

POLICY, PRINCIPLES AND PROCEDURES CARING FOR ADULT PATIENTS (16+) WITH LEARNING DISABILITIES WITHIN A HOSPITAL SETTING

Unique ID: NHSL.

Category/Level/Type: 1

Status: Published

Date of Authorisation: September 2013 Review Date: Sept 2016

Date added to Intranet: September 2013

Key Words: Learning Disabilities

Comments:

Page 1 of 34

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Version: 1

Authorised by: Clinical Policy Group

Key Messages	<p>A learning disability may be defined as a state of arrested global development, occurring pre, peri or post-natally. Some people with a learning disability may have an identifiable cause for their condition, for example genetic conditions such as Down's syndrome.</p> <p>People with a learning disability have the same rights of access to health care and treatment as anyone else - this fact should never be in dispute. It is totally unacceptable to refuse or to offer inferior treatment because:</p> <ul style="list-style-type: none"> ▪ the patient has a learning disability and / or ▪ difficulties in obtaining informed consent <p>This policy and procedure document applies to all staff employed by NHS Lothian working in an inpatient setting who may provide care to this patient group.</p> <p>People with learning disabilities are extremely vulnerable within a hospital setting and the purpose of a risk assessment is to minimise their vulnerability by identifying, assessing and controlling risks.</p> <p>The impact of a person's cognitive impairment can vary enormously. Most adults will have abilities and capacity in many areas of their life – although they may need support in some aspects of daily living. Others may need considerable support with skills and decision-making.</p> <p>A guardianship order is a court appointment which authorises a person to take action or make decisions on behalf of an adult with incapacity. A guardianship order can be in relation to property and financial matters, personal welfare, or a combination of these.</p> <p>The principles of the Adults with Incapacity Act should be considered at all times. This means in practice that any procedure should be in the patient's best interests, it should be the least restrictive option. Practitioners should also take account of the patient's past and present wishes.</p> <p>The policy can be found at Homepage>Healthcare>Clinical Guidance</p>
Minimum Implementation Standards	<p>Good Practice for Managers</p> <ul style="list-style-type: none"> • Has identified the staff in his or her area to whom this policy applies and has given the policy (or selected excerpts) to them. • Has assessed the impact of the policy on current working practices, and has an action plan to make all necessary changes to ensure that his or her area complies with the policy. • Has set up systems to provide assurance to him or her that the policy is being implemented as intended in his or her area of responsibility. <p>Good Practice for Employees</p> <ul style="list-style-type: none"> • Has read the policy (or selected excerpts) and considered what it means for him or her, in terms of how to conduct his or her duties. • Has completed any mandatory education or training that may be required as part of the implementation of the policy. <p>Has altered working practices as expected by the policy.</p>

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1. INTRODUCTION

This policy and associated procedural documents have been developed to support the care of patients with a learning disability within a hospital setting.

A learning disability may be defined as a state of arrested global development, occurring pre, peri or post-natally, but before adulthood. 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 patient who is totally dependent on others for all aspect of care to individuals who, while appearing independent, have special health needs, such as challenging behaviour, mental health problems or intractable epilepsy.

2. AIM OF THE POLICY AND ASSOCIATED PROCEDURAL DOCUMENTS

To provide a set of principles and pathways for all NHS Lothian employees to ensure that a high standard of care is provided throughout the patient's journey.

To highlight the issues of consent and advocacy for people with a learning disability and enhance communication between the patient, carer and health care professionals.

3. KEY OBJECTIVES

- To improve and maintain staff and patient safety in conjunction with other relevant NHS Lothian policies.
- To ensure staff have a set of principles and procedures to meet the needs of patients with a learning disability.

4. SCOPE

This policy and procedure document applies to all staff employed by NHS Lothian working within a hospital setting who may provide care to this patient group.

The principles of this policy and associated procedure documents should be adhered to, with clear lines of accountability and responsibility identified and agreed.

5. EVIDENCE BASE

There is overwhelming evidence that a significant proportion of health needs go unrecognised and untreated and that there are many barriers of health care experienced by people with learning disabilities. The Scottish Government has identified it as a core principle that people with a learning disability have the right to live inclusive lives and has made it an obligation of NHS Boards to ensure that they fulfil their duty of care to enhance access as part of the inclusion agenda (Scottish Executive 2000, Scottish Executive 2008, Scottish Government 2013).

This is supported by legislation which includes the principles of the European Convention on Human Rights, The Adults with Incapacity (Scotland) Act 2000, the Disability Rights Commission (DRC) Act, (1995) and the Disability Discrimination Acts (1995 and 2005) and the Equality Act (2010), which makes it illegal to discriminate against a person with a disability.

These Acts require Public Services to make a reasonable adjustment *to* meet the needs of people with disabilities and to promote positive attitudes towards disabled people.

PRINCIPLES & PROCEDURES FOR THE MANAGEMENT OF PATIENTS WITH A LEARNING DISABILITY

CARING FOR PATIENTS WITH LEARNING DISABILITIES WITHIN A GENERIC HOSPITAL SETTING

1. DEFINITION OF A LEARNING DISABILITY

The most widely used definition of a learning disability can be found within the Scottish Executive (2000) document 'The Same As You?'

'People with learning disabilities have a significant, lifelong condition that started before adulthood, that affected their development and which means that they need help to:

- Understand information
- Learn skills;
- Cope independently.'

In practical terms for the learning disability service it is people who have an IQ of less than 70. This may mean that they are unable to communicate their own needs fully or comprehend the information they are given. They may present with behavioural problems or mental health needs, which necessitate additional support to enhance the standard of care.

2. CORE PRINCIPLES

People with a learning disability will therefore have a cognitive impairment and the core principles of Care Management for Adult Patients (16+) with a Cognitive Impairment in a generic Hospital Setting should be followed. Each clinical area should consider the need to develop specific pathways to enhance the journey of care for each patient. These local/specific pathways should be developed using the core principles (appendix 1).

The four core principles have been identified as may being crucial components to consider in the care of people with a learning disabilities. These are risk assessment, capacity and consent, consultation with others and discharge planning.

3. RISK ASSESSMENT

People with learning disabilities are extremely vulnerable within a hospital setting and the purpose of a generic risk assessment is to minimise their vulnerability by identifying, assessing and controlling risks.

Risk assessment tools have been developed to assist staff in the hospital setting to identify specific care needs or risks for an individual patient. The aim is to provide staff with the information to develop and maintain a risk assessment in a consistent and transparent way (appendix 6).

Risk assessments are designed to enhance and complement the staff's existing skills of observation, communication and assessment and will help manage any risk identified. This additional information should be used to develop a comprehensive patient care plan.

By taking all of these points into account staff should use the generic risk assessment to determine whether the needs can be managed using existing resources or if they are such that additional support may be required. It is important to note that the risks identified may change during the patient's journey and risks may require to be reassessed in response to the changing needs of the patient,

The principles of the Adults With Incapacity Act should be considered at all times as well as the core principles of both the Mental Health (Care and Treatment) (Scotland) Act 2003 and the Equality Act 2010.

3.1 Completing A Risk Assessment

The patient or the person accompanying the patient with learning disability should be assisted to complete the basic generic risk assessment (appendix 6).

If they are not able to give sufficient or complete information then the assessor should consider additional sources of information, having obtained consent if appropriate.

Other sources could be:

- Main carer – whether formal or informal
- Residential care staff
- Community learning disability team/ Community psychiatric team/ care of the elderly team
- Primary care staff

Some patients or carers may find certain aspects of the assessment difficult to discuss, such as mental health or aggression issues and therefore these tools should be used in a sensitive manner.

If the basic generic assessment indicates an overall medium to high score, risk management strategies should be identified on the second page and the guidelines given used to formulate an action plan for the admission.

This could include:

- Increased observation, this may be inclusive of one-to-one nursing care.
- Negotiation with carers/ family/ social care staff re attendance level or contact numbers for advice
- Maintaining accurate communication of events or treatments
- Implementing written guidance provided by carers/ family or document accurately any verbal guidance
- Adapting or introducing equipment.

In addition:

- When discussing invasive, intensive or significant clinical decisions gain a consensus of opinion rather than a singular or isolated opinion.
- Staff should respect patient confidentiality and as far as possible remain flexible.
- Where boarding and transfer are required to accommodate new admissions the movement of a learning disability patient should be avoided wherever possible to ensure that a consistent environment is maintained.

4. CAPACITY AND CONSENT

Consent is both a legal requirement and an ethical principle and requires to be obtained by health-care professionals, prior to the start of any examination, treatment, therapy or episode of care.

In Scotland, everyone over the age of 16 is an adult. The law assumes that an adult can make their own decisions and can sign legal documents, such as consent to medical treatment (in some circumstances this can also apply to children under the age of 16) provided they have the capacity, which means they are able to understand what is

involved in the proposed treatment, retain the information, be able weigh up the information needed to make the decision and then communicate that decision. People with a learning disability do not necessarily lack capacity. Capacity depends on the circumstances and the decision or action that needs to be taken. Many people are capable of understanding and making a decision about some things but not others.

The impact of a person's cognitive impairment can vary enormously. Most adults will have abilities and capacity in many areas of their life – although they may need support in some aspects of daily living. Others may need considerable support with skills and decision-making.

The Adults with Incapacity (Scotland) Act was passed by the Scottish Parliament in 2000. It offers a range of options to assist an adult who lacks the capacity to make decisions and manage different areas of his or her life. It is possible for another adult to be given powers to make decisions on behalf of someone who cannot act for him or herself, and it provides guidelines within a legal framework to assist health professionals ensure that patients can make informed decisions about healthcare interventions.

The Act says that someone is "incapable" when he or she cannot:

- Act; or
- Make decisions; or
- Communicate decisions; or
- Understand decisions; or
- Remember decisions, because of mental disorder or inability to communicate.
- This does not include people whose **only** problem is that they are unable to communicate if this can be overcome in some way using either human or mechanical help.

The principles of the Adults with Incapacity Act should be considered at all times. This means in practice that any procedure should be in the patient's best interests, it should be the least restrictive option. Practitioners should also take account of the patient's past and present wishes and also the views of significant others, as well as the core principles of the Disability Discrimination Act

Please also refer to NHS Lothian Policy on Consent and see the flow chart in Appendix 7 for guidance and Right to treat? Mental Welfare Commission Scotland (July 2011)

4.1 Assessment of capacity

Adults should be encouraged to make their own decisions, as far as possible, and there should be no intervention in an adult's decision making unless incapacity is proven.

Staff must work on the presumption that every adult patient has the capacity to make decisions about their care and treatment and to decide whether to agree to, or refuse, proposed medical intervention. Only if it is shown that, having been given all appropriate help and support, they cannot understand, retain, use and weigh up the information needed to make a decision or communicate their wishes can an adult patient be regarded as lacking capacity.

Part 5 of the Act gives a general authority to medical practitioners to treat patients who are incapable of consenting to the treatment in question. Medical practitioners

responsible for the treatment are ultimately responsible for determining incapacity and for the issue of the medical certificate confirming incapacity. However, best practice suggests that there should be a multi disciplinary approach, obtaining opinion from those who know the person well, including carers. Once a decision is reached that the adult is not able to give informed consent, a Certificate of Incapacity (Section 47 form) must be completed, which includes a Treatment Plan if appropriate.

The Medical Practitioner's decision is always subject to a right of appeal to the Sheriff. Appeals can be instigated by the adult or anyone who can claim an interest in the adult's welfare or medical treatment.

Common Law gives authority to give life-saving treatment to patients who cannot consent. The Act makes no change to this position.

The Act is concerned only with non-emergency treatment.

The Act also enables Medical Research to be carried out where the patient is unable to consent and provides conditions and rules, which must be followed relating to this research.

4.2 Who has Authority to Treat?

The medical practitioner primarily responsible for the treatment and any other person authorised by the medical practitioner has the authority to treat. This would include nurses, other doctors, physiotherapists, dentists, opticians, etc.

Before the medical practitioner's authority to treat becomes effective he must complete a certificate to the effect that the patient is incapable of giving consent to the treatment in question.

Different treatments can be combined if a treatment plan is attached to the Certificate authorising these.

Once issued the medical certificate can be valid for up to one year and in certain circumstances up to 3 years. It should be noted that more than one certificate could be in place at any one time.

The medical practitioner's general authority to treat an adult will not apply where a 'proxy' has been given the authority to consent to treatment on behalf of the adult. That is, a welfare attorney, welfare guardian or someone acting under an intervention order which gives this authority (see section 4.3). If there is welfare attorney/guardian with power to consent a section 47 certificate is still necessary even though the attorney/guardian are in agreement. If there is no consent treatment cannot proceed. If treatment is to save a life it can be given unless there is an injunction against it.

Where a proxy has been appointed with authority to consent to treatment the medical practitioner is obliged to seek that person's consent as far as is reasonable and practicable before giving the treatment.

The medical certificate issued by the medical practitioner primarily responsible or the consent of a proxy will take the place of the consent of the adult (the patient).

4.3 The role of the Welfare Guardian

A guardianship order is a court appointment which authorises a person to take action or make decisions on behalf of an adult with incapacity. A guardianship order can be in relation to property and financial matters, personal welfare, or a combination of these.

By law, if an adult is unable to make a safe decision about his or her own welfare, a court can appoint someone else to make decisions for him or her. This person is known as a welfare guardian. The law that sets out the role of guardians is the Adults with Incapacity Act (Scotland) 2000, which aims to protect the welfare of adults with a mental illness, learning disability or other mental disorder, including Dementia.

Guardians can make decisions as long as their decisions are in the person's best interest and in line with the safeguards set out in law. This states that a guardian's decision:

- must be of benefit to the person concerned;
- will only be taken when it is really needed;
- must take into account the wishes of the person;
- should restrict that person's freedom as little as possible;
- should only be taken when the person could not make a decision; and
- should involve carers, relatives and people working closely with the person.

An individual can be a private individual, e.g. a relative or friend of the adult, or someone acting in a professional capacity. Where the guardianship order relates to personal welfare matters only, in this case the Chief Social Work Officer for the adult's local authority may be nominated.

5. CONSULTATION WITH OTHERS

As stated, patients with a learning disability are vulnerable within an inpatient setting. They may not be able to give information about their condition, understand what is happening or communicate their wishes. Therefore it is best practice that others who know about them are consulted. This can include a wide range of people, for example:

- Husband/wife or partner
- Other relatives or next of kin
- Carers –formal and informal
- Residential care staff
- Welfare guardians
- Advocates
- Primary care staff – including General Practitioners & Community Nurses
- Acute Hospital Liaison Nurse (for patients with a learning disability)
- Allied Health Professionals
- Social work staff
- Mental Health Officer (MHO)

It is particularly important to consult when considering those risk issues around ability to tolerate treatment, behavioural management, capacity and consent or discharge planning.

It is good practice to consider using an advocacy service (see 5.1) for patients where the person lacks capacity, or where there may be difficult decisions to make or where there is a dispute, or contention, about care.

5.1 Advocates

People with a learning disability have the same rights of access to health care and treatment as anyone else - this fact should never be in dispute. It is totally unacceptable to refuse or to offer inferior treatment because:

- the patient has a learning disability and / or
- difficulties in obtaining informed consent

Independent Advocacy Services have been developed across Lothian to assist patients with a learning disability. Some patients may have the involvement of an Advocate (this should not be confused with a legally trained "Advocate").

All Independent Advocates will have received training and support to work with patients with a learning disability. They can play an important and helpful part during contact with the acute hospital by facilitating communication and ensuring the wishes and rights of the patient are fully respected and considered in all aspects of treatment and care.

Details of the involvement of an Advocate should be recorded in the patient's healthcare record; these details may be provided by the family member / carer. With the patients' agreement the nurse should inform the Advocate of their admission to hospital. It may be that the patient is unable to give permission or lacks capacity – therefore, in circumstances where there is known involvement of an Independent Advocate the family member, Welfare Guardian or accompanying support staff member should be asked to contact the advocate.

Where an Advocate is not involved and the patient may benefit from their service, details of Advocacy services for people with a learning disability can be obtained by contacting the Learning Disability Liaison Nurse or by contacting the agencies directly.

Within Lothian, the 2 agencies providing independent advocacy to people with learning disabilities are: Powerful Partnerships; 0131 478 5501 or Partners in Advocacy: 0131 478 7723/7724.

5.2 Learning Disability Hospital Liaison Nurses

If a patient has been identified as having a learning disability the support of the learning disability nursing service will be in place. This service is easily accessible for other staff within the NHS Lothian looking for specific information regarding learning disabilities. The nurses have a wide range of expertise, knowledge and understanding of the care needs of children and adults with learning disabilities. They are managed by the Community Learning Disabilities Service and have direct links to hospital management (appendix 9)

6. DISCHARGE PLANNING

Due to the additional and more complex needs of the patient with learning disabilities, discharge planning should be discussed with the main carer at the time of admission and any potential difficulties identified. The multi disciplinary team should then formulate a discharge plan at the start to eliminate any potential problems arising which would delay discharge. As well as the ward multidisciplinary team many of those identified in section 5, and in particular the Learning Disability Liaison Nurse, may need to be involved due to the complex nature of issues identified to ensure a co-ordinated and robust discharge plan.

The Learning Disability Liaison Nurse can assist by informing the relevant Community Learning Disability Team or by making a referral for follow-up by other specialist community services e.g. Clinical Psychology. This may be in addition to 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 CLDN Service should be made where the patient appears to have additional care needs, as a result of their learning disability. Some examples for the reason for referral might be:

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

People with a learning disability may require an escort and therefore any transport needs will require advanced planning and the NHS Lothian Chaperone Policy and Safe Transfer / Escort of Patients adopted as required.

Medication and compliance issues for people with a learning disability may require the consultation and advice of the pharmacist/ community pharmacist post discharge to enable systems such as medicines compliance devices to be put in place.

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.

Ward and department staff may wish to consider a follow-up contact to ensure compliance and understanding.

NHS Lothian policy on discharge planning should be adhered to at all times.

7. EDUCATION AND TRAINING

7.1 Raising Awareness

NHS Lothian is committed to ensuring that people with learning disabilities have equal access to all aspects of the NHS so as to have their health needs met. As a result of their health needs, people with learning disabilities are high and frequent users of all areas of the NHS. It is now recognised that some of their health needs differ when

compared to those of the general population and some healthcare workers have limited previous knowledge and practical experience of working with this group. NHS Lothian also has a duty to ensure that where necessary 'reasonable adjustments' to care and treatment, are made thereby complying with the requirements of the Disability Discrimination Act (1995) and the Disability Equality Duty. NHS Lothian is committed to improving the experience of all patients and this includes people with learning disabilities.

7.2 What is available

A number of Learn Pro modules have been developed to provide healthcare workers with an overview and general understanding of the care needs of people with learning disabilities focussing on key issues such as Adults with Incapacity, consent, capacity, communication and enabling access to healthcare. New staff will be encouraged to complete the modules online as part of the NHS Lothian induction and mandatory education. Existing staff will be encouraged to complete them for their own ongoing practice update and education and as part of their Personal Development Plans

NHS Lothian has worked in partnership with Edinburgh Napier University on the development and delivery of degree and postgraduate level modules focussing on promoting access to healthcare for this patient group. The modules can be used towards a degree award or for CPD purposes.

7.3 Who are the target group?

All healthcare workers such as, porters, domestics, nurses, doctors, receptionists and allied health professionals are required to undertake the induction and mandatory update elements.

The NHS Lothian learning disability modules are aimed at healthcare practitioners who come into contact with people with learning disabilities as an occasional part of their role and need to develop further knowledge and skills.

The Edinburgh Napier University modules are aimed at healthcare practitioners who have frequent and regular contact with people with learning disabilities as part of their role and need more advanced knowledge and skills. Practitioners, working in accident and emergency, acute receiving, combined assessment, out patients, respiratory services, gastric service, neuromedicine and primary care are priority areas.

8. CARE MANAGEMENT PATHWAYS

The key elements of this document have been summarised in a series of flow charts that identify different care pathways that patients with a learning disability may take during their contact with the acute hospital. There is a general flow chart which highlights the course of action to be taken if there is a referral for treatment where the patient is suspected to have a learning disability (see appendix 8) and what course of action to take.

There are also a series of care planning flow charts for an elective admission, admission to the Accident and Emergency Department, for theatre and recovery and for outpatient appointments. These have been supplemented with additional information at key points in the patient's journey.

Wards and departments may wish to print and laminate those flowcharts appropriate to their area.

9. CARE PLANNING FOR ELECTIVE ADMISSION

9.1 Pre-admission planning

Whenever it becomes apparent that a patient with a learning disability will require care from an acute hospital, this should act as the trigger for contacting the Learning Disability Liaison Nurse, who can offer advice and support. The Learning Disability Liaison Nurse is in a key position to assist acute care staff to plan and co-ordinate care before, during admission and on discharge.

Systems should be in place so that the Charge Nurse of the ward can be informed in advance by medical or secretarial staff that a patient with a learning disability is to be admitted. This should be activated by staff in the outpatients department, pre-assessment clinic and / or GP who will have already identified that the patient has a learning disability.

The Charge Nurse should be informed of the admission date and where possible, be given a contact name and number for the patient or their main carer.

The Charge Nurse should identify a Named Nurse for the patient who **will be on duty** when the patient is admitted.

Where possible, the named nurse should make contact with the patient, main carer or the professional responsible for their care, several days prior to the admission date to discuss:

- the admission arrangements
- treatment plans
- the individual's current care needs
- any special resources which may be required to be in place for admission. If a prolonged admission is anticipated it may be possible to liaise with the carers regarding the provision of special equipment that may be required by the patient during their stay, i.e. sleep systems, wheelchairs, braces
- The involvement of any other Allied Health Professionals (AHPs), e.g. physiotherapist, occupational therapist, speech and language therapists, or social worker or Community Learning Disability Nurse in order that liaison can take place with relevant community staff
- The need for the involvement of the Learning Disability Liaison Nurse.

The Named Nurse should discuss with the main carer the possibility of their involvement in the delivery of direct care to the patient for part of the time during the period of hospitalisation as per NHS Lothian Delegation of Duties policy.

Where possible, the Named Nurse and main carer should undertake a preliminary assessment of the patient's care needs in order to identify any additional nursing resource requirements. Best practice is to undertake this assessment prior to the patient's admission. The anticipated length of stay and care needs following treatment should also be estimated at this point.

If the main carer is unable to contribute fully to this assessment the nurse should contact the Learning Disability Liaison nurse who may be able to give advice on additional sources of information.

Where the assessment identifies the need for additional nursing and/or other resources the Charge Nurse/Deputy should contact the relevant Clinical Manager to discuss and arrange the required resources.

9.2 Day of admission

The main carer should be invited to accompany the patient on the day of admission and to take part in the admission process (with the patient's consent). It should be made clear that the admission process may be lengthy and a commitment in terms of time is required. Where appropriate, the main carer should be asked to bring in a copy of the patient's current care plan and medication.

A full nursing assessment should be carried out using an appropriate model /tool. It may be necessary to combine the assessment tools from both the place of residence (where appropriate) and the clinical area to which the individual has been admitted. 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 and dignity.

Particular note should be made of the patient's medication regime, including the form of the preparation, times and methods of administration. This may have been tailored very specifically to the individual's needs and should be continued whilst in hospital. Details should be discussed with relevant medical staff and, if necessary, the Clinical Pharmacist in order to ensure continuity of medicating practices during hospitalisation and following discharge.

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 not able to be involved in the direct care of the individual then a communication network and contact point should be ascertained and documented. The main carer should be invited to communicate daily or as often as is mutually agreeable.

If there is no identifiable main carer the named nurse should make contact with the Learning Disability Liaison Nurse and, if required, request their involvement in the assessment and care planning.

With the patient's agreement the named nurse should offer to contact an appropriate person who is regularly involved in the patient's care to make them aware of the admission.

Most patients with a learning disability will have complex discharge planning needs and therefore discharge planning must be discussed at the time of admission. Reference should be made to the core principles of discharge planning and there should be consideration as to the involvement of the Learning Disability Liaison Nurse.

10. PRESENTATION AT ACCIDENT & EMERGENCY

If an individual with learning disabilities is admitted unaccompanied, the named/ triage nurse 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 Accident and Emergency Department. The Learning Disability Liaison Nurse can be contacted for advice and support if available (see appendix 9 for contact details).

The initial risk assessment should if possible be completed by the person or someone who has good knowledge of the patient.

10.1 Consent in an 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 flow chart on capacity Appendix 7.

10.2 Immediate Discharge from Accident and Emergency Department

A referral can be made to the Learning Disabilities Liaison Nurse where the named nurse has any of the following concerns:

- the patient's safety,
- the mental health and/or challenging behaviour,
- the ability to comprehend instructions or follow medication regimens
- their understanding of any follow-up arrangements

10.3 Transfer from Accident and Emergency to an Admitting Ward

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 plus, if available all information provided by the carer / family. An additional nursing resource may be required.

10.4 Admission to a Receiving Ward

When a patient with a learning disability has been admitted via the Accident and Emergency Department, the Named Nurse / nurse in charge 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.

If the patient is unable to provide information regarding their main carer the Named Nurse should contact the Learning Disability Liaison Nurse (Appendix 9) for advice during the hours of 09.00 - 17.00 Monday to Friday by mobile telephone or via the hospital switchboard.

A full assessment of the patient's nursing needs should be undertaken and if not already completed a risk assessment undertaken that should inform the care plan. This will assist to identify the specific nursing resource requirements and should be done, if possible in conjunction with the main carer or Learning Disability Liaison Nurse. Any resource requirements should be communicated to the appropriate Clinical Manager as soon as possible and appropriate support instituted without delay.

Details of the main carer and contact numbers should be clearly documented in the patient's nursing notes.

The protocol for elective admissions should then be followed.

10.5 Communication with Main Carer

The main carer should be involved in decisions regarding care and invited to give feedback on perceptions of standards of care. It may be helpful for the main carer to use a reflective diary.

Care plans should be reviewed with the main carer on a daily basis or as frequently as previously agreed at the beginning of the admission process.

If there are any specific changes or developments in the patient's condition during the duration of hospitalisation the main carer should be contacted as soon as possible (with the patient's agreement) where appropriate.

The risk assessment should be undertaken at regular intervals throughout the period of hospitalisation in order to review the nursing resource needs and make appropriate adjustments.

10.6 Potential Discharge within 72 Hours of Admission

The Named Nurse and members of the multi-disciplinary team should formulate a plan of care as early as possible in the patient's admission to hospital. If it is anticipated that discharge is likely to occur within 72 hours (or less) of admission to hospital, it may be in the patient's best interests to try to ensure that care continues in the receiving ward until the point of discharge.

10.7 Prolonged Admission (greater than 72 hours)

If the multidisciplinary team assesses that the patient requires care that will extend beyond 72 hours, consideration should be given as to whether an early transfer is preferable to enable the patient to adapt to a new and more consistent environment that will facilitate their recovery.

10.8 Temporary Transfer out with the Parent Ward

Transfer or boarding of a patient with a learning disability in order to accommodate other admissions (emergency or elective) must be avoided wherever possible to ensure a consistent environment is maintained

11. CARE OF PATIENTS ATTENDING THEATRE AND RECOVERY

11.1 Pre-operative Preparation

Nursing staff from the patient's ward will contact the appropriate theatre at least 24 hours 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.

A pre-operative visit by theatre/recovery nursing staff will be made a priority. This visit will be arranged with the ward staff in order that a suitable time can be confirmed when the patient's main carer is available. The Learning Disability Liaison Nurse is available to offer support and advice to the patient as well as theatre, recovery and ward staff.

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

The nurse undertaking the pre-operative visit will discuss the following issues with the ward nursing staff, patient and main carer:

- The patient's capacity to consent
- 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

Where there are difficulties the Learning Disability Liaison Nurse can be contacted.

The theatre care plan will be used to document the patient's needs both in the anaesthetic and recovery room.

The main carer will be invited to accompany the patient to the theatre suite with the ward nurse. Where required, the ward nurse will remain with the patient until induction of anaesthesia is complete.

11.2 Local Anaesthetic

Standard pre-procedure preparation is required.

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 understanding of the procedure and any issues relating to his/her compliance with the procedure particularly when the procedure may be protracted. Where the main carer is a nurse it may be appropriate for them to remain with the patient during the procedure.

11.3 Recovery

If the main carer has expressed a desire to be present in the recovery room shortly after the patient has woken from the anaesthetic (after extubation) the recovery nursing staff should contact the ward to notify them that the patient is in recovery.

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 use of the DISDAT tool may be beneficial.

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

12. CARE PATHWAY FOR ATTENDANCE AT OUTPATIENTS

Where a patient with an identified learning disability is to attend for their first out-patient appointment staff should contact the patient or main carer to arrange a suitable time. For the safety and comfort of both the patient and other attendees, it may be necessary to arrange an appointment time to minimise any patient anxiety that might be induced by lengthy waiting in an unfamiliar environment. If there is an identified need for further information, advice or support, then staff should contact the Learning Disability Liaison Nurse.

Where a patient is a regular attendee at the Out-Patient Department the clinic staff should liaise with carers to discuss and identify any specific care requirements that the patient may have during attendance, such as communication, toileting, etc.

Staff should ask the patient or their main carer if they have understood the information and/or instructions given to them during the consultation. It is the responsibility of the information provider, under Equalities legislation – that information is passed to the individual patient in a format that is accessible to the patient; e.g. easy read.

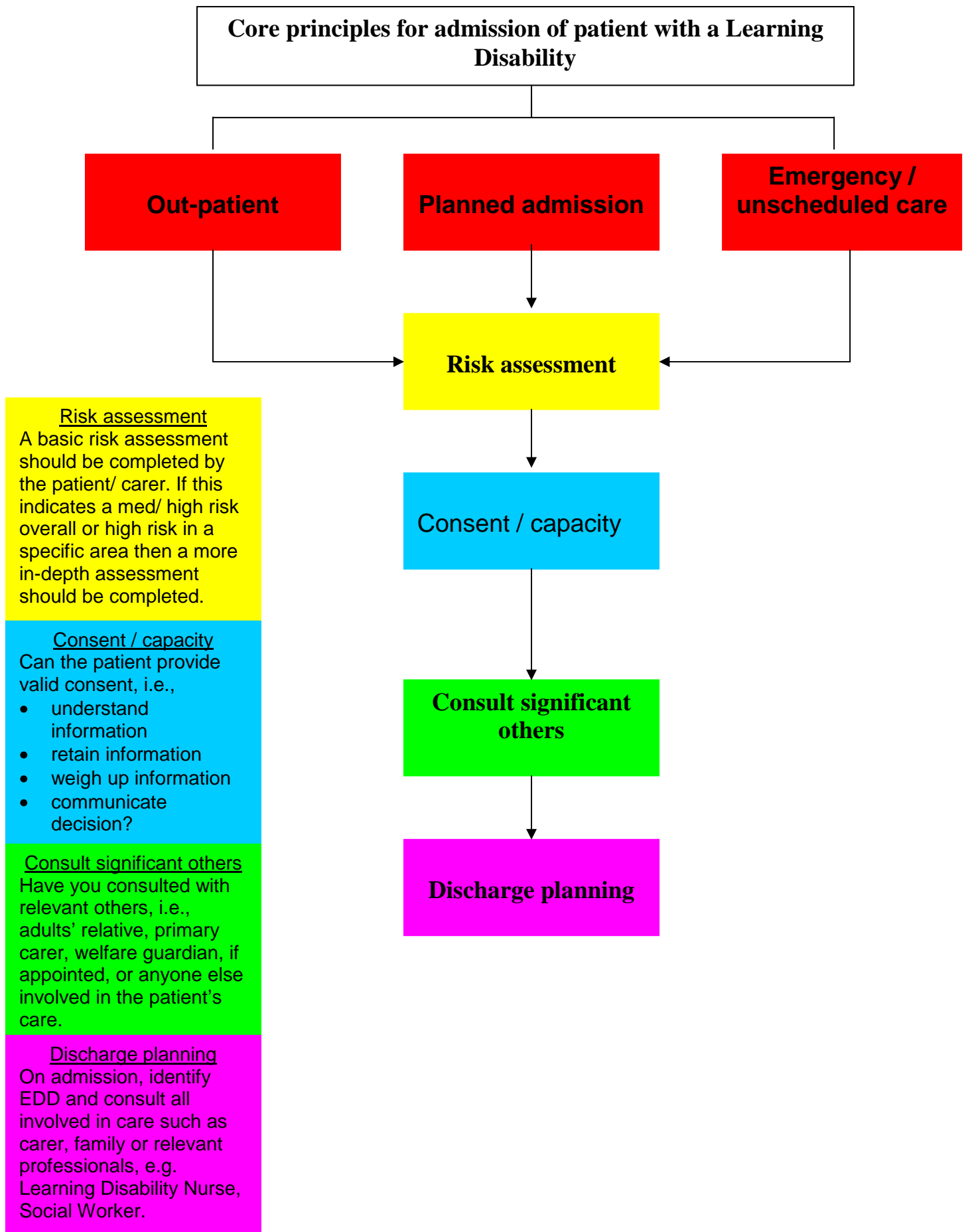
Where a Clinical Support Worker is responsible for co-ordinating the clinic a Registered Nurse should see the patient (and / or carer) before they leave the Department in order to determine any further care requirements.

If there are any subsequent appointments, planned procedures or elective admissions, staff can make a referral to the Learning Disability Nursing Service (appendix 9).

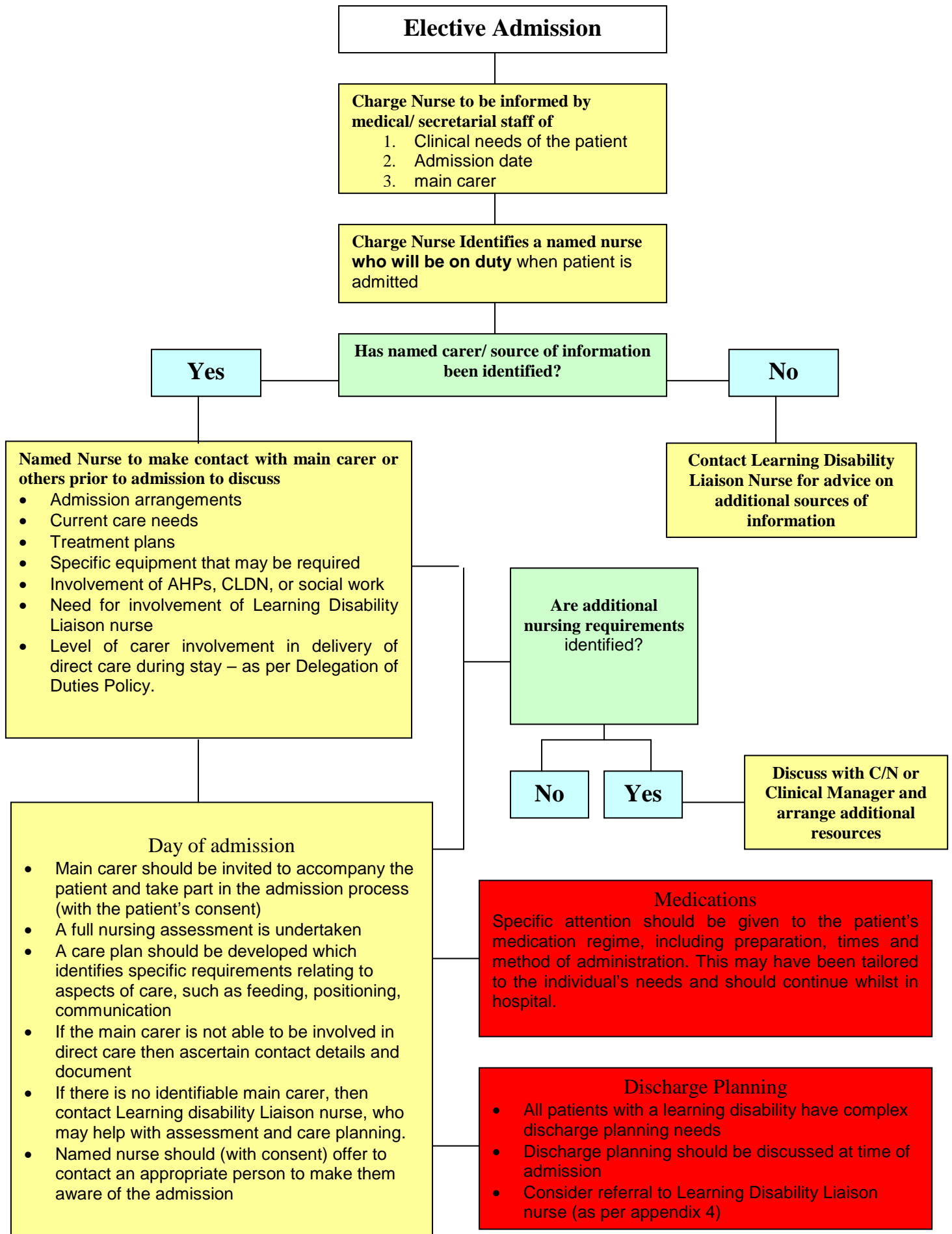
Following an out-patient consultation, nursing staff may identify that the patient has other needs which require to be addressed. Staff may refer a patient directly to the learning disability Service for assessment where there is a need for additional on-going specialist nursing support and advice. This may be for safe self-administration of medications or other additional health needs. For assistance with direct physical care needs a referral should be directed to the District Nursing Service or to the Social Work Department for ongoing support needs.

APPENDICES

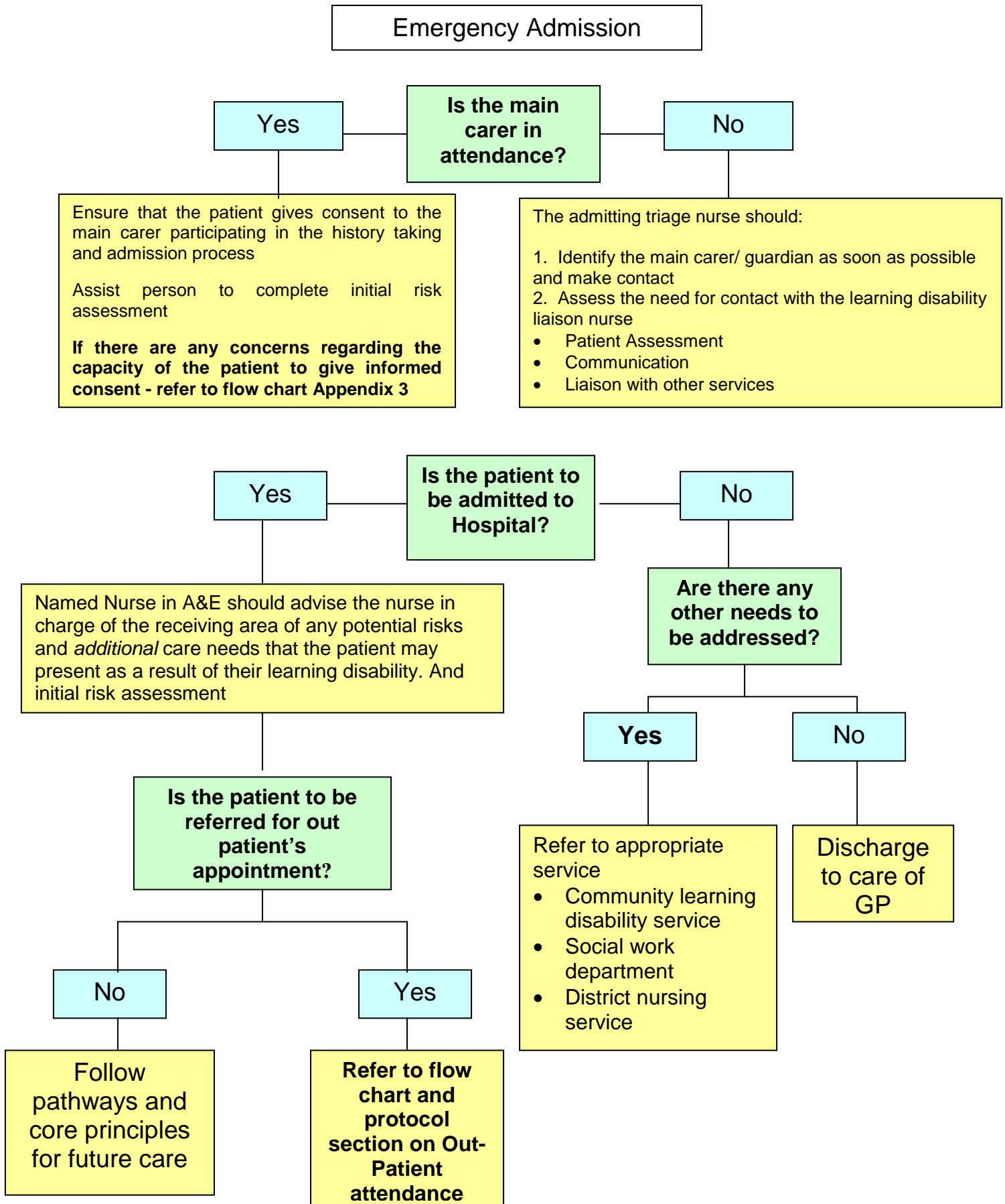
Appendix 1 – Core Principles For Admission Of Patient With A Learning Disability



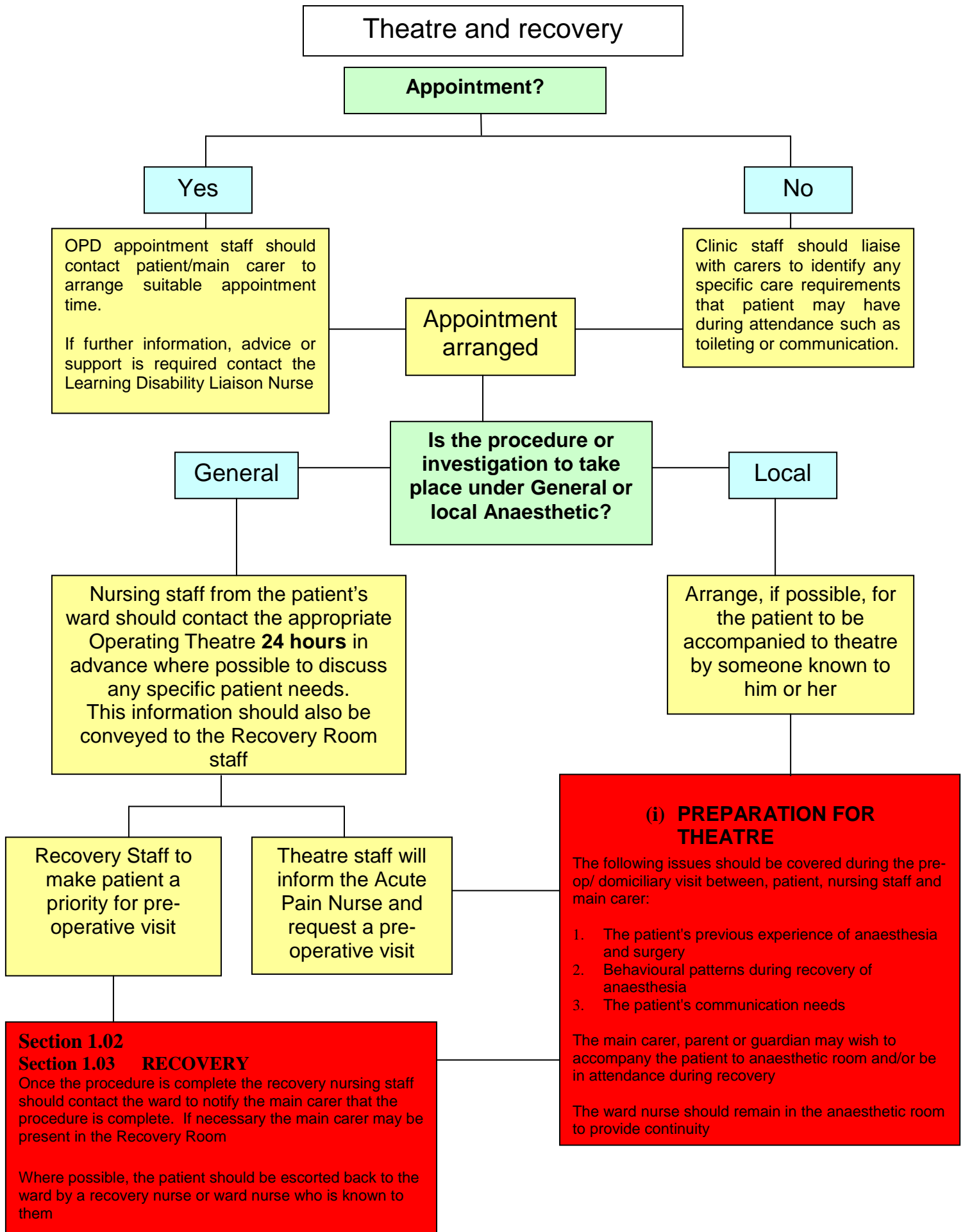
Appendix 2 –Elective Admission



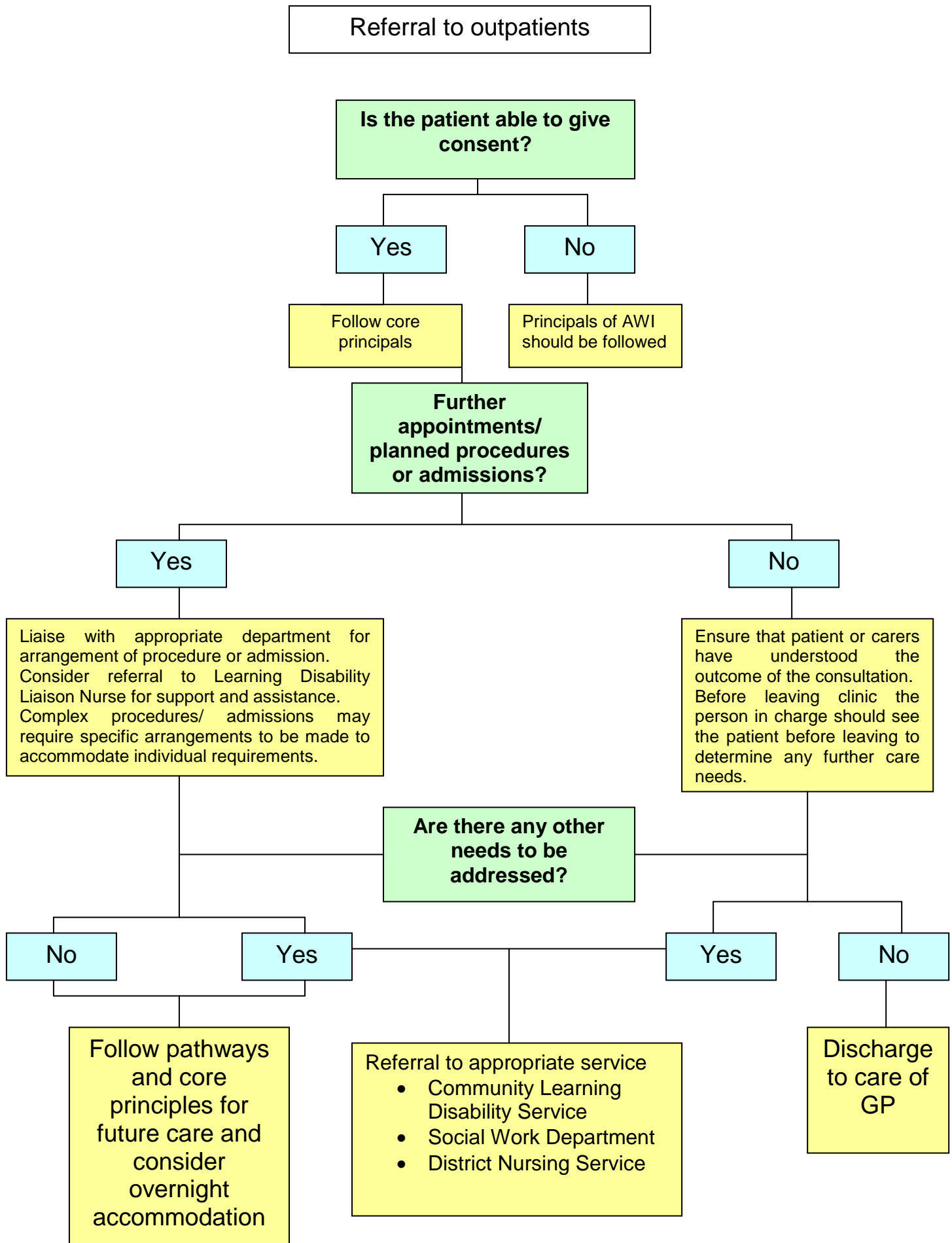
Appendix 3 – Emergency Admission



Appendix 4 – Theatre and Recovery









Appendix 5 – Referral to Outpatients



Appendix 6 – Risk Assessment Tools

Generic Baseline Risk Assessment:

Name		CHI		DOB	
Ward or dept		Date		*Time	

Please place a x in appropriate box	Possibility of occurring 1 	Strong Possibility 2  	Almost certain 3   
Problems regarding personal safety			
At risk of wandering			
At risk of coming out of bed			
At risk of falling			
Seizures			
Other:			
Problems with compliance to treatments			
Problems taking medication			
Risk of removing drip / dressings			
Problems with fasting			
Other:			
Problems with communication			
Unable to understand instruction			
Unable to say what's wrong (e.g. pain).			
Other:			
Problems with the environment / sensory sensitivity			
With noise / lights / smells			
With other people around			
Being in a confined space			
Equipment			
Other:			
Problems with eating and drinking			
Can't eat or drink without assistance			
Risk of choking/ swallowing			
Risk of burning / scalding			
Posture and positioning			
Other:			
Problems with agitation/ aggression			
Verbal			
Physical			
Self-injurious behaviour			
Destructive behaviour			
Other:			
Problems with mental health			
Memory			
Depression			
Hallucinations / delusions			
Isolation/ fear			
Anxiety			
Other:			

Completed by (nurse):			
Discussed with (carer):		Relationship	

Generic Risk Assessment Action Plan

Family / Carer available	NO	YES	24hr / Extended attendance / Visiting time / Phone only	
Name	CHI		DOB	
Ward or dept	Date		*Time	
Legal Proxy [AWI Act]	Power of Attorney		Welfare Guardian	Intervention Order
Identified Risk	Level 1-3	Risk Management		Reviewed with carer
Personal safety				
Compliance with treatment				
Communication				
Environment / Sensory sensitivity				
Eating and drinking				
Agitation / Aggression				
Mental Health				
Completed by:				
Reviewed by:			Date:	

Guidelines for completion of Risk Assessments

To be completed for all patients with a Learning Disability and / or Cognitive Impairment on admission or transfer to each clinical area.

This assessment will provide a baseline of risks, needs and controls which will help to inform current documentation and care plan pathways.

Article I. All staff must at all times

- Consider the principles of the Adults with Incapacity (AWI) Act at all times – Treatment must – be in *Best interests; Least restrictive; Least invasive; Take account of past and present wishes; Take account of significant others;*
- Consider the core principles of the Equality Act - It is your **duty** to make reasonable adjustments to ensure access and equity.

Score 1 Possible



May occur occasionally - has happened before on occasions – reasonable chance of occurring

- Increase observation
- Consider communication
- Adapt environment
- Obtain further information from carers/ family
- Negotiate or identify carer/family attendance
- Make 'reasonable adjustments' as per Equality Duty

Score 2 Strong Possibility



Strong possibility that this could occur - is likely to occur

- As above in 1 but also further assessment is required
- Seek carer/ family names and phone numbers for advice
- Respect confidentiality but be flexible
- Identify a named contact/ nurse with whom carers can pass on / gain accurate information

Score 3 Almost Certain



This is expected to occur frequently and will in most circumstances- more likely to occur than not

- As above in 1 and 2
- Implementing written guidance from carers / family OR document verbal guidance accurately
- Introduce any necessary equipment, i.e. hoist
- Seek advice and gain a consensus of opinion
- Consider consistency of approach/ people involved
- Maintain accurate records
- Ensure valid care plan in place and review regularly
- Share information with carers/ family in timely fashion
- Does the patient have capacity?

Appendix 7 – Adults With Incapacity (Scotland) Act 2000 Part 5 – Medical Treatment – Flowchart

Least restrictive option:
Anything done for or on behalf of the person without capacity should be the least restrictive to their basic rights and freedoms.

Valid consent is:

- Given by a competent person.
- Be given voluntarily.
- Given following receipt of adequate information.

Respect the wishes of the person. A person with capacity has the right to make what might be seen to be eccentric or unwise decisions.

General principles
The Adults with Incapacity Act sets out some basic principles or rules at the very front of the Act. These rules **must** be followed by anyone who takes any kind of action or decision under the Act. The courts, the sheriff and the Public Guardian will use these general principles to decide whether someone should get legal power for another adult or whether actions have been justified.

Test for capacity:

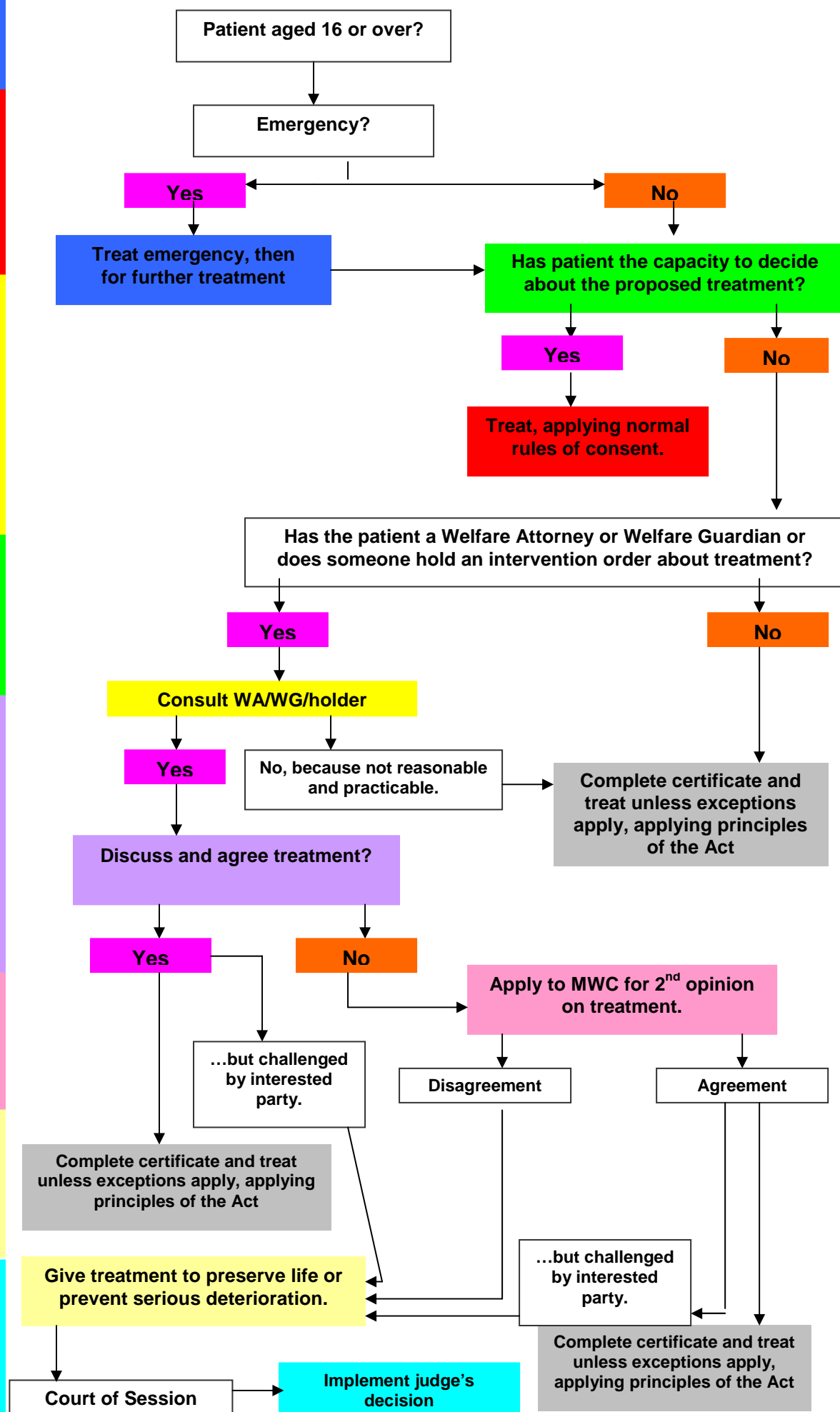
- Understand the information given to them.
- Retain the information long enough to make the decision.
- Weigh up the information available to make the decision.
- Communicate the decision.

Serious medical treatment; which involves providing, withdrawing or withholding treatment in specific circumstances where; in what is being proposed, there is a fine balance between the likely benefits and the risks to the person, or where there is a choice of treatments, and a decision as to which one to use is finely balanced **or** what is proposed would be likely to involve serious consequences for the person.

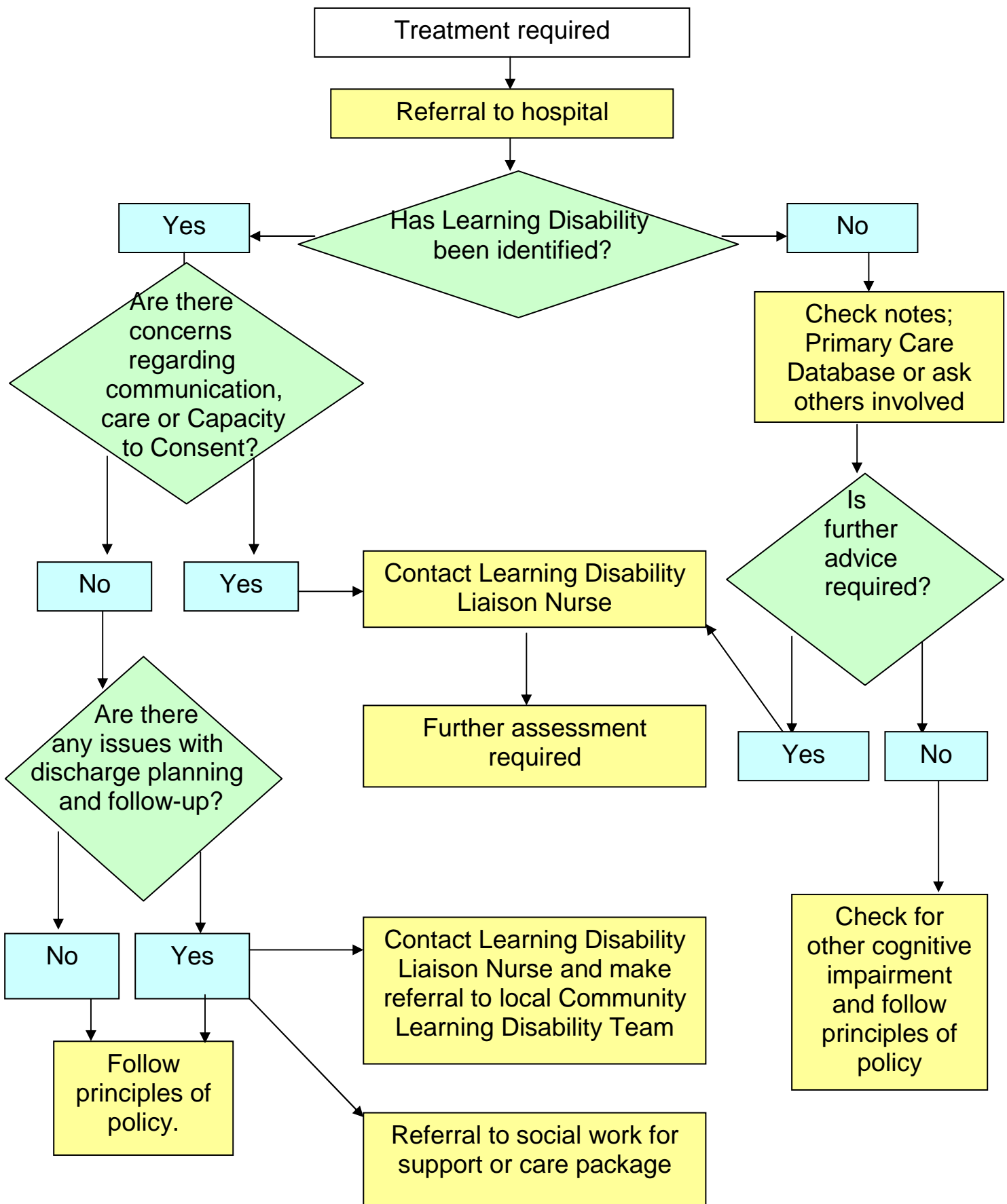
Where disagreement arises between the guardian and doctor, the doctor must ask the Mental Welfare Commission to nominate a second doctor to give an independent opinion on the medical treatment.

Where an appeal has been made to the Court of Session, medical treatment is permitted to save life or to prevent a serious deterioration in health in such circumstances until the application is finally determined.

The sheriff has jurisdiction to give directions to any person exercising functions under the Act. Anyone with an interest can apply. A practitioner can if necessary use this procedure to obtain a ruling on any matter or significant doubt or difficulty.



Appendix 8: Learning Disability Specific Pathways



Appendix 9 - Acute Hospital Liaison Service

The Learning Disability Liaison Nurse can assist with:

- Co-ordination of care – at points of attendance, admission and discharge
- Education within clinical areas and contributing to programmes of education
- Support and advice for acute care staff in relation to personalised care and service delivery
- Collaboration between the agencies involved in service delivery to ensure effective seamless care by undertaking domiciliary home based visits
- Development and enhance standards of care for all patients with a learning disability attending the acute hospital
- Promotion of effective communication with those involved in the patient's care – whether they are community or hospital based
- Support of a relative or a family member with a learning disability who is affected by the patient's illness/ hospital stay
- Promote safety and minimise risk
- Provide accessible information about treatments
- Promote positive experiences and outcomes

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For further information on education please contact the clinical education and development team and or visit there intranet site [here](#).