

GAIN 

GUIDELINES AND AUDIT
IMPLEMENTATION NETWORK

CARING FOR PEOPLE WITH A LEARNING DISABILITY IN GENERAL HOSPITAL SETTINGS

EASY ACCESS VERSION



June 2010

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FOREWORD

These guidelines have been published by the Guidelines & Audit Implementation Network (GAIN), which is a team of health and social care professionals established under the auspices of the Department of Health, Social Services & Public Safety in 2008. The aim of GAIN is to promote quality in the Health Service in Northern Ireland, through audit and guidelines, while ensuring the highest possible standard of clinical practice is maintained.



These guidelines address the needs of an important and vulnerable group in society and to further this aim we have included an example of a possible implementation plan which we hope will ease the adoption of these guidelines under most circumstances.

This guideline was produced by a sub-group of health care professionals from varied backgrounds and was chaired by Maurice Devine, Nursing Officer at the Department of Health, Social Services & Public Safety (Northern Ireland).

GAIN wishes to thank all those who contributed in any way to the development of these guidelines.

A handwritten signature in black ink that reads "Tom Trinick". The signature is written in a cursive, flowing style.

Dr T Trinick
Chairman of GAIN



INTRODUCTION

Going into hospital is stressful for any of us. People feel vulnerable because, as well as being very ill, they find themselves in an unfamiliar place, with people they don't know who are using language they may not understand.

People with a learning disability may feel even more vulnerable. This is because:

- they may find it difficult to communicate
- they may have other health problems as well as the one they are going into hospital with
- hospital staff may not fully understand their needs.

Our health and social care policy recognises that people with learning disabilities are equal and valued citizens of the country. However, studies show that they often find it difficult to get appropriate hospital care.

These guidelines for care delivery will help people with a learning disability to get safe and effective care in hospital.

You will see some words in the text in bold type. We explain these at the end of the document.



ATTITUDES AND VALUES

Best practice means that:

Staff in general hospitals should make sure that they offer people with a learning disability the same range and level of care and treatment as they would offer anyone else.

Hospital staff should:

- see the person not their disability
- make sure that they communicate with the person in a way that is appropriate and sensitive to what the person needs and prefers
- involve people with learning disabilities in decisions, and understand the law around **capacity** and **consent**
- involve carers and **advocates** (people who can speak for the person) when appropriate
- deliver care that focuses on the needs of the person
- get training on learning disability
- deliver dignified, respectful and compassionate care
- not make judgements about people.



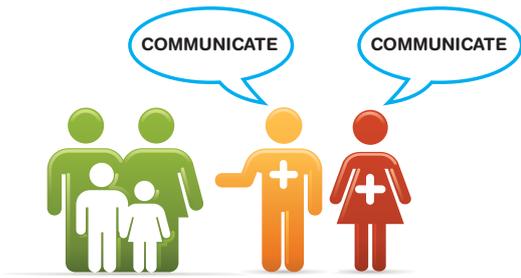
COMMUNICATION

Best practice means that:

Staff in general hospitals should communicate effectively with people who have learning disabilities and with their families and carers. This supports safe care that considers the unique needs of each person.

Hospital staff should:

- find out how each person prefers to communicate
- communicate with the person first but, if necessary, also speak with family and carers about how they can help
- call people by the name they prefer
- speak slowly and not shout
- use plain language
- use gestures, pictures and symbols if they will help
- take time to make sure the person understands what they have said
- pay attention to eye contact, body language and touch
- deal with concerns raised by people with learning disabilities, family or carers immediately
- have regular training in communication skills.



LEARNING DISABILITY TRAINING FOR GENERAL HOSPITAL STAFF

Best practice means that:

All general hospital staff who may have to work with people with a learning disability should receive training. This will help to make sure that people with a learning disability receive care from staff who are skilled and knowledgeable, in a safe and caring place that suits their needs.

The training given to new health and social care students should always include Learning Disability Awareness Training.

All new staff coming to work in general hospitals should receive training in learning disabilities, including training on the law.

People with learning disabilities and their carers should help to design and deliver training for staff.

Hospital staff from each **clinical area**, who can promote the needs of people with a learning disability, should get further training. They could then act as a **link nurse**.



LEGAL ISSUES IN THE DELIVERY OF CARE TO PEOPLE WITH A LEARNING DISABILITY

Best practice means that:

General hospital staff should understand and use legal and professional guidelines when caring for people with a learning disability. They should make sure they deliver care in a safe, fair and effective way that treats the person with a learning disability like everyone else, but takes into account any special needs that the person may have.

A hospital should:

- train staff on the relevant law
- make physical changes to the hospital and to how care is given, to help people with learning disabilities
- try to meet the person with a learning disability, and those close to them, before they come to hospital
- get **consent** properly and not assume that people with a learning disability cannot make decisions about their healthcare



- when appropriate, hold a **'best interests meeting'** about care for people who cannot make decisions about their healthcare
- tell carers what decisions are made about care, if the person with a learning disability agrees
- make sure treatment is never based on how good or bad the person's quality of life seems
- follow exactly the same approach to **'Do Not Resuscitate'** decisions for people with a learning disability as for everyone else.



PREPARING FOR AN OUTPATIENT APPOINTMENT

Best practice means that:

People with a learning disability who have an outpatient appointment will get help to prepare for this.

Before the appointment

The professional who refers the person to hospital should say what support the person is likely to need.

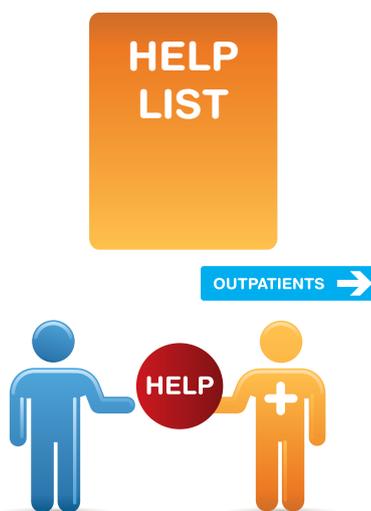
The hospital should invite the person with a learning disability or their carer to contact the outpatient department staff before the first outpatient appointment.

The hospital should try to find out:

- how well the person can communicate
- what physical care needs they have
- how they can help if the person becomes distressed.

The hospital should provide clear information. This should include contact details of staff who can help, and clear directions on how to find the right department in the hospital.

The hospital should try to give people with learning disabilities early appointments



At the appointment

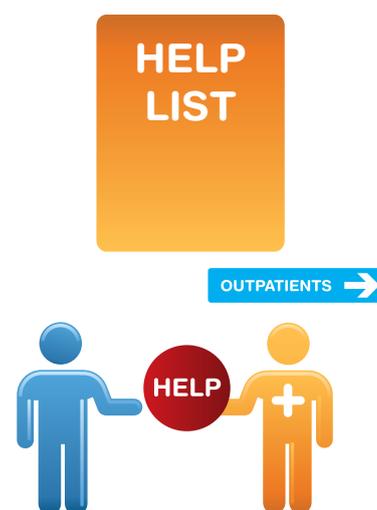
The person should have a place to wait that suits their needs.

Hospital staff should explain to the person in plain language what will happen during the appointment.

Hospital staff should monitor the person's level of comfort, anxiety and understanding of what is happening.

At the end of the appointment hospital staff should clearly explain what will happen next.

They should also contact the local learning disability services, if appropriate.



THE ADMISSION PROCESS AND SUPPORT DURING A HOSPITAL STAY

Best practice means that:

When a person with a learning disability needs to go into a general hospital, the hospital staff should prepare, and also try to help the person prepare for this. This is to make sure they receive safe and effective care throughout the hospital admission process.

Before going into hospital

The person should be able to visit the ward and meet staff.



Carers should be given the opportunity to tell hospital staff about the person's needs.

Staff in the local learning disability services should also help the general hospital staff to understand the needs of the person.

Hospital staff should make sure they have any special equipment they might need for the person.

The person with a learning disability may have a health book that tells others about their health needs. If so, hospital staff should ask to see this information.

The hospital staff should have easy-read information about the ward, the hospital and procedures that they can give to the person.



During the time in hospital

The patient should have a named nurse to look after them.

Hospital staff should introduce themselves to the patient and their carers and show them around the ward.

Hospital staff should explain any treatment and care in plain language and use pictures and symbols where they can help the patient to understand.

If the patient finds it difficult to say how they are feeling, hospital staff should spend more time with them to ensure that they understand what is happening and to monitor changes in their health.

Hospital staff should always care for the patient in a way that respects their dignity and privacy.

If the patient who has learning disabilities needs an operation, staff from the theatres should visit them before the operation and ensure that they understand their needs.



DISCHARGE PLANNING

Best practice means that:

When a person with a learning disability is in a general hospital, their plan of care should include information about how and when they will leave the hospital.

Hospital staff should work with the patient, carers and other health and social care professionals to plan this **discharge**, taking into account the patient's needs.

Hospital staff should clearly explain what happens at discharge and involve the patient in planning it. They should give the patient and carer written information that is easy to read and understand. This should include information about treatment, medicines and follow-up care.

If a person has to receive care or treatment at home, the hospital should train family or carers how to deliver that care.

Hospital staff should give the patient a telephone number they or their carer can ring after they've left the hospital, so that they can ask questions about their care.

Hospital staff should ask the patient, family and carer to tell them what they thought of the care they got when in hospital.



ATTENDANCE AT EMERGENCY CARE SERVICES

Best practice means that:

People with a learning disability who use the emergency care service should get effective care in accident and emergency departments, which takes account of their needs.

Emergency care staff should find out whether the person can wait in the public waiting area without being distressed. If not, they should try to find a quieter area where the person can wait.

Emergency care staff should consider treating people with a learning disability more quickly so they do not have to wait. This is sometimes called 'fast-tracking'.

Emergency care staff should check if the person has documentation that explains how they communicate, or other information that will help the staff care for them.

During **triage** staff should allow extra time to assess the person's needs, explain the plan of care and get the person's **consent**. Family members or carers may be able to help at this time.

Where possible the same nurse should care for the person when they are in the emergency care department.



ATTENDANCE AT EMERGENCY CARE SERVICES CONT'D

The person should get information about their care that is easy for them to understand.

If the person requires further care either in a hospital or in the community, emergency care staff should communicate with these service providers.

When the person is being discharged, emergency care staff should give the person and carer written information that is easy to read and understand. This should include information about medication, treatments or follow-up arrangements.



Community Learning Disability Teams should also provide information to emergency care staff to help them understand the person's particular needs. This is particularly important if the person needs to use emergency care departments a lot.



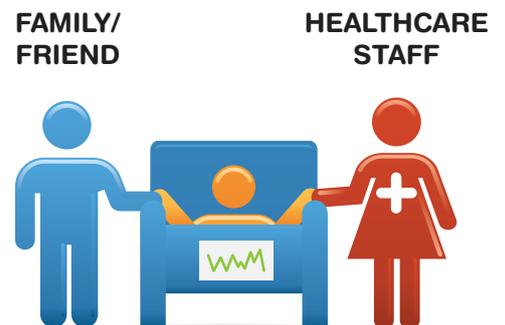
SUPPORT FOR CARERS

Best practice means that:

When a person with a learning disability is in a general hospital, their family members/carers should be seen as healthcare partners throughout their care, working alongside healthcare staff. The person with learning disabilities should agree to this.

Hospital staff should:

- listen to and value carers and involve them in the person's care
- not routinely expect family members, carers or staff from learning disability services to provide direct care to a person who is coming into hospital
- give easy-read information to the person and carer to explain how to make a complaint or a compliment
- deal with complaints quickly and sensitively
- find out if an **advocate** (someone to speak for the person with learning disabilities) is available for the patient
- consider whether the carer would benefit from a **carer's assessment**.

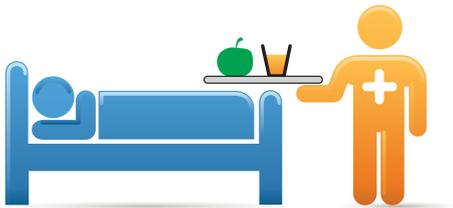


EFFECTIVE NUTRITION AND HYDRATION

Best practice means that:

People with a learning disability in hospital should get high quality nutritional care (food and drink) that meets their needs. This means that hospital staff should assess carefully the needs of people who have learning disabilities to ensure they receive the proper nutrition and get help with eating or drinking if required.

If a patient has swallowing or other problems with eating or drinking they may need some additional help.



Hospital staff should find out if the patient has a health action plan that shows what food and drink they need and what support they might need to eat and drink.

Hospital staff should assess the patient to find out if they are malnourished (have not had enough or the right foods to eat).

Patients who need support with eating and drinking should get help. This includes providing plate guards and non slip mats.

Staff should monitor and record how much food and drink the patient takes.

The hospital should use menus with pictures to help patients choose their meals.



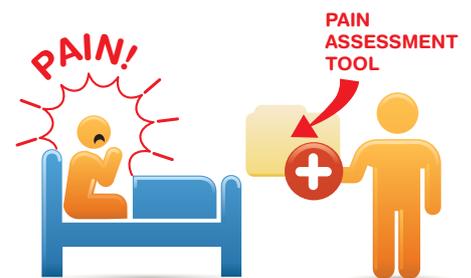
ASSESSMENT AND MANAGEMENT OF PAIN

Best practice means that:

Hospital staff should carefully assess people with a learning disability to find out what pain they have so that they can treat it. Staff should watch closely for how a patient with learning disabilities communicates their pain – either by speaking or by the way they behave.

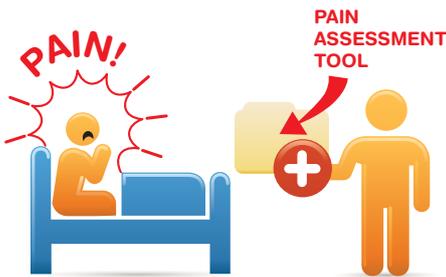
Hospital staff should:

- ask the patient questions about the pain and give the patient plenty of time to reply
- use pictures to help find out where and how bad the patient's pain is
- be aware of the signs and symptoms of pain that the patient may show
- use the skills of specialist pain nurses if they are available
- talk to the family or carer to find out how the patient shows pain and if they have had this pain before



ASSESSMENT AND MANAGEMENT OF PAIN CONT'D

- explain clearly any examinations needed
- watch carefully how the patient reacts to painkillers
- watch for side effects of medicines
- use **pain assessment tools** that are specially designed for people with learning disabilities.



IMPROVING THE EXPERIENCE OF CHILDREN WITH A LEARNING DISABILITY

Best practice means that:

Children with a learning disability who use general hospitals will receive safe and effective services. These will be appropriate to their age and their needs.

If possible, the hospital should gather information about the child before they go into hospital to help staff understand the child's needs.

Children with a learning disability should be seen quickly when they go to hospital.

The child's plan of care should include information about how and when they will leave the hospital.

The child and their family/carers should help to plan the child's care. The child should receive information that they can easily understand.

The hospital should help families to stay in touch with their child in hospital. This includes arranging for them to be with their child during the night.

Children who spend long periods in hospital should get special services like music and art therapy and education.



If a child has to receive care or treatment at home, the hospital should train family and carers how to deliver that care.

There should be regular communication between community and hospital staff, especially at times of admission and discharge.



THE DEVELOPMENT OF THESE GAIN GUIDELINES HAS BEEN INFORMED BY THE USER REFERENCE GROUP

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GLOSSARY

General hospital

a hospital where a patient is treated for a severe illness for a short time

advocate

a person who speaks on behalf of someone else

best interests meeting

a meeting to decide what care is best for the patient given their particular needs

capacity

the ability to understand and make decisions

carer's assessment

a review of a carer's needs

clinical area

a department in the hospital dealing with a particular medical condition or service

consent

to agree to do something



discharge

when a patient leaves the hospital

do not resuscitate

a legal document that states that medical staff should not intervene if a person suffers cardiac or respiratory arrest

link nurse

A nurse who acts as a link between their clinical area and another

pain assessment tools

techniques to find out how much pain a person is in

triage

when hospital staff assess patients to decide how urgently they need treatment



NOTES







Copies of this Audit report may be
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