

CARING FOR ADULT PATIENTS WITH A LEARNING DISABILITY IN THE ACUTE HOSPITAL	Type: Policy Register No: 09116 Status: Public on Ratification
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Consulted With:	Post/Committee/Group:	Date:
Clive Gibson	Lead Nurse for Safeguarding and Dementia (Adults/Children)	November 2017
Julie Green	Dementia Specialist	November 2017
Angela Wade	Associate Director for Nursing for Emergency Care	November 2017
Gemma Bellhouse	Specialist Midwife for Vulnerable Women	November 2017
Therese McCarrick-Roe	Named Midwife for Safeguarding Children	November 2017
Alison Williams	Lead Nurse Specialist Surgery And Outpatients	November 2017
Lynn Thomas	Head of Patient Experience and Public Involvement	November 2017
Brian Mister	Healthwatch Essex, Trustee/Chair of pan impaired groups	November 2017
Lisa Seaman	Hospital Assessment Team Manager	November 2017

Professionally Approved By:		
Lyn Hinton	Director of Nursing	December 2017

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Author/Contact for Information	Sandie Morton-Nance, Hospital Liaison Nurse Specialist Practitioner and Learning Disabilities Lead
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1.0 Purpose

- 1.0 The purpose of this policy is to support the Trust in working with adult patients with learning disabilities (LD) and to communicate effectively with them in order to provide the information and advice they require to ensure the hospital stay is as uncomplicated as possible.
- 1.1 This policy is intended to minimise risk and maximise good practice by ensuring that the actual and potential physical health needs of patients with LD are identified and met appropriately.
- 1.2 Each part of this policy forms an important part of clinical effectiveness and development and is therefore part of the clinical governance requirements.

2.0 Policy Statement

- 2.1 The primary purpose of the Trust is in the promotion of health and the prevention of ill-health to all users of its services.
- 2.2 The Trust recognises the duty of care it has in identifying and meeting the specific physical health care needs of people with LD to ensure equal health outcomes.

3.0 Scope

- 3.1 This policy applies to the practice of Trust staff in the provision of services to people with LD accessing wards/ departments.
- 3.2 It offers protocols to guide practice in specific situations and tools for practitioners to use in meeting the care needs of patients with LD.
- 3.3 This policy reflects the changing culture in the way that health care will be delivered in the future with an increasing focus on the concept of making reasonable adjustments.

4.0 Principles

- 4.1 People with learning disabilities (LD) often experience extreme health inequalities, poor health outcomes, and poor access to healthcare despite their greater health problems and needs. The guiding principles that underpin this policy are those directed through statute Law; Common Law Judgements and Department of Health policies as follows:
 - The Government's National Strategy – Valuing People was published in 2001 and highlights inequalities in accessing healthcare. They place a greater emphasis on the person with LD attending mainstream health care services by promoting choice, rights, independence and inclusion in society to ensure they receive good quality and equitable healthcare.
 - The National Patients Safety Agency (NPSA 2004) identified that patients with learning disabilities are more vulnerable in acute hospitals than the general population due to their additional complex needs. In identifying five priority patients safety areas, their initial focus is the improvement of the safety and quality of healthcare for people with learning disabilities in general hospitals.

- The Treat Me Right report produced by Mencap in 2004, concluded that an inquiry made into the deaths of people with LD would not only evidence the cause of death but could be used as leverage for improving the delivery of health services.
- The Disability Rights Commission Report published in 2006 considered it “alarming” that so little had been done in implementing the recommendations made in The Treat Me Right Report by people with powers to do so; and in 2007 they criticised the lack of strategic change and lack of priority despite their previous report.
- Death by Indifference (2007) detailed six case studies where young people with LD all died in avoidable circumstances in acute hospitals and suggested that people with LD their families and Carers were facing “institutionalised discrimination” in healthcare services.
- The response to this report was an Independent Inquiry into access to health care for people with LD and this culminated in Healthcare for All (2008) which set out key lessons learned and a number of recommendations were made for acute trusts to follow. Sir Michael reported on available evidence of “a significant level of avoidable suffering and a high likelihood that deaths are occurring which could be avoided”.
- The Equality Act (2010) protects against discrimination and requires all services to make reasonable adjustments where needed.
- The above aforementioned have all been key reports which have contributed to a call for a confidential enquiry into premature deaths of people with LD. The Confidential Enquiry into premature deaths of people with learning disabilities (CIPOLD) study (2013) revealed that the quality and effectiveness of both health and social care given to people with LD are deficient in a number of ways. Further key recommendations are made in order to prevent premature deaths for this patient group and this is now a priority for the NHS.

5.0 Equality and Diversity

- 5.1. Mid Essex Hospital Services NHS Trust is committed to the provision of a service that is fair and meets the needs of all individuals.
- 5.2. Working within the social model of disability and towards the principles of independent living giving people choice and control over their lives.
- 5.3 An equality impact assessment is attached to the policy (Refer to Appendix 1)
- 5.3. All healthcare professionals have a duty to make reasonable adjustments when providing treatment to people with learning difficulties.

6.0 Definition of Learning Disability

- 6.1 There can be some confusion with the terminology used between learning disability; learning difficulty and mental health.
- 6.2 Many people with a diagnosis of having an autistic spectrum disorder or cerebral palsy may also have a learning disability although this is not always necessarily the case.
- 6.3 'Learning disability' is the term that the Department of Health use within their policy and practice documents. In Valuing People (2001) they define a 'learning disability' as a:
- Significantly reduced ability to understand new or complex information, to learn new skills – with an impairment of intelligence and social functioning
 - Reduced ability to cope independently which starts before adulthood with lasting effects on development.
- 6.4 The World Health Organisation defines learning disability as; 'A state of arrested or incomplete development of mind'.
- 6.5 Both definitions indicate that these impairments are present from childhood, and not acquired as the result of accident or following the onset of illness.

7.0 Clinical Management

7.1 Generally

- 7.1.1 Prior planning and assessment with reasonable adjustments made is vital if care is to be optimised. This requires close working with the Hospital Liaison Nurse (HLN) Specialist and Learning Difficulties Lead and is further facilitated through the use of the Hospital Passport system and subsequent pathway for inpatients.
- 7.1.2 People with learning disabilities are not always able to express their needs or feelings in words and may resort to behaviours and actions to express themselves. Their behaviours may be seen as challenging and mistakenly interpreted as part of their disability and therefore the need for referral for assessing underlying causes is not identified or supported. This is known as "diagnostic overshadowing". It is therefore important that staff rule out all physical causes. The HLN is able to provide information, support and advice re: positive behavioural support plans.
- 7.1.3 Many people with learning disabilities are "needle phobic". This is difficult to avoid in the hospital setting. If the person has this fear then staff will ensure that there is a ready supply of local anaesthetic i.e. Emla cream so that the insertion of a needle is not felt and will therefore help in alleviating distress.

7.2 Outpatient Attendance

- 7.2.1 The initial contact with the hospital will normally be the first consultation in the Outpatients Department. Staff will check to see if the GP has included a reference to learning disabilities and special needs that the person may have in their referral letter.

- 7.2.2 All patients who have been identified as having an LD should be flagged on electronic IT systems. This gives clinical staff a visual prompt to consider whether reasonable adjustments are required. It also enables patient tracking by the HLN for monitoring and audit purposes.
- 7.2.3 It should be remembered that some people with LD might take exception to flagging process. In the event that staff members are unable to gain consent to implement a flag initially on Lorenzo system then a timely referral to HLN is appropriate.
- 7.2.4 Every effort will be made to ensure that all patients identified to the Trust as having a learning disability will be accommodated at earlier or later appointment times to avoid excessive waits. If this is not possible or is not the patient's/carer's preference then all efforts must be made for patients with learning disabilities to be seen as close to their appointment time as possible to avoid unnecessary anxiety and to achieve maximum benefit from the consultation.
- 7.2.5 The more prepared the patient is for this appointment the less traumatic an experience it will be for them. The availability of easy to understand information leaflets should be sent with the first outpatient appointment and should include the contact details of the named person who will be able to respond to specific queries.
- 7.2.6 The patient should be advised to bring their Hospital Passport with them to the appointment as this will hold important information on where reasonable adjustments need to be made.
- 7.2.7 To aid understanding easy read health information is available for free and can be downloaded from www.meht.nhs.uk . In the event that more specific information is needed then the HLN can assist in adapting the information suited to the needs of the person on request including large print.

7.3 **Emergency Admission**

- 7.3.1 In an emergency situation, all patients identified as having an LD should be flagged on electronic IT systems for patient tracking, monitoring and audit purposes. In the event that Staff members are unable to implement a flag onto Lorenzo IT System then a timely referral to HLN is appropriate.
- 7.3.2 The patient's Hospital Passport should be requested either from the patient, carer or by contacting the place of residence. This will be a source of important information on medical conditions; level of risks; capacity and dependency. If this is not available as much background information should be taken from the patient and a timely referral to HLN is appropriate.
- 7.3.3 It is important for staff to note that not all patients with LD will need additional support from HLN but she should still be alerted to patient admission for patient tracking and audit purposes.

7.4 **Elective Admission**

- 7.4.1 A referral needs to be made to HLN when date of elective admission is known in order that pre-admission assessments are carried out. This will ensure that the Hospital Passport; risk assessments, additional support and reasonable adjustments are all in place prior to admission.
- 7.4.2 Family members and/or paid care staff are to be viewed as partners in care. They can make a major contribution to the effectiveness of treatment and support by providing medical history and other important information. They also help to identify

areas of known risk and therefore help to reduce that risk. Encourage their involvement for they can also contribute to maintaining a patient's safety and dignity whilst in hospital setting.

- 7.4.3 If the patient with LD has very complex needs or challenging behaviour – once the referral has been received then the HLN will write up a complex admission plan and positive behavioural support plan in consultation with full MDT.
- 7.4.4 The Trust has a responsibility to fund any extra support needed in hospital over and above the individually funded support ordinarily available to the person when in their own home. The HLN can assist in carrying out a dependency assessment to determine requirement for 1:1 specialist care.
- 7.4.5 All other usual admission procedures will be followed in line with the Trust organisational policy.
- 7.4.6 In relation to elective admissions, all patients identified as having an LD must be flagged on electronic IT systems for patient tracking, monitoring and audit purposes. In the event that staff members are unable to implement a flag onto Lorenzo IT System then a timely referral to HLN is appropriate.

7.5 Inpatient period

- 7.5.1 Procedures, medication, changes in condition or treatment need to be continuously explained and Staff should check that both the patient and any carers understand the information and are given the opportunity to ask questions.
- 7.5.2 Ensure any actions recommended by HLN at pre-assessment and during hospital episode are being undertaken for example, has an occupational therapy assessment been booked so specialist equipment will be available on discharge.
- 7.5.3 Paid support staff (from the community who are not Trust employees) must also document their time and care given. A copy of this can be requested and placed in patient care records.
- 7.5.4 The HLN will be available to ensure effective communication; information; advice and support where needed.
- 7.5.5 Inpatient transfers for this patient group need to be avoided wherever possible to avoid further disorientation, confusion and distress.

7.6 Discharge Planning

- 7.6.1 For complex discharges a pre discharge meeting is required. Patient, family, community carers, HLN; social care and the Trusts discharge team are all to be involved with planning and agreeing the discharge plan to ensure all support needs and resources are in place for a safe and timely discharge to occur.
- 7.6.2 The HLN will provide an easy read discharge summary; after care leaflet and patient/carer satisfaction leaflet where requested and appropriate.
- 7.6.3 Where care needs have changed significantly a referral to the Hospital Assessment Team (HAT) team will be required to ensure allocation of additional support and funding is made available.
- 7.6.4 The HLN will support the discharge team with CHC checklists; DST's and application for CHC funding where appropriate. The HLN will attend panel.

- 7.6.5 The HLN will support the HATs in decision making where a change of accommodation is deemed necessary.
- 7.6.6 All other usual discharge procedures will be followed in line with the Trust organisational policy.

7.7 Maternity

- 7.7.1 Once an expectant mother has been identified as having a learning difficulty, a referral will be made by the safeguarding midwife at the earliest stage to the HLN and/or community LD team in order to work collaboratively. This will ensure that the LD Nurse is aware of the patient and avoids reactive involvement with the family in the event of Child Protection stages.
- 7.7.2 A high level of professional support is to be extended to both mother and baby to ensure ongoing parenting assessments/monitoring/education can be carried out and support offered where necessary for a positive outcome to be achieved.
- 7.7.3 The Specialist Midwife for Vulnerable Women will assist the midwives with care planning and multi-agency liaison to ensure that there is a robust plan to support women with learning disabilities (LD) and their babies.
- 7.7.4 It is recommended that the named midwife or a small group of midwives follow the patient throughout the pregnancy and birth where possible to provide continuity of care.

7.7.5 The First Visit

At the first visit the pregnancy and birth plan should include information regarding:

- Main carer/s
- Any other services / agencies who should be involved
- Copy of hospital support plan / health action plan
- Special requirements for subsequent appointments
- Plans should commence in preparation for following birth and discharge

7.7.6 Education

- All plans and education for example parent craft/parent education will be provided on an individualised basis and will involve partner and identified persons / carers throughout.
- Additional support / visits will be planned if identified this may include the health visitor, GP; LD nurses, social workers and midwives.

7.7.7 The Birth Plan

- The midwife or LD nurse where appropriate, will accompany the woman to her consultant clinic appointments
- The Specialist Midwife for Vulnerable Women will assist the midwives with care planning and multi-agency liaison to ensure that there is a robust plan to support expectant women with learning difficulties and their babies
- A copy of the pregnancy and birth plan will be inserted into the case notes along with the patient's own copy
- On admission for the birth where feasible a midwife who has been involved should attend. Provision will be made for special visiting for the partner and carers to enable support and education.

- The length of stay will vary to each individual. Discharge arrangements should be made in conjunction with all involved
- Additional follow up appointments will be arranged according for each individual. An emergency contact will be provided to the patient, partner and or main carers

8.0 Reasonable Adjustments

8.1. It is well documented that failure to offer reasonable adjustments has led to poor health outcomes in acute care setting. It is therefore vital that staff comply with the law and make necessary adaptations where ever needed. Here follows just some reasonable adjustments that can easily be embedded into practice.

8.2 Communication

- Use of pictorial menus
- Use Communication Resource Folder to access simple cards for communication with words like YES, NO, PAIN, HURT plus symbols like ? and emotions
- Use accessible information where appropriate (available on intranet)
- Appointment letters in easy read and accessible format
- Use simple language; no jargon; short sentences; be prepared to reinforce and repeat information.
- Ask to see patient's Hospital Passport
- Use of digital listener (available via medical library)
- Use Disability Distress Assessment (DisDAT) tool – to establish and address pain/distress
- Provide a signer/interpreter when required.
- Ensure electronic alert is in place on Lorenzo.
- Ensure ward team is aware and prepared for patient admission
- Ensure usual communication aids/hearing aids/glasses etc are close to hand.

8.3 Time

- Offer an early or late appointment at less busy times
- Keep as close to appointment time as possible – fast track - as delays often cause distress.
- Try and offer a double appointment where ever possible to allow time for processing information and aid understanding.
- Try to carry out as many investigations in any one time to avoid repeat attendances.

8.4 Environment

- Offer a quiet area/side room rather than a busy waiting room
- Consider use of side room for dignity and privacy purposes and especially where the parent/carer is supporting the patient
- As an inpatient avoid transfers as far as possible
- Consider noise levels and sensory overload and aim to reducing these
- Modify use of equipment – i.e. nasal specs instead of mask re: oxygen
- Consider what specialist equipment the patient may need during the hospital stay and ensure this is available
- Consider likely reaction to hospital environment and procedures.
- A preadmission visit – to desensitise the person is sometimes helpful

8.5 Support

- View carers as partners in care – encourage their presence for psychological needs
- Establish the support needed – use dependency assessment tool
- Refer to HLN where appropriate
- Offer pain relief as a matter of routine – don't wait to be asked
- Agree practical arrangements with family/carers.

9.0 Consent

- 9.1 The fact that a patient has a learning disability does not alter the need to obtain informed consent. Many patients with a learning disability do have the capacity to give informed consent - it should not be assumed that they cannot. They must be supported to make decisions; and all practical help must be given before anyone treats them as lacking capacity.
- 9.2 If the patient lacks capacity to make decisions, the Trust has a duty to act in that patient's best interests. The HLN will support and advise staff in assessing capacity.
- 9.3 If the patient does not have the capacity to give consent, treatment is lawful providing it is in their best interest; staff should refer to and abide by the Mental Capacity Act Policy and Consent Policy.
- 9.4 An Independent Mental Capacity Advocate must be instructed and then consulted, for people lacking capacity who have no-one else to support them (other than paid carers).
- 9.5 People with LD may have to be deprived of their liberty to obtain essential treatment and keep them safe. The HLN will support and advise staff in applying for DOL's safeguards.
- 9.6 Where there is an appointee with lasting power of attorney (LPoA) or an appointed court of protection (COP) Deputy – staff will need to inspect or obtain a copy of the documentation to confirm that this is valid and to determine if there are any restrictions on the decisions that they can be made.
- 9.7 The position regarding consent in an emergency situation is no different for a person with a learning disability - ultimately the attending doctor makes the decision to proceed provided it is in the patient's best interest.
- 9.8 Specific legal advice must be sought wherever there are doubt about proposals for certain treatments e.g. sterilisation and the necessity for obtaining consent in relation to such proposals see the References for a DoH guide for people with a learning disability. Please contact the HLN or Safeguarding Team for any necessary support.
- 9.9 It is totally unacceptable to offer inferior treatment because:
- The patient has a learning disability
 - There are difficulties in obtaining informed consent

10.0 Involving Carers in Healthcare and Planning for Discharge

- 10.1 During the admission process the staff should discuss and clearly identify with the carer, roles and responsibilities. Some carers may want to undertake some aspects of care; this is voluntary and staff should be aware that any care needs of the patient are always the responsibility of the hospital staff. Where carers wish to deliver care to the patient whilst they are in hospital then the boundaries about what is expected of hospital staff and what is safe for a carer to do in a hospital setting should be openly discussed, agreed and documented.
- 10.2 Staff will view carers as partners in the provision of healthcare by respecting and listening to their views – longer-term carers are likely to have valuable expertise and be highly skilled in caring for the patient.
- 10.3 Staff will acknowledge carers' own needs, ensuring that they have the relevant information and resources needed to plan effectively for their caring role.
- 10.4 Ensure that carers are involved (rather than just informed) at all stages of the patient's journey. This would include:
- Planning for admission
 - Communication on patient progress during hospital episode
 - Making the decision to discharge the patient
 - Discussing and agreeing practical alterations and preparations for the discharge at home. Carers may need time to make arrangements
 - Agreeing the time of discharge, even the estimated date of discharge giving the carer sufficient notice of the patient's discharge.
- 10.5 Parents/carers staying on the ward will be given access to staff toilet/kitchen facilities. Staff should familiarise themselves with Carers Policy.

11.0 Breaches of this Policy

- 11.1 A risk event form must be completed for all breaches of this policy that result in harm to the patient.

12.0 Monitoring and Evaluation

- 12.1 Evidence will be gathered regarding making reasonable adjustments through annual audit
- 12.2 In consideration of any breaches of the policy – the data gathered from any risk events will be used in order to restore the trusting relationship between carer, patient and health team improve the service by:
- Responding appropriately to complaints
 - Recommendations made by senior management based on learning outcomes
 - An action plan will be implemented surrounding knowledge and performance issues
- 12.3 Local action plans for improvements will be produced in response to the findings. Complaints and PALS cases will also be monitored. These will be passed on to the Patient Experience and Public Involvement Facilitator and HLN which where necessary will prompt a review of this Policy.

13.0 Communication and Implementation of this Policy

- 13.1 The Director of Nursing and the Deputy Director of Nursing will be advised of the revision of this policy and guidelines. The HLN will take responsibility to cascade the information to the Matrons at Nursing and Midwifery Executive Group (NMEG) meeting who in turn will cascade the information within their individual ward/departments.
- 13.2 It is the responsibility of the ward sisters/charge nurses and heads of departments to ensure members of their team are made aware of the policy for implementation and that the policy and procedures folders are updated.
- 13.3 The policy will be uploaded to the intranet and website, once ratified.

14.0 Training and Development

- 14.1 Training on LD/Autism is a statutory requirement since the implementation of the Autism Act (2009) and is available on a rolling programme and facilitated by the HLN.
- 14.2 Heads of departments are responsible for ensuring compliance by making necessary provisions for individual Staff to attend training sessions.

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Equality Impact Assessment (EIA)

Title of document being impact-assessed: **Caring for Adult Patients with a Learning Disability in the Acute Hospital Policy**

Equality or Human rights Concern. (see guidance notes below)	Does this item have any Differential impact on the equality groups listed? Brief Description of impact.	How is this impact being addressed?
Gender	All identified patients with LD will be treated the same Irrespective of their Gender.	Staff communication is encouraged to support people with LD all complaints would be fully investigated and responded to.
Race and ethnicity	All identified patients with LD will be treated the same Irrespective of their race and ethnicity.	The Trust operates within the requirements of the Race Equality Act 2010. Language may be a barrier – interpreters are made available when required.
Disability	It is acknowledged that some patients with LD may also live with other disabilities including mental health & sensory impairments	Information and advice is accessible, up to date, and free from jargon. All areas have disabled access re: wheelchairs; lifts; toilets. Any issues regarding a disability would be taken into consideration at time of patient assessment and all support tailored to meet individual need.
Religion, faith and belief	All patients with LD will be treated the same irrespective of their belief system	There is access to the multi faith chaplaincy team who offer advice, & support for Pts, relatives, carers & staff
Sexual Orientation	All patients with LD will be treated the same irrespective of their sexual orientation.	Trust staff is bound to comply with equalities legislation. Staff training is available for equality & diversity. All complaints would be fully investigated and responded to.
Age	All patients with LD will be treated the same regardless of age.	Accessible information leaflets are available. Staff communication is encouraged to support patients with LD.
Transgender people	All patients with LD will be treated the same irrespective of their gender status	Trust staff are bound to comply with equalities legislation. Staff training is available for equality & diversity. All complaints would be fully investigated and responded to.
Social class	No variance - All patients with LD will be treated the same irrespective of their social class group.	Staff communication is encouraged to support patients with LD.
Finances	Some patients with LD may have additional difficulties with regards to transport/financial concerns.	Accessible information and advice is available regarding facilities; concessions; advocacy services & assessment. Staff communication is encouraged to support patients. LD champions are available within the Trust

Date of Assessment: November 2017

Name of assessor(s): Sandie Morton-Nance

Appendix 2 – Clinical Role of HLN



Appendix Two
Clinical Role of HLN.pdf

Appendix 3 -Outpatient Pathway



Appendix Three
Outpatient Pathway.pdf

Appendix 4 - Elective Admission Pathway



Appendix Four
Elective Admission Pa

Appendix 5 - Theatre & Recovery Pathway



Appendix Five
Theatre & Recovery I

Appendix 6 – Emergency Admission Pathway



Appendix Six
Emergency Admission

Appendix 7 – Maternity Pathway



Appendix Seven
Maternity Pathway.pdf