What is Autism?

## What is Autism?

Autism is a spectrum developmental disorder (ASD) characterised by difficulties with social interaction and communication, and by restricted and repetitive behaviour. All autistic people share certain difficulties, but being autistic will affect them in different ways.

Most commonly people with ASD will present with very specific needs for which you will need to consider making reasonable adjustments. In particular with ensuring effective communication, managing over- or under-sensitivity to sounds, touch, tastes, smells, light, colours, temperatures or pain and supporting specific routines that help the person manage their day to day life and prevent anxiety.

## How do I support people who have a learning disability and or autism in hospital?

People with a learning disability and autism and their family and carers tell us that there are three things that can make a difference to the care and treatment they receive:



**1. Effective Communication**



**2. Give extra time**



**3. Make information easier to understand**



## What advice and support is available?

If you need advice or help supporting a person with a learning disability or autism, please contact the Specialist Nurse for people with learning disability and autism on (01254) 732848 (Ext 82848).

# The Learning Disability Improvement Standards

In June 2018, NHS Improvement (NHSI) published “The Learning Disability Improvement Standards for NHS Trusts.”

Some people with learning disabilities, autism or both encounter difficulties when accessing NHS services and can have much poorer experiences than the general population.

**“People with learning disabilities, autism or both, and their families and carers should ... receive treatment, care and support that are safe and personalised; and have the same access to services and outcomes as their non-disabled peers.”**

Unwarranted variations in care and poorer outcomes sometimes experienced by people with learning disabilities and/or autism mean Trusts need to sustainably improve many of their services.

NHSI recommend doing this by upholding the following key standards:

- 1 Respecting and Protecting Rights:** All Trusts must ensure that they meet their Equality Act Duties to people with learning disabilities, autism or both, and that the wider human rights of these people are respected and protected, as required by the Human Rights Act.
- 2 Inclusion and Engagement:** Every Trust must ensure all people with learning disabilities, autism or both and their families and carers are empowered to be partners in the care they receive.
- 3 Workforce:** All Trusts must have the skills and capacity to meet the needs of people with learning disabilities, autism or both by providing safe and sustainable staffing, with effective leadership at all levels.
- 4 Specialist Learning Disability Services:** Trusts that provide specialist learning disabilities services commissioned solely for the use of people with learning disabilities, autism or both must fulfil the objectives of national policy and strategy.

For more information: The full report is available on the NHSI website: <https://improvement.nhs.uk/>



# Learning Disabilities Mortality Review (LeDeR)

Deaths of people with a learning disability are reported to the Learning Disabilities Mortality Review (LeDeR), who have identified that life expectancy is **19.7** years lower than for people without learning disabilities.

LeDeR also suggests that more than a third of deaths of people with learning disabilities were potentially amenable to health care interventions.

The most commonly reported learning and recommendations were made in relation to the need for:

- a Inter-agency collaboration and communication
- b Awareness of the needs of people with learning disabilities
- c The understanding and application of the Mental Capacity Act (MCA). (LeDeR Annual Report, 2018)

ELHT have been undertaking Learning Disabilities Mortality Reviews since January 2017.

The reviews consider all aspects of clinical care and treatment whilst in our care.

It is important to ensure we have the opportunity to investigate all deaths of patients with learning disabilities.

The LeDeR process compliments and augments our ELHT internal process and will review ELHT care as well as other aspects of service provision including GP, Mental Health, NWAS and Social Services input.

Learning from ELHT Learning Disability Mortality Reviews is presented at the monthly Mortality Steering Group Meeting.

## Learning themes are as follows:

- Need for more timely end of life decisions
- Delays in clinical decision making
- Delay or absent capacity assessments
- Delays in decision making around feeding/ best interest meeting
- Lack of escalation
- Ward moves have impacted negatively on the experience of two patients
- Poor filing of case notes
- Gaps or delays in administration of prescribed medication

## Positive findings:

- Learning disability care bundles and passports usually in place
- Timely assessment and treatment of infection/sepsis
- Appropriate involvement of Specialist Nurse for Learning Disability and Autism
- Examples of excellent family involvement in decision making/ discussions re withdrawal of care/ ceilings of care
- Personalised care planning

# Managing Patient Care

Improved outcomes can be achieved for patients with learning disabilities and/or autism by effective planning, communication and relationship-building. This is likely to reduce the number of appointments missed or failed attempts at procedures.

## Preparation

Consideration should be given to what preparation a patient with complex needs might require in order to achieve good outcomes and a positive experience. For example, patients may be put at ease if supported to visit the ward or department ahead of their appointment or have the opportunity to see the equipment that will be used. Always be ready with everything that you will need so there will be no interruptions or distractions once you start your procedure.

## Communication

People who have a learning disabilities/autism are likely to have difficulty understanding abstract concepts or have limited understanding of the treatments being proposed. Showing the person before you do the procedure can help alleviate anxiety. Many individuals will require such preparation and information in order to make an informed decision and to consent to treatment. It is likely that any intervention will take longer to complete. Remember that, giving time and communicating effectively will improve that experience for the patient.

## Relationship

Developing a relationship is vital when the person is anxious. It is sometimes helpful to have two people attending to the person, one to provide reassurance and distraction and the other to complete whatever intervention is needed.

## Capacity to consent

Assessment of capacity to consent to care and treatment is essential for the planning of ongoing care and decisions about how to manage care effectively. This may include decisions about having blood taken, cannulation for Infusion of fluids and medications and alternative feeding such as insertion of a nasogastric tube.

## Restraint and/or Sedation

Use of any type of restraint - physical or chemical - should be a last resort. In emergency situations the Mental Capacity Act (2005) allows for proportionate restraint to be used. In any other situation, the use of restraint must be discussed and recorded as part of a best interest meeting with the family/carers.

## Support

If it is clear that the person is resistant to intervention, please seek advice and support from the Specialist Nurse for Learning Disability and Autism.



# Consenting to Treatment: Mental Capacity Act 2005

The Mental Capacity Act (2005) (MCA) provides a legal framework for supporting individuals who may lack the capacity to make some decisions for themselves. This may be due to a learning disability, mental health problem, brain injury, dementia, alcohol or drug misuse, side effects of medical treatment or any other illness or disability.

## Five Principles of the Mental Capacity Act MCA

1. A presumption of capacity: Every adult has the right to make their own decision and must be assumed to have capacity to do so unless it is proved otherwise.
2. Supported to make their own decisions: A person must be given all practicable help before anyone treats them as not being able to make their own decisions.
3. Unwise decisions: People have the right to make decisions that others might regard as unwise or eccentric. You cannot treat someone as lacking capacity for this reason.
4. Best interests: Anything done for or on behalf of a person who lacks mental capacity must be done in their best interests.
5. Less restrictive option: Someone making a decision or acting on behalf of a person who lacks capacity must consider whether it is possible to decide or act in a way that would interfere less with the persons' rights and freedoms.

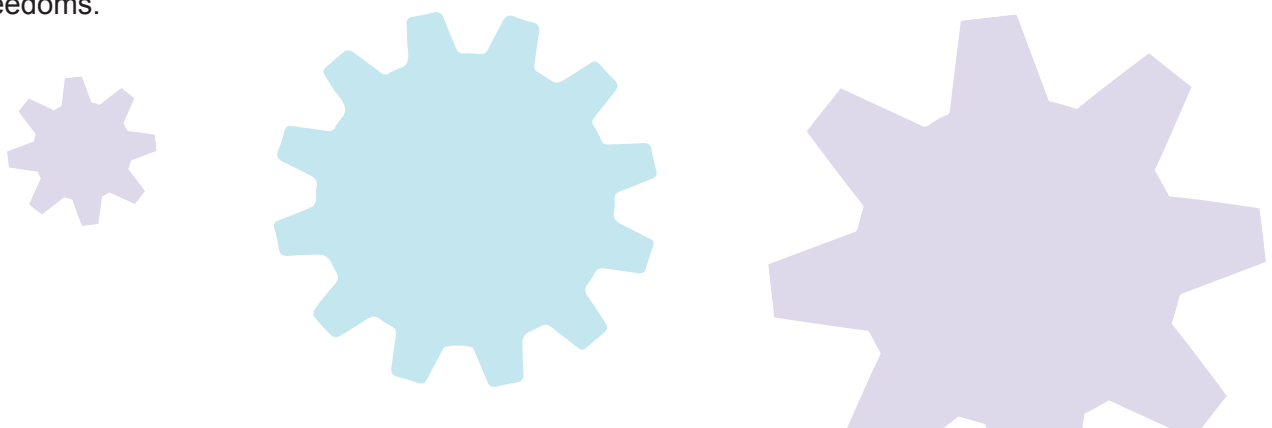
## Supporting People with LD and Autism to Consent

Both the Mental Capacity Act (2005) and Disability Discrimination Act (1995) emphasise the importance of supporting and enhancing an individual's ability to consent to care or treatment. In doing this it may be necessary to adapt the manner in which you convey information regarding the proposed care or treatment - for example by using simple language or accessible health information.

You should also consider that some individuals may require longer to process information and to come to a decision. You may have assessed that the person lacks the ability to make a decision at this time; you may consider if it is appropriate or safe to delay treatment to allow time for work to be done to enhance the individual's ability (capacity) to make a decision regarding the proposed treatment/s.

## Care or Treatment in an Individual's Best Interests

It is essential that you endeavour to discuss your decision to provide treatment in best interest with a person who knows the patient well. Ideally this should be the next of kin or close family member. It is not appropriate to ask employed carers to enter into best interest discussions or sign consent forms. When a person does not have a family member or friend to consult you must refer for an Independent Mental Capacity Advocate (IMCA).





# MCA (2005) Deprivation of Liberty Safeguards (DOLS): When is an authorisation needed?




Some people with a learning disability and autism will be subject to DOLS authorisation at home. If this is the case, we should consider making an application for the person while they are in hospital because the restrictions applied are likely to be the same (Eg needs 1:1 or constant supervision, or would not be free to leave).

The person may not be asking to go, or showing by their actions that they want to, but the issue is about how staff would react if the person did try to leave or if relatives/friends asked to remove them.

If you are unsure whether DOLS is required, please speak with the Safeguarding team.

## Advice and Support

Guidance on MCA (2005) and DOLS can be found on OLI under Clinical Information on the Safeguarding link.



You can also  
contact the  
Safeguarding Team  
for advice or support on  
(01254) 732848 or  
734307



# The Importance of Meeting Communication Needs

**Communication impairments commonly associated with learning disabilities and autism are expressive communication and comprehension. It is likely therefore that you will have to adapt your communication methods accordingly.**

Effective communication is essential when providing information about care and treatment to ensure that the patient can give informed consent. You can help by following this guidance:

- Use simple language and keep your sentences short.
- Explain any difficult or unfamiliar words. For example: Instead of “I will send you for an x-ray” it may be better to say “we will need to take a picture of your arm”.
- Check that the individual has understood: “Can you please tell me in your own words what I have just said”.
- Give the person time to respond.
- Use gestures to emphasise your communication. For example, point to the part of the body you are talking about.
- Use pictures or objects to demonstrate what you are going to do before you do it.
- Consider what ‘Easy Read’ information may be available.
- Be aware of any additional disabilities such as hearing or visual impairment.
- Using a number of communication methods together to support people with complex needs is known as ‘total communication’. This might include a mixture of speech, gesture and accessible written information or pictures. This is the most effective method for providing effective communication.

## Easy Read

For some people with a learning disability it is helpful if information is provided in an easy read format or picture story boards. There are a number of useful Easy Read documents available online:

- <http://www.easyhealth.org.uk>
- <https://www.changepeople.org/blog/december-2016/free-easy-read-resources>
- <http://www.bild.org.uk/resources/easy-read-information>
- [https://community.macmillan.org.uk/blogs/b/new\\_information\\_available/posts/easy-read-cancer-information-for-people-with-learning-disabilities](https://community.macmillan.org.uk/blogs/b/new_information_available/posts/easy-read-cancer-information-for-people-with-learning-disabilities)

You can also contact the Specialist Nurse for Learning Disability and Autism if you would like support to provide Easy Read information for your patients.



# Making Reasonable Adjustments

The Equality Act (2010) places a duty upon all service providers and public bodies to ensure that people who have disabilities can access services on an equal and equitable basis (general duty).

Service providers are required to make 'reasonable adjustments' to the way in which a service or function is carried out to enable disabled people to access services and support on an equal basis.

For people who have learning disabilities to achieve equality of access, services may need to provide more favourable support or treatment to disabled people in order to achieve the same outcomes (Disability Rights Commission, 2007).

What reasonable adjustments are required will depend upon an individual's disability and their specific needs resulting from it. Therefore, both timely and comprehensive assessments of the patients' disability and safety needs are crucial to ensuring that people with disabilities or complex needs receive appropriate care and support.

## What is considered a reasonable adjustment?

- Offering a double or extended appointment to allow for longer detailed explanation
- Use of accessible information to explain diagnosis and procedures
- Providing quiet alternative places to wait for appointments
- Ensuring the person is seen at their appointment time if they have difficulty waiting
- Allowing family/carers to stay with the patient

Examples of some reasonable adjustment are available on:

<https://www.gov.uk/government/collections/reasonableadjustments-for-people-with-a-learning-disability>

## Hospital/Health Passport

An effective way of ensuring that we are meeting the patients' needs is to utilise the Hospital/Health Passport. This should be brought by the patient when they come into hospital. It tells you everything you may need to know about the patients' needs. If they don't have one, copies can be downloaded from the Safeguarding page on OLI.





## Understanding Behaviours that Challenge

“Challenging behaviour” is a term used to describe problem or difficult behaviours which include:

- Physical aggression (eg, biting, kicking, hitting)
- Verbal aggression
- Destruction (eg, breaking things, throwing objects)
- Self-injury (eg, biting self, banging head)
- Any other behaviour that puts the person or others at risk of harm or has a significant impact on the person’s quality of life.

It is not always possible to establish the cause of challenging behaviour but more often than not it is the person’s method of controlling a situation or when they are unable to communicating that they want or do not want something.

### Pain

Often behaviours are a sign that the person is experiencing physical pain. When a new behaviour becomes apparent, this should be one of the first things to be checked out, especially if the person is non-verbal. If you would expect the person to be experiencing pain but they are not verbally communicating this to you then you should consider if pain relief should be prescribed regularly rather than on request.

If the person is non-verbal or has communication difficulties then you should consider completing the Abbey Pain tool or DisDATT - Copies can be found on OLI. This will provide you with known indicators of pain.

### Anxiety

In healthcare situations, behaviour often becomes challenging because the person is anxious and unsure of what is happening or because they have experienced something in the past that they do not wish to encounter again. This is of course a problem for us when we are unable to provide the person with the care and treatment they need.

### What Can I Do?

Preventing the behaviour presenting in the first place is key, but not always easy to achieve. Talking to people who know the person well and planning for interventions is essential.

Once behaviours have started to be displayed it can be very difficult to intervene without the behaviour escalating. In situations where the person is safe then it is advisable to leave the area until the person is calmer and try again at a later time.

# Supporting Family and Carers

Family and/or familiar carers are an invaluable resource in providing care, particularly when the patient is unable to communicate their needs adequately or consistently. However a lack of clarity around the role of family or familiar carers can compromise patient care and safety if roles and responsibilities are not clearly defined.

## Role of Family or Familiar Carer

The role of family or familiar carers is primarily to:

- Enable effective communication, including supporting the patient in understanding their care, diagnosis and treatment.
- Support the clinical team to agree a care plan which appropriately meets the patients' specific needs.
- Provide support emotional support, in particular during clinical investigations or treatment, and advising clinical staff on best approaches.
- Assist clinicians in making 'best interest' decisions where the patient lacks the capacity to make the decision for themselves.

## Responsibilities of Clinical Staff

It is essential that clinical staff remember that they are responsible for the patient while they are in hospital and must lead on all aspects of care and treatment including:

- Best interest decision making
- Care planning and review
- Postural management
- Monitoring nutritional needs
- Manual handling
- Personal care and bathing
- Administration of medication
- Assessment and management of pain relief
- Co-ordination of discharge arrangements







## Things to Consider

It should not be assumed that family carers will remain with the patient during a hospital admission. If family wishes to stay then they should be enabled to do so and should be provided with access to refreshments or break time and suitable sleeping arrangements.

Paid carers may not be commissioned to stay with the person while they are in hospital and only available to attend at visiting times or for planned consultations. In these cases it is essential that the patient has a Hospital/Health passport.

It may also be necessary to consider commissioning the support staff to be with the patient at times during their stay. This should be discussed with the Ward Manager and Matron, and the Specialist Nurse for Learning Disability and Autism. This may be particularly important to have someone who knows the patient well present during ward rounds.

## Carer Awareness e-Learning

Did you know that there is a short e-learning course designed for all ELHT staff groups who may come into contact with unpaid carers and the person they care for?

At the end of this course, you will be able to:

- Recognise who a carer is
- Understand the impact of a caring role
- Identify how to support a carer.

Access is via the Learning Hub.

## Support for Carers

Don't forget that carers might also need help, support and advice. The Carer's Trust provides support, services and recognition for anyone living with the challenges of caring for a family member or friend. They have a webpage dedicated to signposting carers for people with learning disabilities to organisations that can help:

<https://carers.org/article/learning-disabilities>



# Learning Disability Guidelines and Care Bundle

## Learning Disability Guidelines

Policy C087 "Guidelines for the Care of Adults with Learning Disabilities"

When a person with a learning disability is admitted into hospital there are steps that can be taken to ensure that we provide the best possible care for the patient. This information can be found in Policy C087 available on OLI.

## Learning Disability Care Bundle

The learning disability care bundle must commence as soon as learning disability is identified. The care bundle can be found under Clinical Information on OLI.

## Obtaining Patient Feedback

Receiving feedback is essential for us to know if we are getting it right for our service users or if we need to make adjustments to how we provide care.

The Friends and Family Test has been made accessible to enable participation in this activity – this can be found on OLI

We encourage service user participation and have a very active service user self-advocacy group who advise on any issues relating to providing care and treatment for people that have a learning disability and autism.



## Supporting people with a learning disability to access assessment and treatment

### Case study

Joan is a 43 year old woman who is known to have a learning disability. She has been admitted to hospital by her GP for assessment because she has suspected pneumonia. She is known to have hypothyroidism and asthma. She is supported by a carer during the day who says that Joan has refused to accept any interventions by her GP to have bloods taken in the past.

Joan is refusing to allow any observations or investigations. She is refusing to take her regular medication and since her admission 24 hours ago will not take anything to eat or drink.

Assessment of Joan's capacity to consent to her care and treatment is essential for the planning of her ongoing care and decisions about how to manage her care effectively. This may include decisions about having blood taken, cannulation for infusion of fluids and medications and potentially alternative feeding such as insertion of a nasogastric tube.

After considering all the recommendations suggested in the section 'Managing patient care' Joan may still refuse to engage and accept treatment. The clinical observations policy CP37 V1.4 provides guidance on how to proceed when observations and investigations are necessary to assess for deterioration in the patient's condition.

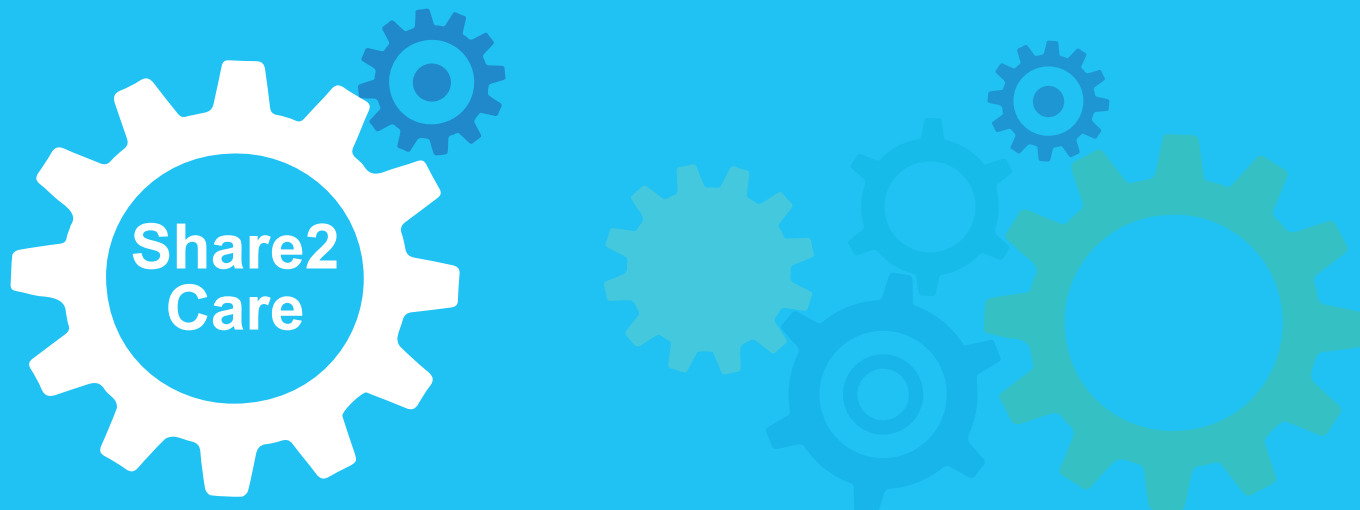
The use of restrictive physical interventions may be required to enable staff to effectively assess or deliver essential care and treatment as discussed previously. The Mental Capacity Act 2005 clearly outlines the healthcare professionals' responsibility, in relation to clinical decision making for treatment that may require holding and restraint.

### Encouraging nutrition and hydration

Not wanting to eat or drink or having swallowing difficulties are common problems noticed when people with a learning disability come into hospital. They are particularly vulnerable to risk of dehydration or malnutrition. As per Policy for the Nutrition and Hydration Provision to Inpatients (ELHT/CP18 Version 4) fluid and food charts must be kept. The individual's eating and drinking care plan must be reviewed whenever changes occur in the patient's condition. Prompt management of these issues is essential.







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