

# Learning Disability Strategy

2018 - 2021



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# 1. INTRODUCTION

## **Bedfordshire Hospitals NHS Foundation Trust are committed to improving the care for patients with Learning Disabilities.**

The trust is committed to delivering care to patients that meet their individual needs and recognises that some patients may be disadvantaged in accessing care and treatment due to disability or other health inequalities.

The Equality Act 2010 (incorporating the Disability Discrimination Act 2005) puts the responsibility on all public services to ensure that no discriminatory practices exist within their organisation and that services meet the needs of the individual. Hospitals have a clear 'duty of equality'. This does not mean treating everybody the same but rather that all hospitals must make 'reasonable adjustments' to meet the needs of disabled people. Bedfordshire Hospitals NHS Foundation Trust are committed to providing a responsive service which recognises the needs of those patients who may be disadvantaged in accessing care and treatment due to disability or other health inequalities.

This strategy has been developed to ensure that all staff are aware of, and follow, best practice in the care and support of patients with a Learning Disability. The Michael Report (2008) 'Healthcare for All' and the Ombudsman report 'Six Lives' (2009) made recommendations on the care of people with Learning Disabilities and this strategy has been developed to aid compliance with the recommendations put forward in these reports and the standards set in the NICE guidance (NG11 and NG93) in regards to Challenging Behaviour and Learning Disabilities and Service Design.

To enable the highest standard of care to be achieved, this policy sets out the guidelines to ensure that patients who have a learning disability will have their specific needs identified and met, ensuring reasonable adjustments are made to appropriate services to be delivered in an acceptable manner.

This policy sets out the standard of care Bedfordshire Hospitals NHS Foundation Trust wish to provide people with a learning disability who access our services.

This strategy had been produced with the guidance and input from key clinical and non-clinical leads across the Trust and partners in Specialist Health Care for those people who have a Learning Disability.

This strategy will be reviewed by the Learning Disability Forum on an annual basis and return to the Trust Board after three years for re-approval.

## 2. BACKGROUND

### 2.1 Defining Learning Disabilities

Learning Disabilities affect approximately 1.5 million people in the UK and are common lifelong conditions which are neither illness nor disease. The term is used in relation to individuals who have the following 3 core characteristics:

- A significant impairment of intelligence, IQ below 70
- A significant impairment of adaptive and/or social functioning (ability to cope on a day-to-day basis with the demands of his/her environment and the expectations of age and culture).
- Age of onset before adulthood (18 years of age)

Learning Disability is divided into four classification groups: mild, Moderate, Severe and Profound. The diagnosis of Profound and Multiple Learning Disability is used when the individual has more than one impairment (i.e. sensory, physical, complex health needs, mental health issues) with the most significant being a Learning Disability. People with Profound and Multiple Learning Disabilities will require support from a carer/s to assist them with most areas of everyday life, such as eating/drinking, washing/dressing and going to the toilet.

#### Learning Disability Does Not Include:

- The development of intellectual, social or adaptive impairments after the age of 18;
- Brain injury acquired after the age of 18
- Complex medical conditions that affect intellectual and social/adaptive functioning; e.g. dementias, Huntingdon's disease
- Specific Learning Difficulties e.g. dyslexia, dyspraxia, dyscalculia, literacy or numeracy problems or delayed speech and language development.

The term 'Learning Difficulties', that is often used in educational services to describe people with specific learning problems, does not indicate that a person has a learning disability as defined above, however it is important to note that these two terms are interchangeable to indicate that a person has a learning disability.

#### People with Learning Disabilities may present as having:

- Difficulties communicating and expressing needs and choices
- Difficulty understanding their diagnosis, treatment options or services available to them
- Difficulty understanding the consequences their decisions can have on their health status
- Difficulties adapting to a hospital environment and the expectations of hospital staff

The amount of every day support a person with Learning Disabilities needs will depend mostly on the severity of the disability. It is important to treat each person as an individual, with specific strengths and abilities as well as needs, and a broad and detailed assessment may be needed.

## 3. ROLES AND RESPONSIBILITIES OF STAFF

### 3.1 Medical Director and Chief Nurse

Learning Disabilities affect approximately 1.5 million people in the UK and are common lifelong conditions which are neither illness nor disease. The term is used in relation to individuals who have the following 3 core characteristics:

#### Responsible for:

- Ensuring Bedfordshire Hospitals NHS Foundation Trust provide a health care service to the local population that is accessible, safe and responsive to the needs of patients including those who may have specific needs arising as a result of a Learning Disability.
- Assuring Bedfordshire Hospitals NHS Foundation Trust Board and public that there are policies, processes and monitoring systems in place so that both Bedford Hospital and Luton and Dunstable University Hospital are compliant in its obligations under the Care Act 2014, Equality Act 2010, Quality/Safety Standards and Government requirements.

### 3.2 All Staff

Learning Disabilities affect approximately 1.5 million people in the UK and are common lifelong conditions which are neither illness nor disease. The term is used in relation to individuals who have the following 3 core characteristics:

#### Responsible for:

- All staff are responsible for ensuring people with Learning Disabilities can access care and treatment at Bedfordshire Hospitals NHS Foundation Trust.
- All staff must recognise that People with Learning Disabilities may have particular needs related to their disability and that consideration must be given to meeting those needs when delivering other services.
- Every staff member has a responsibility to act as an advocate for people with Learning Disabilities who may not be able to clearly express their needs in terms of seeking relief from pain or meeting basic requirements such as eating and drinking.
- Any member of staff, including volunteers that come into contact with a person with a Learning Disability must be aware of what this means, how they should be treated and from where they can find more information and help.

### 3.3 Learning Disability Liaison Nurses

- The Learning Disability Liaison Nurses' key role is to lead in the improvement of effective, accessible quality care delivery within Bedfordshire Hospitals NHS Foundation Trust which is responsive to the needs of people with Learning Disabilities. The Learning Disability Liaison Nurses are responsible for providing highly specialist leadership, guidance and advice that supports the development of acute hospital service good practice. This will be through close collaborative working with healthcare and multi-agency professionals and managing the interface between mainstream services, specialist community services, private and voluntary services and families.
- The Learning Disability Liaison Nurses will support the formulation and support the implementation of the Learning Disability strategy.
- The Learning Disability Liaison Nurses will be made aware of any patients with a Learning Disability who are admitted to Bedfordshire Hospitals NHS Foundation Trust.

Within working hours (Monday-Friday 9-5), the Learning Disability Liaison Nurses will visit every patient with a Learning Disability on admission to complete a risk assessment (see appendix 1) to determine the level of support required from the Learning Disability Liaison Nurse service.

- The Learning Disability Liaison Nurses will advocate for the patient in relation to any reasonable adjustments that may be required to meet the needs of patients with a Learning Disability.
- The Learning Disability Liaison Nurses will work closely with the Outpatient, Emergency and Maternity departments to ensure patients who have a Learning Disability and their families/carers are supported whilst accessing these services (Monday-Friday 9-5).

### 3.4 Clinical Staff

- All clinical staff are required to ensure the needs of patients with a Learning Disability are met through individual assessment and care planning that takes into account the views of the patient and family member/carer and the patient's 'All About Me'(appendix 2) and personal Health Action Plan, if the patient has one.
- The 'All About Me' provides clear and concise information in an easy to understand format regarding the patient's support needs.
- The Health Action Plan belongs to the person with a Learning Disability and should accompany the person for all hospital admissions and outpatient appointments.
- Clinical staff providing care and treatment have a responsibility to ensure that the patient with a Learning Disability is helped to understand the care and treatment provided and staff should allow time to communicate through clear explanation, sign language and use of symbols/pictures as appropriate to the ability of the patient.
- Clinical staff should always act as the patients advocate ensuring that they are given information about their condition and/or treatment in way that they can understand in order to make decisions within the limits of their capacity. It is important that clinical staff acknowledge that family members/carers understand the person with Learning Disabilities best and work in partnership with them to ensure that the communication needs of the individual are met.



## 4. CARING FOR PATIENT WITH LEARNING DISABILITIES

### 4.1 Identification of patients

An electronic alert is available on Extramed and PiMs/IPM. If patients are not flagged in this way, these alerts can be added by staff. Staff should inform the Learning Disability Liaison Nurses when they are aware that a patient with a Learning Disability does not have an electronic flag. The alert is used to identify that the patient has a learning disability and should trigger reasonable adjustments required by that individual. Flags will be applied to those aged 17.5 years and above. For those patient's with a Learning Disability who are under 17.5 years and accessing maternity services (only) a flag will also be applied.

### 4.2 Communication and Patient Information

People with Learning disabilities frequently have difficulties with communication. This may include problems with expression, articulation, comprehension and coping with social situations. This may mean they appear more able than they are. Expression and comprehension do not always function at the same level. People with Learning Disabilities often have a problem understanding complex sentences and abstract concepts and consideration should be given to the context of the information given and the format used. Difficulties are often compounded by being in an unfamiliar environment and being cared for by unfamiliar people.

An individual's capacity to understand and communicate can be affected by a number of factors, including anxiety, pain and distress, unfamiliar people and environments. People with Learning Disabilities may also be unable to describe adequately their symptoms, degree and site of discomfort and may inform staff that they feel fine even when clearly unwell. It is important that when assessing pain in a patient with a Learning Disability that a non-verbal assessment tool (such as the Abbey Pain Tool) is used (see appendix 3).

Feeling unwell or in pain can cause fear, confusion and distress and potentially lead to difficult behaviour and poor co-operation. The health care professional can help prevent problems that may arise from communication difficulties by;

- Gaining information about the person's communication needs from the family or carers. Including:
  - Likes and dislikes
  - Level of comprehension
  - How he/she indicate anxiety/distress
  - What calms/relaxes him/her
  - How he/she indicate pain or discomfort
  - How he/she communicates basic needs e.g. thirst, hunger, and toilet.
  - How to best prepare him/her for examination, procedures, touch etc.
  - Giving information in small chunks appropriate to the level of understanding
  - Using short and terminology free sentences
  - Allowing plenty of time for processing of information and be prepared to repeat information
  - Being prepared to give information in other formats e.g. images, pictures, videos, objects etc.
  - Using basic non-technical vocabulary
- Being prepared to demonstrate procedures first.

## Reinforcement of Information

People with Learning Disabilities may have difficulty in understanding information presented only as written text, and therefore information in easy read format or other media should be provided to promote understanding and to enable people with Learning Disabilities to make informed choices about their care and treatment.

The Learning Disability Liaison Nurses are able to assist in the development of accessible information. There are a number of 'easy-read' resources available about a number of health issues, treatment methods and physical examinations available on the Trusts intranet within the Learning Disability Liaison intranet page.

There are also Learning Disability Resource folders available on the wards and within clinical areas which also lists 'easy-read' and visual resources.

It is important to check that any information given has been understood and, if it is helpful for the person with a Learning Disability to have a familiar person with them, try to arrange this prior to speaking to the patient on your own.

Some people with Learning Disabilities do not communicate verbally and rely on other methods such as gestures, pointing or facial expressions to communicate their needs. In addition to asking the family carer/support workers, staff should utilise the patient's Health Action Plan or 'All About Me' for this vital information. Communication can also be supported with the use of simple picture symbols, also through the use of sign language such as Makaton and British Sign Language.

Some people may utilise their own communication tools, for example: a 'Communication Passport' or communication book which is an individualised communication tool (usually a folder which contains photographs and symbols).

Procedures should never be carried out quickly and without explanation and recognition that the explanation has been understood. Objects or pictures can be useful in explaining any procedures. Also any aids or appliances, such as the use of a beaker or specialised cutlery, must be discussed with the patient's carers; this information should be available in the patient's 'All About Me'.

## 4.3 Support To Make Decisions and Mental Capacity

People with Learning Disabilities must be supported to exercise their capacity to make decisions and to consent to care and treatment where the healthcare practitioner determines that they have capacity to do so.

People with Learning Disabilities may have particular difficulties in relation to decision making and giving consent for some of the following reasons:

- Difficulty understanding relevant information, which is linked to the person's verbal and general cognitive skills (e.g. Difficulties with attention, distractibility) and the methods used to convey information.
- Difficulty retaining relevant information
- Difficulty appreciating the personal significance of information
- Difficulty with reasoning and use of information to arrive at a decision (e.g. concreteness, difficulties with abstracting and generalising)
- Lack of experience of decision making
- Tendency to acquiescence and suggestibility and difficulties being assertive
- Emotional factors such as fear, anxiety and frustration

- Difficulties in expressing choices

Some of these difficulties relate to the person's learning disability in that their cognitive function is limited in some areas. Others reflect the person's social and psychological experience (e.g. relative powerlessness).

Support should be provided to maximise the person's ability to participate as fully as possible in decisions about their life.

If Practitioners feel that a patient lacks capacity to consent to hospital admission, treatment or discharge arrangements please refer to the Mental Capacity Act Policy which provides guidance on assessing capacity and making best interest decisions.

In all departments of the hospitals consideration should be given to the person with Learning Disability's capacity throughout their engagement with services and capacity should be reviewed at every contact, this is particularly important in maternity services. If there are any concerns about completing capacity assessments or making best interest decisions please escalate these concerns to the Learning Disability Liaison Nurses or a member of the safeguarding team (Children's, Maternity or Adults dependent on the age and needs of the patient) for support.

## 4.4 Information Sharing

**All patients have a right to privacy and to control information about themselves.**

Information pertinent to any change in the person's support needs should be shared with paid care staff, but detailed clinical information should be treated sensitively and disclosed only when necessary and on a need to know basis.

It is good practice to identify at the beginning of a care episode how we are to share information with both the family and paid carers. Usually information would be shared with a nominated individual from the patient's family and if the patient is in receipt of care, it would be expected that the patient's family member would share information with the paid carer. However confirmation that the patient is happy for this to occur should be sought and expectations to share information by the family should be clear.

If the patient has limited or intermittent contact with family members and has been deemed to lack capacity to make decisions about care, treatment or who they would like information to be shared with, then the patient should be referred to an Independent Mental Capacity Advocate (IMCA), please refer to the Mental Capacity Act Policy for guidance on completing this referral.

## 4.5 Making Reasonable Adjustments

The Equality Act 2010 requires all health care providers by law to make reasonable adjustments to their services to ensure patients with Learning Disabilities have equal access, care and treatment. Reasonable adjustments are not just about adapting the physical environment. It should also include considerations around communication, approach and attitude.

Clinical areas are responsible for resourcing and providing the reasonable adjustments to be made in their own areas. Advice and guidance can be sought from the Learning Disability Liaison Nurses.

**Examples could include:**

- Giving individuals an appointment at either the beginning or end of the clinic
- Giving longer appointment times
- Placing an individual 1st on the theatre list
- Allowing a family member or carers to stay all the time

- Allow flexible visiting hours for carers/support worker
- Allowing individuals to wear their own clothes to theatre
- Doing other investigations whilst individuals are under anaesthetic
- Giving individuals a quiet place to wait away from the main waiting area
- Offering diversions
- Use of comforters
- Having one to one nursing/maternity care
- Making information easier to understand
- Hiring a bed or chair more suited to their individual needs
- Using a side room
- Allowing more time with meals/drinks etc
- Reduce distracting noise if possible
- Ensuring lighting is not too bright or intrusive as this can be stressful for people with Learning Disabilities

It is important to remember that anything can be reasonable if it supports that individual have safe and equitable access to care that they require.

## 4.6 Carer Involvement

The term 'carer' is used to indicate anyone supporting the person with Learning Disabilities, this could be a family member, relative, support worker, or advocate. It should be recognised that the carer of a person with Learning Disabilities has considerable insight into the care of that person and are in a unique position in understanding their needs. They will also be able to help staff to identify ways to communicate most effectively with the patient.

The patient will benefit if care and treatment is delivered in partnership with the carer, but assumptions should not be made about the level of involvement that the carer is able to provide. Carer's should not be relied upon to provide extra support. However they should be made welcome and encouraged to continue to assist in providing care in partnership with the nursing and medical staff should they wish to do so. Carer's should also be encouraged to participate in the nursing/midwifery assessments, planning care and discharge.

**When a patient is being supported by a carer not directly employed by the Trust, staff must ensure that the carer:**

- receives support in providing care
- has effective two-way communication
- is aware of what care and treatment has been delivered and by whom
- that care and additional support is evaluated and communicated to the carer
- is allowed a break at regular intervals
- is offered drinks at regular intervals
- is allowed to stay with the patient overnight if needed and suitable sleeping equipment is provided
- does not provide 24 hour.

A Carer Information Pack is available for all Carers to enable recognition of their role. Staff should also signpost unpaid carers (family/relatives) to the Carers Lounge where they can receive additional support and advice.

## 4.7 Challenging Behaviour

Some people with Learning Disabilities may exhibit behaviour that other consider challenging. This often occurs in response to communication issues, sensory stimulation, attracting attention, avoiding demands, distress, pain, boredom or environmental factors such as noise or crowds.

This behaviour often results from the interaction between personal and environmental factors and includes aggression, self-injury, stereotypic behaviour, withdrawal and disruptive or destructive behaviour.

It is relatively common for people with a Learning Disability to develop behaviour that challenges, and more common for people with more severe disability. Prevalence rates are around 5-15% in educational, health or social care services for people with a learning disability. Rates are higher in teenagers and people in their early 20's and in particular settings (for example 30-40% in hospital settings).

People with a Learning Disability who also have communication difficulties, autism, sensory impairments, sensory processing difficulties and physical or mental health problems (including dementia) may be more likely to develop behaviour that challenges.

In order to support the person it is beneficial to speak to the patient's carers/support worker to find out what might precipitate any challenging behaviour to try and minimise potential triggers. It is also good practice to ask whether the carer/support worker has any written strategies for coping with the challenging behaviour of the person they are caring for and if a copy can be made available to be used as part of the nursing care plan.

It is also useful to determine whether carers/support workers have any other methods of distraction that they follow with the patient they are caring for which they may help staff to better manage any challenging behaviour. Staff could also find out if there are any activities that the patient particularly enjoys and try to incorporate these into the daily ward routine.

## 4.8 Partnership Working

Multi-agency and multi-disciplinary partnership working is essential to ensuring positive health outcomes for people with learning disabilities. Bedfordshire Hospitals NHS Foundation Trust will support the development of strong partnership working with colleagues from the local Specialist Learning Disability Service in the Mental Health Trust. The Trusts will also endeavour to work together with other health and social care providers such as Adult Learning Disability Social Care Team (ALDT), GP's and members of the Learning Disability Partnership Boards.

Family carers and support workers must be included in planning for both admission and discharge to ensure all information is passed on effectively and avoids anything being missed.

Bedfordshire Hospitals NHS Foundation Trust will actively seek the views of people with Learning Disability, their carers and other partnership groups to inform both policy development and the strategic development of services through the Learning Disability Forum which meets on a quarterly basis at Bedford Hospital and coffee mornings at the Luton and Dunstable University Hospital NHS Foundation Trust.

The Learning Disability Liaison Nurses will also network with other acute trusts to ensure best practice is shared, updated and informed about the regional and national learning disabilities agendas. The Learning Disability Liaison Nurse is a member of the national and regional Access to Acute (A2A) network.

## 4.9 Emergency Admissions

Visits to the Emergency Department (ED) can be extremely stressful for anyone and this is sometimes the experience of People with Learning Disabilities and their carer. Whilst waiting for treatment, staff must ensure that the patient's immediate needs are recognised and addressed as far as possible within the prevailing situation at that time and, if the patient is accompanied, that the carer's views are taken into account to minimise the potential for stress and anxiety.

All people with Learning Disabilities should be seen as high priority, however, there may be a delay in patients being seen if there are higher clinical needs in the department at that time-the decisions rests with the Nurse in Charge of the Department.

Waiting can be difficult for anyone who is ill or in pain, but for patients with a Learning Disability they may find the waiting extremely difficult and this can lead to additional problems, for example, 'behaviours which may challenge'. ED staff should consider offering a quieter waiting area with clear information to the patient and their family/carer if they are with them. Reassurance and effective communication at this stage can often prevent perceptions of lack awareness of and consideration by staff of the patient's needs.

Some reasonable adjustments which may be required:

- Consideration for reduction of waiting time (accelerated pathway)
- Find a quiet area for the person to wait
- Allow person and their carer to leave the ED and return when called
- Early assessment and treatment of pain/discomfort

It must be recognised that in an emergency admission a person with Learning Disabilities may be particularly distressed due to the nature of the admission and may present with anxiety, agitation or challenging behaviour. The person may well be unable to articulate their level of pain and anxiety and be unable to express their symptoms. In this situation staff must contact the person's relatives/carer/social worker/community nurse/advocate as soon as possible. Advice and support should also be sought from the Learning Disability Liaison Nurse.

In the event that a person with Learning Disabilities is brought into the Emergency Department, the following issues must be considered:

- **Pain Management:** A person with Learning Disabilities may express the presence of pain through challenging behaviour (such as verbal/physical aggression to self/others/property, head banging, rocking, hitting parts of the body or similar signs of distress.) It is important to find out what these behaviours mean and establish if they are part of the person's normal presentation or related to their current circumstances. The person's pain needs will need to be discussed on an individual basis, with the patient's carers/family or people who know the patient well or alternatively with input from the pain team within Bedford Hospital or Luton and Dunstable University Hospital and the Learning Disabilities Liaison Nurses.
- **Presence of other disabilities:** The person may have additional mental, physical and sensory disabilities or experience other co-morbidities such as epilepsy.
- **Communication:** Communication will be particularly difficult if the person is distressed and every effort must be made to explain procedures in a quiet and controlled manner and use supportive communication aids where possible.
- **Environment:** The Emergency Department is a challenging environment for those without a disability and may present a particularly frightening environment to a person with a Learning Disability who is unable to understand what is happening to them or simply has a fear of hospitals or unfamiliar places. Where possible it is advisable to utilise a cubicle where privacy and a slightly quieter environment can be provided.

Staff admitting a patient with Learning Disability via the Emergency Department or other routes, must advise the Patient Flow Team and the receiving ward of the patient's enhanced needs, prior to the formal assessment process.

An Emergency Department Care Pathway has been developed for people with Learning Disabilities (appendix 4).

#### 4.10 Elective admissions

When attending the pre-assessment clinic and on admission, the person with Learning Disabilities or their carer/health facilitator/Learning Disability Liaison Nurses will be asked for any copies of care plans and nursing assessments including the 'All About Me' and Personal Health Action Plan if the person has one.

If they do not have a Health/Hospital Passport, this should be completed with them at pre-assessment or on admission. Copies of the 'All About Me' are available in the Learning Disabilities Resource Folder on every ward/department or from the Learning Disability pages on the Trust intranet. Copies can also be obtained from the Learning Disability Liaison Nurses.

In pre-assessment (or on admission if no pre-assessment) the health care practitioner completing the assessment will need to discuss the specific needs of the person and may need to contact the person's family, carer, healthcare facilitator, Social Worker or community nurse to ensure a full assessment of need. A summary of this discussion must be documented in the patient's healthcare record.

**The assessment will include:**

- Swallowing difficulties or dietary needs
- Sensory disabilities such as hearing or visual impairment
- Specific communication needs
- Routine medication, particularly those related to managing epilepsy
- Pain management
- Transport needs
- Special possessions to bring into the hospital
- Discharge arrangements

Where possible the person with Learning Disabilities and carer will be offered the opportunity to visit the ward and familiarise themselves with the hospital and staff caring for them prior to admission. The person with Learning Disabilities will also be offered the opportunity to ask further questions about the planned procedure.

Consideration should be given to combine procedures wherever possible. During anaesthesia, there could be opportunities to undertake blood tests or other procedures to avoid any further distress to the patient.

The pre-assessment appointment (besides pre-ward visits) should be planned with as much time before admission as possible to ascertain information on the patient and the required care levels to disseminate to the admitting ward.

Provision should be made for a side room to lessen anxiety or distress and to give extra space, especially if the patient or carer is staying overnight to support the patient and to accommodate any extra equipment required. Side rooms will be allocated on clinical priority, so may not be available if for example a patient requires it as they are infectious.

The ward staff will need to negotiate with carers and hospital staff if the patient requires enhanced observations within the hospital environment as to who will be providing this.

On admission the patient's Health Action Plan/'All About Me' should be incorporated within the admissions procedure, with all relevant information, particularly that relating to specific support needs available and accessible to all ward staff.

When surgery is required Ward staff should liaise with theatres and recovery staff to ensure that all relevant information is discussed in relation to specific support needs. Parents and carers should be offered the opportunity to accompany the patient to the

Anaesthetic room and attend recovery when the patient wakes following any surgery/procedure to offer support and reassurance.

Theatre/Recovery Pathway (appendix 5)

There should also be a specific focus on planning discharge arrangements to ensure that adequate help will be available on discharge.

#### **4.11 Patients admitted from Residential/Nursing Home or Supported Living**

The residential care home staff should fully appraise hospital staff during the pre-assessment process of any specific requirements for their client. They are responsible for providing the 'All About Me' which provides details of the individuals support needs. This should accompany the patient in the 'Red Bag' alongside other agreed documentation and belongings as agreed in the 'Red Bag' scheme.

The care provider may be able to offer some level of practical support whilst the patient is in hospital which could be discussed at the point of pre-assessment or if admitted as an emergency at the point of admission.

#### **Funding 1:1 Care for people when in acute hospitals.**

Evidence shows that when people with Learning Disabilities need a 1:1 for social communication care or exhibit challenging behaviour they will require carers who know them well to be on the ward to support nursing staff to be able to provide clinical nursing care. Hospital staff are asked to complete the Enhanced Observation Risk Assessment to assist with recognising those that may require additional support, please see Specialising and Observational Needs in Adults Policy.

If it is identified that the patient requires a 1:1 and the care provider is able to offer support any such arrangements may involve the potential for reimbursement to the care provider for the use of their staff member and this must be discussed with the Matron responsible when the patient is admitted.

Alternatively the hospital may choose to provide a 1:1 through its own staffing resource.

#### **4.12 Transfers of Care**

Effective communication of information between professionals, family, carers and support workers is essential during transfers of care. Individuals with Health Action Plans/'All About Me's' should have these updated before all transfers of care and staff receiving the patient should be made aware of this information. When a patient with Learning Disabilities is being transferred from another area of the hospital, the receiving ward manager or senior nurse/midwife in charge has responsibility for ensuring all information regarding risk, support needs and reasonable adjustments required are gathered and acted upon.

Please refer to the Inpatient Pathway (Appendix 6)

## 4.13 Outpatients appointments

Where possible the person with Learning Disabilities and/or carer will be asked to bring in with them the person's Health Action Plan/'All About Me'.

When booking and preparing for clinic appointments or day surgery the following considerations should be made:

- **Time of appointment:** People with Learning Disabilities may find waiting difficult. It is advisable to arrange a first appointment of the day or first on the surgery list. Again this will be dependent on clinical priorities of the day and other patient's needs E.g. diabetic patients may need to go first on the list for day surgery/or paediatric patients may take priority.
- **Length of appointment:** People with Learning Disabilities will take longer to assimilate information and may take longer to examine. It may be necessary to offer double appointment times.
- **Communication Needs:** There may be the need to use other communication strategies or aids during the consultation such as easy read literature, images/pictures or 'objects of reference'.
- **Consent:** A person with Learning Disabilities may have sufficient capacity to consent to the procedure but the level of capacity must be determined on the day. If the person is unable to consent, consideration must still be given to helping the person understand what is going to happen to them.
- **Carer:** The person may well require a carer to accompany them throughout an appointment and into the anaesthetic room and recovery from surgery.
- **Environment:** People with Learning Disabilities can become frightened by things they do not understand so it may be necessary to remove unnecessary equipment or instrumentation. Where available, single rooms or a suitably quiet waiting area should be offered to minimise anxiety levels and avoid risks to other patient's safety if the person is likely to exhibit challenging behaviour.

Where people with Learning Disabilities present with phobias/extreme anxieties or challenging behaviour, consideration to the following areas are a necessity in order to meet their needs:

- Where the person is likely to exhibit challenging behaviour, the relevant nursing/medical staff will liaise with the carer/s to complete risk assessments and plan how they can jointly manage these situations. It should not be assumed that the carer/s will manage all situations independently.
- Mental Capacity Act Assessment (and where the patient lacks capacity, best interest assessments) will need to be completed for any form of chemical or physical/mechanical restraint.

Outpatients Pathway (appendix 7)

## 4.14 Diagnostic Tests and Investigations

Tests and investigations can be very frightening to many people with Learning Disabilities so adjustments should be made to reduce anxiety and distress where possible. This should include:

- Preparing the environment to remove unnecessary equipment
- Ensuring that a carer or family member can remain with the person where possible.
- Providing explanations that are easy to understand and are supported by communication aids such as pictures/signs/symbols.
- Not rushing the person
- Arranging for the person and their carer to leave the clinic/department if a wait is envisaged and then contacting them when their appointment is ready.

An assessment should take place when booking a diagnostic test or investigation to ensure that similar considerations are given to those addressed previously in regards to Mental Capacity to consent and making reasonable adjustments.

**In addition staff should consider:**

- **Privacy and Dignity:** People with Learning Disabilities may be reluctant to undress and will need help and persuasion to do so.
- **Behaviour:** A person with a Learning Disability may react to frightening situations with unusual or challenging behaviour
- **Directions:** People may arrive at an appointment unaccompanied. In these situations additional help may be required to help the person navigate from one department to another.
- **Assistance:** Additional staff assistance may be required to support a person with a Learning Disability during the test/investigation.
- **Chaperones:** Use of chaperones should be considered particularly if undertaking intimate procedures.

Imaging Pathway (Appendix 8)

## 4.15 Maternity Care

Increasingly there is a need for people with a Learning Disability to access maternity services. Around 7% of adults with Learning Disabilities are parents, most having mild to borderline learning disability, which may mean they do not have a formal diagnosis and may be difficult to identify.

Studies show that around 40% of parents with a Learning Disability do not live with their children.

### Issues in pregnancy

One in three women with a Learning Disability have reported moderate to severe levels of stress, anxiety and depression. This may be for a number of reasons including social isolation, poverty, literacy issues and difficulties with communication. They may face much opposition to their desire to parent; they may even face pressure to have their pregnancy terminated.

**The babies of mothers who have a Learning Disability are at increased risk of poor birth outcomes including:**

- Premature birth (28%)
- Low birth weight (22%)

**Reasonable adjustments are required to support accessibility of maternity services for example:**

- Extra time and support at appointments
- Opportunity to have information repeated
- Information about pregnancy and birth choices presented in a way that is easy to understand and utilising easy to read resources.
- Involving family carers and advocates.

Maternity Pathway (appendix 9)

## 4.16 Discharge from hospital

In addition to the procedures laid down in Bedfordshire Hospitals NHS Foundation Trust, discharge policy supplementary actions may need to be taken. Planning for discharge should commence as soon as the patient is admitted. On admission, the patient and/or carer will be advised of a provisional date for discharge. This date will be reviewed on a daily basis and may involve a number of staff from the hospital team. The discharge planner for the ward will liaise with individual/carer about safe discharge to home from hospital.

The Learning Disability Liaison nurse should be informed of any admission of a person with a Learning Disability and dialogue established with the discharge planner. Any factors which may prevent discharge back to the patient's home should be flagged with the discharge planner and the Learning Disability Liaison Nurse as soon as possible. It is possible that the patients needs will change whilst in hospital which will require additional care after discharge.

People with Learning Disabilities may recover better within their own home environment but must also be discharged when it is safe to do so and when adequate support can be provided for both the patient and carer.

For comprehensive discharge planning the process must include the individual, their family and paid supporters/carers and other professionals who are involved in their care e.g. social worker/community learning disability nurses, speech and language therapists, occupational therapists, physiotherapist, dietician, midwifery staff etc.

A person with Learning Disability may also be living with a partner or family member with a Learning Disability and in these circumstances detailed planning of the discharge and support will be required to ensure a safe discharge.

Careful consideration must be given to providing advice, after care and treatment. A person with Learning Disabilities may not understand information provided on medication, management of dressings or follow up appointments. The professional planning the discharge must ensure that all these issues are addressed so that the discharge is safe and appropriate.

The practitioner discharging the patient should provide information in the 'All About Me' (discharge section) covering diagnosis, treatment, when to return for follow up appointments, any possible side effects of medication and details of someone on the ward to contact if necessary.

Staff must ensure they check how the patient usually takes medication and arrange pharmacy to dispense the medication in the format they are used to i.e. blister packs, dossett boxes.

The primary carer must be involved in discussions relating to the patient's discharge arrangements.

If there has been a significant change in the patient's health needs or if the patient has complex health needs then a discharge planning meeting should be considered.

If the patient has no representative, family member or friend, it may be appropriate to request the involvement of an Independent Mental Capacity Advocate (IMCA), this is a mandatory requirement if the patient lacks capacity to consent to a change of accommodation due to a change in need.

## 4.17 Patient feedback

Patients with a Learning Disability should be encouraged to provide feedback about the hospital using the Easy Read Patient feedback form. The Learning Disability Liaison Nurse following each admission will forward these surveys to the patient and the carers for completion and at the Learning Disability Forum will provide an evaluation of the feedback provided on a quarterly basis; any learning for staff will be fed through the daily operational quality meetings/bed meetings.

## 5. TRAINING AND EDUCATION

Bedfordshire Hospitals NHS Foundation Trust has a commitment to improve the knowledge, skills and awareness of all staff who are involved in or who contribute to the patient pathway for people with a Learning Disability. Ensuring that all staff have appropriate skills, knowledge and attitudes is key to ensuring that the agreed pathways deliver high quality care for the individual. Training and education is coordinated and facilitated by the Learning Disability Liaison Nurses and is aimed at all staff across the Trust.

All registered nurses, midwives and clinical support workers are provided with Learning Disability Awareness training. Additional and bespoke training and education is also provided to ensure that appropriately skilled staff are available.

The trust offers the opportunity for face to face training which can be bespoke to specific areas in the Trust to meet their needs, e.g. Theatres, A&E, maternity.

## 6. MONITORING COMPLIANCE

An annual audit of reasonable adjustments will be undertaken by the Learning Disability Liaison Nurses from the Rapid Risk assessment tool to monitor compliance with this policy. In addition, the policy will be audited against the yearly work plan. Patient feedback will also be used to monitor compliance.

### References

DH (2005) *The Mental Capacity Act 2005*. London: The Stationary Office.

DH (2009) *Valuing People Now: A new three year strategy for people with learning disabilities: "Making it happen for everyone"*. London: The Stationary Office.

DH (2010) *The Equality Act*. London: Department of Health

Heslop, P, Blair, P, Fleming, P, Houghton, M, Marriot, A, Russ, L (2013). *Confidential enquiry into premature deaths of people with learning disabilities (CIPOLD) Final report*. Bristol: Norah Fry Research Centre.

MENCAP (2004) *Treat Me Right! Better healthcare for people with a learning disability*. London: Mencap

MENCAP (2007) *Death by indifference. Following up the Treat me right! Report*. London: Mencap

MENCAP (2012) *Death by Indifference: 74 deaths and counting-A progress report 5 years on*. London:

Mencap. Michael, J (2008). *Healthcare for all: a report of the independent inquiry into access to healthcare for people with learning disabilities*. London: The Stationary Office.

Parliamentary and Health Ombudsman (2009) *Six Lives: the provision of public services to people with learning disabilities*. London: The Stationary Office

NICE guidance (NG11 and NG93) *in regards to Challenging Behaviour and Learning Disabilities and Service Design*.

Hospital Number  
Surname  
First name  
Address/postcode  
  
Date of Birth

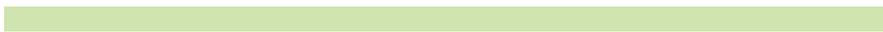
## Appendix 1 – Risk Assessment Tool-Learning Disabilities

Date of admission

Date completed

ALL ABOUT ME / Hospital Passport in Place :    **Yes**     **No**

Learning disability  in place:    **Yes**     **No**

- LOW RISK 
- MEDIUM RISK 
- HIGH RISK 

Please tick appropriate level for each domain. Any medium or high score requires action.

	Assessment criteria	Action / Outcome:
<b>Personal Safety</b>	<ul style="list-style-type: none"> <li>• <i>No issues identified.</i></li> <li>• <i>May require regular observation and checks to ensure safety, but otherwise can manage own safety.</i></li> </ul>	<input type="checkbox"/> LOW
	<ul style="list-style-type: none"> <li>• <i>May require increased level of checks, prompting or reassurance to manage own safety.</i></li> <li>• <i>Has an additional need that may have an impact on personal safety i.e. sensory difficulties / physical disability.</i></li> </ul>	<input type="checkbox"/> MEDIUM
	<ul style="list-style-type: none"> <li>• <i>Unable to recognise own needs or manage own safety: may walk around unsupported, may remove medical devices, may increase risks to safety of others.</i></li> <li>• <i>May require continuous observation and management of posture to maintain airway.</i></li> <li>• <i>High risk of falls.</i></li> <li>• <i>Current safeguarding issue</i></li> </ul>	<input type="checkbox"/> HIGH

	Assessment criteria	Action / Outcome:
<b>Swallowing, Nutrition, Hydration</b>	<ul style="list-style-type: none"> <li>No history of, or current concerns with swallowing.</li> <li>Eats and drinks well.</li> <li>May require regular prompts to ensure adequate food and fluid intake i.e. encouragement / reminding.</li> </ul>	<input type="checkbox"/> LOW
	<ul style="list-style-type: none"> <li>Requires safe positioning or additional support for eating / drinking.</li> <li>NIL BY MOUTH and has enteral feeding</li> <li>History of recurrent chest infections or unintentional weight loss.</li> </ul>	<input type="checkbox"/> MEDIUM
	<ul style="list-style-type: none"> <li>Assessment indicates high risk of dysphagia.</li> <li>Modified food / diet or thickened fluids indicated.</li> <li>Requires 1:1 support with eating and drinking</li> </ul>	<input type="checkbox"/> HIGH
<b>Communication</b>	<ul style="list-style-type: none"> <li>Good verbal communication and understanding</li> <li>Some verbal communication and uses non-verbal systems to supplement this.</li> <li>Requires additional time to process information and respond.</li> </ul>	<input type="checkbox"/> LOW
	<ul style="list-style-type: none"> <li>Uses non-verbal signs, facial expression, body language or behaviour to communicate.</li> <li>Requires extra time and information in alternative formats to aid understanding</li> </ul>	<input type="checkbox"/> MEDIUM
	<ul style="list-style-type: none"> <li>Communication may be non intentional and requires interpretation by familiar carers.</li> </ul>	<input type="checkbox"/> HIGH
<b>Mental capacity</b>	<ul style="list-style-type: none"> <li>No issues identified.</li> <li>Responds appropriately to interaction and information being given</li> <li>Is able to ask appropriate questions in response to information given</li> </ul>	<input type="checkbox"/> LOW
	<ul style="list-style-type: none"> <li>Unable to participate in discussions pertaining to information about treatment / interventions.</li> </ul>	<input type="checkbox"/> MEDIUM
	<ul style="list-style-type: none"> <li>Unwilling to participate in discussions pertaining to information about treatment/ interventions.</li> </ul>	<input type="checkbox"/> HIGH

	Assessment criteria	Action / Outcome:
<b>Epilepsy</b>	<ul style="list-style-type: none"> <li>• No known seizure activity</li> <li>• Historical seizure activity/Seizures are well controlled</li> </ul>	<input type="checkbox"/> LOW
	<ul style="list-style-type: none"> <li>• Unpredictable seizures / seizures not currently well managed.</li> <li>• Seizure activity increased by illness or anxiety</li> <li>• Seizure activity may introduce increased risk to patient or others.</li> </ul>	<input type="checkbox"/> MEDIUM
	<ul style="list-style-type: none"> <li>• Seizure activity is prolonged and may lead to loss of consciousness.</li> <li>• History of airway obstruction or aspiration during seizures.</li> <li>• Seizure activity places patient or others at significant increased risk.</li> </ul>	<input type="checkbox"/> HIGH
<b>Behaviour and Emotional Needs</b>	<ul style="list-style-type: none"> <li>• No issues identified.</li> <li>• May become anxious in new environments, needing reassurance and extra time.</li> <li>• May occasionally display behaviour which is perceived by others as challenging but, usually responds to support and explanation.</li> </ul>	<input type="checkbox"/> LOW
	<ul style="list-style-type: none"> <li>• Frequently displays behaviours which may be perceived as challenging and may require additional support to ensure safety of self and others.</li> <li>• Sometimes displays aggressive behaviours.</li> </ul>	<input type="checkbox"/> MEDIUM
	<ul style="list-style-type: none"> <li>• Significant hospital phobia or difficulties waiting.</li> <li>• Very frequently displays aggressive behaviours to self or others and presents as high risk of harm.</li> </ul>	<input type="checkbox"/> HIGH
<b>Pain</b>	<ul style="list-style-type: none"> <li>• Able to spontaneously identify pain and can communicate its whereabouts and severity.</li> </ul>	<input type="checkbox"/> LOW
	<ul style="list-style-type: none"> <li>• Pain may need to be recognised by others (body language, changes in behaviour) but patient is able to answer basic questions with prompting, support and time. May need additional accessible information to aid this process.</li> </ul>	<input type="checkbox"/> MEDIUM
	<ul style="list-style-type: none"> <li>• Pain cannot be spontaneously indicated by the patient. Anticipation and interpretation of needs by others is paramount to ensuring timely pain management is provided.</li> </ul>	<input type="checkbox"/> HIGH

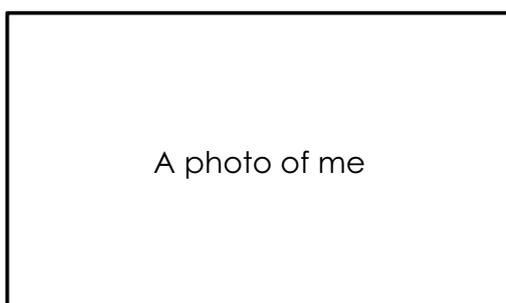
*This document can be accessed via the staff intranet following the link for Departments/Learning Disability/All about me.*

## All About Me

**My name is:** \_\_\_\_\_

**I prefer to be called:** \_\_\_\_\_

**This booklet will help you to get to know me while I am in hospital.**



**I live at:** \_\_\_\_\_



**I was born on:** \_\_\_\_\_



**My doctor is:** \_\_\_\_\_



**My carer is:** \_\_\_\_\_



**My carer's telephone number is:** \_\_\_\_\_

## Non-Communicative Pain Tool | 2017

Please use this guide to assess pain for patients who cannot communicate their pain score Evolve: 001927

Below are examples of how to calculate the pain score – please document total score alongside other observations

1. Vocalisation (eg whimpering, groaning, crying)	0	1	2
2. Change in body language (eg fidgeting, rocking, guarding, withdrawn, looking tense, frowning, grimacing, frightened)	0	1	2
3. Behavioural change (eg confusion, eating etc)	0	1	2
4. Physiological change (eg temp, pulse, bp, sweating, flushing, palor)	0	1	2
5. Physical changes (eg skin tears, pressure ulcers, arthritis, contractures)	0	1	2

Remember – you are looking for **CHANGES** on movement **TOTAL =**

**Mild pain 1-3      Moderate pain 4-7      Severe pain 8-10**

- Is the pain **ACUTE?** (sudden onset and short duration – ie procedural pain, trauma pain)
- Is the pain **CHRONIC?** (pain of long duration – ie arthritis, back pain)
- Is the pain **ACUTE on CHRONIC?** (a combination of Acute and Chronic)

***If score over 3 please take action ie: - reposition patient, Medication,***

Pain Team – Luton & Dunstable Hospital

**A person with a learning disability presents at A&E**

Reception staff to fast track or offer quieter place to wait if required ask person or carers what additional help or support may be needed.

\*Reasonable adjustments need to be considered at every stage in the process.

**\*Examples of Reasonable Adjustments:**

- Involve Carers
- Does patient need quiet area to wait
- Ask what additional help is needed
- Ensure 'All about Me' booklet in place. If not, give one to carer to complete as soon as possible
- Offer quiet place to wait
- Offer side room if required
- Fast track patient if they cannot tolerate a noisy environment
- Use words people can understand
- Explain every procedure clearly and simply
- Find out how the patient communicates
- Safe and effective handover or transfer

**Triage the Patient**

- The nurse will ensure patients safety and deal with immediate health care need.
- Check whether the patient is a **regular attendee** and whether an existing care plan in A&E folder.
- The triage process does not necessarily have to happen in A&E (e.g. it could be in EAU or a side room).
- Can the patient be **fast-tracked** to EAU or preferably a **base ward** to prevent anxiety & distress caused by multiple moves?
- Are family **carers** or paid carers with the patient? If not, do they need to be? Carers usually have essential information and need to be involved in assessment.
- Has the patient brought in a care plan / **All about Me** or other document to support caring? If not, print one off (intranet site: Departments>Learning Disabilities>Templates).

- Gather all relevant information. Complete CAS Card.
- Identify the main carer/guardian and contact them as soon as possible.

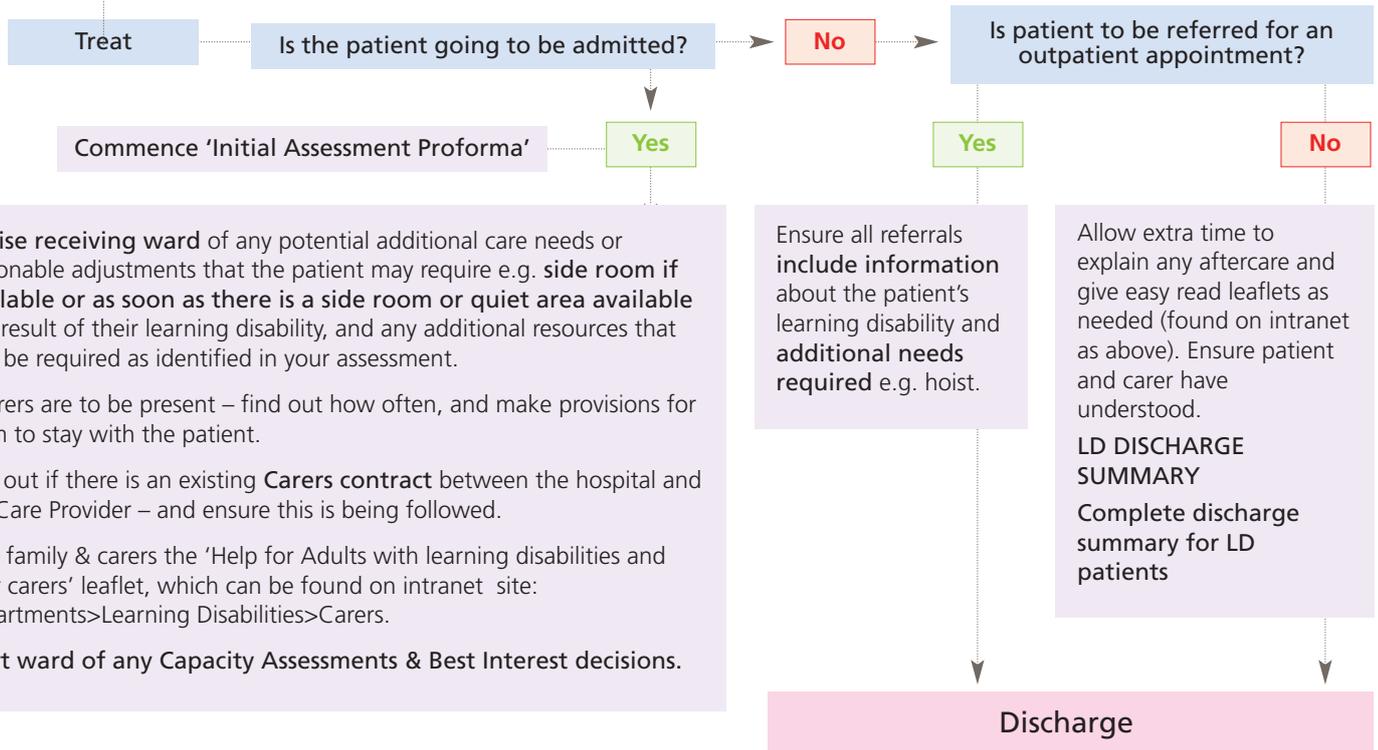
- Ensure all information about the patient's needs is **handed over to the doctor**.
- Refer to the Learning Disability Liaison Nurses (Ext 8271 or Bleep 377 – Mon-Fri 9-5).

- Is the patient a **vulnerable adult**? If so, has the Hospital SOVA lead been informed?

Explain treatment options/ procedures, attempt to seek **easy read information** to gain informed consent (some examples on intranet under Departments>Learning Disabilities>Easy Read Health Leaflets).

If patient is unable to give **informed consent** or you question their ability, refer to the **Trusts Mental Capacity Act Policy & Guidance** in order to complete a Mental Capacity Assessment and Best Interest decision.

Any treatment done in the patients 'Best Interest', as per Trust process, must be recorded clearly in the patient's notes.



## Care of a Patient with a Learning Disability: Theatre/Recovery Pathway

### A person with a learning disability after having surgery

Reception staff to offer quieter place to recover if required ask person or carers what additional help or support may be needed.

\*Reasonable adjustments need to be considered at every stage in the process.

#### \*Examples of Reasonable Adjustments:

- Involve Carers
- Does patient need quiet area to wait
- Ask what additional help is needed
- Ensure 'All about Me' booklet in place.
- Offer quiet place to wait
- Offer side room if required
- Fast track patient if they cannot tolerate a noisy environment
- Use words people can understand
- Explain every procedure clearly and simply
- Find out how the patient communicates
- Safe and effective handover or transfer

#### Theatre Staff

- The nurse will ensure patients safety and deal with any reasonable adjustments required.
  - Check whether the patient has an existing care plan and All About me document
  - Can the patient be **fast-tracked to a base ward if staying overnight or fast tracked home** to prevent anxiety & distress caused by multiple moves?
  - Are family **carers** or paid carers with the patient? If not, do they need to be? Carers usually have essential information and need to be involved in the recovery.
  - Has the patient brought in a care plan / **All about Me** or other document to support.
- IF from residential or nursing care home check for **red bag** caring? If not, print one off (intranet site: Departments>Learning Disabilities>Templates).
- **Consent & Capacity** needs to be considered alongside the Trusts Guidance & Policy.
  - Consider all **\*Reasonable Adjustments** (opposite).

- Gather all relevant information.
- Identify the main carer/guardian prior to going to surgery and contact them as soon as possible when patient is going to recovery.

- Ensure all information about the patient's needs is **handed over to the ward if staying overnight.**

- Refer to the Learning Disability Liaison Nurses (Ext 8271 or Bleep 377 – Mon-Fri 9-5).
- Is the patient a **vulnerable adult**? If so, has the Hospital SOVA lead been informed?

Is the patient going to be admitted?

Yes

No

**Advise receiving ward** of any potential additional care needs or reasonable adjustments that the patient may require e.g. **side room if available or as soon as there is a side room or quiet area available** as a result of their learning disability, and any additional resources that may be required as identified in your assessment.

If carers are to be present – find out how often, and make provisions for them to stay with the patient.

Find out if there is an existing **Carers contract** between the hospital and the Care Provider – and ensure this is being followed.

Give family & carers the 'Help for Adults with learning disabilities and their carers' leaflet, which can be found on intranet site: Departments>Learning Disabilities>Carers.

Allow extra time to explain any aftercare and give easy read leaflets as needed (found on intranet as above). Ensure patient and carer have understood.

#### LD DISCHARGE SUMMARY

Complete discharge summary for LD patients and give to the patient intranet/Dept/Learning disability

Is patient to be referred for an outpatient appointment?

Ensure all referrals include information about the patient's learning disability and **additional needs required** e.g. hoist. Contact the LDLN for support Ext: 8271 or Bleep :377

Safe Discharge

**Has the patient been identified as having a Learning Disability?**

Yes

No

**On Admission ward nurse to ensure that:**

- The Initial Nursing Proforma has been completed.
- The **Learning Disability Liaison Nurse** aware of this patient (ext 8271: bleep 377)
- The patient has an **All about Me** booklet. If not, please give them/their carer a blank one to complete. This should be kept on patient's bedside for ALL to read.
- Matron has been informed of this patient – this is a Trust protocol – and documented.
- Any previous care plans / care needs of the patient (including regular medication) are being met and recorded.
- If the patient requires a procedure or surgery; ensure the doctor completes a **Mental Capacity Assessment** & holds a **Best Interest Meeting** – family/carers/LD Nurses should be invited to support with this assessment. If no family then a referral for an IMCA to attend should be made.
- If there are any safeguarding concerns please inform the Trust's Adult Safeguarding Lead (Toni Doherty – bleep 448).
- The Learning **Disability Champion** on your ward (if there is one), is aware of this patient.
- Have carers been given copy of the Trust's 'Guidance for Carers of Patients with a Learning Disability'?
- Carers will know the patient best – please consult them and involve them in care planning.
- Carers cannot always be present – please ensure a risk assessment is completed and if a 1:1 required the Trusts 'Specialising Policy' should be used.
- Ensure any identified **Risks** or any **\*Reasonable Adjustments\*** (see opposite) **made** are recorded in the patient's notes

**On Discharge the coordinator to ensure that:**

- The LD Nurses have been informed of discharge.
- Carers &/or social services are happy with the discharge plans - will a discharge meeting need to take place (usual practice for complex health needs)?
- Carers have visited the patient and confirmed that the patient back to their 'usual self' and safe to go home.
- The patient's original or new care package has been re-instated at home prior to discharge.
- Dr (or named nurse) has completed the Learning Disability Discharge Summary Sheet (using clear/simple language. (Intranet/LD Dept/Discharge summary)

It is good practice to ask all patients: 'Do you have any support needs we can help you with'?

By doing this we can ensure that we are not discriminating against any individual under the **Equality Act 2010** (see below).

If unsure and you suspect the patient may have a Learning Disability please contact the Learning Disability Liaison Nurses (LDLN's) for advice in confidence (Tel: ext 8271 bleep 377).

**The Equality Act 2010**

It says: '*Services are required to make 'reasonable adjustments' to enable everyone to access them*'.

**Examples of 'Reasonable Adjustments' include:**

- Offer side room on ward if required (especially if family or carers will be staying with the patient). Not all patients will require a side room – especially if they are **vulnerable and need constant supervision/monitoring**.
- Use words people can understand – especially on discharge letters (keep it simple & clear). Find out how the patient communicates
- Ensure all tests and procedures are carried out promptly (not waiting around) to reduce anxiety.
- Ensure patient and family/carers fully understand any information regarding care needs/procedures/medication etc.
- Give Easy Read information on health and procedures (examples can be found on the Trust Intranet site:  
**Departments>Learning Disabilities>Templates**)
- Explain every procedure clearly and simply; use pictures or objects if possible (these can be found in the wards **Learning Disability Resource Folder**).
- Ensure consent issues are considered and the Trusts Mental Capacity Act Guidance is followed (i.e. capacity assessment & best interest decision). The Learning Disability Nurses or Adult Safeguarding Lead are available for support.
- Ensure a **safe and effective handover**, transfer or discharge. Inform receiving areas of any specific patient care needs prior to transfer – Consider if professional care planning meeting is required.

## Care of a Patient with a Learning Disability: **Outpatient Care Pathway**

Disability.

Appointments manager to contact Senior Out Patients Nurse if Learning Disabilities, or an identified need, is highlighted in the referral letter or flagged as an **ALERT** on i.PM.

Out-Patients to ensure needs noted and passed on to appropriate exam room i.e. hoist required, quiet waiting area, fast track. Remember to make and record any '**reasonable adjustments**' required by the patient. NB. Examples of Reasonable Adjustments on intranet: **Home Departments > Learning Disabilities**

**At appointment patient and/or carer to give completed All About Me & Health Action Plan** to outpatient staff to support nursing staff in providing appropriate care and support.

If patient does not have an **All About Me**, staff will offer a blank one for patient/carers to complete (can be found on above intranet site).

Is the patient going to be admitted?

Yes

No

Ensure a detailed handover is given to the ward with all relevant patient information

Keep carers informed and involved

Patient to be given full explanation of additional tests or investigations

Use easy read leaflets photo stories if possible, \*examples below.

Consider Capacity Assessment, see Trust Guidance.

Follow up appointment given?

Ensure written down on card with date, time and month separately e.g. 1pm (afternoon) on Wednesday 2nd May 2012

**Patient Discharge**

**Clinic flexibility**

To avoid added distress for the patient, it is worth considering changing the patient's clinic time to avoid busy waiting rooms and late running clinics. Quiet rooms should be made available if possible and prioritise patient if they are becoming anxious and distressed.

**\*Easy Read** advice and leaflets available on Keep carers informed and involved [www.easyhealth.org.uk](http://www.easyhealth.org.uk)

**Good Practice:**

1. GPs to have a referral template, provided by the Trust, to ensure L.Disabilities are recorded.
2. Notes tagged with 'More Time Please'.

Care of a Patient with a Learning Disability: **Imaging Department Patients Care Pathway**

If a Learning Disability is identified on request from G.P./clinician or on IPM; Place patient on respective waiting list.

Send easy read appointment, also request patient bring their Health Action Plan and All About Me with them.

Offer first appointment of the day if possible

Can a 'double' appointment be made to give more time to the patient?

Inform the Learning Disability Liaison Nurses of patient's appointment.

Consider inviting the patient to visit the department prior to appointment

If a Learning Disability is identified on request from G.P./clinician or on IPM; Place patient on respective waiting list. Send easy read appointment, also request patient bring their Health Action Plan and All About Me with them.

At appointment patient and/or carer to give completed 'All About Me' to Imaging staff. If patient does not have one staff will offer a blank one to be completed by patient/carer.

Is the patient going to be admitted?

Yes

Ensure a detailed handover is given to the ward.

No

Patient to be given full explanation of tests or investigations.

Use easy read leaflets/photo stories if possible useful website: [www.easyhealth.com](http://www.easyhealth.com)

Follow up appointment given?

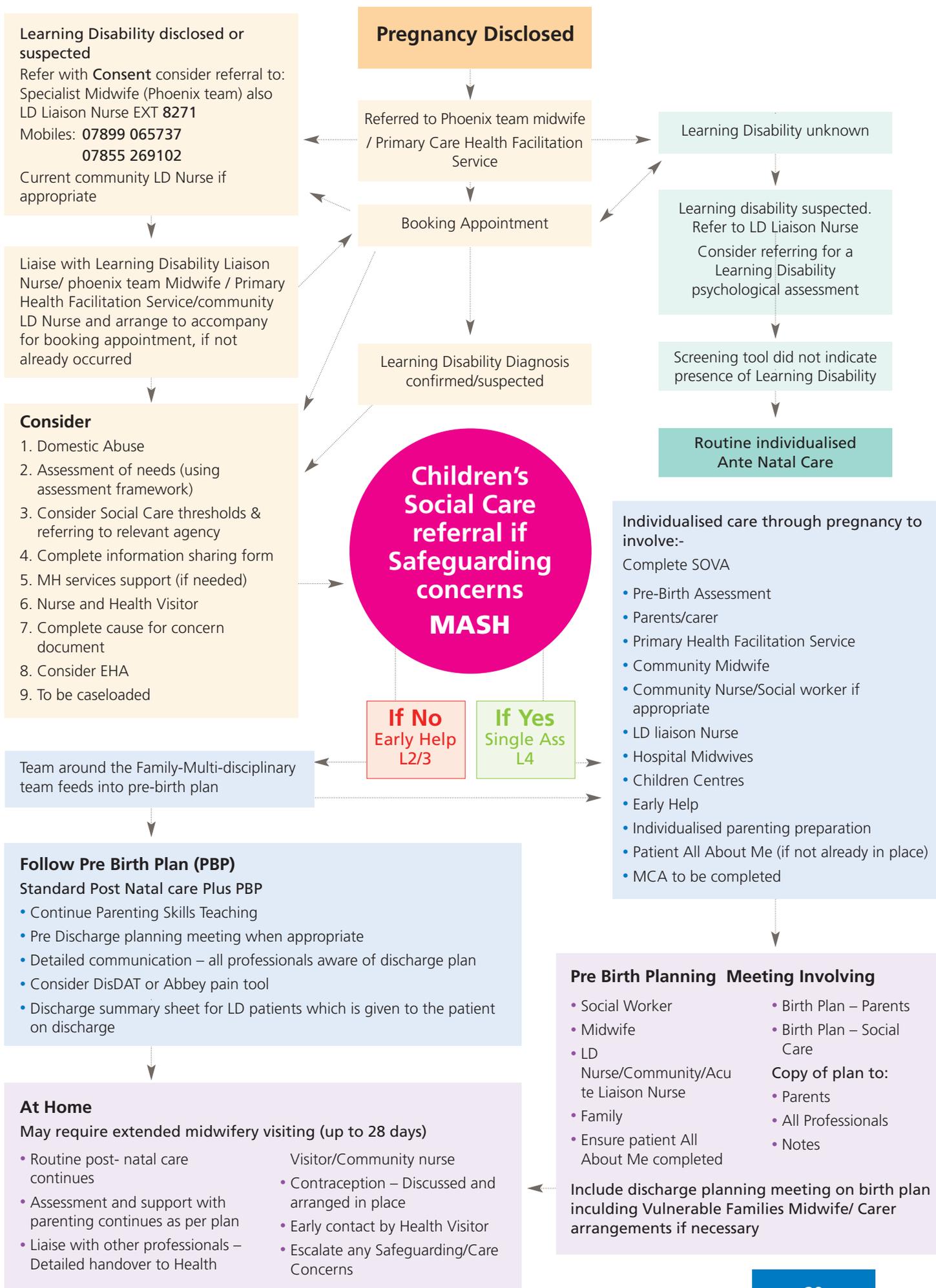
Ensure written down on card with date time month separately e.g. 1pm (afternoon) on Wednesday 2nd May 2012

**Clinic flexibility**

To avoid added distress for the patient, it is worth considering changing the patient's clinic time to avoid busy waiting rooms and late running clinics. Quiet rooms should be made available if required.

**End result = Happy patient**

## Care of a Patient with a Learning Disability: **Maternity Care Pathway**



This strategy is Luton based although Luton and Dunstable Hospital are working together with Bedford Hospital.

This strategy follows principles and guidelines to that of Bedford Hospital.

### **Luton and Dunstable Hospital – 01582 718271**

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