

1. Introduction

These guidelines mirror Coventry and Warwickshire Partnership Trust's care guidelines for all healthcare staff involved in the care of people with learning disabilities in acute hospital settings and are specific to those receiving a service at Warwick Hospital. The aim is to ensure that individuals with a learning disability who are accessing Warwick hospital care are able to have their needs met in an equitable way to that received by other patients in the hospital setting.

Evidence shows us that the health needs of people with a learning disability are greater than that of the population as a whole (Philpot, 2004). Furthermore they are more likely to use acute services; 26% of people with a learning disability are admitted to general hospitals every year, compared to 14% of the general population (National Patient Safety Agency, 2004).

An individual with a learning disability may be unable to communicate their needs or be able to understand information they are given. In addition some individuals with a learning disability may have mental health problems, challenging behaviour or a physical disability. These factors are likely to make caring for someone in the acute setting a complex process.

Learning Disability was defined by the Department of Health in 1991 as

'A significantly reduced ability to understand new or complex information, or to learn new skills 'impaired intelligence'

'A reduced ability to cope independently which started before adulthood, with a lasting effect on development 'impaired social functioning'

A learning disability is not an illness; it is a lifelong condition which is nearly always present from birth. With the right kind of help and support, many people can acquire practical and social skills, even if this takes longer to attain than usual.

Some people with a learning disability have an identifiable cause for their condition, for example a genetic condition such as Down syndrome or Tuberous sclerosis. However, for many people it is not possible to identify the primary cause of the learning disability- the important factor is to recognise the functioning abilities of the individual person.

People with learning disabilities present with a wide spectrum of care needs, ranging from the person who is totally dependant on others to meet all their care needs, to the person who, while appearing independent, may have specific additional needs such as mental health problems, challenging behaviour, epilepsy, diabetes, etc.

Like the rest of the population, people with learning disabilities have diverse personalities and characters. People's background and family circumstances will also vary, and these factors must be considered, along with the nature and degree of learning disability.

The nature of people's learning disability varies widely, and this will affect the kind of support they will require. Learning disabled people will find it more difficult to

understand new or complicated information. They also find it harder than other people to learn new skills. Some people may not speak and need to find other ways of communicating with those around them.

For the purposes of this document the terminology 'patient' refers to an individual with a learning disability.

2. Admission

The Department of Health document, 'Discharge from Hospital: Pathway, Process and Practice (2003)', recommends that hospitals should develop protocols for admission to acute care for people with a learning disability.

The rationale for these guidelines is to ensure an equitable service for patients with learning disabilities using Warwick hospital. It also aims to promote a patient-centred approach to service delivery for this vulnerable group of people.

3. Acute Liaison Nurse for Learning Disabilities

The Acute Liaison Nurse for Learning Disabilities can provide additional support at every stage of the acute admission process, from out patient appointments to emergency admissions.

The additional support with admission, for example, may include accompanying the patient to the ward if this is required.

If additional support is required for the patient during an elective hospital stay, a multi-disciplinary meeting to arrange this must be held prior to the admission.

The Acute Liaison Nurse for Learning Disabilities can offer information on specific syndromes and can also assist with the sourcing and development of easy-read information.

Additional support may be required from the patient's existing care team from the community. The LD nurse can identify what needs should be met by paid carers and ensure that the ward staff are aware of this arrangement. For example, if the paid carers are assisting with personal hygiene needs of the patient, they need to be aware of potential tissue viability issues, and be sure to hand them over to the ward staff to ensure accurate recording is maintained. Information on those learning disabled individuals who are MRSA positive, for example, should be shared with all those who come into contact with that individual.

4. Elective Admission

See **Appendix 1** for Practice Guidance: Planned Admission.

5. Pre-operative Assessment and Out Patient appointments

Some learning disabled patients may require an 'initial visit' to the clinic to familiarise themselves with the environment. The Acute Liaison Nurse can assist in facilitating the initial visit, and identify any issues/additional requirements the patient needs for the clinic appointment.

Please refer to appendix 5: Top 10 Tips for Effective Consultations

Most learning disabled patients admitted for elective surgery or treatment will attend the pre-operative admission clinic for assessment.

In addition to the standard assessment, the following should be recorded:

- Does the patient have a patient passport? (details of which can be found on the SWFT Intranet under safeguarding).
- Level of outside carer involvement available (if any) during hospital admission and who is responsible for arranging and funding. Paid carers may take on a limited role of providing only social support or behaviour management whilst someone is in Warwick hospital, with all nursing and personal care being provided by ward staff for example.
- Are there any relatives who need to be contacted? Or (if the patient lives in a residential home) establish who the key worker is and ensure that information about the patient's care and health needs is shared with the person responsible for the patient's care on discharge. The Acute Liaison Nurse for Learning Disabilities can assist with this, and can facilitate a discharge planning meeting.
- Is any specific equipment required? If so what and who will provide it?
- How does the patient's disability affect their day-to-day lives and support needs?
- Is there any training or educational needs to increase or maintain their level of independence (for example, managing diabetes or enteral feed training)?
- Establish current medication regime and the form in which it is given. Many people with a learning disability have complex medication regimes which have been finely tuned over time. It is important for pre-admission medication regimes of long term medications, for example anti-convulsants, are adhered to while the patient is in hospital.
- Ability to consent to treatment

The Pre-operative assessment clinic staff should also:

- Confirm admission arrangements
- Inform the Ward Manager of the patient's needs and admission date
- If required, make a referral to the Acute Liaison Nurse for preparation work with the patient and carers and ward staff.

Many learning disabled patients will have no additional support needs and the care required will be as for other patients with the same medical condition. However, consideration should always be given to the fact that patients who have a learning disability may have limited formal numeracy and literacy skills and may need information adapted accordingly.

They may also require specific support for accessing written information, such as choosing meals from the menu for example. Hospital staff should not assume that because they have left a glass of water or plate of food by a patient's bedside that that person will necessarily understand that it is meant for them.

Some patients are anxious about receiving medical treatment (DOH, 2003). A pre-admission hospital visit may be arranged to reduce fears and minimise anxiety for the patient. A visit can be arranged by contacting the Pre-operative Assessment Clinic or the Acute Liaison Nurse for Learning Disabilities.

6. Consent and Capacity (Elective Procedures)

- Consent to examination or treatment must be obtained in accordance with the Trust's Consent Policy (2004), guidance issued from the Department of Health (2001) and in line with the Mental Capacity Act (2005) **(please refer to appendix 7 for the five main principles from the MCA)**
- Capacity assessments must be completed in line with the Mental Capacity Act (2005) staff may also have to refer to the DoLS procedure if it is thought there may be issues relating to deprivation of liberties.
- When provided with appropriate information and time, many people with a learning disability can make this decision for themselves
- Many carers still hold the belief that they can consent on behalf of an individual who lacks capacity (to make decisions). They cannot legally do this, although it is good practice to consult with the patient's carers or relatives
- When an individual lacks capacity, treatment can only be given if it is deemed by the clinician to be in a person's 'best interests'. It is good practice for 'best interest' decisions to be made with input from other members of the multi-disciplinary team. Advice can also be sought from an independent advocacy service **(Appendix 8)**

- Any 'Best Interests' meeting should involve all professionals actively involved in the patients care, both from the acute setting and the community teams, as well as family and friends. When discussing 'best interests' in relation to medical treatment, the following must be considered; the least restrictive option for treatment, explore all available options, determine what the patient's wishes would be, have this meeting recorded and documented clearly in the patients notes.

7. Emergency Admission

See **Appendix 2** for Practice Guidance: Acute Admission

8. Initial Assessment

If the patient with a learning disability is unaccompanied and requires support, the nurse must attempt to identify the main carer and make contact with them as soon as possible, providing the patient has given consent for this (if they are able). If the patient cannot provide any verbal or written information, contact should be made with the Acute Liaison Nurse or the Social Services Department, for advice and support.

Outside of normal working hours, the on call Community Learning Disability Nursing Team may be called for advice via the switchboard at Brooklands Hospital.

If staff are unable to contact these agencies, they should contact the police for advice.

If the patient is very anxious and finds it difficult to sit in a waiting area:

- Consideration must be given to 'fast tracking' the patient through the department. (This information must also be passed onto relevant departments such as X-ray – (DOH 2003)
- Offer the patient access to an alternative waiting area, *and/or*
- Allow opportunity to walk around, either in the hospital building or outside, until it is their turn to be assessed for treatment

9. Communication

- All patients need a careful explanation of any treatment they are going to have and any follow up treatment
- Clinical and nursing staff must ensure that information is given in a clear and simple way without using jargon. Staff must ensure learning disabled patients are treated as such and are not spoken to in a childlike or patronising way

- Some learning disabled people may not fully comprehend the instructions they may need to follow after discharge from the department. If possible, the patient should receive written/pictorial information to take away with them so they can refer to this at home and / or share it with carers/friends
- Many people with a learning disability find it easier to understand what is going to happen to them if they are given information with pictures or photographs in it. This helps them make sense of what is happening and feel more prepared for dealing with new experiences (Hannon, 2003). There are a limited number of information booklets, which have been developed locally and nationally, which show procedures, such as having an x-ray or an ultrasound being carried out. These are available from the Acute Liaison Nurse for Learning Disabilities and some are on the Learning Disability Services section of the intranet (Coventry and Warwickshire PT site)
- The patient may not be able to advise staff if they are in discomfort or pain. People with learning disabilities are less likely to complain until something is seriously wrong (Leifer, 1996). Patients with a learning disability will have the same pain management needs as others who have undergone similar treatment or surgery
- There are specialist tools for monitoring pain in patients with a learning disability. These can be provided by the Clinical Nurse Specialist (acute pain) or by the Acute Liaison Nurse for Learning Disabilities. They are also available on the intranet

10. Referral to Other Agencies

- If the patient has no literacy skills and has great difficulty in correctly following instructions, for example, about new medication, a referral should be made to Social Services (preferably with the patients consent) expressing concerns that the individual may not be able to comply with treatment because of their limited understanding and this may impact on their longer-term health
- A referral to an appropriate agency (e.g. Community Learning Disability Nursing Team / Mental Health Crisis Team) should also be considered if there are other concerns about the patient's on going health needs, mental health, coping ability and safety

11. Advocacy

People with a learning disability have the same rights of access to health treatment as anyone else. It is unacceptable to withhold treatment because:

- a. The patient has a learning disability
- b. There are difficulties in obtaining informed consent

The role of the advocate is to be part of the process in enabling the patient to make informed decisions.

Where there is no family involvement, and it is deemed the patient does not have capacity to consent to treatment, the patient may need a referral to IMCA the Independent Mental Capacity Advocate (See Appendix 8 for Advocacy Service contact details)

12. Care planning

- Care plans that are developed must ensure that any special needs that the individual has are met. This may include:
 - Mobility
 - Positioning
 - Nutrition and feeding
 - Use of specialist equipment e.g. use of plate guards
 - Medication regime prior to admission
 - Any Safeguarding issues (which must be addressed using the Warwickshire Safeguarding Vulnerable adults procedure)

- Patients with learning disabilities should always be encouraged to take an active role in the planning of their care if they are able to do so. Information and documentation may need to be adapted to meet this purpose. When assessing and planning care for a patient with a learning disability you should always ask the patient to give their views before referring to carers. If the patient is unable to provide medical history due to their acute condition or learning disability, ask the carer to assist in providing information, and check if the patient has a Health Book, or Hospital Passport.

- Some people with learning disabilities who live in social care residential settings should have a plan of care, which may provide useful information about communication needs and pre-existing health conditions.

- The patient will need to be orientated to the ward by being shown around the environment including where the bathroom and toilet are situated

- It should not be assumed that the patient would need or want a side room. Some individuals may feel very isolated if placed in a side room

- Many patients benefit from the application of a local anaesthetic cream prior to the sighting of a cannula or administration of any injection

13. Surgery

- If the patient is very distressed pre-operative sedation may be required. This must be discussed by the clinical team and form part of the patients care plan
- A patient who is very anxious on the day of their treatment or surgery may be less distressed if there is an opportunity for their carer to accompany them to the anaesthetic room and be available in the recovery room after the surgery has taken place
- The liaison nurse may be able to provide this support to the patient if they are already known to the Learning Disability service

14. Discharge

Please use in conjunction with the Warwickshire Discharge Policy

- Many patients with learning disabilities will have complex discharge planning needs. This applies across the spectrum of disabilities, from those with a mild learning disability to those with high levels of support need
- The Acute Liaison Nurse for Learning Disability should be involved in discharge planning from the point of admission to help ensure arrangements are appropriate. The Liaison Nurse will link with the hospital discharge co-ordinators as well as the Community Learning Disability Team and the hospital and community social work department
- It should not be assumed that the patient would be discharged into a setting where they have an extensive care package. For example people living in supported living may only have a few hours of care each day. A care package or change of care may need to be set up whilst the patient is still in hospital
- It is recognised that people with a Learning Disability may take additional time and need extra support when recovering from a period of ill health or surgery (DOH 2003). Their rehabilitation needs are still important, and may be able to continue post-discharge, with support from specialist Learning Disability community practitioners.
- Involving specialist Learning Disability practitioners is likely to aid the process of recovery as advice can be given in managing individuals needs (DOH 2003)
- If the patient does not understand after-care instructions, such as taking new medication, advice must be sought from either social services or the Acute Liaison Nurse for Learning Disability; otherwise the person's health may be compromised. A list of useful contacts that may be able to support with discharge is available on the Learning Disabilities section of the intranet

15. Contributors

Disability awareness group	Warwick Hospital
Sarah Finan	Practice Development Facilitator
Colleen Ingham	Senior Nurse Manger, Learning Disabilities
Suzi Miller	Service User
Sally Tilsley	Practice Development Facilitator

References and Further Reading

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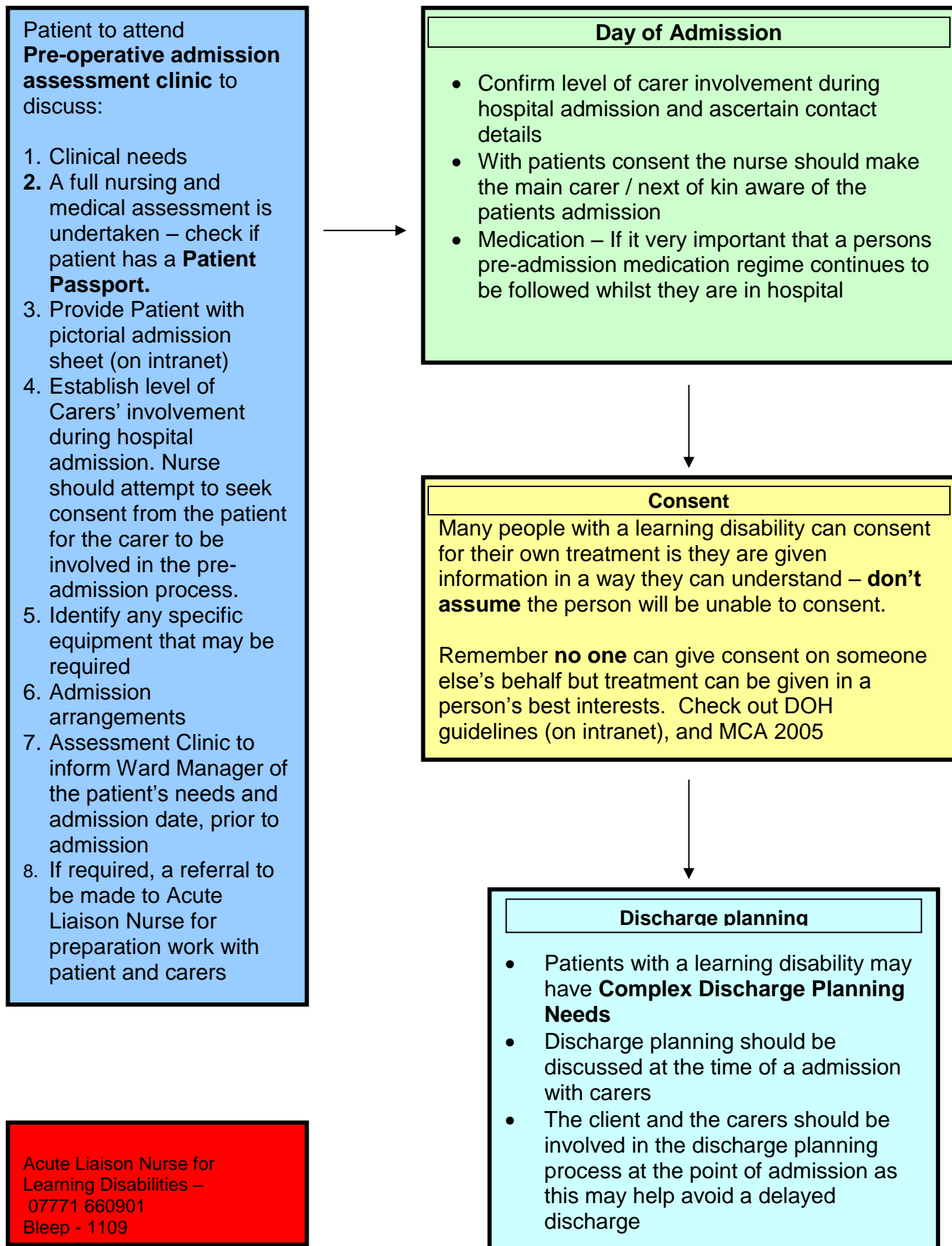
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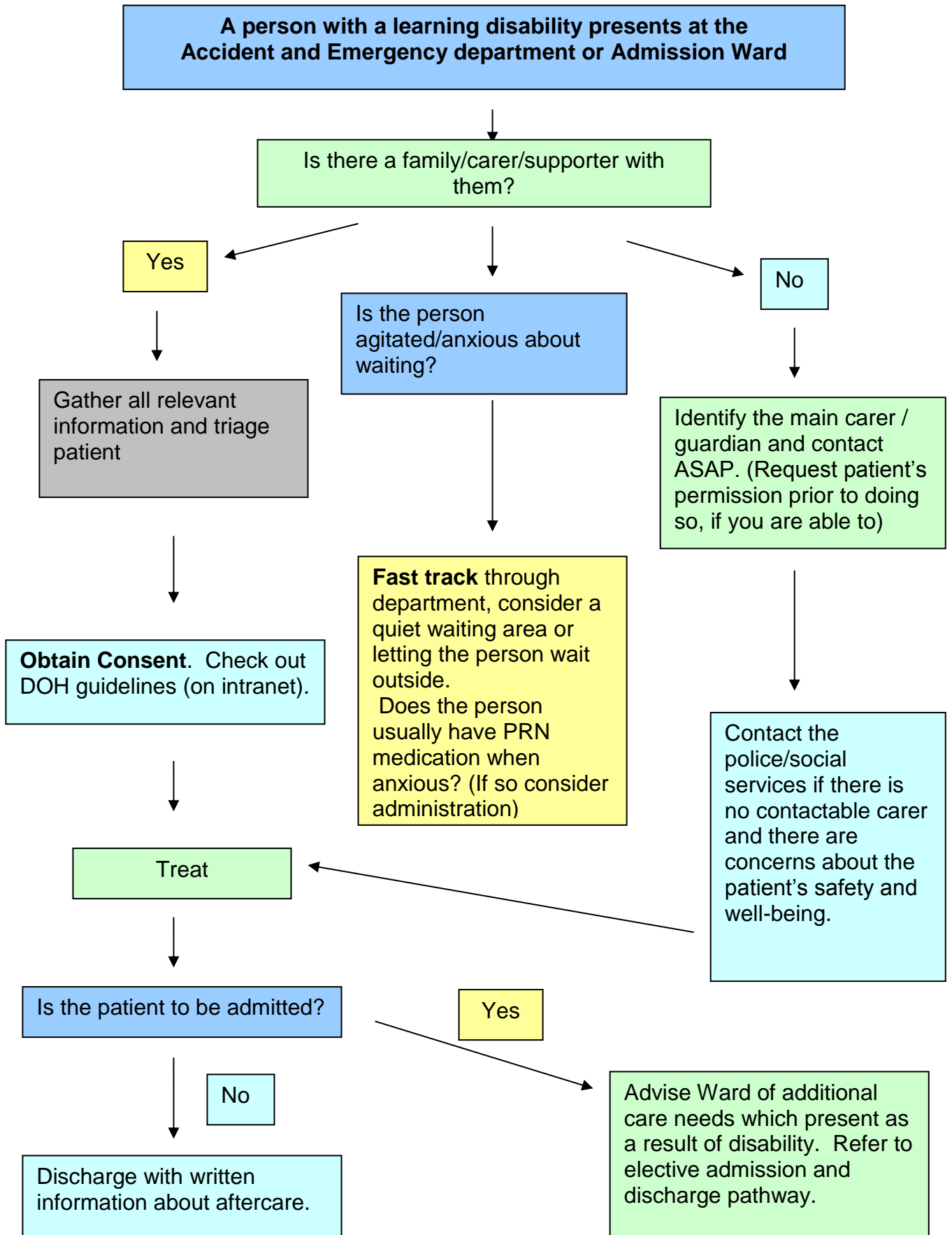
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Appendix 2

Practice Guidance: Emergency Admission



**Practice Guidance: Discharge
(In conjunction with Hospital Discharge Policy).**

Patients with learning disability – planning for discharge:

Many patients with learning disabilities will have *complex discharge planning* needs therefore consider the need for a **Multi-disciplinary planning meeting**.

Specialist services play an important role in helping Acute Hospital staff understand the needs of people with a learning disability (DOH 2003) and should therefore be involved in MDT meetings.

Locally, in addition to the Community Learning Disability Nursing Team, there are specialised Allied Health Professionals.

Problems with Rapid Discharge:

‘Discharge from Hospital: Pathway, Process and Practice’ (DOH 2003) identifies that the emphasis on rapid discharging means some people with a learning disability are returning to the community when their needs have not been identified, treated or met.

It is important to understand that many paid carers who support people with a learning disability do not have any nursing or health based training and will therefore need follow up support and advice if they to provide appropriate aftercare for the patient.

Family carers of people with learning disabilities are often older carers. Do they have the physical ability to manage additional health needs?

Discharge paperwork:

Most patients who have a learning disability (even those with a mild learning disability) will have limited reading skills. It is therefore important to explain to the patient any aftercare information, such as new medication, follow up appointments etc. Concept of times may be difficult for individuals when taking new medication.

Refer to intranet site for further information and consider if a person may need additional support such as homecare, in order to successfully follow up aftercare advice.

Issues to consider before discharge:

Does the person need extra time to recover because of additional physical and mental health problems?

Can the individual realistically return to their previous home environment?

Can carers deal with additional health needs?

**Acute Liaison Nurse
for Learning
Disabilities –
07771 660901
Bleep - 1109**

Appendix 4

Contacts

- A specialist Learning Disability Speech and Language Service is provided by Coventry and Warwickshire Partnership Trust and can be contacted via Brooklands on 0121 7796981
- The Advocacy Service in North Warwickshire is called Independent Advocacy and they can be contacted on 01926 887990
- The Integrated Disability Team will carry out Social Services Carers Assessments and offer support. They can be contacted on 01926 410410.
- The Acute Liaison Nurse for Learning Disabilities is based at Warwick hospital. She can be contacted on 0771 660901 or bleep 1109
- Out of hours support for people with Learning Disabilities can be contacted via the Community Learning Disability Team on 01926 317746
- A specialist Learning Disability Dietician service is provided in the community by Warwickshire PCT and she can be contacted on 02476 865098
- The lead for Safeguarding and DoLS is Tracey Redgate and she can be contacted on 01926 478113

Appendix 5

Top Ten Tips for Effective Consultations

1. Offer the first appointment of the day.
2. Offer a double appointment
3. If the patient has to wait, due to service constraints, if the patient or their carer has access to a mobile 'phone they should be called just when the consultation is about to begin. This allows them to leave the waiting area if it is too crowded.
4. Talk to the patient about their symptoms. Be aware of communication issues. Do not use medical jargon. Re-phrase questions to test their understanding.
5. Ask the patient to explain in their own terms. Note the terms used to assist future consultations.
6. When talking about time, relate it to events, for example the time of medication. Rather than say 'it needs to be taken twice a day' use a phrase such as 'take it with your breakfast and supper'.
7. Explain or demonstrate what will happen. It may be beneficial to the patient to use symbols or pictures to illustrate procedures.
8. Take time to understand. Sometimes it may be useful to get clarification of issues from carers or relatives.
9. Do not make assumptions. People with learning disabilities feel pain, get ill, and have the right to appropriate treatment.
10. Refer to the relevant professional if required. Provide a health check if the person has not had one recently. Signpost to specialist services if necessary.

Appendix 6

Top Ten Tips Explained

People with learning disabilities often have difficulty with crowded areas, small spaces and waiting for long periods of time. When put in this situation they may become distressed, and this can also upset other patients.

By offering the first appointment, the waiting time is reduced, and the waiting room is less crowded.

This gives the best possible start to the consultation.

People with learning disabilities often need more time to process and share information. They may have communication issues and require information to be provided in an alternative format, such as pictures or symbols.

If they are offered a double appointment there is more time and less rush.

People with learning disabilities have a right to be treated with dignity and respect. It is therefore important to talk to the patient about their symptoms.

Be aware of the communication issues, and the use of signs, symbols and pictures. Do not use medical jargon, and do not relate medical issues to other things, for example calling the urinary system 'plumbing' as this may confuse, or may be taken quite literally.

Re-phrase the questions to test understanding, as people with learning disabilities may give the answer they think you want to hear.

People with learning disabilities may use their own terms to describe their symptoms, for example 'itching' may actually mean 'pain'. If such a term is clarified during a consultation it should be documented as it may assist in future consultations or if other professionals are involved in the persons care.

People with learning disabilities may have already had negative experiences in medical settings, which cause them to be anxious and scared about routine tests such as blood pressure.

It is therefore important to explain or even demonstrate what will happen, and how it will feel. You may need to inform the patient that you will need to examine them, or 'look at the part of you that hurts'.

There may be issues around consent and capacity to consent to treatment. The proper procedures must be put in place, capacity assessment, best interests meeting, accessing the Independent Mental Capacity Advocate (IMCA)

Sometimes, even after all steps have been taken to communicate with the patient, you may not have enough information, and in those situations it is useful to get clarification from the carers who know the patient well.

It has been well documented that people with learning disabilities may have increased health needs, and syndrome specific conditions.

It is important never to make assumptions, use all diagnostic tools to ensure the best diagnosis and treatment for the patient. Be aware of the community learning disability team (CLDT) and how to contact them for information and specialist Learning Disability services.

Appendix 7

The Mental Capacity Act 2005

Five Principles;

1. Every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proven otherwise
2. People must be supported as much as possible to make their own decisions before anyone concludes that they cannot make their own decisions.
3. People have the right to make what others might regard as unwise or eccentric decisions.
4. Anything done for or on behalf of a person who lacks mental capacity must be done in their best interests.
5. Anything done for, or on behalf of, people without capacity should be the least restrictive of their basic rights and freedoms

Appendix 8

POhWER

advocacy, making your voice heard

imca

Independent mental
capacity advocacy

IMCA Referral Form Warwickshire, Coventry & Solihull

<u>Client Name:</u>			
<u>Date of Birth:</u>			
<u>Home Address, postcode, tel</u>			
<u>Location, postcode, tel.</u>			
<u>Date referral made:</u>			
Warwickshire		Coventry	Solihull

Reason for Referral (please tick)

Serious Medical Treatment	
Move to accommodation (NHS body)	
Move to accommodation (Local Authority)	
Safeguarding Vulnerable Adults Procedure (LA)	
Care Review (NHS or LA)	

State Specific Decision (Proposed Options)

Significant dates

When does the decision need to be made by?	
Please give details of any impending meetings or deadlines	

Referrer and Decision Maker's Contact Details:

	Referrer	Decision Maker (If not referrer)
Name:		
Job Title and Team:		

Address:		
Postcode:		
Tel/Mobile:		
Email:		

Contact person for access to records

Specific Cultural and Communication Needs			
Language		Ethnicity	
Gender		Religion	
Sexuality		Disability	
Other (Specify)			

Decision Maker's Confirmation

The decision maker is the individual within either the Local authority or the NHS body who has the responsibility for making the decisions on issues of change of accommodation or serious medical treatment on behalf of the client who has been assessed as lacking capacity on either issue. Therefore only the decision maker is able to confirm the following. *

* I confirm that for the above issue I am the Decision Maker on behalf of *(insert NHS body or local authority)* for decisions regarding *(insert client name)*.....

Name	Signature	Date

Please give details of any family or friends and the reasons why you have deemed them inappropriate to consult:

Name/relationship	Reason for not consulting

* I also confirm that I deem *(insert client name)* to have no-one appropriate to consult regarding this issue (excepting safeguarding adults referrals).

Name	Signature	Date

* I also confirm that *(insert client name)* has been deemed to lack capacity to make a decision regarding the above issue. The person making the decision with regard to the client's lack of capacity in this issue is *(insert name)*
 Their relationship to the client is

Name	Signature	Date

Please return this form to the IMCA team by **fax** to **0845 337 3052**, email to IMCA@pohwer.net or post to **POhWER IMCA, iBIC Holt Court South, Jennens Road Aston Science Park, Birmingham B7 4EJ**. If you have any queries please contact the IMCA duty team by **phone** on