CARING FOR ADULT PATIENTS WITH A LEARNING DISABILITY IN THE ACUTE HOSPITAL

CROSS REFERENCE
This Strategy/ Policy should be read in conjunction with:

<table>
<thead>
<tr>
<th>Cross Reference</th>
<th>Progress and date of approval</th>
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<tbody>
<tr>
<td>TCP 074 Policy for Consent to treatment or examination</td>
<td>Approved March 2007</td>
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<tr>
<td>TCP199 Mental Capacity Act Policy</td>
<td>Approved 2007</td>
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<tr>
<td>TCP 172 Privacy and Dignity Policy</td>
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Manager Responsible: Senior Nurse Practice Development

Policy Author: Senior Nurse Practice Development
Community Learning Disabilities Nurse Manager

Date: December 2008

Policy Number:

Version Number: 1

Approving Committee: Trust Clinical Policies
## Consultation and Ratification Schedule

<table>
<thead>
<tr>
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<tr>
<td>Learning Disabilities Group</td>
<td>May and July 2008</td>
</tr>
<tr>
<td>Trust Clinical Policies Group</td>
<td>November 2008</td>
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<tr>
<td>Community Learning Disabilities Team</td>
<td>May, June, July, Oct and Dec 2008</td>
</tr>
<tr>
<td>Gina Behar-Spicer</td>
<td>November 2007</td>
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<tr>
<td>Jane Kingsbury</td>
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<td>Shaun Marten</td>
<td>Sept 2007</td>
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Adapted from Guidelines developed by Lothian University Hospital Trust and Lothian Primary Care NHS Trust.
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INTRODUCTION

This collaborative protocol has been developed to support the care of patients with a learning disability when they access acute hospital services.

WHAT IS A LEARNING DISABILITY?

Learning Disability may be defined as a state of arrested global development occurring pre or post-natal. Some people with a learning disability may have an identifiable cause for their condition, for example genetic conditions such as Down's Syndrome.

This includes:
- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence)
- A reduced ability to cope independently (impaired social functioning)
- Which started before adulthood, with a lasting effect on development (DoH 2001 – Valuing People)

For many patients it is not possible to identify the primary cause of the learning disability - the important factor to recognise is the functioning ability of the individual patient. People with a learning disability present with a wide spectrum of care needs, ranging from the person who is totally dependent on others for all aspects of care to individuals who, while appearing independent, have special health needs, such as challenging behaviour, mental health problems or epilepsy. Generally a diagnosis of learning disability is made before 5 years of age or when a child starts schooling.

A person may be identified as having complex care needs when, by virtue of a pre-existing learning disability, they may be unable to communicate their own needs fully or comprehend the information they are given. They may present with difficulties which necessitate additional support to enhance the standard of care whilst in the acute hospital. Others may also have a profound physical and / or sensory disability.

This guidance has been developed jointly by acute and learning disability services. It places the patient firmly at the centre of care

The aim of this collaborative protocol is to:

- Enable the wards to audit their delivery of care standards against the Essence of Care benchmarks.
- Enhance communication between the patient, carers and health care professionals.
- Highlight issues of consent and advocacy for people with a learning disability.

"Main carer" refers to the individual who holds main responsibility for the care of the patient, irrespective of whether the person is normally cared for at home or in the community. This person may be an informal carer, parent/relative, nurse, support
worker, social worker or residential care worker. Occasionally a person with learning disabilities has no carer input due to their high level of independence. Throughout this protocol there will be references to the hospital resource pack, available in all wards and departments, health action plans and the use of care passports to enhance communication and care.

FLOW CHARTS

The key elements of this protocol have been summarised into a series of flow charts which identify different care pathways that patients with a learning disability may take during their contact with the acute hospital.

- Core Principles of Patient Care
- Elective Admission
- Emergency Admission
- Out-patient Attendance
- Patients attending Theatre and Recovery.

The specific care issues outlined in the flow charts are described in detail throughout this document.

ROLE OF THE LEARNING DISABILITY LIAISON NURSING TEAM (LD Liaison Team)

The role of the hospital liaison nurse is to assist acute staff to provide the best possible care to the patient with learning disabilities. This is a new service for BSUH from November 2008.

They will accept referrals from any source whether this is direct from the patient, their carers, community services, ward staff or GP's. It is important that, if the patient has the capacity to give or withhold consent, the patient is asked for their consent before a referral is made to the hospital liaison nurse. Such consent should not be assumed if the patient has capacity.

Scope of the role

The liaison nurse is available across all areas of the acute hospital service to;
- Support the patient from pre-admission to post discharge, where needed.
- Ensure that by virtue of having a learning disability, the patient is not excluded from any aspect of health care available
- Offer on the spot advice and support to acute care staff
- Support the patient to understand delivery of care
- Co-ordinate care
- Enhance and develop standards of care
- Promote effective communication
- Provide education within clinical areas and contribute to programmes of education
- Develop accessible resources
- Support carers
• Influence discharge process to ensure adequate provision
• Case Manage chronic patients and frequent users of acute services.
PRINCIPLES OF INFORMED CONSENT

- Patient consent is required in all areas of care/treatment.
- Consent cannot be given on behalf of another adult, unless there is a relevant Health and Personal Welfare Lasting Power of Attorney.
- All patients must be treated as equal, having the same rights to care.
- It should not be assumed that patients with a learning disability cannot give informed consent.
- Clinical staff should assess the capacity of the patient to give consent; provided the patient does not object, assistance should be obtained from the people who know them best.
- All care given must clearly be in the patient's best interests; ultimately the attending clinician may make a decision to proceed without consent.
- Liaise with people who know the patient e.g. main carer or parent.
- Patients with a learning disability should not be excluded from treatment unless clinically indicated.
- Consider Mental Capacity Act core principles.
- Seek support from the LD Liaison Team.

Patient referred for treatment or admission
- Elective
- Investigations
- Outpatients
- Accident and Emergency and other Receiving Areas

Pre-admission Planning
- liaise with
  - Patient and carer
  - LD Liaison Team
  - Patient's community supports
  - Other agencies e.g. Social Work
  - Primary Care Team
  - Community Learning Disability Team

Admission to the Acute Hospital

Complete Nursing Assessment & Learning Disability Dependency Assessment Scale
- Assess need for additional nursing/caring resources
- Inform LD Liaison Team of admission
- Ensure carer involvement at an appropriate and mutually acceptable level
- Ensure good communication between all parties

Investigation and / or Treatment as an Out Patient
- Inform LD Liaison Team

Care delivered according to care plan and protocols

Discharge Planning
Refer to Trust Discharge Planning Policy and follow appropriate flow chart.
Ensure involvement of
- Patient
- Carers
- Other agencies e.g. social work
- Primary Care Team
- Community Learning Disability Team as required
- LD Liaison Team
OUT-PATIENT ATTENDANCE

Role of the Outpatient Nurse

Where a patient is a regular attendee to the Out-Patient Department the clinic nursing staff will,

- Liaise with the main carer (if they have one) to discuss and identify any specific care requirements that the patient may have during attendance
- Check care passport and / or health action plan for information pertinent to the appointment.

Where the individual is known to have learning disabilities, inform LD Liaison Team who will be able to support patient or team where needed.

The outcome of this discussion may include, where appropriate, scheduling the appointment to the first or other suitable slot on the clinic list. The outpatient nurse can reschedule an individual’s appointment, where it is felt to be appropriate. The reasons for first or early appointment include

- Reduce the delay to see doctor
- Waiting room emptier and quieter
- If patient is anxious / restless will not disturb as many other patients.

Where it is ascertained that an appointment at a specific point in the clinic list would be preferable to meet the specific needs of a patient, this will be marked on the Patient Administration System in order that all subsequent appointments are made at a suitable time.

If a patient is attending the Out-Patient Department by ambulance, it may not be possible to guarantee the appointment time.

Following the out-patient consultation, the nurse will make contact with the patient and their main carer to ensure that they have understood the information and/or instructions given to them during the consultation. Best practice could include either the recording of the consultation as an audio tape for the patient to replay later at home or a typed letter explaining test results, diagnosis and treatment options. The LD Liaison Team maybe able to assist with this.

Following the out-patient consultation, out-patient staff may make a follow-up telephone call or formal referral to the LD Liaison Team or the Community Learning Disability Team. This may be for assistance with following instructions, or for patients who appear to lack an appropriate support network and have additional health needs.

Where a Health Care Assistant is responsible for co-ordinating a clinic, a Registered Nurse must see the patient before they leave the Department in order to determine any further care requirements.

Regular attendees should have a key clinic nurse.
The patient or main carer should be advised to make contact with Clinic Nursing Staff to discuss details of the appointment and any specific needs / resources required for the first and future appointments. Contact the LD Liaison Team where additional support may be needed.

If an appointment at the beginning of a clinic list is preferable, this should be marked on the Patient Administration System. **NOTE** - if ambulance is the required mode of transport it may not be possible to guarantee the appointment time.

If a Health Care Assistant is responsible for co-ordinating a clinic, then the patient should be seen by a **Registered Nurse** prior to leaving the department to determine any further care requirements.

**FLEXIBILITY OF CLINIC APPOINTMENTS**
For the safety and comfort of both the patient and other patients attending the clinic it may be necessary to alter the patient’s appointment time in order to minimise any patient anxiety that might be induced by lengthy waiting in an unfamiliar environment. The Nurse-in-Charge of the clinic has the authority to take a flexible approach based on patient needs.

Does the outcome of the appointment indicate that investigation or admission to the acute care setting is required?

- Liaise with staff in the department responsible for the investigation
- Consider a referral to LD Liaison Team for support and assistance with preparation of the patient

- Does the patient require a follow-up clinic appointment?
- **Ensure patient and carer understand the outcome of the consultation. If you suspect they don’t, refer to the LD Liaison Team who can assist**
PRE-OPERATIVE ASSESSMENT

Preparation for admission to Brighton and Sussex University Hospitals NHS Trust

All patients requiring elective surgery will have pre-operative assessment and it is at this time specific needs are noted and forwarded to the surgical teams. Whenever it becomes apparent that the patient has learning disabilities, consider the involvement of the LD Liaison Team to help prepare the patient and the acute staff team.

Role of the Pre-assessment Nurse

The main carer should be invited to accompany the patient to, and to be involved in the pre-operative assessment (with the patient's consent).

Where appropriate, the main carer should be asked to bring in a copy of the patient's current health action plan, care passport and medication.

Particular note should be made of the patient's medication regime, including the form of the preparation, times and methods of administration (which may be tailored very specifically to the individual patient). This needs to be communicated to the admitting ward.

Where the assessment identifies the need for additional nursing and / or other resources, the pre-assessment clinic nurse should contact the Learning Disabilities Liaison Team, so that they are able to support the person who is coming into hospital and discuss and arrange the required resources, with the ward manager and/or matron of the admitting ward.

The nurse undertaking the pre-operative assessment will discuss the following issues with the patient and main carer; this will be documented and then cascaded to ward staff and theatre staff

- The patient's previous experiences of anaesthesia and surgery
- Any known behavioural patterns which may become evident when the patient recovers from the anaesthetic
- The patient's communication needs
- Whether the main carer wishes to accompany the patient to the anaesthetic room and/or to be present in the recovery room shortly after the patient recovers from the anaesthetic
- Whether a ward nurse needs to stay with the patient in the anaesthetic room until the patient is asleep to provide continuity of care and support

The Acute Pain Nurses will be informed by learning disability liaison nurse that there is a patient on the theatre list with a learning disability and request that a pre-operative visit be made by them to discuss pain assessment and management with the patient, their main carer and the ward nursing staff.
**ADMISSION**

Where at all possible, transfer of a patient with a learning disability between or within wards in order to accommodate other admissions (emergency or elective) should be avoided, to ensure a consistent environment is maintained.

**Role of the Ward Manager**

The Ward Manager should identify a Nurse for the patient who *will be on duty* when the patient is admitted, and be the named nurse for the patient.

The ward manager is responsible for contacting the LD Liaison Team nurse about the admission of a person with learning disability.

**Role of Named Nurse**

**On Admission**

On admission the Named Nurse should discuss with the main carer their wishes regarding their involvement in the delivery of direct care to the patient, for part of the time, during the period of hospitalisation. Any care delivered by residential home carers or relatives is to be seen as goodwill on their part and not an obligation: - the hospital Trust has a duty of care to provide adequate support.

The Named Nurse should check provision has been made to meet all anticipated care needs identified by ward staff, or identified by the carer if they have agreed to provide guidance on this. Advice on anticipated care needs may also be given by the LD Liaison Team.

Where possible, the Named Nurse and main carer should undertake an admission assessment of the patient's care needs. Full use of the expertise of the main carer should be made in order to facilitate a thorough assessment. The assessment should take account of the individual's physical, psychological, social and cultural needs. This should inherently consider a person's needs with regard to the protection of individuality, vulnerability and dignity.

Particular note should be made of the patient's medication regime, including the form of the preparation, times and methods of administration (which may be tailored very specifically to the individual patient). These details should be discussed with relevant medical staff and the Clinical Pharmacist in order to ensure, unless clinically inappropriate, continuity of medicating practices during hospitalisation.

The Named Nurse will find out from carers, relatives etc what the patient was usually like before they became ill.

It is important for the ward to have contact details for carers and / or relatives and to know the order/ circumstances in which to call them.

The anticipated length of stay and care needs following treatment should also be estimated at admission and communicated to the patient and main carer by the named nurse.
A care plan should be developed which also identifies any specific requirements relating to aspects of care such as positioning, sensory stimulation or feeding requirements. The care plan should be discussed with and made available to the main carer (with the patient's consent).

If the main carer is unable to contribute fully to this assessment, the nurse may contact the LD Liaison Team for advice and assistance in the assessment process.

**Ongoing Care during Hospitalisation**

If carers and relatives choose to assist, then their welfare must be considered e.g. relieving them for breaks. Drinks should be provided. Consideration should be given to providing a room for breaks / making drinks / family members to meet away from client to discuss treatment options or future needs.

If the main carer is not able to be involved in the direct care of the individual, then they need a communication system to ensure they are kept informed of all developments and treatments, and know who to contact on the ward for updates.

Remember to include the patient in conversations and consultations.

A person with a learning disability may not be able to indicate their level of pain or request pain relief. The person may have a high or low pain threshold. Carers may be able to advice on this as well as on behaviours the person exhibits when in pain / distress.
CARE OF PATIENT WITH A LEARNING DISABILITY IN THE ACUTE HOSPITAL

Elective Admission

Ward Manager to be informed in advance by medical and / or secretarial staff of the patient's:
1. Clinical needs
2. Admission date
3. Main carer

Consider a referral to the LD Liaison Team

Ward Manager to identify a Named Nurse and ensure that they are on duty on the day of the patient's admission

Does the patient assessment identify that the patient required additional nursing support?

Yes

NO

Named Nurse to make contact with main carer or other prior to admission to discuss:
- Admission arrangements
- Current care needs
- Specific equipment that may be required
- Carer involvement during hospital admission

The Nurse should also
- Seek consent from the patient for the carer to be involved in the admission process
- Undertake an assessment of the patient's care needs using the Learning Disability Assessment Scale to identify if the patient requires additional nursing support. The LD Liaison Team may be able to provide additional advice for this assessment
- Where appropriate, ask for a copy of the patient's existing care passport, health action plan from the carer

MEDICATIONS
Specific attention should be given to the patient's medication regime including preparation, times and method of administration; these may have been tailored to the individual patient's needs and should continue while in hospital.

EFFECTIVE COMMUNICATION
Consider the use of an audio recording of the explanation of the clinical procedures, so that the patient may replay the tape and / or a typed letter of diagnosis, tests and treatment.

DAY OF ADMISSION
- A full nursing and medical assessment is undertaken
- If the main carer is unable to be involved in the admission process then ascertain contact and document
- With the patient's consent the Nurse should make an appropriate person or the LD Liaison Team aware of the patient's admission, if needed

DISCHARGE PLANNING
- Patients with a learning disability have complex discharge planning needs
- Discharge planning should be discussed at the time of admission
- Ward staff and hospital social worker to identify appropriate community support has been identified and arranged.
- Liaise with the LD Liaison Team
CARE OF ADULT PATIENT WITH A LEARNING DISABILITY
ATTENDING THEATRE & RECOVERY

Pre-operative preparation

Role of the Nurse

The ward will contact the appropriate theatre in advance to confirm that the nursing staff are aware that the patient has a learning disability and to discuss any specific needs that this may present.

The theatre nurses will then communicate this information to the recovery nursing team.

For elective cases a pre-operative visit to the theatre by the patient may assist with alleviation of fear due to the unknown.

For elective patients the theatre nurse will inform the acute pain nurse that the patient with learning disability has been admitted (the acute Pain nurses should be aware of the expected admission).

Information obtained by the pre-assessment nurse will be made available to theatre staff.

The LD Liaison Team is available to offer support and advice to the patient as well as theatre, recovery and ward staff. The team will also facilitate the completion of the Dependency Assessment to identify if extra resources are needed.

In Theatres and Recovery

Role of the Nurse

- The theatre care plan will be used to document the patient's needs both in anaesthetic and recovery room.
- The main carer will be invited to accompany the patient to the anaesthetic room, if they wish to, with the ward nurse.
- Where required, the ward nurse and carer will remain with the patient until induction of anaesthesia is complete.
- In the event of emergency surgery it will be the responsibility of Recovery nurse, to inform the Acute Pain Nurses and the LD Liaison Team.
- The B.S.U.H. privacy & dignity policy should be followed at all times.

Recovery

Role of the Nurse

If the main carer has expressed a desire to be present in the recovery room shortly after the patient has woken from the anaesthetic, the recovery nursing staff should contact the ward to notify them that the patient is ready for the main carer where applicable to come to the recovery area.
Appropriate pain assessment techniques should be implemented to ensure adequate pain management. The support of the Acute Pain Nurse should be sought as required.

The recovery nurse / ward nurse known to the patient will transfer the patient back to the ward.

**Patients requiring local anaesthetic only**

Standard pre-procedure preparation is required.

**Role of the Nurse**

Where possible, a pre-operative visit by the nurse who will be with the patient in theatre should be made. The nurse should discuss with the ward nurses, patient and main carer the patient's understanding of the procedure and any issues relating to his/her compliance with the procedure, particularly when the procedure may be protracted.

On rare occasions, to assist with co-operation and tolerance, it may be appropriate for a member of the LD Liaison Team to remain with the patient during the procedure.

**Patients attending as an out-patient for investigations which involve anaesthesia**

In circumstances where the patient attends for an Out-Patient investigation that is of a complex nature requiring general anaesthetic (e.g MRI Scans) specific arrangements should be made to accommodate the individual requirements.

Individual Requirements may include:

- Admission the night before in order to guarantee fasting if indicated
- Ensuring that the patient is first on the list
- Effective pre-attendance planning should help to ensure that patients with a learning disability receive their investigation / treatment without the need to cancel or defer appointments.
- Preparation of accessible information for the specific patient journey/procedure - use of photo, objects of reference. The outpatient nurse, should seek assistance from the LD Liaison Team when the referral for such investigation is made.

The appointment details sent to the patient's home should include a screening questionnaire to determine the patient's suitability for the procedure. The clinician should determine risks and benefits of the proposed scan need to be considered in the light of the patient's anticipated tolerance of the procedure.

The main carer should be invited to accompany the patient to the procedure room and also invited to be present in the shortly after the patient wakes from the anaesthetic.
CARE OF PATIENT WITH A LEARNING DISABILITY IN THE ACUTE HOSPITAL

Patients attending Theatre and Recovery

A PATIENT REQUIRES AN EMERGENCY / ELECTIVE OPERATION, PROCEDURE OR INVESTIGATION

Nursing staff from the patient's ward should contact the appropriate Operating Theatre up to 24 hours in advance where possible to discuss any specific patient needs. This information should also be conveyed to the Recovery Room staff.

Is the procedure or investigation to take place under local anaesthetic?

YES

Patient to make a pre-operative visit to Recovery room if possible or photographs shown may assist especially if consent is being sought.

The LD liaison Team is available to offer support and advice to the theatre and recovery team.

RECOVERY

Once the procedure is complete the recovery nursing staff should contact the ward to notify the main carer that the procedure is complete. If necessary the main carer may be present in the Recovery Room.

Where possible, the patient should be escorted back to the ward by a recovery nurse or ward nurse who is known to them.

PREPARATION FOR THEATRE

The following issues should be discussed during the pre-op visit between patient, nursing staff and main carer:

- The patient's previous experience of anaesthesia and surgery
- Behavioural patterns during recovery of anaesthesia
- The patient's communication needs

The main carer or next relative may wish to accompany the patient to anaesthetic room and/or be in attendance during recovery.

The LD liaison Team is available to offer support and advice to the theatre and recovery team.
EMERGENCY ADMISSION

Presentation to Accident and Emergency Department

If an individual with learning disabilities is admitted unaccompanied, the triage nurse should attempt to identify a main carer and make contact with them as soon as possible.

CONSENT IN THE EMERGENCY SITUATION

Where there are particular concerns regarding the capacity of a patient with a learning disability to give informed consent the named nurse should refer to Brighton Sussex University Hospitals Consent Policy.
Immediate discharge from Accident and Emergency Department

A referral can be made to the LD liaison Team where the named nurse has any of the following concerns:

- The patient’s safety,
- Mental health and/or challenging behaviour,
- The patient’s ability to comprehend instructions or follow medication regimens

See Hospital Resource Pack for further information on learning disabilities.

Transfer from Accident and Emergency to an Admitting Ward

Role of the A&E Nurse

Where a patient with a learning disability is to be transferred to an admitting ward the Named Nurse in Accident and Emergency should advise the nurse in charge of the receiving ward and provide an initial assessment of the patient's care needs.

Emergency Admission to a Ward

Role of the Nurse in charge of the ward or named ward nurse

Contact the LD liaison Team

If a patient with a learning disability has been admitted from A&E or MASU, without a carer, the admitting nurses should attempt to identify a main carer and make contact with them as soon as possible. This contact should take place as early as possible in the patient's admission to the acute hospital. Details of the main carer and contact numbers should be clearly documented in the patient's nursing notes.

If the patient is unable to provide information regarding their main carer the Nurse should contact the LD liaison Team, who can check with the duty social worker of the Community Team for People with Learning Disabilities. A full assessment of the patient's nursing needs should be undertaken, if possible in conjunction with the main carer.

Any resource requirements should be communicated to the appropriate Ward manager or matron as soon as possible and appropriate support instituted without delay. Follow the Dependency assessment scale. The LD liaison Team can assist with completion of this.

The flow chart for elective admissions should then be followed.
Ensure that, if the patient has capacity, s/he is asked to consent before the main carer participating in the history taking and admission process.

If there are any concerns regarding the capacity of the patient to give informed consent - refer to B.S.U.H.Capacity / Consent Policy

The admitting triage nurse should:

1. Identify the main carer / guardian as soon as possible and make contact, with the patient's agreement if able.
2. Assess the need for contact with the LD Liaison Team and make contact if appropriate. This service can assist nurse with:
   - Patient Assessment
   - Communication
   - Liaison with other services

Is the patient to be admitted to the acute hospital setting?

If the named nurse / triage assesses that the patient requires further support refer the patient to the LD liaison Team

Refer to flow chart and protocol section on Out-Patient attendance

IMPORTANT
PATIENTS WITH A LEARNING DISABILITY WILL REQUIRE COMPLEX DISCHARGE PLANNING WHICH SHOULD COMMENCE AT THE TIME OF ADMISSION

Refer to flow chart and protocol section on Elective Admission procedures
CARE OF PATIENT WITH A LEARNING DISABILITY IN THE ACUTE HOSPITAL

Discharge Process

Role of the Nurse

Discharge should be discussed with the patient and the main carer at the time of admission, wherever possible.

In the first instance all patients with a learning disability should be considered to have complex discharge planning needs. The policy on discharge planning should be adhered to at all times. Refer to the LD Liaison Team for support with this.

Consider referral to the District Nursing Service, which should be contacted for "standard" community nursing follow-up e.g. suture/clip removal, dressings, aids etc.

The nurse should assess if a formal referral to the Community Learning Disability Team should be made where the patient appears to have additional care needs, as a result of their learning disability. Reasons for referral might include e.g. :-

- The need for special nursing support to assist with independent living and function within the community
- If the nurse has concerns regarding the ability of the patient to cope following discharge.

Again the LD Liaison Team will assist with this.

On the day of discharge, the main carer should be issued with a copy of the patient's discharge plan detailing the patient's care needs on discharge and arrangements for support in the community, plus follow up appointments etc.

The G.P. must be notified of the day of discharge.

Patients must not be discharged until confirmation of care package start, particularly if new care packages have had to be arranged by Social Worker / C.L.D.T., has been obtained.

Role of the Hospital Liaison Team

If the patient has one, the Health Action Plan should be updated with latest diagnosis and treatment plan and a copy sent to the GP.

Role of the Social Worker

The Hospital Social Worker will liaise with the Community Learning Disability Team and the Hospital LD Liaison Team as needed.
COMMUNICATION - DURATION OF HOSPITALISATION

See the ward resource pack for tips on good communication

Communication is essential between all parties - the nurses, doctors, therapists, carers and the patient.

Consider the use of an audio recording of meetings with the medical, nursing and/or therapy staff so that the patient may replay the tape afterwards and listen again to the information that has been given.

Also consider typed letter with details of tests, diagnosis and future treatment options so carers can discuss with client.

Communication with Patient

- Remember to include the patient in conversations and consultations.
- Refer to B.S.U.H. privacy and dignity policy.
- Refer to care passport.

Communication with Main Carer

The main carer should be involved in decisions regarding care and invited to give feedback to the ward manager and matron on perceptions of standards of care.

Care plans should be reviewed with the main carer on a daily basis or as frequently as previously agreed, unless the patient is able to be involved or make decisions in their own right.

If there are specific changes or developments in the patient's condition during the duration of hospitalisation, the main carer should be contacted as soon as possible - or at the time(s) at which the main carer has asked to be contacted - (with the patient's agreement if able).
CONSENT

Consent - Refer to B.S.U.H. Consent Policy + Mental Capacity Act Principles

Consent can present ethical dilemmas for health care professionals. Careful consideration needs to be given before seeking informed consent from any patient. The fact that a patient has a learning disability does not alter the need to assess whether or not the patient has capacity to give or withhold consent to the proposed procedure; to assess whether or not they may have this capacity at some other time if they do not have it at the moment; and to assess whether or not the procedure can wait until such time as the patient may in the future have capacity. This may cause concerns when the health professional is unclear whether the person with the learning disability has the capacity to understand the implications of the procedure they are being asked to consent to, and indeed the whole notion of giving or withholding consent.

It is not acceptable or legal for a parent or carer to give consent on behalf of an adult with a learning disability.

The LD liaison team can assist staff with this process

When seeking informed consent, the health professionals involved should consider carefully the patient's level of understanding and comprehension - this may involve contacting people who have a detailed knowledge of the patient. The use of language and presentation of information should be appropriate to the patient.

An assessment of capacity should always be undertaken in order to determine whether or not the patient has capacity to give or withhold consent to the proposed procedure - Refer to B.S.U.H. Consent Policy for Procedure.

Usually, if the patient is not competent to give consent, treatment is lawful provided it is in their best interest. In many cases it is not only lawful to treat an individual unable to give consent but it is a common law duty to do so. The position regarding consent in an emergency situation is no different for a person with a learning disability – ultimately, if the patient lacks capacity, the attending clinician makes the decision on what action is in the patient's best interest.

The Mental Capacity Act Code of Practice lists certain forms of treatment that give rise to special concern, such as sterilisation, which should be referred to the judicial system for consideration before proceeding if the patient lacks capacity to give or withhold consent.

Specific legal advice must be sought whenever there is doubt about proposals for treatment and the necessity for obtaining consent in relation to such proposals. See BSUH Consent Policy. Always consider principles and procedures of the Mental Capacity Act 2005 and Code of Practice 2007

The decision-maker has a statutory obligation to make a referral to an independent mental capacity advocate (IMCA) if the patient has no unpaid carer or next friend to advise/support them and consideration is being given to providing non-emergency serious medical treatment.
APPENDIX 1 - LEARNING DISABILITY DEPENDENCY ASSESSMENT SCALE

Background

The Lothian Learning Disability Dependency Assessment Scale has been developed to assist nurses in the acute hospital to identify the special care needs that may be present when caring for a patient with a learning disability. It is important to recognise that the Assessment Scale is designed to enhance and complement the nurse’s existing skills of observation, communication and assessment. The additional information obtained from the assessment made using the Dependency Assessment Scale should be used to assist with the development of a comprehensive patient care plan.

Guidance on completion

Assistance and training in the use of this tool is available via the LD liaison team

The nurse should use their interpersonal and communication skills to assess the care needs in a sensitive manner. Some patients or carers may find certain aspects of the assessment awkward, such as those contained in the section on Mental Health Needs, and as such, care and sensitivity should be exercised when completing this section.

It should be considered good practice to obtain information that may assist with the assessment of the patient’s care needs prior to admission to the acute hospital. It is acknowledged that this is not possible in all cases. It could be that the patient is unable to provide the nurse with all the details required during assessment. If this is the case, the nurse should consider additional sources of information, having first obtained the patient’s consent (if the patient is assessed as having the capacity to give or withhold this). These sources could include:

- The main carer
- Relatives
- Residential Care Staff
- Community Learning Disability Team
- Primary Care Staff

Method

The nurse should systematically assess the patient in relation to each category, identifying their current level of dependency according to each assistance level. The four assessment categories are:

- Self Care/Nursing Support
- Communication and Safety
- Mental Health Needs
- Nursing Procedures

It is important to recognise that the overall Assistance Level Score cannot itself determine the need for additional nursing support. It is the balance of the scores across the four categories which will give guidance to nursing staff of the patient
specific care requirements, and offer an indication of the most appropriate nursing resource required to meet the care needs.

In appropriate circumstances the role of the main carer should be taken into account when completing the Dependency Assessment Scale, together with his/her availability and desire to participate in direct basic care. This factor could have a direct influence on the nursing resource required.

It is the responsibility of the assessing nurse to discuss the assessment findings with the nurse-in-charge of the clinical area, who can then identify the level of nursing resource required. They should consider the following recommendations:

**A - Self Care/ Nursing Support**
A high score in this category only would indicate the possible need for additional support from a Health Care Assistant/Auxiliary.

**B - Communication & Safety**
A high score in this category only would indicate the need for specific supervision and observation. This may be required on a continuous or intermittent basis and should be judged in relation to the assessment of the patient in Categories A, C & D.

**C - Mental Health Needs**
If the patient is assessed at Assistance Level 2 across one or more categories then consider whether support from a Health Care Assistant would be appropriate.
If the patient were assessed at Assistance Level 3 or 4 in one or more categories it would suggest the need for support from a trained nurse.
If the patient is assessed at Assistance Level 4 in one or more categories then consider the need for a trained nurse with additional skills e.g. RNLD/ RMN.

**D - Nursing Procedures**
If the patient is assessed at Assistance Level 1 or 2 across one or more categories then consider whether support can be met within existing trained nursing resources.
If the patient is assessed at Assistance Level 3 or 4 across one or more categories then consider whether a dedicated trained nurse resource may be required.
If the patient is assessed at Assistance Level 3 or 4 plus has care needs identified in categories A, B & C then a dedicated trained nurse resource may be required.

It is possible that the patient will be assessed as having care needs across all categories. Where this is the case it is important to look at the balance across the categories and make an informed professional judgement about the nursing resource that may be required.

The named nurse should assess the patient using the Dependency Assessment Scale to determine the most appropriate method of meeting any additional care needs. Where possible these care needs should be met from existing resources. If this is not possible, additional nursing support should be requested from the Clinical Manager, who may in turn, contact the relevant Nurse Bank.
Frequency of assessment

The Learning Disability Dependency Assessment Scale should be completed initially at the time of admission and subsequent reassessment should be completed as required in response to the changing needs of the patient. Examples include: Pre surgery/procedures (where the patient may present with needs not initially identified); post surgery/procedures (where the patient’s support and supervision needs are increased); and where the anxiety / stress associated with hospitalisation is seen to be affecting the patient’s ability to cope with the situation

This information is summarised in the form of a flow chart in Appendix 2.
APPENDIX 2 – LEARNING DISABILITY DEPENDENCY ASSESSMENT SCALE: ACUTE CARE SETTING
BRIGHTON & SUSSEX UNIVERSITY HOSPITALS NHS TRUST

NAME: | WARD: | DATE:
---|---|---

<table>
<thead>
<tr>
<th>A SELF CARE / NURSING SUPPORT</th>
<th>B COMMUNICATION &amp; SAFETY</th>
<th>C MENTAL HEALTH NEEDS</th>
<th>D NURSING PROCEDURES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assistance level / support required for:</td>
<td>Assistance level / support required to:</td>
<td>Assistance level / support required to:</td>
<td>Assistance level required by the patient during:</td>
</tr>
<tr>
<td>Personal hygiene (0-2)</td>
<td>Enable patient to safely leave the ward environment (0-2)</td>
<td>Protect the patient at risk of self-harm (deliberate/accidental) (N/A or 4)</td>
<td>Preparation for technical procedures (N/A, 2-4)</td>
</tr>
<tr>
<td>Nutritional needs (0-4)</td>
<td>Enable the patient to maintain personal dignity (0-3)</td>
<td>Protect the patient at risk of attempted suicide (N/A or 4)</td>
<td>Inter operative procedures (N/A, 2-4)</td>
</tr>
<tr>
<td>Fluid intake (0-4)</td>
<td>Maintain the safety and dignity of patients/relatives (N/A, 0-3)</td>
<td>Care of the patient who presents with challenging behaviour:</td>
<td>Post intervention/operative procedures (N/A, 2-4)</td>
</tr>
<tr>
<td>Elimination (0-4)</td>
<td>Enable effective communication (0-2)</td>
<td>- violent behaviour (N/A, 2-4)</td>
<td>Safe administration of medicines (N/A, 1-4)</td>
</tr>
<tr>
<td>Pressure Areas (0-2)</td>
<td>Provide appropriate support and explanation (0-2)</td>
<td>- destructive behaviour (N/A, 2-4)</td>
<td>Intravenous therapy (N/A, 1-4)</td>
</tr>
<tr>
<td>Safe mobility (0-2)</td>
<td>Input required to carers to facilitate communication &amp; explanations (0-2)</td>
<td>- hyperactive behaviour (N/A, 2-4)</td>
<td></td>
</tr>
<tr>
<td>Sleep (0-4)</td>
<td>Enable the patient to participate in social &amp; occupational activities (0-2)</td>
<td>- socially inappropriate behaviour (verbal, uninhibited) (N/A, 2-4)</td>
<td></td>
</tr>
</tbody>
</table>

**Will the carer provide direct care / be in attendance? Circle Yes - during the day only, Yes - day & night, Yes - available during procedures, No.**

**Assistance level rating scale**
- N/A = Category does not apply to this patient
- 0 = No assistance required, capable of safe, independent care
- 1 = Assistance/supervision required some of the time to enable independent care
- 2 = Assistance/supervision required most of the time to ensure patient's safety
- 3 = Assistance/supervision required continuously: patient totally dependent and incapable of independent care
- 4 = Nursing support required from qualified practitioner to provide therapeutic relationship / maintain safety / provide technical nursing care
APPENDIX 3 - LEARNING DISABILITIES DEPENDENCY ASSESSMENT SCALE - FLOW CHART

A Self Care / Nursing Support

Level 1
Level 2
Meet within existing resources

Level 3
Level 4
May require additional HCA (Auxiliary)

B - Communication & Safety

Level 1
Level 2
Meet within existing resources

Level 3
Additional resource required (+ review in relation to other category scores)

C - Mental Health Needs

Level 2
May require Clinical Support Worker

Level 3 or 4
May require trained nurse support

D - Nursing Procedures

Level 1
Level 2
Meet within existing resources

Level 3 or 4
Dedicated trained nurse support

Level 3 & 4
(+ review of other category scores)
Dedicated trained nurse resource?

Identify balance across all categories - Make an informed judgement about the additional nursing resource required. The LD liaison team can assist in this decision making.
APPENDIX 4
ROLES AND RESPONSIBILITIES OF THE LEARNING DISABILITY LINK NURSE

Role and Responsibilities of the Link Nurse

The aim of introducing a team of Link Nurses throughout the Trust is to have named individuals who can assist with the assessment and delivery of a patient's care needs.

Each ward or department should have access to a Link Nurse.

The Link Nurse have a central role on promoting ‘best practice’ in relation to the care and treatment of patients with a learning disability coming into contact with the Acute Hospital. They will act as a point of contact for patients, carers and health professionals. The Link Nurse will receive direct support from the LD Liaison Team.

Patients with a learning disability will come into contact with a wide range of Trust services and through a number of referral mechanisms. The Link Nurse will be knowledgeable about the range of services relevant to their own area and be in a position to act as a resource and to help problem solve.

The Link Nurse will work closely with the LD Liaison Team to:

- Assist with the implementation of the learning disability protocol by means of local training and communication with nursing and medical colleagues, clients, carers, care staff and Trust Managers.
- Liaise with colleagues within their clinical area, providing them with advice, support and guidance on the care needs of patients with a Learning Disability.
- Raise awareness of the LD Liaison Team by informing staff of their role and responsibilities and the route for making a referral if indicated.
- Liaise and assist clinical staff to offer pre-admission hospital visits if indicated.
- Act as a resource for nurses in the clinical area regarding the use of the Dependency Assessment Scale.
- Participate in the Audit of the Learning Disability liaison service.
- Assist with the review and evaluation of the Disability.
APPENDIX 5
LEARNING DISABILITY LIAISON TEAM CONTACT DETAILS

Office is situated - Top Floor, room SP305, Southpoint, 8 Paston Place, Brighton, BN2 1HA

Email address
alice.ellis@sussexpartnership.nhs.uk
beky.golds-jones@sussexpartnership.nhs.uk

Telephone 01273 696955 extension 4975

Bleep 8514

Team members
The liaison service consists of two Band 6 Learning Disability Nurses who are qualified and have extensive experience in the field of learning disability health care. They are a resource for every department in BSUH. The team have close links with the Community Learning Disability team and will assist with referrals to this team.

Community Learning Disability Team
Patients referred must have a definite diagnosis of a learning disability and, if they have the capacity to make such a decision, should also be in agreement with the referral.

The Brighton & Hove Community Learning Disability Team also includes:

- Nurse specialists in Learning Disabilities
- Clinical Psychologists
- Counsellor
- Psychiatrists in Learning Disability
- Occupational Therapist
- Speech & Language Therapists
- Physiotherapists
- Social Workers / care managers
- Carers Assessor
- Behaviour Support Team

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