

No Decision About Me Without Me

Understanding the Mental Capacity Act

A Department Guide for:

- Safeguarding Adults at Risk
- Mental Capacity Act
- Supporting Patients with a Learning Disability

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Safeguarding Adults at Risk

Patients have the right to be treated with dignity and respect at all times and to be involved in all decisions regarding their care.

Safeguarding adults is a fundamental part of maintaining the safety of our patients who may be unable to protect themselves. Adults may be vulnerable to harm for many reasons such as mental health issues, dementia, learning disability, frailty and illness.

All staff within the health setting have a role to play in protecting adults who may be at risk of harm either through abuse or neglect.

What is Abuse?

'A violation of an individual's human rights by any other person or persons.'

'Abuse can occur in any relationship and may result in significant harm to, or exploitation of, the person subjected to it.'

'In the context of safeguarding adults at risk, a person's vulnerability is related to how able they are to make and exercise their own informed choice free from duress, pressure or undue influence of any sort.'

Sussex Multi-Agency Policy and Procedures for Safeguarding Adults at Risk Version 3: May 2013 NB Having capacity does not mean a person is not vulnerable to harm or exploitation.

Categories of Abuse

- Physical rough handling, assault, unreasonable physical restraint
- Emotional/psychological bullying, intimidation, name calling, verbal behaviour that affects a person's self-esteem and well being
- Sexual non-consenting sexual act or behaviour
- Financial fraud, theft, misuse of funds for personal gain
- Neglect care needs not met, breaching duty of care
- Discrimination inequality of care, psychological abuse linked to a characteristic such as age, race, disability, sexuality
- Institutional rigid routine, processes organised to meet staff need, lack of dignity and respect, disrespectful attitude

Other Concerns

- Domestic abuse threatening behaviour, violence or abuse between adults who have been or are intimate partners or family members regardless of gender or sexuality
- Human trafficking movement of a person from one place to another into conditions of exploitation, using deception, coercion, abuse of power or abuse of someone's vulnerability
- Honour based violence violence committed with degree of collusion from family and/or community
- Radicalisation process by which people come to support violent extremism and in some cases join terrorist groups

How might I notice concerns?

- Abuse or neglect may be deliberate or unintentional
- You may become concerned about something a patient tells you
- You may see a friend or relative or even a member of staff speaking to a patient or behaving towards them inappropriately
- You may be worried that a patient is not being cared for properly for example, not helped with washing, or not helped with feeding when they need it. Equally you may see a patient you know is Nil by Mouth being given food or drink either by a visitor or member of staff

Raising Concerns

- Speak to the nurse in charge as soon as you become concerned. They may need to
 work with other professionals to put measures in place to ensure the safety and
 well-being of the patient.
- Some issues can be dealt with there and then; others may need reporting and investigating in line with our safeguarding procedures.
- If you do not feel able to speak to the nurse in charge or ward manager; or if you
 would like some help or advice please contact one of the Safeguarding Adults team
 on ext. 64740/64972/8046
- Safeguarding Alert Forms are available through the Intranet on the Teams and Depts/ Safeguarding Adults page
- For all patients at RSCH and Brighton based sites please use the Brighton and Hove alert form
- For all patients at PRH use the West Sussex Alert form
- For patients at Bexhill Renal Satellite Centre please contact East Sussex Social Services
- For patients at Worthing Satellite Centre contact West Sussex Social Services
- Alternatively you can contact Adult Social Care for help or advice:

For patients on RSCH site:

Hospital Social Work Team, RSCH ext. 4001

Out of hours - Brighton and Hove - Social Care Emergency Duty Team - 01273 295555

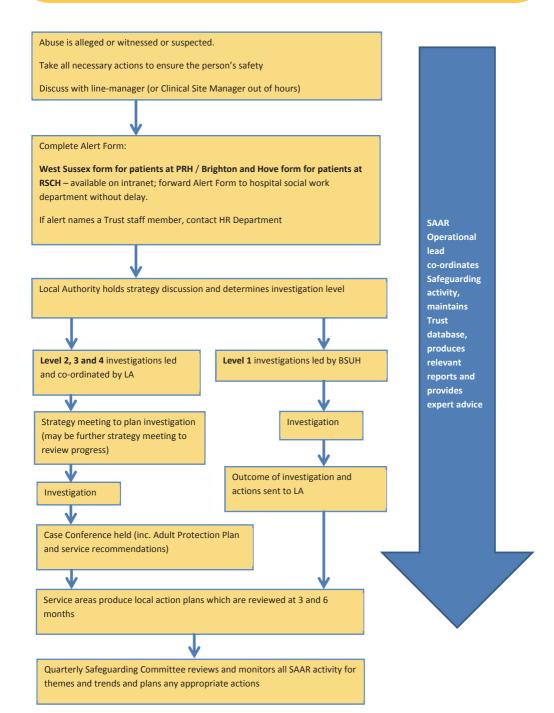
For patients on PRH site:

Hospital Social Work Team, PRH ext. 8381

Out of hours - West Sussex - Social Care Emergency Duty Team - 01903 69442

Safeguarding Adults at Risk

Process for alerting and recording when abuse is suspected



Self-Neglect

Self-neglect can be an extremely difficult and challenging area of work faced by health care professionals. The Sussex Multi-Agency Procedures to Support People who Self-Neglect have been developed to provide guidance for staff.

What is self-neglect?

Self-neglect is defined in the multi-agency procedures as "the inability (intentional or unintentional) to maintain a socially and culturally accepted standard of self-care with the potential for serious consequences to the health and well-being of the individual and potentially to their community."

An individual may:

- Be unable or unwilling to provide adequate care for themselves
- Decline community healthcare support/refuse prescribed medication
- Refuse to allow access to health and/or social care staff in relation to personal hygiene and care
- Fail to attend external appointments with professional staff whether social care or other organisations such as housing
- · Neglect household maintenance resulting in hazards, potentially to others in adjacent housing
- Live in very unclean and/or unsanitary conditions posing a risk to own health and potentially to the community
- Present with poor personal hygiene including dental hygiene, malnutrition, dehydration, sores and/or pressure damage

This list is not definite or exhaustive.

What do I do if I have concerns?

- It is important to remember that a patient with capacity has the right to make unwise decisions.
- Any intervention whether the patient lacks capacity or not needs to be a proportionate response based on the risk of harm or significant harm.
- Professionals must ensure a person-centred approach, where the individual is treated with dignity and respect. The aim is to empower the patient to make informed decisions and lead an independent life as much as possible.
- Multi-agency communication must be in line with information sharing and governance procedures.
- If you have concerns that a patient may be at risk of harm due to self-neglect, speak to the nurse in charge. It may be that the patient needs to be assessed under the Mental Capacity Act or the Mental Health Act and appropriate measures put in place.
- Contact Social Services or the Safeguarding Adults Team for further advice and guidance.
- The Sussex Multi-Agency Procedures are available on the Intranet: Teams and Depts/ Safeguarding Adults pages.

Prevent

Prevent is part of the Government's counter-terrorism strategy known as CONTEST

The focus is on working with vulnerable individuals who may be at risk of being exploited and drawn in to terrorist activity

Healthcare professionals have a key role in working collaboratively with other agencies

Role of staff within BSUH

Staff may become aware of unusual changes in the behaviour of patients and/or colleagues. These should not be viewed in isolation but may include:

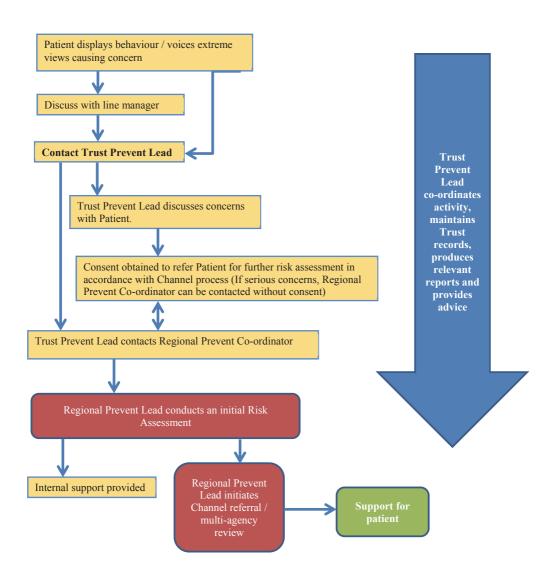
- Family reports of unusual behaviour or friendships
- Patients/staff accessing extremist materials on line
- Use of extremist/hate terms to exclude others
- Writing or artwork promoting extremist messages
- Staff are expected to attend any Prevent training or awareness sessions provided
- All staff are expected to be aware of their responsibilities in relation to safeguarding vulnerable adults
- Staff are expected to discuss any concerns that a vulnerable adult is at risk confidentially with the Trust Prevent lead.

For further information or to discuss concerns regarding Prevent, contact the Associate Director for Quality and Safeguarding on ext. 64740

Building Partnerships, Staying Safe The health sector contribution to HM Government's Prevent strategy: guidance for healthcare workers. Department of Health 2011

Prevent

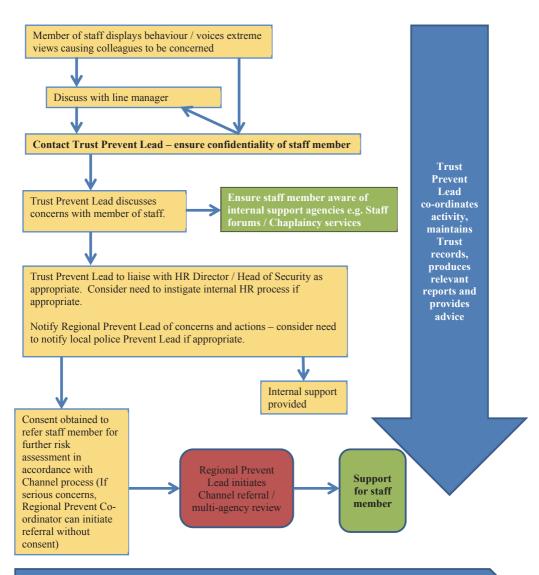
Process for alerting and reporting concerns relating to patients



Adult Safeguarding concerns to be managed as per the Sussex Multi-Agency Policy and Procedures Safeguarding Children concerns to be managed as per the BSUH Safeguarding Children and Young People Policy

Prevent

Process for alerting and reporting concerns relating to staff



Adult Safeguarding concerns to be managed as per the Sussex Multi-Agency Policy and Procedures Safeguarding Children concerns to be managed as per the BSUH Safeguarding Children and Young People Policy



Mental Capacity Act (2005)

The Mental Capacity Act Is a law relating to decision making for people with an impairment or disturbance of the mind or brain. Capacity refers to an individual's ability to make a decision at the time it needs to be made. Capacity is decision specific.

The Act has 5 principles:

- Everyone is assumed to have capacity to make a decision, unless it can be shown they lack capacity
- It is important to take all possible steps to help people make a decision for themselves
- People have the right to make unwise decisions
- Anything done for or on behalf of an individual who lacks capacity must be in their best interests
- Anything done for or on behalf of an individual who lacks capacity must be least restrictive of their rights and freedoms

The assessment of capacity uses the two stage test.

Stage 1

Does the person have an impairment or disturbance of the mind or brain? Does that impairment or disturbance mean the person cannot make the decision in question, at the time it needs to be made?

Stage 2

If the answer to **Stage 1** is **'Yes'** a number of questions need to be considered. Can the person do the following?

- Understand the information relevant to the decision, including the consequences of making or not making the decision
- Remember the information for long enough to make the decision
- Weigh up all the information in order to make an informed decision
- Communicate their decision in whatever way works for them

If the patient is unable to demonstrate any one of the four parts being assessed in Stage 2, they will be deemed as lacking the capacity at that time to make that particular decision.

Who should assess capacity?

The professional proposing the treatment, procedure or examination must assess the patient's capacity to consent. This may be the Surgeon carrying out the operation, the physiotherapist attempting to mobilise the patient or the nurse attempting to take a patient's blood pressure.

For decisions relating to discharge arrangements such as the level of care package required at home or moving into residential care, capacity can be assessed by the social worker working with the patient.

What if someone lacks capacity?

- All decisions made must be in the patient's best interests
- A family member or long standing friend must be consulted regarding the best interest decision.
- If a person does not have family or a friend to act on their behalf then an Independent Mental Capacity Advocate must be consulted.

Best interest decisions should be made with:

- Input from the individual wherever possible
- · Consideration of the individual's views, beliefs, values, any previously expressed wishes
- Avoidance of discrimination
- Consultation of relatives, carers, long standing friends etc...
- · Consideration of the relevant circumstances
- The least restrictive option

If a patient aged 18 or over has previously made an **Advance Decision** to refuse the treatment being offered and the relevant circumstances are applicable to the current decision to be made, treatment **may not** be given in their best interest. A valid and applicable Advance Decision acts as the best interest decision.

A patient must have capacity at the time of making an Advance Decision to refuse treatment in the future when they may lack capacity.

Restraint is permitted under the Act if:

- The person restraining the patient who lacks capacity truly believes it is necessary to prevent harm to that patient
- The amount or type of restraint used and it's duration is proportionate to the risk
- The least restrictive option is chosen

Capacity assessments and best interest decisions must be fully documented in the patient's medical notes

Making 'unwise' choices

If someone has the capacity to make a decision, and they make what is considered an 'unwise' decision, then staff must respect this. However, they are still able to:

- Ensure the individual has all the relevant information, and provide any new relevant information
- Review the decision if things change
- · Encourage positive choices
- Explore any other options for care and treatment that may be applicable

Deprivation of Liberty Safeguards (DoLS)

- A patient must be age 18 or over
- They must be assessed as lacking capacity to decide whether to receive the necessary treatment or care
- They must be assessed as lacking capacity to understand the risks of leaving hospital at that time
- The decision to deprive them of their liberty must be proportionate with no lesser restriction available
- The DOLS must be in place for the least amount of time necessary and must be reviewed if the patient regains capacity
- Application for DOLS authorisation can be made by a senior nurse on behalf of the Trust
- The patient and their next of kin, close friend must be informed of the DOLS. If the
 patient has no relative of close friend an IMCA/best interest assessor will be consulted
 as part of the authorisation
- A copy of the DOLS authorisation must be sent to the Lead Nurse Safeguarding Adults/ Associate Director for Quality and Safeguarding
- The Coroner must be notified of any patient who dies in hospital while subject to a DOLS authorisation

There is a wide range of information available regarding the Mental Capacity Act on the BSUH intranet:

Teams and Depts/Safeguarding Adults
Teams and Depts/Learning Disability

For further advice and to book training on the Mental Capacity Act, contact the Lead Nurse for Safeguarding Adults on ext. 64972

For advice and training to Support Patients with a Learning Disability contact the Learning Disability Liaison Team on ext. 64975

RED

DO NOT ATTEMPT CARDI	OPULMONARY I OW NATURAL D		
			ed 16 years and over
DNACPR adult (Feb 2013) BSUH Brighton and Sussex NFS University Hospitals NHS Trust	te all boxes (Affix pati	ent label to both copies of	form)
Date of DNACPR order:			
/ /	Address		
	Date of birth		
DO NOT PHOTOCOPY	NHS and/or hospital	number	
In the event of cardiac or respiratory be made. All other ap		rdiopulmonary resuscita d care will be provided.	ation (CPR) will
Does the patient have capacity to If "YES" go to box 2.	make and communicat	e decisions about CPR?	YES / NO
If "NO", has the patient appointed an a decision refusing CPR which is rele If "YES" the Attorney <u>must</u> be consul	evant to the current cond		YES / NO
If "NO", are you aware of a valid Adva			ne YES / NO
All other decisions must be made in	the patient's best interes	s and comply with current	t law.
Summary of the main clinical probunsuccessful or not in the patient' this here and in boxes 3 & 4)			
3 Summary of communication with decision has not been discussed with the decision has not been discussed by the decision has not been d			
Date of discussion:	Name of Attorney (if a	ppropriate)	
4 Summary of communication with	the patient's relatives,	riends or carers.	
Date of discussion: Name and relationship to patient:			
5 Consultant making the advanced decision or authorising the emergency decision			
If applicable please enter review date here	e:, or review	criteria here:	
If this is an <u>indefinite</u> decision please state	te here:		
Signature:	Name:	Date: _	
6 In an emergency: Name of junior of (ensure decision discussed with the tion and state his/her name and po	ne most senior doctor	(<u>F2 and above)</u> completi vailable prior to Consul	ng this form tant authorisa-
Name of senior doctor:		Position:	
Name:		Position:	
Signature:	Date:	Time:	

RED

BSUH DNACPR/allow a natural death form - guidance on completion

Patient details (name, DOB, NHS and / or hospital number MUST be recorded)

- A patient identification label containing the patient's full name, address, date of birth, NHS and hospital number should be used. Please place labels on both copies. Alternatively these details can be written clearly in black ink
- The date the DNACPR order was made should be written in the box provided

Sections 1, 2, 3, 4, and 5 must be completed immediately for an advance decision. A form will only be valid if the sections are correctly completed. Section 6 must be completed immediately if an emergency decision has been made, which must be authorised within 96 hours (section 5) by the Consultant.

1. Capacity/advance decisions

Record the assessment of capacity in the health records. Ensure that any Advance Decision is valid for the patient's current circumstances. If the patient has appointed an Attorney for Health & Personal Welfare to make a decision refusing CPR (on their behalf), which is relevant to the current condition, this overrides any Advance Decision.

16 and 17 year olds: Whilst 16 and 17-year-olds with capacity are treated as adults for the purposes of consent, parental responsibility will continue until they reach age 18. Legal advice should be sought in the event of disagreements on this issue between a young person of 16 or 17 and those holding parental responsibility.

2. Summary of the main clinical problems and reasons why CPR would be inappropriate, unsuccessful or not in the patient's best interest

Be as specific as possible. No reasonable chance of success and multiple co-morbidities are acceptable phrases, however as much information as possible should be provided to support the decision not to resuscitate. Avoid, using words like futility or frailty without adding further comments about the rationale. Terms such as quality of life should <u>not</u> be used without clear reference to further information in the health records. The space in this box is small and it is good practice to expand on the rationale for the DNACPR decisions in the health records and cross reference. If the decision is the patient's and they have capacity please state this here and in boxes 3 and 4 with any other additional and relevant information (see below).

3. Summary of communication with patient or Attorney for Health & Personal Welfare

State clearly what has been discussed and agreed. If this decision was <u>not</u> discussed with the patient, state the reason why this did not happen. It is not essential to discuss CPR with a patient that is in the final stages of a terminal illness, where CPR would be unsuccessful (see section 2 above), and a discussion would cause distress without any likelihood of benefit. In this situation, this should be recorded. If the patient has appointed an Attorney for Health & Personal Welfare to make decisions on their behalf, that person <u>must</u> be consulted. This Attorney may be able to refuse life-sustaining treatment on behalf of the patient if this power is included in the original Lasting Power of Attorney. If the decision is the patient's please state this. State here if this is the patient's wishes and any other relevant information.

4. Summary of communication with patient's relatives, friends or carers

If the patient does not have capacity, a discussion with relatives or friends is recommended to help the clinical team to make a best interest decision based on what the patient would decide if able to do so. If the patient has capacity, ensure that discussion with others does not breach confidentiality. State the names and relationships of relatives, friends or other representatives with whom this decision has been discussed. More detailed description of the discussion should be recorded in the health records where appropriate. State here if this is the patient's wishes and any other relevant information.

5. Consultant making the advanced decision or authorising the emergency decision

This should be completed by the Consultant. If a review date is agreed this should be stated here. There must be plan to review the decision, recorded in the health records and the nurse informed should write the review date in the nursing record. If there is specific review criteria please summarise here and expand in the health records (as with review date above). If this is an indefinite decision (no review date or review criteria) please write this. Both the name and signature of the Consultant is required, and a date should be included.

6. In an emergency: Name of <u>junior or middle grade doctor (F2 and above)</u> completing this form (ensure decision discussed with most senior doctor available prior to Consultant authorisation and state his/her name and position here)

An advanced DNACPR decision can only be made by a Consultant. If not available (i.e. out of hours), an F2+ can make an emergency DNACPR decision. This must be discussed with the most senior doctor on the team available on site. His/her name and position must be stated in this box. The DNACPR form should completed by the junior doctor making the decision. A time must be specified. If there is any doubt about the decision then the on call Consultant for that speciality should be contacted. The decision must be authorised and the form signed by a Consultant within **96 hours**. The situation should **never** arise where a DNACPR decision is reversed by default, and resuscitation attempted, because a form has not been signed and is considered no longer valid.

Guidance on use and distribution of the red and grey DNACPR forms

Red forn

The original DNACPR form has a **red** border to distinguish it from the grey Decision Record document. It is recognised by all healthcare providers, including the South East Coast Ambulance Trust (SECAMB), across the South East Coast NHS region. There are local variations but the general design and layout are the same

The **red** form is the 'active' form – the one a ward or community based team (eg GP, DN) or ambulance crew will seek to know if a valid DNACPR order is in place. It is to be considered the patient's property and should go with the patient from one care setting to another. It does not constitute part of the care record.

When in hospital, hospice or care home the completed **red** form should be placed in the front of the patient's health records. This should be the first document in view in the health records

When at home the **red** form may be stored in the community care folder where available. It may also be stored using the green Message in a Bottle system. This system is recognised and used by SECAMB.

Grey form

The grey Decision Record is part of the patient's care record and should remain in the health records of the originator.

Communicating the decision using the grey form/E Oasis discharge information

To communicate the DNACPR decision to other healthcare professional in a timely manner the grey Decision Record can be faxed, photocopied or scanned on request to healthcare professionals involved in the patients care, including the ambulance service, GP, hospital, hospice, district nurse, Out of Hours Service etc. For all discharges a record of the patient's resuscitation status will be recorded on the E Oasis discharge system.

Discharging the patient

On transfer from one care setting to another the active **red** DNACPR form should travel with the patient and the grey Decision Record should remain in the originator's notes. See communicating the decision above.

Review of DNACPR decisions

In the many cases when a clinician signs a DNACPR form this would be done so in the expectation that the decision would remain valid until death occurs due to the patient's poor health status. However where the clinical circumstances and patient's condition may change the decision about CPR will need to be reviewed. The responsible clinician, depending on the general health status of the patient, will determine the future review and enter this on the DNACPR form. They will need to make appropriate arrangement for the review to take place.

If new information is found by any member of the health care team that may bring into question a previous DNACPR decision, it is their responsibility to raise it with the senior clinician so that a review of the decision can be triggered.

Cancelling DNACPR decisions - the red form

In circumstances where the DNACPR decision is no longer clinically applicable and therefore needs to be cancelled, the **red** DNACPR form should be removed from the patient's health records, crossed through with two lines and highlighted with the instruction "This order is cancelled", signed, dated and filed normally in the clinical history section of the health records. In addition a suitable entry must also be made in the patient's health records.

Cancelling DNACPR decisions – the grey form

The red/grey forms are self carbonating and when the red copy is cancelled this should carbonate through, however where available the grey Decision Record should be crossed through, signed and dated. The change in situation should be communicated to other agencies involved in the patient's care that received the original notification. This process needs to include all those who have received a copy of the original grey form and may be done by faxing a copy of the cancelled form to those concerned.

Definition of Learning Disabilities

Is "a state of arrested or incomplete development of the mind that includes significant impairment of intelligence and social functioning."

(World Health Organisation 1992

Learning disability includes the presence of:

"A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning); which started before the age of 18."

(Valuing People 2001)

A learning disability can affect someone's life in many ways:

- Reduced ability to understand new or complex information
- Reduced ability to learn new skills
- Unable to cope independently
- Limited social and communication skills
- Associated physical and sensory disabilities (affects vary depending on the individual, their life, life experiences and severity of brain damage)

Take time to find out what constitutes a bad time for this person, and what you can do so as not to exacerbate the situation.

Important information to know

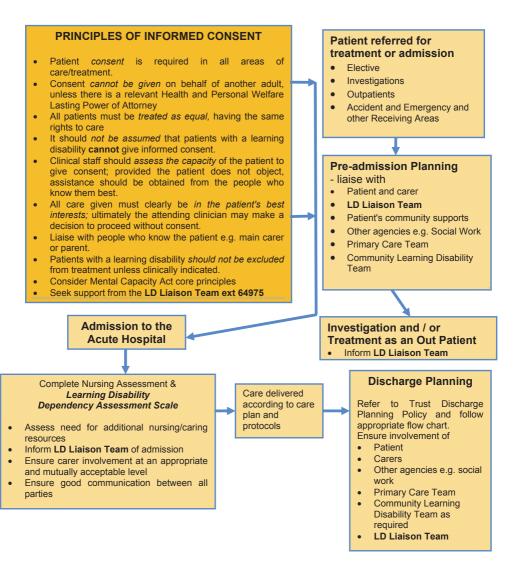
- Many people with learning disabilities lead full independent lives in the community, making their own choices, with varying levels of support. (Valuing People, DoH 2001)
- Flow charts on the Core Principles in the care of a patient with a learning disability in the acute hospital can be found in the LD policy
- Resources relevant to the care of people with a learning disability can be found on the BSUH info-net under Learning Disability Team
- REMEMBER people with a learning disability are PEOPLE first

How to refer to the Learning Disability Liaison Team

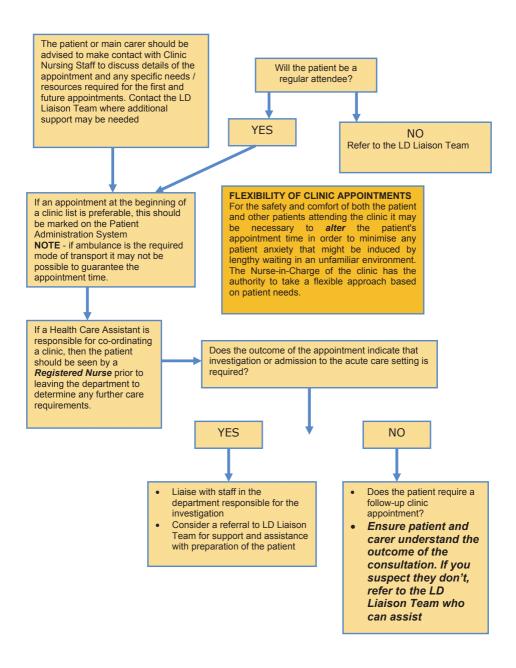
Anyone can contact us for support, information and advice and training:

- Telephone us: 01273 664975 or ext 64975
- Email: LDLT@sussexpartnership.nhs.uk
- For advice or referrals about community support contact: CTLD 01273 295550

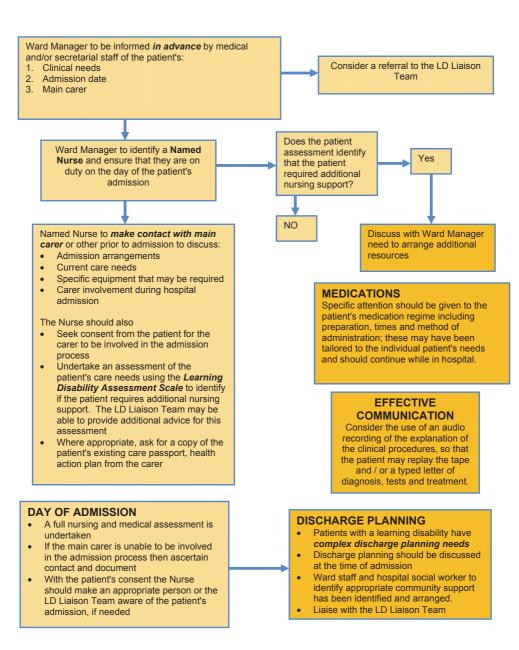
Care of patient with a learning disability in the acute hospital Core Principles



Care of patient with a learning disability in the acute hospital Out-Patient Attendance

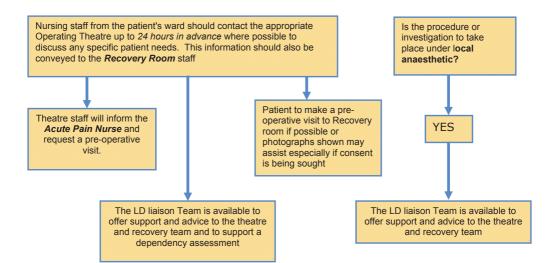


Care of patient with a learning disability in the acute hospital **Elective Admission**



Care of patient with a learning disability in the acute hospital Patients Attending Theatre and Recovery

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



PREPARATION FOR THEATRE

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

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

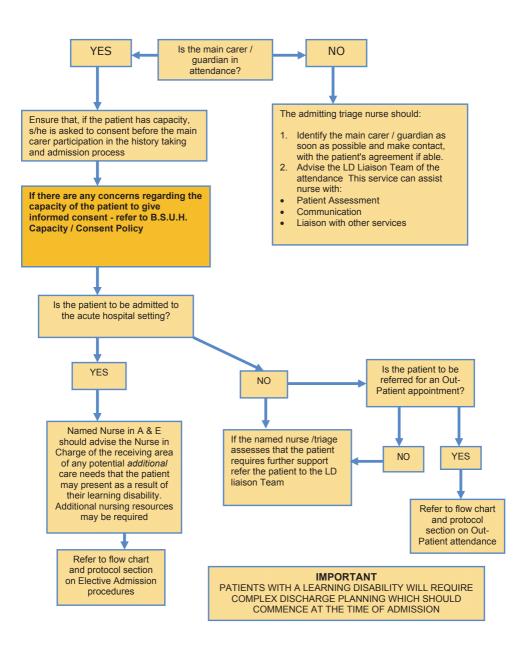
The main carer or next relative may wish to accompany the patient to anaesthetic room and/or be in attendance during recovery

RECOVERY

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

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

Care of patient with a learning disability in the acute hospital Emergency Admission





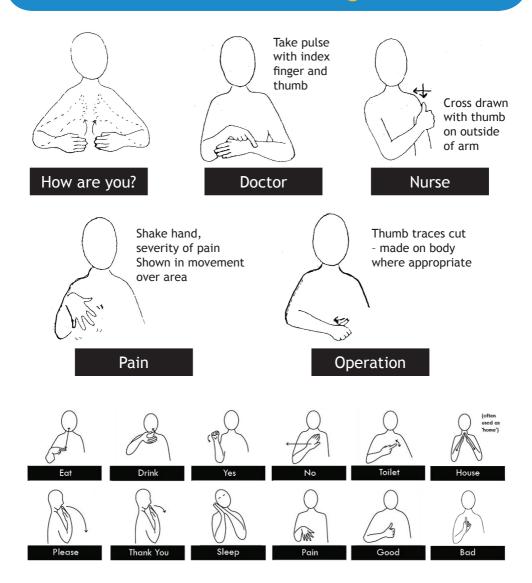
How can you support communication

- Speak with people who know the patient well to find out how they communicate
- Would it be helpful to have someone who knows the patient with you
- Does the patient have a Hospital Passport/DISDAT or other information about their communication
- Introduce yourself and say who are
- Think about your position are you can they see you/your face
- Is it a good time to talk to the patient; are they comfortable tired or in pain
- Do you need to reinforce what you are saying with pictures, drawings, signs or objects
- Use your observation skill to see what a patient may be trying to tell you using body language, gesture

Handy Hints when communicating

- Make sure you have their ATTENTION before you start
- Speak SLOWLY and CLEARLY
- STRESS the KEYWORDS
- **REPEAT** yourself
- Give them TIME to understand
- DEMONSTRATE where possible
- Use a CALM and QUIET environment
- CHECK their (Ask them to tell you what you've said in their own words)
- Use OTHER ways of communicating like DRAWING, GESTURES, FACIAL EXPRESSIONS, and WRITING etc!

Useful makaton signs



- The main benefit of using signing with speech is that it makes communication visual
- People can see what you are saying as well as hearing it
- · Please use speech as well as signing
- For more signs www.makaton.org