

Supporting patients with learning disabilities

Good practice guidelines



Supporting information can be found on [Source: learning disability project](#); including copies of the tools and assessments.

Produced by:

Darryl Chapman, Acute liaison nurse for vulnerable patients

February 2010

Table of Contents

| | |
|--|-----|
| About people with learning disabilities..... | 3 |
| The impact of learning disabilities | 3 |
| Duty to promote disability equality | 4 |
| Supporting effective communication | 6 |
| Supporting admissions and discharges | 7 |
| Preparing individuals for admissions or clinical interventions | 7 |
| Clinical tools..... | 8 |
| Supporting family or familiar carers..... | 9 |
| Consenting to treatment: The Mental Capacity Act (2005) | 11 |
| Supporting people with learning disabilities to consent to treatment | 12 |
| Carrying out care or treatment in an individuals ‘best interests’ | 12 |
| Involving specialist learning disability teams | 13 |
| Using and creating accessible information | 14 |
| Quality assurance (Essence of Care) | 15 |
| References | 16 |
| Useful contacts | 177 |
| Appendix 1 Admission and discharge procedure (learning disabilities)..... | 18 |

About people with learning disabilities

Patients with learning disabilities will need special consideration to ensure that they receive care and treatment which meets their specific needs and maintains their safety.

The National Patient Safety Agency (2004) concluded that patients with learning disabilities are particularly vulnerable when in acute hospital settings leading to varying degrees of harm as a result.

Frequently people with learning disabilities have a number of complex needs. These may include impairments in functional skills, communication and additional sensory impairments; as a result an individual may be disorientated, confused or anxious in a setting which is unfamiliar.

In addition, individuals with multiple disabilities or complex health problems are likely to use health services (including acute hospital services) on a regular and frequent basis.

The impact of learning disability will often mean:

- The person will be less able to understand and retain new or complex information,
- They will require that you use simple language and explain things that may be unfamiliar,
- They may be at greater risk of swallowing difficulties,
- The person be less able to communicate pain or discomfort,
- May rely on others to meet some or all of their basic needs or to maintain their safety.

(Department of Health, 2001)



Possible Indicators of the Presence of a Learning Disability

Difficulty following instructions

Difficulty understanding and processing information

Difficulty understanding abstract concepts such as time or directions

Repetition of phrases in conversation without expanding on the content

Duty to promote disability equality

Disability Discrimination Act (1995) places a duty upon all service providers and public bodies to ensure that people with disabilities can access services on an equal and equitable basis (general duty). Service providers are required to make **'reasonable adjustments'** to the way in which a service or function is carried out to enable disabled people to access services and support on an equal basis.

The Act was amended in 2005 and now requires public bodies take steps to actively promote the rights of people with disabilities (specific duty).

In order to achieve equality of access for people with learning disabilities services may need to provide more favourable support or treatment to disabled people in order to achieve the same outcomes (Disability Rights Commission, 2007).

What reasonable adjustments are needed will depend upon an individual's specific disability related needs. Therefore both timely and comprehensive assessments of individual's disability related and safety needs is crucial to ensuring that people with disabilities or complex needs receive appropriate care and support.

The following are examples of reasonable adjustments that may be required by patients with learning disabilities.

Consider offering extended or double appointments where this would assist to support effective communication

Consider offering a **choice of appointment time**, for example the first or last appointments may suit particularly anxious patients or those who find sitting in busy waiting areas difficult

Use the hospital passport to ensure that you have gathered information about a person's safety and disability related needs (see the section on Clinical tools)

Consider using pictures or diagrams to enhance patients understanding of disease or planned treatments/procedures

Ensure that you **have recorded individuals specific access needs** and the names of family carers or community professionals who can provide support or additional information.

Review patient information leaflets and ensure that staff have access to easy read leaflets for patients with learning disabilities

Below are some examples of reasonable adjustments made for people with learning disabilities or complex needs

Outpatients department, St Marys Hospital

The outpatients department prioritises patients with learning disabilities and complex needs. It aims to provide a personalised service to individuals and carers.

The department has developed good working relationships with Westminster Learning Disability Partnership and Kensington & Chelsea Community Team for People with a learning disability.

The department has developed a video for people with learning disabilities about coming for an ENT appointment.

West London centre for sexual health

Working with Hammersmith & Fulham Community Team for People with a Learning Disability; the centre has developed a specialised service for clients with learning disabilities.

The Pearl Service has been designed to specifically meet the unique needs of people with learning disabilities. This includes offering an extended appointment, using easy read information & educational materials and adapted communication.

The service has been recognised by the Department of Health and Hammersmith & Fulham PCT (Tracey Harrow Award) as an example of best practice with regards to achieving equality of access to healthcare for people with learning disabilities.

Supporting effective communication

Communication impairments are commonly associated with learning disabilities; whether with regards to expressive communication or comprehension. It is likely therefore that you will have to adapt your communication to meet the needs of people with learning disabilities.

The following guidelines may help to ensure that your communication is appropriate to the needs of people with learning disabilities.

- Ensure that your communication is clear. Use simple language and keep your sentences short
- Explain any difficult or unfamiliar words. For example: “I will send you for an x-ray” it may be better to say; “we will need to take a picture of your arm”
- Check that the individual has understood: “Can you please tell me in your own words what I have just said”
- Give the person time to respond
- Use gestures to emphasise your communication: point to the part of the body you are talking about
- Use pictures or objects to demonstrate what you are going to do before you do it
- Consider what ‘Easy Read’ information may be available
- Be aware of any additional disabilities such as hearing or visual impairment

Total Communication

Total Communication is about using a number of communication methods together to support people with complex needs. This might include a mixture of speech, gesture and accessible written information or pictures.



Supporting admissions and discharges

The Trust has an **admission and discharge procedure for people with learning disabilities** (appendix 1) which is intended to ensure:

- Any disability related support needs are identified
- Clinicians are supported to agree care or treatment plans and any reasonable adjustments that are needed
- To ensure that advice is sought from the specialist community learning disability team or the persons main carer
- Effective discharge plans are made in a timely manner
- That a health action plan is completed by the person's community support worker

Preparing individuals for admissions or clinical interventions

Improved outcomes can be achieved for patients with learning disabilities or complex needs by effective planning and will likely reduce the number of appointments missed or aborted.

Consideration should be given to what preparation a patient with learning disabilities or complex needs might require in order achieving good outcomes and a positive patient experience.

For example patients may be put at ease if supported to visit the ward or department ahead of their appointment or have the opportunity to see the equipment that will be used.

Patients with learning disabilities are likely to have difficulty understanding abstract concepts or have limited understanding of the treatments being proposed.

Additionally, many individuals will require such preparation and information in order to make an informed decision and to consent to treatment.



Clinical tools

There are number of clinical tools which are aimed at assessing the needs of patients with learning disabilities, complex needs or who are unable to effectively communicate their own needs.

Copies of the tools can be found on Source: learning disability project

My Hospital Passport or Vulnerable Patient Form

The hospital passport is designed to capture essential information about the needs of vulnerable patients unique needs; including how the person communicates, information on assessing pain and supporting the person to consent.



The Hospital Communication Tool

This comprises a comprehensive resource for those with limited communication or needing support with communication; it includes drawings, photographs and diagrams.

Additionally, some patients may have their own communication tools or aids; which they should be encouraged to bring into hospital.

Risk, dependency and support assessment tool

The risk, dependency and support assessment is designed to identify risks to a patient with learning disabilities whilst in an acute hospital setting. This includes both physical risks as well as risks to the effective outcome of the hospital stay and any additional support that may be required to support appropriate and safe care.

The assessment tool offers a framework to assist in deciding if an additional support is needed to reduce risk during a hospital stay and to identify the person or agency that is best able to provide that support.

It is recommended that the Risk, Dependency and Support Assessment is used by the nurse in charge of the ward alongside the patient and those who know the patient best (e.g. paid support staff, family members or advocates).

The Abbey Pain Scale

The Pain Scale is designed to assist in the assessment of pain in individuals who are unable to clearly articulate their needs. It is a movement based assessment; meaning that it is based on observations whilst the person is being moved e.g. during personal care, pressure area care or mobilising.

Supporting family or familiar carers

Familiar carers are an invaluable resource with regards to providing care that is appropriate to patients needs; in particular where individual patients are unable to communicate their needs adequately or consistently.

A lack of clarity around the role of familiar carers can, however, compromise the continuity of care and patient safety.

The role of family or familiar carers is primarily to:

- Facilitate effective communication, including supporting the patient to comprehend information
- Support the clinical team to agree a care plan which appropriately meets the patients specific needs
- Provide support emotional support; in particular during clinical investigations or treatment or advise clinical staff on best approaches
- Support the patient to make decisions (consent) relating to care and treatment
- Assist clinicians in making 'best interest' decisions; where the patient lacks the capacity to make a specific decision

Clinical staff are responsible for providing personal and nursing care including:

Care planning and review

Postural management

Monitoring nutritional needs

Manual handling

Personal care and bathing

Administration of medication

Assessment and management of pain relief

Co-ordination of discharge arrangements

Practical support for carers who remain with the person

It should not be assumed that family carers will remain with the patient during a hospital admission; however, where carers choose to stay it is essential that you agree any practical arrangements such as parking, breaks and refreshments.

It would also be important that someone who knows the individual and their communication well must be present when ward rounds happen.

Carers support organisations

It should be borne in mind that hospital admission and subsequent discharge home is likely to have an effect on family carers. What additional support or resources informal carers are likely to need should be considered and discussed as a part of effective discharge planning.

Where appropriate carers should be signposted to carers support organisations for advice or support.

Additionally, the specialist learning disability teams (social services) may be able to offer an assessment of carers needs (see pages 16 and 17 for information about the teams and contact details).

Details of local carers organisations:

Carers Network Westminster

Telephone: 020 8960 3033, Monday to Friday, 9am - 6pm

Email: info@carers-network.co.uk

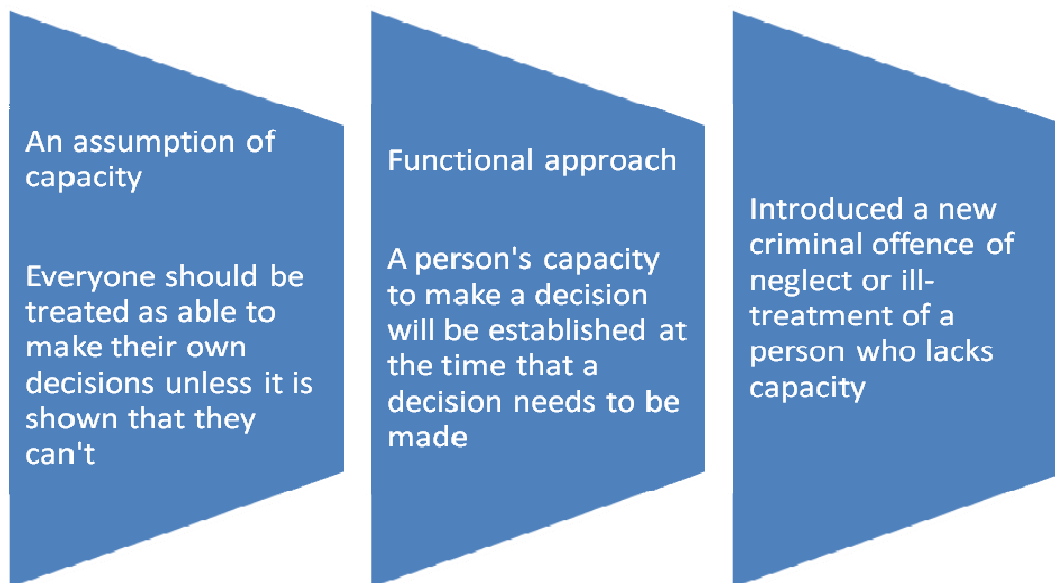
The Princess Royal Trust Hammersmith & Fulham Carers Centre

Telephone: 020 8563 8014 or 020 8563 8019

Consenting to treatment: Mental Capacity Act (2005)

The Mental Capacity Act (2005) provides a legal framework for supporting individuals who may lack the capacity to make some decisions for themselves.

This may be due to a learning disability, mental health problem, brain injury, dementia, alcohol or drug misuse, side effects of medical treatment or any other illness or disability.



The functional test of capacity (consent)

The Mental Capacity Act adopts a functional approach (set out below) with regards to assessing whether an individual has the capacity to make a specific decision.

1. Does the person have a *general understanding* of what decision they need to make and why?
2. Does the person have a *general understanding* of the likely consequences of making or not making this decision?
3. Can the person retain information in relation to the decision and to use and weigh-up information relevant to the decision?
4. Can the person communicate their decision?

If the person is unable to carry out one or more components then s/he cannot be considered to have capacity.

Supporting people with learning disabilities to consent to treatment

Both the Mental Capacity Act (2005) and Disability Discrimination Act (1995) emphasise the importance of supporting and enhancing an individual's ability to consent to care or treatment. In doing this it may be necessary to adapt the manner in which you convey information regarding the proposed care or treatment; for example by using simple language or accessible health information.

It should also be borne in mind that individuals may require longer to process information and to come to a decision. Additionally, whilst you may have assessed that the person lacks the ability to make a decision at this time; you may consider if it is appropriate or safe to delay treatment to allow time for work to be done to enhance the individual's ability (capacity) to make a decision regarding the proposed treatment/s.

Carrying out care or treatment in an individual's best interests

The Mental Capacity Act (2005) makes specific provisions and safeguards with regards to carrying out care or treatment in an individual's best interests; where an individual lacks the capacity to make a specific decision. The Act supports clinical staff when undertaking care or treatment in an individual's 'best interests'

The Act does not define the term best interests but instead provides a checklist of factors which must be taken into account when deciding if a course of action is in that persons best interests.

'Best interests' Checklist

- Consider all the relevant circumstances; what might the persons wishes have been had they the capacity to make this decision?
- Could the person gain capacity in the future with further information, teaching or support or due to a fluctuating condition?
- Encourage the person to participate as fully as possible
- Consider the views of other relevant people (where practicable and appropriate)
- Consider whether the outcome could be achieved in a less restrictive way
- What are the persons known values & beliefs

You must not make any 'best interest' decisions on the basis of the individual's age, appearance, behaviour or condition. If the decision is with regards to life sustaining treatment; you must not be motivated to bring about the persons death.

Involving specialist learning disability teams

Frequently patients with complex needs are supported by primary care services or specialist community learning disability teams. It is vital that clinical staff draw upon the expertise of these professionals and teams.

Specialist teams may be able to support with:

Supporting the assessment of the care and nursing needs of those with complex disabilities whom they support in the community,

Advising on previously successful approaches to support or communication,

A source of specialist expertise regarding the impact of learning disabilities,

Supporting clinical staff with issues of consent or 'best interests' decision-making

Supporting effective discharge arrangements; including supporting any necessary changes to community care packages as a result of changed health or social care needs.

By using the **admission and discharge procedure** (appendix 1) you will be able to confirm if the patient is supported by one of the specialist community teams as well as promoting multi-disciplinary and multi-agency working.

Frequently the community learning disability teams are a multi-agency and multi-professional in nature and include:

Social workers,

Case co-ordinators,

Specialist learning disability nurses,

Clinical psychologists,

Speech and language therapists

Behaviour therapists,

Dieticians,

Physiotherapists,

Psychiatrists,

Music/art therapists.

The specialist teams undertake assessments of an individual's social care needs as well as commissioning/ purchasing social care support packages.

Using and creating accessible information

Easy Read is one way of making information more accessible to people with learning disabilities.

Easy read is an approach using easy language, photographs or drawings to enable people with learning disabilities to better understand written information. It can be additionally used to comply with the Disability Discrimination Act (1995) as a reasonable adjustment for disability. Easy read may also be of benefit to other patients who require information in an easier to read format.

Easy Read is not always the answer

Easy Read is not the only way to communicate with people with learning disabilities. Sometimes video, talks, presentations, drama, murals, role-play or posters can be better ways of communicating complex or sensitive information.

Easy Read is a tool for increasing the number of people with learning disabilities who can access information. It should be remembered, however, that not every person with a learning disability is able to use Easy Read; many people with learning disabilities will require additional support to access information, via support workers or carers, and some may also require information in audio or video formats.

The Trust is working to develop easy read information for people with learning disabilities. Examples of which can be found on [Source: learning disability project](#)

Quality assurance

The following benchmarks have been agreed with regards to the standards of care for patients with learning disabilities in acute hospital settings.

Essence of Care:

Benchmarks for safety of patients with learning disabilities in acute healthcare settings

| Factor | Benchmark for Best Practice |
|--|---|
| 1 Care is safe & appropriate | Patients have a comprehensive & ongoing assessment of their unique support needs. |
| 2 Making reasonable adjustments | Reasonable adjustments with regards to the provision of care & treatment are agreed and recorded in the patient record or care plan |
| 3 Orientation | Patients are fully orientated to the ward or department and feel safe |
| 4 Carers needs | Carers are given sufficient support & information to allow them to carry out their caring role |
| 5 Participation | Patient & carer or advocate are regularly & actively involved identifying care & safety needs |
| 6 Co-ordination | Care & support is effectively co-ordinated and where necessary or appropriate involves specialist learning disability services or social care provider |
| 7 A positive culture to learn from complaints & adverse events | There is a no blame culture which allow a vigorous investigation of complaints, adverse incidents & safeguarding alerts and ensures that lessons are learnt and acted on |

References

Department of Health (2001) *Valuing People, a strategy for people with learning disabilities*

Disability Discrimination Act (1995) c.50 London: HMSO

Disability Discrimination Act (2005) c.13 London: HMSO

Disability Rights Commission (2007) *Equal treatment: Closing the Gap. Investigation into Health Inequalities for people with mental health issues and learning disabilities.* London: Disability Rights Commission

Home Farm Trust, Valuing People Support Team (2009) *Working Together: Easy steps to improving how people with a learning disability are supported when in hospital.*

Mental Capacity Act (2005) c.9 London: HMSO

Michael, J (2008) 'Healthcare for All': Report of the Independent Inquiry into access to healthcare for people with a learning disability

National Patient Safety Agency (2004) *Understanding the patient's safety issues for people with a learning disability.* London: HMSO

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

Useful contacts

Acute liaison nurse for vulnerable patients (fixed term post until July 2011)

Telephone: 020 3312 1848 email: darryl.chapman@imperial.nhs.uk

Westminster Learning Disability Partnership

Telephone: 020 7641 7411

Kensington & Chelsea Community Team for People with a Learning Disability

Telephone: 0207 313 6843

Hammersmith & Fulham Community Team for People with a Learning Disability

Telephone: 020 8383 6464