Trust Guideline for the Management of Patients with Learning disabilities and or Autism

A Clinical Guideline recommended for use

In: All staff in JPUH

By: Rebecca Crossley

For: Patient with learning disabilities and or Autism

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Copy of complete document available from Trust Intranet
Quick reference guidelines

7. Mental Capacity Act 2005
8. Mencap Death By Indifference 74 Deaths and Counting (April 2012)
10. Six lives progress report 2010
11. Autism Act 2010
12. Equality Act 2010
13. Disability Discrimination Act 2005
14. CIPOLD was a Confidential Inquiry into premature deaths of people with learning disabilities that took place between 2010 and 2013.

Trust Guideline for the Management of Patients with Learning
disabilities and or Autism

Objectives

The objective of the Guideline is to:

Ensure comparative health outcomes for people with learning disabilities and Autism. The Trust recognises that people with a learning disability may have difficulty in understanding information presented only as written text and will endeavour to provide a range of information in easy-read formats or other media to promote understanding and to enable people with a learning disability to make informed choices about their care and treatment.

All departments and units will be encouraged to develop easy read information in a range of formats including pictorial pathways, letters and the use of other media to promote understanding of the proposed care and treatment pathway and to enable the PWLD and/or Autism to make informed choices about their treatments.

In short the objective of the Policy is to:

To ensure that acute services provided to PWLD and/or Autism are equitable and safe.

To provide a responsive service to meet PWLD and/or Autism individual needs and that makes reasonable adjustments for their disability.

To offer guidance and support to hospital staff when caring for PWLD and/or Autism

To set out the standards to demonstrate the Trusts commitment to address the health inequalities that this patient group face.

Rationale

Several national documents and investigations have highlighted the issues faced by people with learning disabilities PWLD and or Autism when accessing acute services.

The Disability Discrimination Act 2005 now Equality Act 2010 makes it unlawful for service providers to discriminate against PWLD and/or Autism. The Equality Act and Autism Act require organisations to make reasonable adjustments to accommodate their specific or additional support needs.

Mencap reported the tragic deaths of six individuals during their hospital stay (“Death by Indifference” 2007) Followed by (Death By indifference 74 Deaths and Counting 2012. This report highlighted the need for improved services and care for PWLD and/or Autism in acute hospitals.

In 2008 Sir Jonathon Michael carried out an independent inquiry into access to healthcare for PWLD and/or Autism (Healthcare for All: 2008). It made specific recommendations to acute hospitals on the best practice for care for PWLD and/or Autism along with subsequent reports including,

http://powwow/intranet/clientfiles/2015714112342_2015%2007%203rd%20transf
oring-care-progress-report.pdf
http://powwow/intranet/clientfiles/2015714112242_Working%20Together%2020f
inal.pdf
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In 2009 the Ombudsman investigated the deaths of individuals in the Mencap report (Six Lives: The provision of public services to people with learning disabilities: 2009). CIPOLD was a Confidential Inquiry into premature deaths of people with learning disabilities that took place between 2010 and 2013. Funded by the Department of Health, it aimed to improve the health and well-being of people with learning disabilities by carrying out an inquiry into their death, it has just been announce that there is to be a national review of Mortality in PWLD and/or Autism. In this trust we are already committed into reviewing the Deaths of PWLD and/or Autism.

The Care Quality Commission (CQC) qualified these reports by setting specific indicators for acute and specialist trusts. All NHS Trusts will be inspected and measured against these. (Indicator’s on access to healthcare for PWLD and/or Autism /2010). Monitor also has similar indicators these have now removed but remains a focus in the inspection process.

Glossary / Definition of Terms Used

<table>
<thead>
<tr>
<th>Term</th>
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<tbody>
<tr>
<td>LDLN</td>
<td>Learning Disability Liaison Nurse</td>
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<td>PWLD</td>
<td>People with Learning Disabilities</td>
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<tr>
<td>Autism</td>
<td></td>
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<td>CQC</td>
<td>Care quality commission</td>
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<td>DDA</td>
<td>Disability Discrimination Act</td>
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<td>LD</td>
<td>Learning Disabilities</td>
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<td>Learning Disability and Autism</td>
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<td>EOE</td>
<td>East Of England</td>
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<tr>
<td>FADS</td>
<td>Family &amp; Diagnostic Services Division</td>
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<tr>
<td>PEG</td>
<td>Percutaneous Endoscopic Gastrostomy</td>
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Broad recommendations

PWLD and/or Autism have the right to the same level of medical and nursing care as that of the general population. However they have specific needs which must be addressed. Evidence shows that health needs of PWLD and/or Autism are greater than that of the general population as a whole and that PWLD and/or Autism face several key issues when accessing the services of acute hospitals (valuing people DOH 2001 &2007) Death by Indifference 74 deaths and counting (Mencap 2012)

- Patient Safety
- Communication
- Staff attitudes, understanding and awareness of their needs
- Consent/capacity issues
- Information in accessible format on treatment options, complaints procedures and appointments
- Inequitable service delivery that does not take into account their disability and make reasonable adjustments
- Issues around safe transfers of care i.e. admission and discharge.
- Increasing need to use maternity services

Trust Values:

This policy is in line with the Trust’s values of putting patients first, aiming to get it right, recognising that everybody counts and doing everything openly and honestly. The policy incorporates these values throughout and an Equality Impact Assessment is completed to ensure this has occurred.
Specific Operating Guidelines

The Disability Discrimination Act (DDA), Equality Act Autism Act and reasonable adjustments

The DDA, Equality Act and Autism Act requires all health care providers by law to make reasonable adjustments to their services to ensure PWLD and/or Autism have equal access 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.

Examples could include:

• Giving individuals an appointment at either the beginning or end of a clinic.
• Giving longer appointment times.
• Placing an individual 1st on the theatre list.
• Allowing a family member to stay all the time.
• Allowing individuals to wear their own clothes to theatre.
• Doing other investigations while individuals are under anaesthetic.
• Giving individuals a place to wait away from the waiting room.
• Offering diversions use of comforters.
• Having one to one nursing.
• Making information much easier to understand.
• Hiring a bed or chair more suited to their individual needs.
• Allowing more time with meals/drinks etc.

Remember anything can be a reasonable adjustment if it supports that individual have safe and equitable access to the care that they require.

Ethnic minority groups
The Trust is committed to meeting the needs of all minority groups. Staff must be aware that PWLD and/or Autism who are also from an ethic minority group may have specific difficulties in communicating their cultural needs and wishes e.g. diet, dignity, same sex care.

Sensory disabilities

There are a higher percentage of sensory disabilities amongst PWLD and/or Autism. These are sometimes undiagnosed or missed because of a range of complex issues that the individual may have.

Patient safety

The Ombudsman’s report (2009) and National Patient Safety Agency (2004) state that “PWLD and/or Autism have a significantly higher risk of adverse events happening to them whilst they are in hospital”.

The Trust has developed a rapid risk assessment to support identification of specific risk areas and need for extra support. Please see appendix 5
This assessment must be completed on admission for every PWLD and/or Autism admitted to the Trust and stored in their health records.

Difficulty swallowing (Dysphagia) and choking

Linked physical disabilities can cause increased risk of aspiration pneumonia, (46% PWLD and/or Autism v 15% others National patient safety agency 2004

All staff must assess the individual’s risk in this area. A referral to the speech and language therapist (SALT) to conduct a swallow assessment and provide advice can be made.

The individual must have a dysphagia care plan detailing posture, feeding, suction needs etc.

Decisions to insert a Percutaneous Endoscopic Gastrostomy (PEG) must be taken after a full best interest decision meeting.

Nutrition, Hydration and self-care

Individuals may need extra support to maintain their own nutrition, hydration and hygiene needs whilst in hospital. This should be done through risk assessment followed by comprehensive care planning and supervision as required.

PWLD and/or Autism may not understand “nil by mouth” directives. Health care professionals must take extra steps to ensure that they do not access food or drink in these circumstances and help them to understand the reason for this.

Epilepsy

Epilepsy is co morbid in a significant number of PWLD and/or Autism. It accounts for a large number of acute hospital admissions. Epileptic seizures increase the risk of physical injuries, aspiration and deprivation of oxygen.

Most PWLD and/or Autism who have pre-diagnosed epilepsy will have an epilepsy care plan which they should carry with them. There will also be information about their condition in their health books.

Epilepsy monitoring charts must be kept which detail; description of seizure, length, recovery etc.

Key health Professionals involved the PWLD and/or Autism care must be kept informed of any changes in medication or management regimes.

Carers and family should be consulted to give insight into behaviours or situations that may precede a seizure.

Danger to self

Reasonable adjustments in the form of extra supervision may need to be made for all of the following. It is important that staff consider using the “one to one” policy and risk dependency and support assessment tool.

Falls
Trust Guideline for the Management of Patients with Learning disabilities and or Autism

Staff should follow the Trust Guideline for the Management of Falls in Adult Patients

Self-injurious behaviour
Some PWLD and/or Autism may display self-injurious behaviour. Carers and family who know the patient well must be involved in advising on methods to minimise this.

Check if the individual has pain, this may be their only way of expressing distress.

Lack of insight into dangers
Individuals with LD may have lack of or low insight into everyday dangers. Care must be taken with sharp objects, medicines, hot water, hot food and drink, open windows etc.

Mental health
PWLD and/or Autism can experience the full range of mental illness that affect the whole population. Symptoms are not always recognised because of communication difficulties. Staff must be aware that people with Downs's syndrome have a much higher incidence of early onset dementia than the rest of the population.

Positive behaviour management Strategies reducing the need for restraint whilst acting in best interests

Some individuals may react with behaviour viewed as challenging when about to undergo a procedure or treatment. Consideration must be given as to whether this procedure is absolutely necessary and what adjustments can be made to meet the individual needs/wishes/likes of the patient. If the person lacks capacity a best interest meeting must decide that the procedure needs to go ahead. The meeting will discuss and decide on the least restrictive method for achieving the required outcome, (Consent policy, refer to your Mental Capacity Act 2005 code of practice and Clinical Restraint Policy – Management and Guidance on the use of). A risk assessment will also need to be completed.

Some individuals may need safety sides whilst they are in bed. Some PWLD AND/OR AUTISM AND/OR AUTISM have poor control of their body posture which may cause them to slide in the bed. This increases the risk of becoming entrapped in safety sides. Hospital staff must follow the safety side matrix (policy on safety sides), conduct a risk assessment and develop an appropriate care plan. The individual may need extra supervision whilst in bed.

Transfers of care

Risk to PWLD and/or Autism is raised significantly during transfers of care. Communication of information between professionals, family and care givers are essential.

Individuals with health books/hospital passports should have these updated before all transfers of care. (See appendix 6)

Transfers of care

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Diagnostic overshadowing

PWLD and/or Autism sometime experience diagnostic overshadowing. This may be for several reasons including:

- Difficulty in describing symptoms.
- Attitudes of medical/nursing staff.
- Lack of cooperation with investigation/examination.
- Poor access to screening services.
- High or low pain thresholds.
- Atypical physical presentation.

All health care professionals must be vigilant and observant.

The family or carer who knows the individual best is well placed to describe changes to the person’s health and must be listened to.

Different methods of assessment may need to be considered e.g. pain charts, distress charts.

PWLD and/or Autism must not be excluded from diagnostic tests because of their learning disability.

Pre admission and initial contact with hospital

Preparation for coming into hospital as an emergency or planned admission must be part of an individual’s pathway.

Prior to admission support staff/carers or relatives should support the individual to understand what coming into hospital involves and prepare them accordingly. This may be through contacting the LDLN and use of information DVDs, pre visits, desensitisation programmes, and accessible information. If the community learning disability team is involved in the individuals care, they should also participate in this process.

GPs should ensure that the hospital is made aware that the patient has a learning disability.

Medical secretaries and administration staff are usually the first point of contact in the acute hospital system. They must be aware that when a patient is identified as having a learning disability this must be entered on the hospital PAS system.

This information must be cascaded to the assessing nurse, medic or health care professional and preparation for reasonable adjustments to be made. This may include contacting the liaison nurse, sending information in an accessible format, adjusting appointment times etc.
Elective Admissions

Where possible the PWLD and/or Autism be fully assessed in the pre assessment clinic. The person with a learning disability will receive in addition to the standard documentation, literature describing coming into hospital in an easy read format.

The LDLN will be informed of their impending admission. The nurses contact details will be offered to the PWLD and/or Autism and their carer.

The rapid risk assessment must be initiated in this department and this information cascaded to the admitting ward.

The ward may need to consider making reasonable adjustments e.g. arranging a side room, one to one support etc.

Specific focus will be given to planning discharge arrangements to ensure that adequate help will be available on discharge.

When attending the pre-admission assessment and on admission, the person with a learning disability or their carer / health facilitator will be asked to bring into hospital any copies of care plans and nursing assessments including the personal Health Action Plan.

In pre-admission the assessment nurse will discuss the specific needs of the person and may need to contact the person’s healthcare facilitator, social worker or community nurse to ensure a full assessment of need. The LDLN will assist with process as necessary. 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 hospital
- Discharge arrangements

Where possible the person with a learning disability and carer will be offered the opportunity to visit the ward and familiarise themselves with the hospital prior to admission.

The person with a learning disability will be offered the opportunity to ask further questions about the planned procedure.

Where possible the person’s health care facilitator / social worker / community nurse will be contacted and advised of the admission as appropriate.

Outpatient Appointments, Diagnostic Tests and Investigations

In the event of an outpatient appointment the LDLN can work with individuals pre admission to help them understand the process for their investigation. She has access to a number of media resources to assist this.
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If the person’s appointment has been booked via ‘Choose and Book’ the details of the person’s disability may not be apparent until the day of appointment and adjustments may be required on the day.

Where possible the person with a learning disability and / or the carer will be asked to bring in with them the person’s Health Action Plan and Hospital Passport.

Details of the person’s health care facilitator / social worker / community nurse should be checked and recorded.

PWLD and/or Autism who require routine clinic visits and/or appointments for diagnostic tests may require reasonable adjustments to accommodate their individual needs for example:

- **Time of appointment** –
  People with a learning disability may find waiting difficult.

- **Length of appointment** –
  People with a learning disability will take longer to assimilate information and may take longer to examine.

- **Communication needs** –
  All diagnostic and pre admission areas must produce information as easy read literature, pictures or models.

- **Consent** –
  A person with a learning disability 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 room in Surgery.

- **Environment** –
  People with learning disabilities and or Autism can become frightened by things they do not understand so it may be necessary to remove unnecessary equipment or instrumentation.

- **The LDLN can advise on desensitization programmes e.g. needle phobia.**

- **Individuals should be offered EMLA cream or Ethychloride Spray to numb the area.**

- **It is worth considering whether blood can be taken whilst an individual is under anaesthetic for another reason.**

Where possible the person with a learning disability and or Autism and carer will be offered the opportunity to visit Day Surgery prior to admission.

Tests and investigations can be very frightening to many people with a learning disability so adjustments should be made to reduce anxiety where possible. This should include:
Preparation for Admission

- 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.
- Not rushing the person.

An assessment should take place when booking a diagnostic test or investigation to ensure that similar considerations are given to those issues addressed in addition staff should also consider:

- Privacy and Dignity - People with a learning disability may be reluctant to undress and will need help and persuasion to do so.
- Comforters - People with a learning disability and or Autism may feel the need to hold a comforter throughout a procedure and should be helped to do so as long it does not compromise patient safety.
- Behaviour - A person with a learning disability and or Autism may react to a frightening situation with challenging behaviour.
- Directions - People with a learning disability 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 or investigation.

Emergency Admissions

In the event of an emergency admission:

It must be recognised that in an emergency admission a person with a learning disability may be particularly distressed due to the nature of the admission and may present with 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 carer / health care facilitator / social worker / community nurse as soon as possible along with the LDLN.

In the event that a person with a learning disability and or Autism is brought into the Accident & Emergency Department, the following issues must be considered:

- Pain - A person with a learning disability may express the presence of pain through challenging behaviour, head banging or similar signs of distress. Early assessment and treatment of pain is crucial.
- Presence of other disabilities -
The person may have additional sensory disabilities or suffer from other co-morbidities such as epilepsy.

- **Communication**
  Communication will be particularly difficult if the patient 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**
  Accident & Emergency is a challenging environment for those without a disability and may present a particularly frightening environment to someone with a learning disability who is unable to understand what is happening to them. Where possible it is advisable to put a person with a learning disability into a cubicle where privacy and a slightly quieter environment can be provided.

**Discharge**

The JPUHFT guidelines for the management of discharge process for adult patients, aims to ensures that all patients that are ready to be discharged from hospital, do so in a safe, timely and effective manner.

Planning for discharge should commence as soon as a person with a learning disability and or Autism is admitted. People with a learning disability may recover better within their own home environment but must only be discharged when it is safe to do so and when adequate support can be provided for both the patient and carer.

People with a learning disability may require additional support on discharge and the patient’s carer, health care facilitator, community nurse or social worker should be informed so that planned support can be arranged prior to discharge.

A person with a learning disability may live with a partner or family member who also has a learning disability and in these circumstances detailed planning of the discharge and support will be required to ensure a safe discharge.

For comprehensive discharge planning the process must include the individual, their family and/or paid supporters and other professionals who are involved in their care e.g. Community Learning Disability Nurse, Specialist Physiotherapist etc. They can support the gathering of accurate information and identification of potential risks to safe discharge.

Staff must ensure that they check how the individual usually takes their medications and arrange Pharmacy to dispense their tablets in the format they are used to i.e. Blister packs, dosset boxes, boxes with larger print and additional accessible information leaflet etc.

Staff must check with residential care homes if documentation is required to allow care staff to administer any new medication.

Information on diagnosis and treatment plans including follow up appointments should be added to the “Health Book” and new Health Action Plans (HAP)

Careful consideration must be given to providing advice for after-care and treatment. A person with a learning disability may not understand information provided on medication, management of dressings or follow-up appointments. The nurse planning the discharge must ensure that all these issues are addressed so that the discharge is safe and appropriate.
Flagging and Keeping Data

The Department of Health and Care Quality Commission require all acute hospitals to put data collection systems in place to monitor the treatment pathways and quality of care that PWLD and/or Autism receive.

A Learning Disability flag is to be added to the IPM system for patients known to have a learning disability

Staff without access to PAS should ask the ward clerk or department administrators to do this. Please contact LDLN with necessary details.

PWLD and/or Autism must be supported to understand the Patient Advisory Liaison service (PALS) and complaints system. The LDLN will monitor patient satisfaction via forums and user surveys.

Staff Training /Qualifications

The Trust will support the provision of training to enable staff to understand the additional needs that people with a learning disability and or Autism may have and to develop the knowledge and skills to be able to provide a responsive service that meets those needs.

As per recommendations set out in the Michaels report (2008), Autism Act 2010, NHS EOE 2010-2021 CIPOLD 2014, ensure that curricula include mandatory training in Learning disabilities and/or Autism and involves people with learning disabilities/Autism and their carers.

Clinical audit standards

This policy will be reviewed biannually by the Learning Disability Steering Group to ensure that it continues to support the Trust in developing its strategy to meet the requirements of people with learning disabilities.

The implementation of this policy will be supported by an annual work plan which will be monitored quarterly by the Learning Disability Steering Group.

The Learning Disability Steering Group will submit an annual report to the Clinical Governance Committee summarising the work of the Steering Group and the Trust’s progress in developing services to meet the needs of people with learning disabilities.

Clinical Audit Standards:

To ensure that this guideline is compliant with the above standards, the following monitoring processes will be undertaken:

1. Continual review through the Trust Learning Disability Health Action Focus Group.
2. Through annual patient satisfaction surveys
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The authors listed above drafted this document on behalf of James Paget University Hospital who has agreed the final content. During its development it has been circulated for comment to:

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Medical Director – Nick Oligbo
Director of Nursing, Quality and Patient Experience – Elizabeth Libiszewski
Deputy Director of Nursing - Julia Hunt
Palliative Care & End of Life – Julie Broom
Elective Division – Tracey Bitters
FADS Gynaecology – Angela Wakeley
Emergency Division – Jan McKirdy
Theatres – Gail Banham/Jane Griffiths
Lead Nurse Emergency – Jacky Copping
Head of Education & Practice Development – Sharon Crowle
Site Services – Simon Kirk
Paediatrics WD 10 – Justine Goodwin
Newberry Clinic – Amma Oppong-Diseng
Head of Infection Prevention Control – Linda Hawtin
Elective Division – Sarah Morris
FADS Head of Midwifery Services – Gloria Rowland
Emergency Division – Sarah Plume
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Learning Disability Team Manager – Steve Nice
Learning Disability Team Manager – Andy Crumbly

Comments received during this process were addressed prior to ratification

Distribution list/ dissemination method

As above Via Intranet
Appendices

Appendix 1

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Appendix 2

Learning Disabilities Steering Group

Terms of Reference

Purpose

The Forum will:

- Develop systems and processes to address equity of access and equality of care for people with learning disability in the acute hospital.
- Make recommendations to the Equality and Diversity working group for making reasonable adjustments to services for people with learning disabilities.
- Assist staff to develop a person centred approach with adherence to the Human Rights Act, Disability Discrimination Act and Mental Capacity Act.
- Ensure that the views of people with learning disabilities and their carers are integrated into Trust plans and that the patient experience is central to the delivery care and quality improvements.
- Ensure that processes are put in place to and monitored to be compliant with new policy documents, guidance or national drivers that impact upon the care and treatment of people with learning disability in the acute setting.
- Ensure systems are in place for data gathering, monitoring and assessment.

Areas of responsibility

The Steering Group is primarily concerned with the delivery of safe, high quality patient centred care for people with learning disabilities. This will be achieved through ensuring that the appropriate structures, processes and controls are in place.

Structures

- Work within the comprehensive programme of systems in the Trust that implement safe and appropriate care delivery. Ensure that these meet the needs of people with learning disabilities or that the new systems are developed to do this. E.g. - Risk assessments and dependency.
- Support the work of the acute liaison nurse and ensure that the posts primary task is to meet the needs of patients with learning disabilities whilst in the hospital.
- Within the Organisation, have a culture of open and honest reporting and management of any situation that may threaten the quality of the patients.
Access to patient information is in accordance with all relevant legislation and guidance including Caldicott, The Data Protection Act and Human Rights.

- Work within the mechanisms for Patient and Public Involvement with reasonable adjustments made for people with learning disabilities.
- that all information is available in accessible format.
- Work with wider learning disability and or Autism professional community to ensure integration of services and consistency across the region.

Processes:

- Ensure clinical staff is given the knowledge, support and information to care for people with learning disabilities and or Autism in their area. Through:
  * Training
  * Inline resources
  * Link nurse system
  * Bespoke work
  * LD liaison nurse

- Ensure that all managers, clinical and non-clinical staff are given information to understand the needs of people with learning disabilities and or Autism and their carers whilst in the acute hospital
- Ensure the needs of BME patients with learning disabilities and or Autism are assessed and considered.
- Ensure that there are policies and guidelines in place that meet the needs of people with learning disabilities and or Autism.

Outcomes:

- The Health Action Focus Group will assist the Trust to meet the highest standards and expectations of Government directives e.g. CQINN, QUIP. Healthcare for all.
- The Health Action Focus Group will ensure that all health aspects of “Valuing People Now” are integrated across the Trust and their effectiveness is continually monitored.
- Data will be gathered on:
  * Admissions
  * Length of stay
  * Patient satisfaction
  * SUIs. Death rates

- There will be evidence of continuous improvement.
- Demonstrate that lessons are learned from adverse incident incidents, complaints, litigation and examples of good practice, and are disseminated within the Trust (and beyond if appropriate)
- The Health Action Focus Group chair will coordinate and produce an annual learning disabilities report.
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Support and dissemination:

- Ensure the work of the Health Action Focus Group is adequately supported and effectively communicated throughout to the Trust Safeguarding Vulnerable Adults Committee.
- Report Health Action Focus Group activity to the Partnership boards and National networks.

Resources:

- Ensure that systems and processes are in place and reviewed to support the needs of people with learning disabilities and or Autism.
- Ensure adequate human resources are available to support learning disability and or Autism activity in the Trust.

Membership:

Joint Learning Disability Team Manager Chairperson
Acute Liaison Nurse – Specialist Midwife
Adult Social Services representative
Safeguarding Lead
Link Nurses
Health Care Facilitator (LD service)
Patient representative
Patient/Carer Forum representative
Learning Disabilities and or Autism representative
Allied HCP representative
Advocacy Group representative
Suffolk Learning Disability Team representative

Meeting arrangements:

Meetings will be held bi-monthly and
- Arranged 12 months in advance
- Agenda’s and papers to be published 5 working days in advance of the meeting
- Minutes of the proceedings to be taken
- Minutes to be made available on the intranet
- All meeting documentation will be made available in accessible versions

Reports:

To the Trust Safeguarding Vulnerable Adults Committee
## Document Control:

<table>
<thead>
<tr>
<th>Version</th>
<th>Author</th>
<th>Date</th>
<th>Circulation</th>
<th>Comments</th>
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<tr>
<td>1.0</td>
<td>Dawn Collins</td>
<td>June 2006</td>
<td>Members of the Learning Disabilities Steering Group</td>
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<td>2.0</td>
<td>Stevie Read</td>
<td>September 2010</td>
<td>Safeguarding Adults</td>
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<td>3.0</td>
<td>Rebecca Crossley</td>
<td>November 2011</td>
<td>Committee</td>
<td></td>
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<td>4.0</td>
<td>Rebecca Crossley</td>
<td>May 2015</td>
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<td>5.0</td>
<td>Rebecca Crossley</td>
<td>May 2018</td>
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</table>

Ratified at:

Date Ratified:

Review Date:

Effective Date
Appendix 3

Learning Disabilities/Autism and Safeguarding Vulnerable Adults
Link Practitioner Role Description

Role purpose
➢ To promote and act as a principle point of contact for patients with Learning Disabilities and/or autism (PWLD and/or Autism /A), their families, department staff and the acute liaison nurse

➢ To act as a resource, disseminate information and be an advocate for patients with PWLD and/or Autism /A that access services in their area.

➢ To act as a resource to other staff within their unit for safeguarding adults issues.

Key duties and Responsibilities
• To disseminate and cascade updated information about PWLD and/or Autism /A and safeguarding: Ensuring all staff are aware of the vulnerable adult resource folder available on the Trust intranet.

• To contribute towards the area/department compliance with the Equality Act (2010) Raising understanding of what constitutes a reasonable adjustment.

• To encourage the participation and uptake of staff to complete the e learning training packages for safeguarding vulnerable adults and learning disability.

• To develop as required accessible information relevant to their area. To signpost other staff to the resources available to support the development of accessible information e.g. photo symbol bank, easy health website.

• To ensure that patient information leaflets are displayed in their area that give information on reporting abuse, PALS and complaints and that easy read versions are also displayed.

• Act as the patients advocate and support colleagues to understand and use the Trust consent policy, Mental Capacity act (2005) and Human Rights act (1998).

• To offer support and advice to relatives and carers using recommendations in the Trust carers policy and learning disability policy.

• To understand barriers to communication and act as a resource to staff for using alternative methods or tools for communication.

• To ensure that PWLD and/or Autism /A have the LDA alert code added to the PAS System.

• To assist staff to identify risks for people with a learning disability or autism.

• To have knowledge of the Trust safeguarding policy and signpost staff to appropriate action if they have concerns

Professional responsibilities
➢ It is expected that nominated link practitioners will keep up to date with developments in learning disability/autism and safeguarding issues in their own
Trust Guideline for the Management of Patients with Learning disabilities and or Autism

clinical area through attendance at link practitioner meetings and through regular mandatory updates.

Role specification

<table>
<thead>
<tr>
<th>Qualifications</th>
<th>Knowledge and experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Trust employee</td>
<td>1. Has attended the Trust learning disability study day.</td>
</tr>
<tr>
<td></td>
<td>2. Attended the Trust safeguarding vulnerable adult training and mandatory updates</td>
</tr>
<tr>
<td></td>
<td>3. Working in the clinical area for one year.</td>
</tr>
<tr>
<td></td>
<td>4. Previous experience working with learning disabled or vulnerable people.</td>
</tr>
<tr>
<td></td>
<td>Essential</td>
</tr>
<tr>
<td></td>
<td>Essential</td>
</tr>
<tr>
<td></td>
<td>Essential</td>
</tr>
<tr>
<td></td>
<td>Desirable</td>
</tr>
<tr>
<td></td>
<td>Desirable</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Skills and abilities</th>
<th>Training and development</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Interest in learning disability and vulnerable adults</td>
<td>1. Regularly attend link practitioner meetings</td>
</tr>
<tr>
<td></td>
<td>2. Enthusiasm for improving services PWLD and/or Autism /A</td>
</tr>
<tr>
<td></td>
<td>3. Ability to be creative in supporting reasonable adjustments.</td>
</tr>
<tr>
<td></td>
<td>4. Good communication skills</td>
</tr>
<tr>
<td></td>
<td>5. Uses the email system to access disseminated information.</td>
</tr>
<tr>
<td></td>
<td>Essential</td>
</tr>
<tr>
<td></td>
<td>Essential</td>
</tr>
<tr>
<td></td>
<td>Essential</td>
</tr>
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<td>Essential</td>
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<tr>
<td></td>
<td>Essential</td>
</tr>
<tr>
<td></td>
<td>Essential</td>
</tr>
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</table>

Copy of complete document available from Trust Intranet

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Author Rebecca Crossley
Valid until: July 2018
Document Ref: JPLCG0061 V1.1
Trust Guideline for the Management of Patients with Learning Disabilities and or Autism
Copy of complete document available from Trust Intranet
Appendix 4

Carers Contract

Family Carers Contract

FAMILY CARER’S CONTRACT

Patient’s ID

Date:

This agreement is to support you in maintaining your role as a Family Carer while the person you care for is a patient in this hospital. This contract recognises that as a Family Carer you are an expert in providing day to day care to the person and that you can help staff in looking after the Patient and meeting his / her needs.

The following contract is a written agreement drawn up between the nursing staff and allied health professionals and you as the Patient’s Carer. Where the Patient is able to exercise choice it also includes the agreement and wishes of the Patient. It describes how we can work in partnership for the benefit of the Patient and specifies which responsibilities we as hospital staff undertake to provide and those aspects of care that you will be continuing to provide.

Arrangements for visiting or staying on the ward.

How you can continue to act as a Family Carer without affecting the other Patients on the ward.

What aspects of personal care will be provided by the Family Carer.

What aspects of personal care will be provided by hospital staff.

How you can be involved in feeding the Patient or administering medication.
Whether you can be present when the Patient is examined, receives treatment or has a consultation with the Doctor.

What information about the Patient’s condition it would be helpful for you to share with staff.

How you will be involved in decision-making regarding the Patient’s care, treatment and discharge.

Who you should speak to if you have concerns about the Patient or your own treatment as a Family Carer.

Name of Family Carer (PRINTED)…………………………………………………………………………………………

Signature of Family Carer ……………………………………………………………………………………………

Signature on behalf of the Trust …………………………………………………………………………………………

Signature of Patient (where appropriate)………………………………………………………………………………..
### Appendix 5

**Rapid Risk Assessment**  
for patients with  
Learning Disabilities and/or Autism  

<table>
<thead>
<tr>
<th>Assessment criteria</th>
<th>score</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Personal safety</strong></td>
<td></td>
</tr>
<tr>
<td>• No issues identified</td>
<td>0</td>
</tr>
<tr>
<td>• Requires regular observation and reinforcement to maintain safety</td>
<td>1</td>
</tr>
<tr>
<td>• Level of learning or physical disability requires half hourly checks to maintain safety</td>
<td>2</td>
</tr>
<tr>
<td>• Mental health status affects ability to maintain safety</td>
<td></td>
</tr>
<tr>
<td>• Additional sensory disability, blind or deaf</td>
<td></td>
</tr>
<tr>
<td>• Unable to maintain own safety due to level of learning disability/autism, may wander, remove medical devices e.g. cannulas, drains</td>
<td>3</td>
</tr>
<tr>
<td>• Complex physical disabilities require continuous observation and management of posture to maintain airway.</td>
<td></td>
</tr>
<tr>
<td>• High risk of pressure area breakdown (Waterlow)</td>
<td></td>
</tr>
<tr>
<td>• High risk of falls (falls assessment)</td>
<td></td>
</tr>
<tr>
<td>• Safeguarding issue identified</td>
<td></td>
</tr>
<tr>
<td><strong>Swallowing, Nutrition, hydration</strong></td>
<td></td>
</tr>
<tr>
<td>• No previous or current history of swallowing issues</td>
<td>0</td>
</tr>
<tr>
<td>• Previous history of swallowing issues but has not been formally assessed</td>
<td>1</td>
</tr>
<tr>
<td>• Requires support to ensure adequate food and fluid intake</td>
<td></td>
</tr>
<tr>
<td>• Requires safe positioning or additional support for eating/drinking/non oral feeding</td>
<td>2</td>
</tr>
<tr>
<td>• History of recurrent chest infections or unintentional weight loss</td>
<td></td>
</tr>
<tr>
<td>• Assessment indicates high risk of Dysphagia</td>
<td></td>
</tr>
<tr>
<td>• On modified food/thickened fluids</td>
<td></td>
</tr>
<tr>
<td>• Requires one to one support whilst eating/drinking for safe swallowing</td>
<td>3</td>
</tr>
<tr>
<td><strong>Communication</strong></td>
<td></td>
</tr>
<tr>
<td>• Good verbal communication and understanding</td>
<td>0</td>
</tr>
<tr>
<td>• Indicates when/where has pain</td>
<td></td>
</tr>
<tr>
<td>• Some verbal communication uses non verbal systems to supplement.</td>
<td>1</td>
</tr>
<tr>
<td>• Requires additional time to process information and respond.</td>
<td></td>
</tr>
<tr>
<td>• Uses some non verbal signs, facial expressions, body language or behaviour to communicate.</td>
<td>2</td>
</tr>
<tr>
<td>• Requires extra time and /or information in alternative formats</td>
<td></td>
</tr>
<tr>
<td>• Extremely limited communication</td>
<td></td>
</tr>
<tr>
<td>• Requires support from carers to interpret need.</td>
<td>3</td>
</tr>
<tr>
<td><strong>Mental capacity</strong></td>
<td></td>
</tr>
<tr>
<td>• Assessment indicates no capacity issues.</td>
<td>0</td>
</tr>
<tr>
<td>• Can make own decisions and/or consent to treatment with clear explanation</td>
<td></td>
</tr>
<tr>
<td>• Understands simplified explanation of procedures</td>
<td>1</td>
</tr>
<tr>
<td>• Requires reinforcement, extra time, accessible information to support decision making</td>
<td></td>
</tr>
<tr>
<td>• Has difficulties understanding complex treatments/interventions but will consent with reinforcement and support.</td>
<td>2</td>
</tr>
<tr>
<td>• Is unable to understand, retain, weigh up, communicate back and make decisions related to treatment/interventions (lacks capacity).</td>
<td>3</td>
</tr>
<tr>
<td>• Very unlikely to comply with treatment/interventions</td>
<td></td>
</tr>
<tr>
<td><strong>Epilepsy</strong></td>
<td></td>
</tr>
<tr>
<td>• No known seizure activity</td>
<td>0</td>
</tr>
<tr>
<td>• Seizures well controlled by medication or infrequent</td>
<td>1</td>
</tr>
<tr>
<td>• Poorly controlled or unpredictable seizures</td>
<td>2</td>
</tr>
<tr>
<td>• Seizure activity increased by illness or anxiety</td>
<td></td>
</tr>
<tr>
<td>• Seizure activity is prolonged or difficult to recognise leading to loss of consciousness.</td>
<td>3</td>
</tr>
<tr>
<td>• High risk of airway obstruction or aspiration during seizures (history)</td>
<td></td>
</tr>
<tr>
<td><strong>Behaviours and Anxieties</strong></td>
<td></td>
</tr>
<tr>
<td>• No issues identified</td>
<td>0</td>
</tr>
<tr>
<td>• May become anxious in new environments, needs reassurance and extra time to reduce anxiety</td>
<td>1</td>
</tr>
<tr>
<td>• May display inappropriate behaviour, needs clear boundaries and reinforcement</td>
<td></td>
</tr>
<tr>
<td>• Regularly displays inappropriate behaviours e.g. stripping.</td>
<td>2</td>
</tr>
<tr>
<td>• Sometimes displays aggressive behaviours</td>
<td></td>
</tr>
<tr>
<td>• Severe hospital phobia or unable to wait</td>
<td></td>
</tr>
<tr>
<td>• Regularly displays aggressive behaviours to self or others, high risk of injury.</td>
<td>3</td>
</tr>
<tr>
<td>• Requires own carers to manage needs.</td>
<td></td>
</tr>
</tbody>
</table>

All documents relating to **Learning Disabilities and/or Autism** are on the Trust intranet site: Departments learning disability Autism

Authors: SR, TJ, BS  
Rapid Risk Assessment  
Version 4  
Page 25 of 35  
DSG Approved: November 2011, reviewed/amended July 2015 and reviewed/amended July 2018
# Rapid Risk Assessment for patients with Learning Disabilities and/or Autism

**Authors:** SR, TJ, BS

**Rapid Risk Assessment Version 4**

**DSG Approved: November 2011, reviewed/amended July 2015 and reviewed/amended July 2018**

---

## Score = 0-8 Low Risk:

**Care Bundles**

<table>
<thead>
<tr>
<th>Low Risk</th>
<th>Tick on completion</th>
<th>Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complete all Trust risk assessments i.e. Falls, Waterlow, MUST,</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Implement basic nursing care monitoring charts e.g. fluid charts, food charts, epilepsy charts.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Refer to Trust learning disabilities policy the Trust Intranet; or liaise with link practitioner for further advice.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Liaise with carers to identify usual support and communication needs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Check if known to the community learning disability team (see below)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ensure LD or autism code added to PAS (with consent)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Document decisions in relation to patients mental capacity Is the person able to?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Understand the information relative to the decision</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Retain information long enough to make the decision</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Use or weigh up the information to make the decision</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communicate the decision back by appropriate means</td>
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## Score = 9-12 Medium Risk:

**Care Bundles**

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<tr>
<th>Medium Risk</th>
<th>Tick on completion</th>
<th>Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increase level of supervision and observation</td>
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<td></td>
</tr>
<tr>
<td>Confirm level of support that can be offered by carers, document on care plan.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consider increased support needs. Use Trust Policy for Therapeutic Observations (Including Specializing) in Adults</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Use alternative methods to assess potential clinical issue e.g. distress tool, abbey pain scale (on LD site)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Make referrals to appropriate health care professionals e.g. SALT, Physiotherapist, Dietician etc.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>If not known / active to the Community learning disability team. Make referral to Acute Liaison Nurse service</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

## Score = 13-18 High Risk:

**Care Bundles**

<table>
<thead>
<tr>
<th>High Risk</th>
<th>Tick on completion</th>
<th>Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complete learning disability emergency admission plan (on trust document site)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agree additional support needs with senior nurse.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ensure principles of the Mental Capacity Act are followed in relation to best interest and consent.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arrange MDT meeting to support safe discharge planning and continuing care needs.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**DOCUMENT ALL ACTIONS CLEARLY IN THE PATIENT’S HEALTH CARE RECORDS**

---

**Acute Liaison Nurse for people with learning disabilities:** Rebecca Crossley Rebecca.crossley@jpaget.nhs.uk bleep 1785 ext 3732 mob 07772749155

**Community Learning Disability Teams:**

- **City** 01603 638520
- **East** 01493 448400
- **South** 01953 450800
- **North** 01263 835200
- **West** 01553 666680

**Adult social services – 03448008014**

**Assessment completed by:**

**Print name:**

**Signature:**

**Date (dd/mm/yy):**

---

Authors: SR, TJ, BS

Rapid Risk Assessment

Version 4

DSG Approved: November 2011, reviewed/amended July 2015 and reviewed/amended July 2018
Hospital Passport
For vulnerable people coming to James Paget
University Hospitals Foundation Trust

My name is:

If I attend an appointment or go into hospital this passport needs to go
with me and stay with me at all times.

Please look at it
It tells you

• Things you MUST know about me
• Things that are important to me
• My likes and dislikes

This information belongs to me. Please return it to me when I go
home.
Things you must know about me

Name: 
Likes to be known as: 
Date of Birth: 
Address: 
Tel No: 

How to communicate with me:

Contact person: 
Relationship 
e.g. family member, Support Worker: 
Address: 
Tel No: 

My support needs and who gives me the most support:

Date completed by: 
Things you must know about me

Allergies:

Heart/Breathing problems:

Risk of choking, Dysphagia (eating, drinking & swallowing):

GP:
Address:
Tel No:

Other services/professionals involved with me:

Spiritual needs:
Religion:
Religious Needs:
Ethnicity:

What makes me anxious, upset or worries me (e.g. the dark, noise, crowds etc) and how do I show this?

What helps me when I feel like this?

Date completed by
Trust Guideline for the Management of Patients with Learning disabilities and or Autism

Things **you must** know about me

Current medication:

My medical / social history and treatment plan: please include Epilepsy care plan

Medical Interventions: (how to take my blood, give injections, BP etc)

How I take medication: (on food, in liquid form, by injection)

Date completed ______________________ by ______________________
**Things that are important to me**

<table>
<thead>
<tr>
<th>Section</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>How you know I am in pain: (posture, skin colour, sounds)</td>
<td></td>
</tr>
<tr>
<td>Moving around: (Posture in bed, walking aids, transfers, hoisting)</td>
<td></td>
</tr>
<tr>
<td>Personal care: (Dressing, washing, etc)</td>
<td></td>
</tr>
<tr>
<td>Seeing/Hearing: (Problems with sight or hearing)</td>
<td></td>
</tr>
<tr>
<td>How I eat: (Food cut up, help with eating, consistency of food)</td>
<td></td>
</tr>
</tbody>
</table>

Date completed __________________________ by __________________________
Things that are **important** to me

How I drink: (drink small amounts, thickened fluids)

How I keep safe: (Side room, Low bed, Bed rails, and support from familiar staff)

How I use the toilet: (Continence aids, help to get to the toilet)

Sleeping: (Sleep pattern/routine)

Date completed __________________________ by __________________________
My likes and dislikes

**Likes**: for example - what makes me happy, things I like to do, things that are important to me, i.e. watching TV, reading, music, routines.

**Dislikes**: for example food I don’t like, physical touch, needles

**Things I like**

Please do this:

**Things I don’t like**

Don’t do this:

Date completed __________ by ________
Appendix 7 – Mental Capacity Assessment Record

Mental Capacity Assessment Record

Decision/s required:

**STAGE 1**
Does the patient have an impairment of, or disturbance in the functioning of the mind or brain? (Please give details e.g stroke, dementia, confusion, significant learning disability, mental disorder, intoxication etc):

If ‘No’ the patient has capacity to make a decision at this time

This condition is (please circle):
Permanent ☐ Temporary ☐ Fluctuating ☐

If temporary or fluctuating can the decision be put off until the person regains Mental Capacity?

**STAGE 2** (Patient must answer yes to all sections if deemed to have capacity)
Do you consider the person is able to understand the information relevant to the decision?
Yes ☐ No ☐
Do you consider the person is able to retain the information for long enough to be able to make the decision?
Yes ☐ No ☐
Do you consider the person is able to use or weigh that information as part of the process of making the decision?
Yes ☐ No ☐
Do you consider the person is able to communicate their decision?
Yes ☐ No ☐

What help has the person been given to pass the above tests?

On the balance of probabilities the patient does / does not have the capacity to make this decision at this time. (delete as necessary)

This decision is to be reviewed on (insert date)........................................................................................................

Date: .......................................................... Time: ..........................................................

Assessor .......................................................... Signature: ..........................................................