NHS England

Getting it right for people with learning disabilities

Going into hospital because of mental health difficulties or challenging behaviours:

What families need to know

Foreword

The way the NHS provides care to vulnerable individuals at a time when they need our help most should be our absolute priority and act as a true litmus test of quality of care more broadly in the NHS.

Making sure that care is compassionate, dignified and person-centred in whatever setting is paramount to what we do at NHS England. Ensuring that people with learning disabilities who have a mental health problem, or exhibit behaviours that are perceived as challenging, receive the right support continues to be our priority.

To make this happen for everyone, strong leadership and partnerships working with commissioners, providers, health care professionals, regulators and people with learning disabilities, their families and carers will be needed. The role of families and carers in this is often underestimated and understated. I am really pleased that NHS England has been able to support the development of this booklet, as going into hospital is a significant life event for people with learning disabilities and their families and carers.

This booklet recognises the unique contribution that carers and families make to the lives of their relatives. It was produced with carers who have had direct experience of hospitals and it draws on what would have helped them in supporting their relatives.

I do hope that this will be a useful information resource for other carers who find themselves in similar situations.

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Acknowledgements

This booklet has been developed as a result of the collective experience and advice of parents and siblings of people with learning disabilities. Very sincere thanks are owed to all those who took part in meetings to develop the content, and to those who commented on drafts.

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This booklet was written by Angela Cole and Alison Giraud-Saunders for NHS England.

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Welcome

This booklet is for parents, brothers and sisters, grandparents, aunts and uncles, cousins, good friends – anyone who cares about and is close to a person with learning disabilities. It will help you to protect their interests if they are admitted to hospital because of mental health difficulties or because they present behaviours that are challenging.

The booklet was developed with the involvement of family members of people with learning disabilities who have spent time supporting people in hospital units. The content of each section reflects their experiences and what they feel family members really need to know.

In 2012 the Panorama television programme uncovered criminal abuse at an in-patient Assessment and Treatment Unit for people with learning disabilities called Winterbourne View. It led to staff being prosecuted and the unit closing down. A report from the enquiry[1] highlighted that families were often not involved in decisions about where people were sent, parents and siblings found it difficult to visit and families' concerns and complaints were often not acted on.

This booklet should give you information and confidence to challenge such practices.

There's a lot in this booklet about the law and people's rights. It focuses on information that is likely to be relevant to most people, but there is much, much more that hasn't been included. Where possible we have indicated where you can find more detailed information.

We hope that you find the booklet helpful.

This booklet gives you

1. Information so that you don't feel powerless;
2. A picture of what you and the person you care about should expect to happen: the standards that services should achieve;
3. Suggestions about things you could do to help make sure the person you care about receives the right treatment and support.

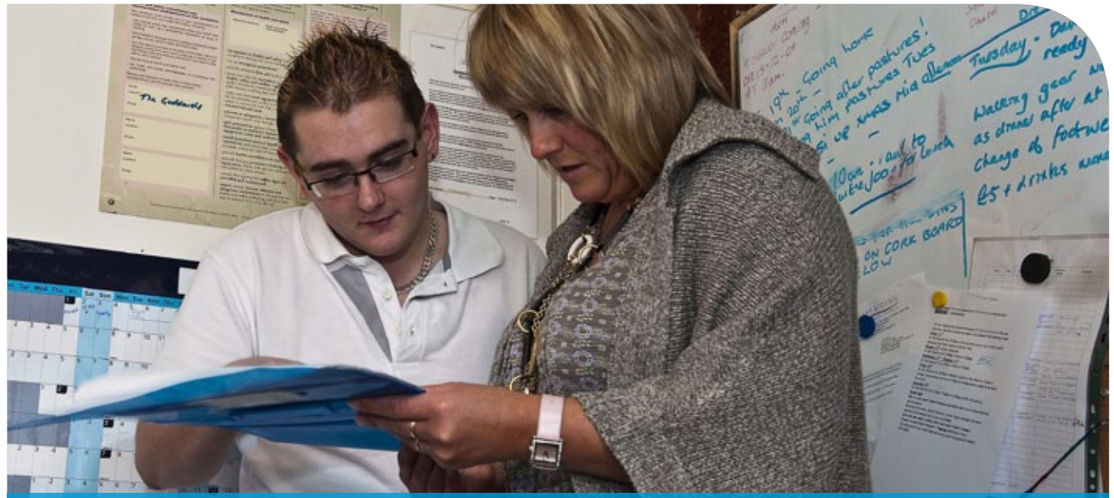
   These suggestions are flagged up by a 'things to do' symbol
4. Links to helpful organisations and further information.

   These links are flagged up by a 'signpost' symbol

Getting support

The law relating to this area is quite complex. This booklet gives you an overview, but it is strongly advised that you get advice from a solicitor if you are unhappy about your loved one's legal position in hospital.

[1] *Transforming Care: A national response to Winterbourne View Hospital DoH Dec. 2012*



Some Key Messages

Based on their own experiences, the family advisers said if you want to advocate successfully for a person who needs to go into a hospital unit, it is really important that you:

- try to get good assessment and treatment for the person at home first, to avoid them having to go into hospital;
- visit and have lots of contact with the person if they do go into hospital (if they want it);
- encourage other people in the person's wider circle to maintain regular contact;
- provide the hospital team with detailed, background information, for example copies of letters;
- create a positive relationship with the team by being as calm as possible, and not confrontational;
- are open to advice from the professional team;
- give advice and 'explain' things about the person to the team;
- don't make assumptions - ask questions so you understand what is happening, and why;
- attend meetings, and send someone else if you can't;
- support the advocate who is linked to your loved one by providing information and meeting with them;
- stay observant – and raise any concerns you have promptly.

How and why people go into hospital units

People with learning disabilities who have mental health problems and/or behaviours that present significant challenges may be admitted to different kinds of hospital units.

Specialist Assessment and Treatment Units	General Psychiatric Units	Secure Units

Why are people admitted?

There are several reasons why a person may be admitted to a hospital unit. For example:

- their behaviour has changed and become too difficult to manage at home;
- they pose a serious risk to themselves or others;
- they have a mental health problem that has flared up and become very serious;
- they have committed a criminal act and their admission is ordered by a Court;
- there isn't a community-based assessment and treatment service in their area.

People are usually admitted when one or more professionals agree that the person would benefit from being assessed and treated away from their home.

Most go into Specialist Assessment and Treatment Units that are just for people with learning disabilities. The majority of these units are run by NHS Trusts, but a significant number are run by independent organisations[2]. Many people have been admitted to units a long way from their home, their family and friends, and have stayed in them too long. The Government has said this must change and, as a result of the Winterbourne View report, better services will be developed in local areas to assess and treat people at home. Fewer people should be admitted to Assessment and Treatment Units in the future.

But some people, will however still need to be admitted to hospital for treatment, and change to community services in local areas may not happen immediately. That's why this booklet has been written.

[2]Between 2006 and 2010 about 60% of Assessment and Treatment care was provided by NHS Trusts, and 40% by the independent sector. By 'independent' we mean private and voluntary organisations. Assessment and Treatment Units and Other Specialist Inpatient Care for People with Learning Disabilities in the Count-Me-In surveys, 2006 to 2010 Glover G and Olson V DH/IHAL Sept 2012

How is the decision made to admit a person?

The Mental Capacity Act (2007) and the Mental Health Act (1983) are the main laws that govern admission.

A person may agree to be admitted to hospital as a voluntary patient or they may be 'sectioned' and become a detained patient.

Exploring alternatives

There are some important things for you to consider:

- Are you confident that community services has explored all the options for assessing and treating the person you care about at home?
- Are you confident that your loved one has had enough information and support to make their own 'informed decision' about going into hospital, and that they have the capacity to do so?
- Are you clear about what will happen if s/he doesn't agree to be admitted voluntarily?

If the answer to any of these is 'no', you could:

- ask for an urgent meeting with the psychiatrist and community learning disability team to explore alternatives to admission and to develop a plan for assessment and treatment at home. Offering your support and involvement may help;
- make sure the person you care about gets information and support to understand and make their own decision about going into hospital. If you can't give support yourself, ask the community learning disability team to make an urgent referral for an advocate.

The Law

The Mental Health Act focuses on 'mental disorder' - conditions such as schizophrenia, depression, anxiety disorder, obsessive-compulsive disorder, eating disorders, personality disorders, Autistic-Spectrum Condition, dementia, behavioural changes due to brain injury and mental disorders due to drug use. The definition includes learning disability, but only where it is associated with abnormally aggressive or seriously irresponsible behaviour.

A person may be admitted for 'assessment' to decide whether they have a mental disorder, which type, and how they might respond to treatment. This is done under Section 2 of the Mental Health Act.

A person may be admitted for 'treatment'. This is done under Section 3 of the Mental Health Act.

a) voluntary admission

A person with learning disabilities aged 16+ may agree to be admitted to a hospital unit as a 'voluntary' or 'informal' patient *if they have the mental capacity to consent* and a psychiatrist agrees it is in their interests.

If the person you care about lacks capacity to consent, they can still be admitted to hospital as an informal patient under the Mental Capacity Act 2005[3] if the admission is in their best interests and does not deprive them of their liberty.

As a 'voluntary' or 'informal' patient the person has the freedom to come and go from the unit, but the doctor in charge of their care can stop them leaving if professionals believe there are risks to the person or to other people. The doctor would apply for the person to be detained for 72 hours under the Mental Health Act[4], giving the unit time to decide whether to apply for the person to be detained for treatment - see (b) overleaf.

Alternatives to admission

Make some suggestions to the professionals. Could the money that would be spent on a hospital placement be used to:

- create a bespoke package of accommodation and intensive, skilled support to keep the person out of hospital, reducing risks to the person and to other people?
- give the person 24hr, intensive, skilled support in their home whilst they are assessed by community teams and a treatment plan developed?
- commission an organisation known to have specialist expertise in learning disability and challenging behaviours, or learning disability and mental health – such as the Tizard Centre - to assess the person and develop a person-centred intervention and support plan?

Making decisions and giving consent

The Mental Capacity Act applies to people aged 16+. Everyone is assumed to have capacity to make decisions themselves if given enough information, support and time. It protects people's right to make their own decisions and to be involved in any decisions that affect them.

Professionals will judge whether the person you care about has the capacity to make their own decision to go into hospital. You can help by telling them about his/her usual ways of communicating, and how people can help him/her to understand their choices.

The Mental Health Act allows treatment to be given *regardless* of whether people have the capacity to consent to it.

[3]Section 5 of the Mental Capacity Act 2005
[4]Section 5(2) of the Mental Health Act 2007
[5]Mental Health Act Code of Practice

Speaking up

Psychiatrists, psychologists, and other health and social care professionals can appear very powerful people. If you:

- feel anxious about speaking to professionals
- don't speak English as your first language
- are worried that you won't understand the legal points or the jargon

…make sure you have someone with you when you meet them. Choose someone you trust and who you know will be able to help you.

…think about what you want to ask or to say in advance.

It will help everyone.

Nearest Relative

This is not necessarily the same as someone's next of kin. The following are treated as relatives under the Mental Health Act: husband, wife or civil partner (including a person s/he has been 'living with' for six months or more); son or daughter; father or mother; brother or sister; grandparent; grandchild; uncle or aunt; nephew or niece. The nearest relative has a number of powers:

- They can object to an application for admission under section 3. Admission can then only go ahead if the County Court makes an order for the nearest relative to be 'displaced'.
- They have the power to discharge their relative from detention under sections 2 and 3. The nearest relative must give the hospital managers 72 hours notice in writing, to an 'authorised person' at the hospital. Within this period, the clinician responsible for the person's care and treatment (the 'Responsible Clinician'), may issue a 'barring certificate' which prevents the nearest relative from discharging the person for six months. If a barring certificate is issued, the nearest relative has 28 days to apply to the Mental Health Tribunal for discharge.

Patients have the right to apply to the County Court to displace their Nearest Relative, and County Courts can displace a Nearest Relative that it thinks is not suitable to act as such.

There is a very helpful and much more detailed briefing about the rights and powers of the 'Nearest Relative' on the MIND website, at: www.mind.org.uk/information-support/legal-rights/nearest-relatives-under-the-mental-health-act/

b) compulsory admission ('sectioning')

Professionals are expected to consider all alternatives to compulsory admission to hospital[5], so sitting down with them and exploring the options on page 7 could really help.

To be detained under the Mental Health Act - or 'sectioned' - a person must be suffering from a mental disorder that:

- requires assessment or treatment, and which
- needs to be given in hospital in the interests of their own health or safety or to protect other people.

The sections of the Mental Health Act that people usually mean when they talk of someone "being sectioned" are sections 2 and 3. They are known as 'civil sections':

- Section 2 is a compulsory admission to hospital for up to 28 days so that the person can be **assessed** (or assessed and then given treatment). The section can't be renewed, but an application can be made to continue detaining the person in hospital for treatment, under Section 3 of the Mental Health Act.
- Section 3 is a compulsory admission to hospital **for treatment**, where treatment cannot be provided unless the person is detained in hospital, and appropriate medical treatment is available. The detention is initially for up to six months, but can then be renewed by a further six months, and then a year at a time. A person can be 'discharged' from a section before it comes to an end, and the Nearest Relative can apply for this to happen – see opposite.

Three people must agree that the person needs to be detained in hospital:

- an Approved Mental Health Professional (AMHP) – usually a social worker - or the Nearest Relative
- a doctor who has received special training
- a registered medical practitioner.

Your loved one may not realise or accept that they are unwell and may not want to have treatment that is clearly needed. Because of this, they may need to be compulsorily admitted to hospital as a final resort – but it needs to be a very carefully considered step.

If you are involved in a situation where there is the possibility that your loved one will be 'sectioned', it will be helpful if you:

- tell the doctor or Approved Mental Health Practitioner if the person is known to professionals in the community learning disability health and social work teams. Ask for specialist staff from those teams to be involved in the decision. If necessary, call them;
- give the professionals information about how your loved one communicates, and what they need to do to communicate well with him/her;
- tell them about, or show them your loved one's Health Action Plan or person-centred plan, or any support plans;
- tell them about his/her usual patterns of behaviour and what's different at the moment;
- tell them about anything you think may have triggered the change in behaviour (such as a bereavement, a change of medication, a recent health problem, etc);
- talk with the professionals about the risks to the person and to others, including the risks that may come from an admission to hospital. Talk about options for managing risks without a hospital admission.

The doctor recommending admission to hospital may be a specialist learning disability psychiatrist who already knows the person you care about. That does not mean they know everything they need to know about your person and their current situation. You can help them make a good decision for your loved one by doing all of the things listed above.

c) admission in a crisis or emergency situation

Some people with learning disabilities are assessed and 'detained' under the Mental Health Act after being picked up by the police or being treated at A&E:

a) because of concern for safety

If the police find a person in a public place who they believe has a mental disorder and is in need of immediate care, or control, they can remove them to 'a place of safety', such as a hospital. Other places can be considered, such as a residential care home or the home of a relative or friend who is willing to accept them temporarily.

A person can be held in a place of safety[6] for up to 72 hours until an Approved Mental Health Professional (see page 8) and doctors have assessed them and decided if they have a mental disorder. The Mental Health Act Code of Practice says it is desirable for either a consultant psychiatrist in learning disabilities or an Approved Mental Health Professional experienced in working with people with learning disabilities to carry out the assessment where it appears that the detained person may have a learning disability.

A person can also be removed to a place of safety if they are in their own home and refuse to let a doctor or Approved Mental Health Professional in to see them[7]. A magistrate's court order has to be obtained before the person can be removed.

b) after being arrested

If a person is suspected of having committed a crime they may be arrested and taken to a police station. They have the right to a solicitor whether they have committed a crime or not.

If the police suspect, or are told that the person may have a mental disorder (see page 7), they must arrange for a doctor to assess them. The doctor will advise whether s/he is well enough to be questioned and well enough to remain in the police station. If the person is not, then the police must ensure they are admitted to hospital or possibly even be returned home.

The police must *not* question a person with learning disabilities without an 'Appropriate Adult' present. An Appropriate Adult can be a family member, a professional or another person independent of the police, but it cannot be the solicitor provided by the police.

For more information about people with learning disabilities and the criminal justice system have a look at:

Staying Positive: The Criminal Justice System and Learning Disabilities (easy read information) Go to: www.rcpsych.ac.uk/pdf/StayingPositiveLD.pdf

[6] *Section 136 of the Mental Health Act 1983*
[7] *Section 135 of the Mental Health Act 1983*

If you think these kinds of crisis could happen to your loved one, because they have a mental health condition or because they can present very challenging behaviours, it is important that you make a plan with them to help avoid an emergency admission to hospital. For example, you could:

- identify some people who know him/her well who should be contacted in an emergency (it may be their solicitor, an advocate, you), and who could also act as their Appropriate Adult if needed;
- identify a place that s/he likes going to that agrees to be used as a place of safety, and has appropriate support on hand;
- make sure that your loved one carries a card that tells people about their condition, any medication they take, who should be contacted in an emergency, and a good 'place of safety' for them.

d) admission through the courts

If someone with learning disabilities has committed a crime and is mentally unwell at the time of sentencing, a court can order their admission to hospital for an initial six months, which can then be renewed. This is called a section 37 order. In very serious cases, a Crown Court may add a section 41 restriction order "without limit of time". This means that they cannot be discharged from hospital without permission from the Ministry of Justice.

People with learning disabilities admitted to hospital by the courts will be placed in secure units, which means that they are not free to come and go. These are 'forensic' mental health services. 'Forensic' means 'pertaining to the law' - specialist services for people who have been arrested, who are on remand or who have been to court and found guilty of a crime. They are an alternative to prison for people who have mental disorder and offer specialist treatment and care.

If the person you care about is arrested, find out if there is a local liaison and diversion service, and make sure they are referred to it.

Liaison and diversion services

All police stations and courts should have access to 'liaison and diversion services' to make sure people with mental health problems or learning disabilities who have offended are 'diverted' from the criminal justice system to more appropriate health services. A national network of services is being set up.

Before a person is admitted

The family members advisory group stressed the importance of action to avoid admissions. They identified a number of expectations:

- families receive good information about how to get support for their relative - who to go to, and what response they should expect if problems arises;
- family members are listened to and get a positive response when they say that things are starting to become difficult. Problems are addressed early;
- a person known to be at risk of admission has a comprehensive, multi-disciplinary assessment, which includes their history – their story so far;
- there is an up-to-date 'snapshot' of the person's preferences and support needs – a profile that can immediately be given to a unit if the person needs to be admitted;
- it is demonstrated that all options to keep a person in their home setting have been worked through, including positive behaviour support. It is demonstrated that an in-patient admission really is a last resort. Three important questions are asked:
  - Is this the right route for this person?
  - How could an admission damage him/her in the long-term?
  - Have all alternatives really been exhausted?
- there is a clear justification for the placement that states what the benefits are expected to be for the person;
- no-one should be sectioned or admitted voluntarily under the Mental Health Act without a learning disability specialist professional present when the decision is being made.

Use this as a checklist to help make sure that these things happen.

About the unit

If the person you care about is going to be admitted to a hospital unit, of whatever kind, you will probably be concerned about where it is, what it's like, and what it does. In essence, will it be a good place for your loved one to be, and is there anything you can do to make sure that it is?

Where it is

In the past a lot of people with learning disabilities have been placed in hospital units a long way away from their home, family and friends. The government has said this must end and people should get support and treatment close to home.

If your loved one is going into an Assessment & Treatment Unit for people with learning disabilities, you should expect it to be in, or very near to their home area. Professionals in the local learning disability service will make a recommendation about which unit someone should go to. Often the decision is based on where there is a bed available. If you or your loved one is unhappy with the recommendation:

- make it clear that you are unhappy about the location and say why. Make sure that your objection is recorded on file;
- make sure that the local learning disability commissioner(s) knows you are objecting to the location – they may be involved in agreeing to pay for it;
- have another go at discussing and exploring alternatives to admission and try to develop a plan for your loved one to be assessed and treated at home, ask the Learning Disability Nurse or doctor for their contact details;
- if you feel you need to accept, ask for your travelling expenses to be paid, and consider asking for your loved one to be transferred to a hospital nearer home as soon as a bed is available (if another move would not be detrimental to him/her).

If the person you care about is thought to have a mental health condition, the most local placement to their home is likely to be in a general psychiatric unit. Don't just dismiss the idea out of hand because it's not a unit for people with learning disabilities. The equality laws say that mental health services should make 'reasonable adjustments' so that they are accessible and effective for all, which includes people with learning disabilities and people with autism who have mental health issues[8].

A national commitment

NHS England has made a commitment to champion the involvement of patients and carers in making decisions about, and managing their own care and treatment, *including having a choice of provider wherever possible.*

Securing equity and excellence in commissioning specialised services
NHS National Commissioning Board
Nov. 2012

[8] *The Equality Act 2010 and the Health and Social Care Act 2008*

Independent Mental Health Advocates (IMHAs)

…support people who are detained under the Mental Health Act. Their role is to help patients participate in decisions about their care and treatment, and help them understand and exercise their rights, including making applications for reviews by Mental Health Act Managers and the Mental Health Tribunal.

Questions to ask

If your loved one is admitted to a general psychiatric unit, talk to the staff team about how they will:

- provide information that s/he can understand about the ward and all aspects of their care;
- involve your loved one in, and adjust their assessment to ensure they are getting meaningful answers to the questions;
- involve professionals from the learning disability service, to make sure they are 'getting it right';
- support your loved one to make their own decisions;
- keep your loved one safe within the patient group.

What that means in practice is that a person could be supported on the ward by a nurse with specialist learning disability training, they could get easy read information, could continue to be seen by their own specialist learning disability psychiatrist, could access adapted treatment programmes and, potentially - if they have support staff paid for through a personal budget - those staff could carry on working with them in the hospital setting. Staying local allows continuity – which may be more beneficial to your loved one than being in a specialist 'learning disability' unit that is miles away from their home.

A local hospital placement may not be possible for everyone. For example:

- if the person you care about is sent to a medium security unit by the courts, there may not be one with beds available in a ward specifically for people with learning disabilities in your local area;
- secure units specifically for women with learning disabilities are few and far between across the country.

If your loved one is being sent to a medium security unit by the courts, or is already placed in one and you are finding visiting difficult, you could:

- talk to NHS England's specialised commissioning team about the location of the hospital and request that your loved one be placed near home (assuming s/he wants that); go to www.england.nhs.uk/contact-us
- ask your loved one's Independent Mental Health Advocate or solicitor to request that s/he be moved to a hospital nearer home.

What it does and who it's for

There are several different types of unit that a person with learning disabilities could be placed in for assessment and treatment.

Assessment and Treatment Units for people with learning disabilities

People placed in Assessment and Treatment Units may be voluntary patients or they may be admitted under the Mental Health Act. They may have mental health problems and/or present seriously challenging behaviours, and they may be admitted from their home or as a 'step-down' from a secure unit. Some have more security features than others. Some are more community-based than others. As all of this suggests, they are quite variable.

At the time of writing, a national service specification for specialist learning disability services is being developed that will make clear what Assessment and Treatment Units for people with learning disabilities should be achieving. It will be available through the Department of Health website during 2014 and beyond. Go to www.gov.uk

General psychiatric units

Acute Psychiatric Admission Wards receive people with suspected mental health problems as voluntary or compulsory patients. People generally stay for a short period while they are assessed and receive some initial treatment. Many people are discharged after a few days or weeks, though some may transfer to a psychiatric intensive care unit for more treatment.

Psychiatric Intensive Care Units are for people experiencing *acute* mental illness and provide short-term intensive care and treatment in a locked environment. People are admitted under a compulsory order ('sectioned'). There are commonly higher than normal staff to patient ratios; locked doors; windows with restricted opening; search of bags on entry, and removal of dangerous items; controlled access to areas such as the kitchen and garden.

Rehabilitation and Recovery Units are for people who need more time to prepare for their return to community life. Some are locked units, used as a 'step down' for people who have been in secure accommodation.

'Secure' accommodation means that the unit has measures in place to ensure a safe environment in which to deliver treatment. There are secure units for young people under 18 years of age, as well as units for adults.

There are different levels of secure hospital accommodation, and all have activity and education programmes.

Low secure services are for people detained under the Mental Health Act who, because of the level of risk or challenge they present, cannot be treated in open settings.

Medium-security psychiatric units treat people who have been admitted by the courts under the Mental Health Act, people transferred from prison under the Mental Health Act, and people transferred from an ordinary psychiatric hospital ward because it is felt they need to be treated in a more secure setting. They are run by a range of NHS and independent organisations.

High-security hospitals like Ashworth, Rampton, and Broadmoor are used to treat people who are thought to pose a significant danger to the public. Rampton Hospital is the country's sole provider of High Secure Forensic Services for patients with a learning disability.

When you first visit someone in a secure unit it can be quite a disturbing experience because of the security systems in place – such as airlock entry door systems, giving you a panic alarm, having to leave some belongings in lockers at the entry, locked doors to meeting rooms, being escorted, and more. It really helps to talk to other people about what it's like before you go.

Don't let the security put you off visiting, and don't let it put you off asking questions. The person you care about needs the contact, and you need information. The staff in medium and low secure units are nurses and health professionals – they are there to help.

Visiting arrangements vary between different units. Visitors to higher security units may have to book in advance and show identification. So check when your loved one is first admitted.

Do read the factsheet on forensic services produced by Rethink, available to download at www.rethink.org. It will answer a lot of your questions about secure hospital units.

What it's like and how good it is

There are a number of ways you can get a flavour of what a hospital unit is like, and how good it is. The more routes you explore, the more complete the picture will be.

- Look at the latest inspection report for the hospital on the Care Quality Commission website: www.cqc.org.uk. Each report includes direct feedback from patients;
- Look at the website for the organisation that runs the hospital. It will tell you what they are trying to achieve, what services they run, and who manages those services. It will also give you contact details for further information;
- Talk to other families who have experience of the unit. Ask your local learning disability team, or the hospital unit, to put you in touch with some families, or with the unit's family support group if there is one;
- Contact the hospital advocacy service and ask for copies of any recent reviews or evaluations carried out by patients, so you can see what people say about their experiences and treatment;
- Request an information leaflet about the hospital and about the specific ward that your loved one will be on;
- Ask the local social services department how many safeguarding alerts there have been for people at the unit in the past year (if necessary you can do this through a Freedom of Information request).

Registration and Inspection

Hospital units have to be registered with the Care Quality Commission, which then monitors them against standards of quality and safety. CQC carries out an inspection at least once a year and publishes the report on its website.

Freedom of Information requests

The Freedom of Information Act gives you the right to ask any public sector organisation for all the recorded information they have on any subject. Anyone can make a request for information – there are no restrictions on age, nationality or where you live.

Contact an organisation by letter or email to make a request. You should include your name, an address where you can be contacted, a detailed description of the recorded information you want. You should receive it within 20 working days. If the organisation needs more time, they will contact you and tell you when you can expect it.

Information about the unit

The family members' advisory group said that it is essential to get good information, and to get some of it very quickly. Good services:

- give the person and their family verbal and written information immediately, even where it's an emergency admission;
- give the information in an accessible format that is right for the person, and make sure it is explained to them within 24 hours of admission;
- talk through the information with the family within 24 hours of admission, which may be by phone or face-to-face.

The information should include:

- contact details for the unit, and names of key staff;
- the aims of the service/unit and how it operates - its staffing, who does what, handover times, daily patterns, etc;
- visiting times and rules, parking facilities and reimbursement of visiting expenses, including where family members can eat or rest during their visits;
- what patients can and can't do - e.g. any areas they can't access, what things are locked away or have to be asked for, how they get access to things they need like phone calls and money, etc;
- how, and what information is shared with people and with their families – e.g. about changes to staffing, 'incidents', meetings, etc;
- what happens next, after someone has been admitted, and when the first meeting will take place that the person and their family can contribute to (the timeframe);
- the person's legal status if they have been admitted under the Mental Health Act, and what it means for them;
- the person's rights as an in-patient and under the Mental Capacity Act, and how they will get help to speak up - advocacy support;
- how any cultural requirements and language issues will be addressed;
- what will happen to welfare benefits whilst the person is an in-patient, including carers benefits if the person lives with family;
- what will happen about any other services they normally use;
- how planning for discharge happens, and who is involved;
- what family members can do, and what information they can provide to help ensure treatment plans are right for their relative;
- what the policy is on use of control, restraint and seclusion, and how the family will be involved in deciding the approaches to be used to deal with challenging behaviours;
- how a family member can raise concerns or make a complaint.

If you are not given this information, make sure you ask for it!

The National Institute for Health and Clinical Excellence (NICE) says that wards and psychiatric units should feel safe, should give people privacy and space, and offer separate toilets, washing facilities and sleeping accommodation for men and women. When someone is admitted to a ward they should be told:

- the name of the member of staff who will be coordinating their care, and how they can be contacted;
- why they have been admitted and, if it's under the Mental Health Act , what it means, how long they will be detained, and their right to appeal against that decision;
- about their right to complain about the care they receive;
- their rights on agreeing to treatments;
- how to get independent advice and advocacy support;
- what may happen if they behave in a disturbed/violent way.

NICE says that information should be provided in a way that is suitable for the person, and they should get help to understand it if needed. For example, if someone's preferred language is not English, they should be able to have an interpreter. The information should be repeated to ensure that the person understands it.

Support for your loved one

The advisory group said that families need to make sure that:

- on admission, their loved one is given verbal *and* written information (in a suitable format) about how they can get help to speak up i.e. advocacy support;
- an independent advocate skilled in supporting people with learning disabilities makes contact with their loved one within two days of admission, and then at least every four weeks during their stay;
- the advocate gives the person active support around their legal position before, at and after any Care Programme Approach meeting (see page 20), Mental Health Managers meeting, Review Tribunal and/or Appeal;
- the care coordinator from the community learning disability team checks to make sure that the person is seeing their independent advocate regularly.

…and support for you too

The advisory group said that family members need support in their own right when their loved one is admitted to hospital, and they should be:

- linked up with other families for peer support;
- given contact details of a person who is independent of the unit and the provider, who they can talk to and discuss the situation – an independent family advocate. If a family member doesn't contact the advocate, the advocate should contact them.

Don't forget about yourself! Ask for these things too.

Getting involved and being heard

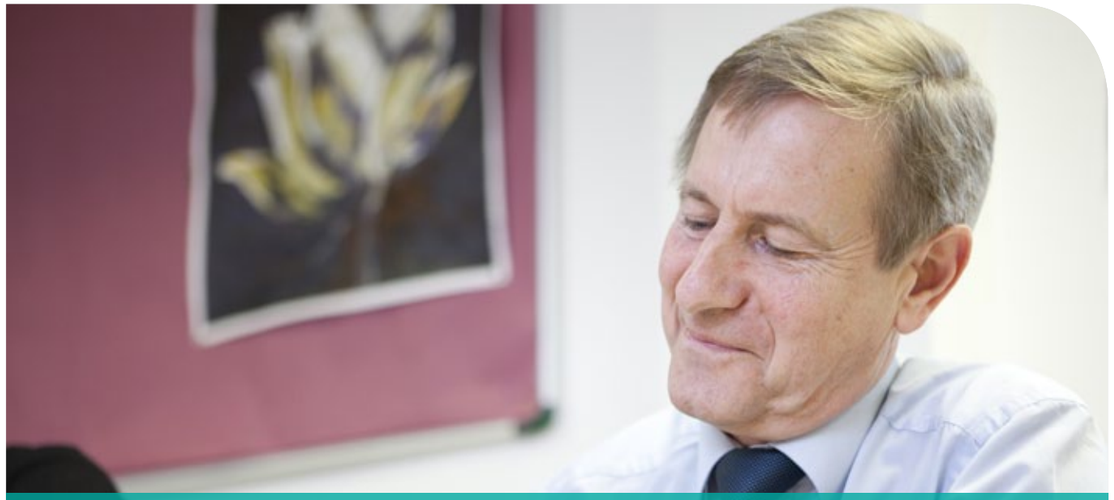
People with learning disabilities and their families can feel powerless when faced with professionals talking about the Mental Health Act, units with locked doors, staff with bundles of keys, panic alarms, rules…

Even Assessment and Treatment units based in ordinary houses are bound by health service regulations, jargon, routines and procedures. Whatever the setting, it's really important that families feel involved and able to speak up about their loved one's support and treatment.

To do that, you need encouragement, information and support. The family members who worked on developing this booklet identified a number of things that hospital units can do to create a positive partnership with family members.
Asking questions and giving staff feedback about these things might help the hospital unit to involve you well.

What services can do to increase family involvement

- have clear guidelines on how and when families are to be involved in planning for their relative, and consistently apply them;
- give families links to/contact details for other families who have experience of in-patient services;
- offer families independent advocacy support in their own right, within a week of the admission, and regularly ask if they need any additional support for themselves;
- welcome family members to access their relative's room at any time, subject to the person's agreement;
- welcome family members to access communal areas at all times (subject to the needs of other patients), and welcome families to eat a meal with their relative;
- agree with the family what 'situations' they will automatically be informed about by the service;
- actively do things to encourage family involvement, such as regularly asking if they have any questions or need anything explained;
- show respect to family members, and do not talk about families in disparaging ways (e.g. as 'troublemakers' or 'over-protective');
- listen when family members express concerns, and respond in a professional way: family members are respected for asking questions about what is happening, and are given answers to their questions;
- invite families to contribute to all meetings that are specifically about their relative, and ask questions that help them to contribute;
- notify families of the dates of meetings at least 21 days in advance, ensure they get papers for meetings at least seven days in advance, and the notes from meetings within seven days. Meeting times are set that enable family carers to attend;
- fully involve family members in discharge planning, and give more than one moving-on option for families to consider with their loved one;
- give families guidance on how they can challenge/raise a concern about what is happening for their relative, who they should talk to, how soon they should expect a response, and what they can then do if they are not satisfied.



Rights and responsibilities

This section gives an overview of who is responsible for what, and what rights you and your loved one have whilst they are in hospital.

Paying for the hospital stay

Hospital placements are paid for by the National Health Service which means that they are free to patients.

Some local authorities actually pay the bills for hospital placements on behalf of the health service because the local health and social care organisations have put their money together for people with learning disabilities.

Making sure that the hospital delivers good support

The **commissioner** of services for people with learning disabilities in your loved one's local area has an important role in relation to hospital placements. The commissioner will have to agree to pay for the hospital placement if it is a voluntary admission, or pick up the bill if it is a compulsory admission. They are responsible for agreeing a contract with the organisation that runs the hospital, which sets out what will be provided and the quality standards, and for making sure that the placement is monitored. Local health or social care staff should attend reviews, which feeds into the contract monitoring.

If you have concerns about the quality of the service your loved one receives in hospital, it can help to copy any correspondence to the local learning disability commissioner.

Coordinating care

The commissioner is responsible for making sure that your loved one has a **care coordinator** from their local area – usually a health or social work professional from a community learning disability team – to make sure that they get appropriate help and treatment in hospital and then return home as soon as possible, with whatever support they need. In many instances, someone who is admitted to hospital will already have a named community nurse or social worker, who will follow them through their hospital admission and return home.

Being clear about the purpose

The advisory group said that families should ask the care coordinator for:

- a clear statement about the purpose of the hospital admission for the person, and why this unit has been chosen;
- an individualised contract with the unit that shows what is being paid for, and what the unit is expected to do/achieve for the person. The person and their family should be given a copy.

The care coordinator should:

- contribute information about your loved one for their assessment, and contribute to the hospital care plan;
- maintain regular contact with your loved one to monitor how they are progressing and what's happening to them;
- make sure that they are having contact with an independent advocate;
- maintain contact with key family members, keeping you informed and involved;
- attend your loved one's reviews, Care Programme Approach meetings, and Mental Health Tribunals (if s/he is sectioned), and provide reports – see page 20-22;
- lead on developing a discharge plan, and making it happen.

If your loved one is detained under the Mental Health Act and/or is in secure accommodation, the care coordinator will need to have very good knowledge of the Mental Health Act. They will also need to have enough time to carry out all the responsibilities listed above. In practice, care coordinators vary in their knowledge and skills, and have competing demands from other people. If you feel that the care coordinator is falling short in their responsibilities towards your loved one, don't let it drift. Write to the learning disability commissioner through your local Clinical Commissioning Group, state the facts about what has not been done and request action to address them.

Coordinating treatment

In hospital your loved one will have either an 'Approved Clinician' or a 'Responsible Clinician' to coordinate their treatment, and in some cases both. They are professionals who are registered and approved by the Department of Health to carry out a number of responsibilities under the Mental Health Act.

The Responsible Clinician does not have to be a psychiatrist. It can be another doctor; a chartered psychologist; a qualified nurse in mental health or learning disabilities; a registered occupational therapist; or a registered social worker. A patient's Responsible Clinician should have the most appropriate expertise to meet their main treatment needs.

All patients *detained* in hospital for assessment or treatment must have a Responsible Clinician. The Responsible Clinician has the power to:

- grant patients leave of absence from the hospital, and discharge them from detention;
- renew a detention order with agreement of another professional (from a different profession) who has been involved in the patient's treatment;
- block discharge from detention requested by a Nearest Relative (see page 23);
- recommend transfer to guardianship (see page 23);
- make a Community Treatment Order (see page 24), or recall a person to hospital and revoke a Community Treatment Order.

A doctor or Approved Clinician in charge of the treatment of a voluntary patient also has the power to prevent them from leaving hospital[9].

Before going into hospital your loved one's treatment may have been coordinated by a psychiatrist from a community learning disability team. S/he will liaise with the Responsible Clinician in the hospital and is a good person to talk to if you have concerns about treatment.

Decision-making and mental capacity

The Mental Capacity Act says that people over the age of 16 should be presumed to have the capacity to make their own decisions, unless it is shown otherwise. However, the Mental Health Act allows people to receive treatment for mental disorder regardless of whether they have the capacity to consent – in other words, if a person is assessed as needing treatment, they can be 'sectioned' and given it whether they consent or not.

Just because a person has learning disabilities or is detained under the Mental Health Act does not necessarily mean that they are unable to make decisions for themselves. Your loved one's capacity to make a decision should be assessed, and each decision be treated in its own right. Many people who go into hospital are capable of making all of their own decisions, if they are given the right information and support. For others, their decision-making ability is occasionally affected and only for short periods, for example, during a period of disturbed behaviour. When considering someone's mental capacity a health or social care professional should ask, "Is this person, at this particular time, capable of making this particular decision?"

You can help staff at the hospital to get it right – so your loved one can make their own decisions – by telling them how you do it, or what usually works. For example, how you present choices to the person; what words you use; whether visual clues, like pictures, are helpful; whether it matters if there are distractions, etc. The more you help the staff, the more likely they are to succeed.

The Mental Capacity Act allows decisions to be made for people who lack the capacity to make their own decisions, in their 'best interests'. A person making a decision on behalf of your loved one must:

- consider all the relevant circumstances;
- consider whether s/he will have capacity to make the decision in the future and if the decision should therefore be delayed;
- support their participation in decisions affecting him/her;
- consider the person's expressed wishes and feelings, and beliefs and values;
- take into account the views of carers, people with an interest in the person's welfare, or those appointed to act for the person.

Help to get it right

To ensure that your loved one gets well coordinated, effective treatment, build a positive relationship with their Responsible Clinician and help the team by giving them information about:

- how your loved one communicates, and what they need to do to communicate effectively with him/her;
- treatments that have helped in the past;
- treatments that have been tried but not worked;
- any current medication, and any medication to avoid;
- any cultural requirements around the giving of treatment;
- behavioural programmes and interventions that have been tried, and the results.

[9] *under section 5(2)*

Sometimes a 'best interests meeting' will be held to allow everyone involved to express their views. Whoever is making the decision, such as a doctor who is considering treatment, will then have to weigh up all the factors to decide what is in the person's best interests.

The Court of Protection (Tel: 0300 456 4600) can appoint substitute decision-makers – 'deputies' - to make decisions in a person's 'best interests' on health and welfare or financial matters. A deputy may be appointed when an ongoing series of decisions need to be made. They only have the right to make decisions that the person does not have the capacity to make. In most cases the deputy will be a family member or someone who knows the person well. In cases where a person's affairs or needs are very complex the Court of Protection might appoint a deputy who is independent of the family.

The Challenging Behaviour Foundation has produced an information sheet for families about deputyship: 'Getting legal authority to make decisions about money, property & welfare'. Go to: www.challengingbehaviour.org.uk/cbf-resources/information-sheets/making-decisions---the-law.html

The Mental Capacity Act allows people to make a written statement about their wishes and preferences in case they lose decision-making capacity in the future. These statements are not legally binding, but should be considered when decisions are being taken. If your loved one is at risk of being admitted to a psychiatric unit or Assessment and Treatment unit in the future, and has particular requirements and preferences – for example, related to their culture, or their treatment choices – you could support them to write an 'advance decision' statement whilst they are well and able to make informed decisions. If they do this, it is important to let professionals know about it.

There is a lot more detail, and many hints and tips for families about how to use the Mental Capacity Act, in 'Using the Mental Capacity Act: A resource for families and friends of people with learning disabilities' Go to: www.hft.org.uk/Supporting-people/family-carers/Resources/MCA-guide/

Key principles of the Mental Capacity Act

- All adults have the right to make decisions for themselves unless it can be shown that they are unable to make them.
- Everyone should be given all the help and support they need to make a decision before anyone concludes that they cannot make their own decision. People must make an effort to provide all the necessary information in a way the person can understand and make it easy for them to try and explain what their preferences are.
- People are allowed to make unwise decisions. Because we think the decision is unwise, it doesn't mean the person lacks capacity to make that decision.
- Any actions taken, or decisions made on behalf of someone who lacks capacity must be done in their best interests, after considering what is known about their preferences, and involving them in making the decision.
- Any act done for, or any decision made on behalf of someone who lacks capacity should be the *least restrictive option* possible.

Decision making and keeping people safe

The Mental Capacity Act allows a person who lacks capacity to be physically restrained to prevent him or her from being harmed. For example, a member of staff can physically stop a person from hitting their head against a wall. BUT the restraint must be proportionate to the likelihood of the person suffering harm and also to the seriousness of that harm and must not amount to a 'deprivation of liberty'. For example, it would not be acceptable for a carer to tie the person down to prevent them from banging their head against the wall.

It is an offence to ill-treat or wilfully neglect a person who lacks capacity.

Deprivation of Liberty Safeguards (DoLS) cover people who do not have mental capacity and are in hospitals or care homes, but do not apply to people who are *detained* under the Mental Health Act. People should be cared for in a way that limits their rights or freedom of action as *little as necessary*. Where their rights or freedom of action are to be significantly limited, the decision-maker must follow an authorisation process before the person can be lawfully deprived of their liberty. Examples of deprivation of liberty include loss of independence because of being under continuous supervision and control, and a person's access to their friends or family being restricted.

There are complexities in relation to detention under the Mental Health Act, and it is recommended that you consult MIND's guide to the Mental Capacity Act and DoLS at www.mind.org.uk/mental_health_a-z/8059_mental_capacity_act

BUT – if you are concerned that something is happening to your loved one that might be said to be a deprivation of their liberty, do something. Speak to the Responsible Clinician or hospital manager to see if you can agree on changes to reduce restrictive practices. If there is no DoLS authorisation in place and the manager does not think that one is necessary you can approach your local NHS Clinical Commissioning Group or local authority and ask them to investigate whether an unlawful deprivation of liberty has occurred.

Confidentiality

People in a hospital unit have the right to confidentiality. Information about their diagnosis, condition, prognosis, treatment and other personal matters must be kept confidential by health professionals. Confidential information may only be given to relatives if the patient consents, and should only be given to other people in very limited circumstances.

Where a person lacks the capacity to consent to sharing their personal information the principle is that the decision must be in their 'best interests'.

As a family member, actively involved in supporting a person, you can argue that sharing the information will help you to make sure they receive the best treatment and support.

CPA in a nutshell

The Department of Health describes CPA as "simply a term for describing the process of how services assess needs, plan ways to meet them and check that they are being met" and says:

You should always feel able to ask workers to explain this process clearly to you.

Consent to treatment

If your loved goes into hospital as a voluntary patient, their consent must be obtained before treatment is given. Whether as a voluntary or detained patient, they should be given information about what their treatment is, what it will achieve, any likely side effects, what will happen if the treatment is not given and what alternatives there are.

Ask to be there when the information is given so that you can help your loved one to understand and to ask questions, and so that you have the information too. If your loved one agrees, it should not be a problem. If you are their appointed Deputy or have Power of Attorney, you should expect the hospital team to give you all the information.

A person can be treated with medication without their consent for three months from the date of their detention. However, if they still do not consent after that time, the hospital has to get a recommendation from a 'second opinion appointed doctor' (SOAD) that the treatment is "appropriate" and should continue.

Electroconvulsive therapy (ECT) can be given with a person's consent. If they lack capacity to make a decision, it can be given with the approval of a second opinion appointed doctor.

The law on consent to treatment is different in relation to a person's *physical health*. Consent is needed for treatment of any physical health problems your loved one has whilst in the unit unless doctors suspect they may be related to their mental disorder. Consent is subject to the provisions of the Mental Capacity Act.

If you are unhappy about the treatment being given to your loved one, you should discuss it with the Responsible Clinician. If still unhappy, make a formal complaint using the hospital's complaints procedure. If that doesn't produce a satisfactory outcome, then the Care Quality Commission should be contacted.

The Care Programme Approach and reviews

If your loved one goes into a hospital unit, you will hear staff talking about the Care Programme Approach (CPA). This is a way of assessing, planning and reviewing the needs of someone with a mental disorder – making sure that their treatment, care and support is well coordinated.

People with learning disabilities who have mental health difficulties or present challenging behaviours often have CPA meetings, whether they are in a hospital unit or not. So, it may not be a new thing for you or them.

CPA means that there is a formal written care plan which details any risks as well as what should happen in an emergency or crisis. A CPA care coordinator is identified to make sure that assessment, planning and reviews happen. You and your loved one should be given their name and contact details.

There is a very helpful leaflet and DVD for people and their families - 'Making the CPA work for you' - available to download free from the Department of Health. Go to http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_083651.pdf

The Department of Health makes it clear that the CPA process should treat family carers as important partners, providing valued care and support. You should be kept up-to-date and involved in the care plan (with your loved one's agreement), and should be included in CPA reviews.

What should a CPA meeting be like?

- A CPA review meeting can be chaired by anyone. It does not have to be the Responsible Clinician or a manager.
- Your loved one should be involved – even if they don't want to be at the meeting, the unit should show how they have tried to help them take part and give their views.
- People should make you feel welcome and comfortable. It should not be intimidating.
- You should be introduced to everyone at the start.
- If your loved one is detained, their Independent Mental Health Advocate should be there .
- The people there should be closely involved in your loved one's care.
- Your loved one's care coordinator from the community team should be there.
- Your loved one's treatment and care plan should be the focus of the meeting.
- Recovery and discharge should be talked about at every meeting.
- You should be encouraged and given space to ask questions, give information and your views.

If English is not your first language, talk to the unit manager when your loved one is admitted about what they can do to help you in your discussions with hospital staff, and so that you can take part in meetings. Best practice is that interpreters should be provided.

If your loved one is detained in hospital under a section of the Mental Health Act, they will have CPA review meetings *and* Mental Health Act Managers meetings. They may also have Mental Health Tribunals (see page 22).

Being kept in hospital

Even if your loved one goes into a hospital unit as a voluntary patient, they can later be kept in hospital – detained – if professionals feel they continue to need treatment *in the interests of their own health or safety or to protect other people.*

If your loved one has been admitted to hospital for assessment under Section 2 of the Mental Health Act – see page 7 – they can only be kept beyond 28 days if detention for compulsory treatment under section 3 of the Mental Health Act is agreed.

If they have been 'sectioned' and admitted to hospital for a period of treatment for up to six months, their detention can be renewed for a further six months, and then a year at a time.

The power to keep people in hospital lies with the person's Responsible Clinician, but the written agreement of a second professional is needed to renew a period of compulsory treatment. The second professional must come from a different profession and be involved with the care of the patient. If there is a difference of opinion, the compulsory detention would not be renewed. The Mental Health Act Managers for the hospital are also required to consider and approve the renewal of compulsory detention orders.

A good CPA care plan will include -

- basic details about your loved one;
- details of the team supporting your loved one at the unit, and in the community;
- their legal status under the Mental Health and Mental Capacity Acts, details (as appropriate) of their Independent Mental Health or Mental Capacity Advocate and when Mental Health Tribunals should take place;
- consent – to treatment, and to information being shared – and if your loved one can't consent, who will make decisions in their best interests;
- 'All About Me' - a profile that helps people understand your loved one, which includes how to communicate well with them, relationships with family and friends, important aspects of their history, their general health, likes, dislikes, preferences, cultural and language requirements, what they need help with day-to-day. The profile should help staff to understand and treat your loved one as an individual;
- your loved one's mental health or behavioural assessment – why they need treatment, what it is, and what it's aiming to achieve;
- an assessment of risks - both to your loved one, and that your loved one may pose to others – and a plan of how the risks will be managed, including what should happen in an emergency, and how their behaviour will be managed if it becomes difficult;
- your loved one's treatment plan, and timescales for reviewing the treatment;
- what your loved one will do during the day whilst they are in hospital– activities, education, groups, etc;
- how they will keep in touch with their life outside of the hospital unit, so they can pick things up again when they leave e.g. looking after their home, their employment, benefits, post, contact with friends and relatives, etc;
- plans for CPA review meetings.

You can help to make sure that it is a good plan by providing information and using the checklist above to suggest things to be added to the care plan.

Challenging detention

'Transforming Care' made it clear that people with learning disabilities often stay in hospital units for too long. Many are detained under the Mental Health Act, and the detention period is repeatedly renewed. Sometimes it is more about inadequacies in discharge planning than about their health or safety or to protect other people.

Make sure that discharge plans are continually considered, and challenge the detention if it no longer appears to be in your loved one's interests.

Oversight and Appeals

Mental Health Act Managers

These are *not* the people responsible for the day-to-day management of the hospital. Mental Health Act Managers are non-executive directors of the hospital - a bit like school governors - and are responsible for ensuring that the Mental Health Act is used properly. They are often referred to by staff as 'hospital managers', which is confusing – so ask staff who they are talking about.

They are important because they have the power to discharge someone from detention in hospital, to consider reports for the renewal of detention orders, and to refer people to a Mental Health Tribunal.

You can apply for the Mental Health Act Managers to review your loved one's detention order. A member of the ward team will be able to give you and your loved one the contact details.

Your loved one can apply for a review of their detention as many times as they want, at any time, but hearings are rarely heard within 28 days of a previous review or if a Tribunal is due within the next 28 days. People have the right to have a relative, advocate or legal representative at the hearing. The Managers receive written reports before the review hearing, from medical, nursing and social care staff. Your loved one should receive a copy of these reports.

Mental Health Tribunal and Appeals

The Tribunal is an independent panel for patients who are detained in a hospital unit under the Mental Health Act. A detained patient can appeal to the Tribunal to discharge them from detention. A Tribunal has a legal member (usually a solicitor or a barrister, who chairs the Tribunal meeting), a doctor (usually a psychiatrist), and a community member with some mental health experience. It has the power to:

- discharge patients from hospital;
- recommend leave of absence;
- recommend supervised community treatment, decide on a delayed discharge, conditional discharge or transfer to another hospital;
- reconvene if their recommendations are not complied with – although the hospital is not legally obliged to follow their recommendations.

Tribunal Hearings take place at the hospital. The patient, hospital doctor and social worker will be there, and the person can invite their nearest relative or carer. If the patient does not want to attend the hearing, the Tribunal will check that they have decided this themselves. If so, then the Tribunal may go ahead with the hearing in the patient's absence.

Patients who appeal to the Tribunal are entitled to fully funded legal representation through the Legal Aid scheme. You can search for mental health solicitors on the Community Legal Advice website. Go to: http://legaladviserfinder.justice.gov.uk/ or call 0845 345 4345

There are rules about how often patients can appeal to the Tribunal, and about how soon their appeal has to be heard. A person can apply once in each period of detention and be legally represented. More details can be found on the MIND and Rethink websites.

A detained patient automatically has a Tribunal hearing in the first six months of detention, without having to apply. After that, a person is referred automatically every three years if they have not made an application for a Hearing in the interim. For people under 18 years old, it's every year.

Having time 'on leave' from the hospital

Your loved one's Responsible Clinician has the power to allow him/her to leave the ward and the hospital for short periods of time. This is called Section 17 leave. They may ask your loved one to keep to certain conditions, such as returning within a certain time.

The Mental Health Act Code of Practice emphasises that:

- leave is an important part of a treatment plan;
- the patient should be involved in the decision and should agree that it can be discussed with other people; and
- leave should be well planned, as far in advance as possible.

If your loved one is in hospital voluntarily and tries to leave the hospital against the advice of a professional, who judges that it would not be in their best interests because of the risks involved, a nurse qualified to work with people with mental health conditions or learning disabilities can detain them for up to six hours, or until a doctor or approved clinician arrives.

Playing your part

If your loved one is with you 'on leave', help them to keep to any conditions that have been set. If they don't it may affect decisions about future leave.

Access to health records

People have the right to see their health records under the Data Protection Act 1998. However, medical professionals holding the records have the right to hold information back if they think it may harm a person's physical or mental health. Without doubt, people with learning disabilities would find their raw health records inaccessible and confusing, and would need a great deal of support to go through them and understand them.

If you are concerned that your loved one's records are inaccurate or misleading and want to check the information, you can make an application to see them on your loved one's behalf if you are their Deputy. If you are not, and your loved one can't give their consent, there may need to be an assessment (under the Mental Capacity Act) of whether it would be in their 'best interests'.

As a starting point, talk to your loved one's Responsible Clinician to see if you can clarify the records that way.

If you then want to proceed, why not contact the Rethink Advice & Information Service for further information and advice.

Discharge and care after leaving

For people in anything other than high security hospitals, the purpose of in-patient assessment and treatment is to help them 'recover' to the point where their behaviours no longer pose a risk to themselves or others and they can return to community life. In-patient units should be actively working towards a person's discharge from the moment of admission.

So, how can someone be discharged from hospital?

If your loved one is a *voluntary* patient they can leave at any time, but may be prevented from doing so if there are thought to be risks to them or others – see pages 7, 21 & 22.

If they want to leave, you can help them to do so. But, if you want to make sure that there will be support for them after they leave, try to make sure it happens in a planned way. The better the support your loved one gets when they go home, the less likely it is that they will end up back in hospital. Have a look at pages 33 – 35 for ideas about what could help.

If your loved one has been *detained* in hospital under a section of the Mental Health Act, they can leave when:

- the detention comes to the end of its time period and is not renewed;
- the order is discharged by their Responsible Clinician (see page 18). The Responsible Clinician must discharge if the medical conditions that justified the admission under the Mental Health Act no longer apply;
- the Mental Health Act Managers (see page 22) hold a meeting – a hearing – and decide to discharge;
- the Mental Health Tribunal (see page 22) has a formal hearing and decides to discharge;
- the 'Nearest Relative' (see page 8) ends detention. They have to give the Mental Health Act Managers at least 72 hours' notice in writing. If the Responsible Clinician does not object, the person can then leave with their Nearest Relative. However, discharge can be stopped if the Responsible Clinician makes a report within the 72 hours that says the person would be likely to act in a manner dangerous to self or others. The 'Nearest Relative' can then apply to the Mental Health Tribunal within 28 days.

A person may be discharged and allowed to leave hospital *with conditions*, through Guardianship under the Mental Health Act. This allows a 'guardian' to be appointed to encourage people to use services or to live in a particular place, and may be used with people who risk danger or exploitation:

- the person must continue to have a 'mental disorder' (see page 7);
- a guardian must be necessary for the welfare of the person or for the protection of others.

In most cases the local authority is named as the guardian, but it could be a friend or relative. The guardian can make some decisions on behalf of the person. These decisions must be the least restrictive possible and made in the person's best interests.

A person's Nearest Relative can apply for guardianship to be agreed and arranged, but guardianship cannot proceed if the Nearest Relative objects to it.

A guardian has three powers:

- they have the right to decide where the person lives;
- they can require the person to attend specified places for treatment, work, education or training;
- they can demand that a doctor, Approved Mental Health Professional (AMHP) or other specified person is able to visit the person where they live.

Guardianship initially lasts for six months and can be renewed for a further six months, and then annually.

More on challenging detention

If *you* feel that your loved one should no longer be detained in hospital, it will help if you can show that:

- their mental health condition or behavioural issues have decreased since their admission to hospital;
- their behaviour is unlikely to be a danger to themselves or to other people;
- they will get support that minimises any risks to themselves or others;
- they will have access to treatment in the community if they need it;
- they want to leave hospital and are happy with the plans;
- their advocate agrees that the plans are in their interests.

A Supervised Community Treatment Order can be considered if a person still needs to receive treatment for their own health or safety or the protection of others. Appropriate treatment can be provided outside of hospital, and the Responsible Clinician needs to be able to recall the person to hospital if they think there is an increased risk to the person or someone else.

It *cannot* be used for people who have been in hospital voluntarily or under Section 2 of the Mental Health Act. The Responsible Clinician applies for a Community Treatment Order before a person's detention comes to an end. It can be for up to six months, and can be renewed for another six months, and then a year at a time. An Approved Mental Health Professional (AMHP) must agree. Under a Supervised Community Treatment Order people can be recalled to hospital and detained again if they do not meet the conditions. It cannot be used for some groups of detained patients.

Having medical check-ups and taking prescribed medication may be conditions of a Community Treatment Order, but a person cannot be forced to have treatment without their consent when they are living in the community. They would have to be recalled to hospital. If that happens, a decision has to be made within 72 hours about detaining them again in hospital or letting them go home.

A person can be discharged from a Community Treatment Order by their Responsible Clinician, the Mental Health Act Managers, their Nearest Relative or the Mental Health Tribunal if they feel it is no longer required.

Benefits and risks

If you are applying to discharge your loved one from detention in hospital, suggesting that there is a Supervised Community Treatment Order may be a helpful way forward. It may help ensure your loved one gets the support they need after they leave – but it needs careful consideration because of the power to return your loved one to hospital.

Care and support after leaving

It is essential that people who have been in hospital get good care and support after they leave, and that they are followed-up by local community services. So, how do you ensure that it happens?

People who have been *detained* in hospital for treatment or have been on a Community Treatment Order have a right to 'aftercare' under Section 117 of the Mental Health Act. It should be planned before they leave hospital as part of the discharge planning process. For more information about good discharge planning look at pages 33 - 35.

What is 'aftercare'?

Aftercare might include a placement in supported housing, a planned programme of behavioural support, help managing money, regular meetings with a psychiatrist, anger management – it is about what the individual needs to keep them well in the community.

People who have been detained in hospital should not have to pay for their aftercare, whether from health *or* social care services.

If your loved one has been in hospital as a *voluntary* patient, there are a number of things you can do to make sure s/he gets the support they need after they leave:

- if no-one from their local community learning disability team was involved with your loved one before their admission to hospital, inform the team that s/he has been admitted and ask for their support. It's possible they may not know about the admission;
- if your loved one *was* known to their local community team before they went into hospital, ask who the care coordinator will be, and stay in contact with that person. Keep talking to them about planning for discharge;
- if no-one from the community team turns up for your loved one's CPA meetings or Mental Health Act Manager's meetings, ask to see the team manager to agree who will do what for future meetings;
- follow the guidance on good discharge planning on pages 33 - 35;
- if your loved one doesn't get active support from the community team whilst they are in hospital make a complaint. Planning for support after discharge is so important that it can't be left to chance.

Your rights versus your loved one's rights

As a family member you will already know that this is a difficult and complex area. There are particular difficulties around professionals breaching their duty of confidentiality to a person in order to share information with their family.

The Royal College of Psychiatrists and the Partners in Care campaign advise family members that, when a person is not able to understand what is happening, doctors (and other professionals) usually recognise the need to involve the carer in discussions and decisions. However, if you find that a professional is unwilling to involve you as a concerned family member, you should:

- ask your loved one if you can stay with them when they see the professional in question. If the person consents, then the professional will probably agree;
- talk to other family members as they may have some helpful suggestions;
- try to talk to other professionals who may be able to help 'open the door'.

If you are struggling with these issues, have a look at:

Sharing mental health information with carers: pointers to good practice for service providers. A Rethink/Department of Health briefing on carers and confidentiality. Download or order via www.rcpsych.ac.uk/about/campaigns/partnersincarecampaign/carersandconfidentiality.aspx.

Carers and confidentiality in mental health: issues involved in information sharing. Download from the Royal College of Psychiatrists website. Go to www.rcpsych.ac.uk/about/campaigns/partnersincarecampaign/carersandconfidentiality.aspx

Human rights

The Human Rights Act 1998 "provides a legal framework for service providers to abide by, and for service users to demand that they are treated with respect for their dignity."[10] It is designed to ensure that public authorities pay attention to people's rights and can be used to bring court proceedings where human rights have been breached or may potentially be infringed.

The provisions of the Act ensure that the claiming of human rights by one individual does not ride roughshod over the rights of others or of the local community or wider society. Public authorities providing services have a duty to maintain this balance.

Individuals carrying out statutory functions under the Mental Health Act, such as Responsible Clinicians and Approved Mental Health Professionals, are considered to be 'public authorities' under the Human Rights Act, including those working in private or independent hospitals.

If you think that your loved one's rights have been, or are being infringed by an NHS agency or local authority, you can take legal action through the UK courts.

[10] *A life like any other? Human rights of adults with Learning DisabilitiesJoint Commitee on Human Rights 2008*

Getting to grips with the law

The family adviser group said you should try to make sure that:

- your loved one is given verbal and written information about their legal status and their rights, in a format that is accessible for them, and is supported by someone independent from the unit to understand what it means for them. As a minimum it should explain:
  - What rights they have as a 'voluntary' or 'detained' patient
  - How decisions are made under the Mental Health Act, and who makes them
  - How they can influence decisions
  - How they can challenge decisions - the appeals process
  - What the Mental Capacity Act means for them, and how and when best interest decisions would be made
  - Whether Deprivation of Liberty Safeguards apply (and what they are)
  - What the Human Rights Act means for them
  - How they can get help to speak up - advocacy support through Independent Mental Health Advocates and Independent Mental Capacity Advocates, and formal legal representation
- your loved one gets *active* support in relation to their legal position before, at, and after any CPA meeting, Mental Health Managers Meeting, Tribunal and/or Appeal;
- you receive the same information, as well as information about your own rights, and what you can do, under the different Acts and in different situations, to advocate for your loved one;
- that staff supporting your loved one have been trained to understand issues around consent and mental capacity.

We hope that this booklet is a helpful starting point, and that you will pass information on to other family members who you meet when visiting your loved one in hospital.

Assessment and treatment

When a person is admitted to hospital, staff should carry out an assessment to work out the best treatment and care for them, then draw up a care plan detailing what is proposed during their stay on the ward. The National Institute of Clinical Excellence (NICE) says patients should be involved in planning and reviewing their hospital-based care and treatment, and family members should be involved if their relative agrees.

The hospital team will ask your loved one questions as part of the assessment. S/he may like a friend or family member to be there for support. You may also be anxious that, if your loved one doesn't understand the questions, the team will make an inaccurate assessment. You could talk to your loved one and the team about whether you, or someone else close to them, should be there to help.

If you are going to be present, remember that your role is to support your loved one with communication – not to answer questions for him or her. The team will want to talk to you, as part of the assessment - so you can give your views then.

What you can do to help

- Your loved one may be quite frightened being admitted to hospital, which may add to their disturbed behaviours. Think about what you can do to help them settle. Taking them some of their favourite things – such as music, food, clothes, photos – may help, but make sure that the ward staff write down what you have taken in so that it goes home with your loved one when s/he is discharged. There may be restrictions on what people can have with them on the ward, so ask about those first.
- Make sure that the hospital team have the names and contact details for staff who have been working with your loved one in the community, before they were admitted to hospital. Ask your loved one if s/he agrees for those people to be contacted for information, and do it with one of the hospital team so they can record that consent has been given.
- Hospital staff will want to know what your loved one is like normally, when they are not showing the behaviours that have led to their admission. They will want to know about their likes and dislikes, things that are important to them, and much more. It's important to give the hospital team copies of documents that might help them understand your loved one. Documents like their person-centred plan, a profile of their communication, their Health Action Plan, their social care assessment and any other documents you think might help.

Who and what?

Your loved one will have a member of staff at the hospital who will coordinate their assessment. It's important to ask who that person will be.

A number of different professionals may contribute to the assessment:

- A psychiatrist will assess your loved one's state of mind, and whether they have a mental illness.
- A psychologist will assess their behaviour and functioning, and how they relate to the world around them. They may use observations, interviews, and tests .
- A behaviour specialist, usually a nurse, may also be involved in assessing how best to support a person presenting very challenging behaviours .
- A speech and language therapist may assess their communication, identifying how they express themselves and how they can be helped. Understanding how a person communicates is essential for good assessment.
- An occupational therapist may assess what your loved one enjoys doing, their abilities and independent living skills, and how best to structure their day.
- A social worker will assess your loved one's whole situation and what life was like before their admission – their history, their relationships, their home life, their occupation, their wishes.
- A physiotherapist may assess your loved one's mobility and any access issues.

There may also be assessments by other therapists, such as an art or music therapist. It will depend on the individual and their needs.

All of these get put together to help the professional team work out what treatment and support your loved one needs. This is incorporated into the CPA care plan – see page 21. As they learn more about your loved one, the treatment and support plan will change and develop.

As part of their assessment the professionals will also consider the risks that your loved one faces, and that s/he may pose to others. They will develop a 'risk management plan'. The risk assessment and management plan is a really important part of your loved one's care plan because decisions about whether or not a person should be detained in hospital focus on risks. Ask to see the risk assessment at regular intervals – it should change as your loved one's mental state or behaviour changes. If it doesn't, ask for it to be updated.

The team may use specific tests, designed for use with people with learning disabilities, to help them in their assessment. If you want to know which tests they are using, and what they are for, don't be afraid to ask.

There is a helpful overview of the assessment process in *Mental health nursing of adults with learning disabilities* RCN guidance 2010.

'Functional behaviour assessment'

If a person is displaying serious challenging behaviours, such as self-injury, aggression to others or destructive behaviours, a 'functional assessment' can help to uncover the reasons behind that behaviour – what the person gets from it. For example, it may get the person attention, or get them out of having to do something. Knowing the function allows changes to be made that help reduce the challenging behaviour.

Understanding communication

Use these headings to map out what you know about your loved one's communication – and then pass it on to the hospital team. It will help them to understand your loved one quicker, which will help the assessment.

- His/her main ways of communicating are:
- What people need to do to communicate well with him/her:
- This is how s/he shows that they are happy:
- This is how s/he shows that they are unhappy or sad:
- This is how s/he shows that they are frightened or anxious:
- This is how s/he shows that they are angry:
- This is how s/he shows that they are bored:
- This is how s/he shows that they are in pain:

It will also help if you can tell staff what they need to do to respond well at those times.

Addressing health needs

Make sure that you tell the hospital team about your loved one's health, and that the information is written on file. Tell them about:

- current health issues;
- current medication, and any recent changes to it;
- any medication that s/he has had a bad reaction to;
- how any medication is usually given, and who does it;
- pattern of seizures if s/he has epilepsy;
- any allergies;
- any illnesses that run in your family;
- the last annual health check;
- recent medical investigations, and the name of the specialist seen;
- forthcoming appointments (e.g. optician, dentist, outpatients, etc).

Make sure your loved one's GP knows that they have been admitted to hospital

Physical health assessment

Physical health problems can lead to people presenting challenging behaviours or mental health problems. It's important that your loved one's general state of health is assessed, especially if this has not been done prior to their admission.

If s/he has difficulties with communication, the staff team may need your help to work out if your loved one is showing any signs of pain. Help them to understand your loved one's non-verbal communication by providing the information in the understanding communication box on page 27.

Being physically examined by someone you haven't met before can be a challenging experience for most of us. Try to make sure that you or another member of the family is with your loved one when examinations are carried out, if they want someone to be there. If you can't always be there, agree which member(s) of staff will support your loved one in your absence.

If your loved one is due to have their **annual health check** during the time that they are in hospital, tell the ward manager. Ask them to organise it.

Treatment

The professional team will develop a treatment plan for your loved one that aims to address the mental health or behavioural issues that led to their admission to hospital. It will be based on their assessment and may include any combination of medication, behavioural interventions, 'talking therapies', or other therapies.

Medication

People with learning disabilities may be prescribed psychiatric medications, sometimes called psychotropic or psychotherapeutic medications. There are a lot of different kinds and all have potential benefits and potential side-effects.

Remember, medication should only be given with a person's consent. If they lack the capacity to make a decision about taking the medication, it can be given as long as it is their 'best interests' – see page 20.

If your loved one is prescribed medication they should be carefully monitored or observed for side-effects. You can help to make sure that the medication is right for your loved one by:

- asking what the medication is for, what effect it should have, and what side-effects there might be;
- asking what alternatives have been considered, and why they were ruled out;
- making sure that there is a date to review the medication;
- telling the hospital team about any effects that you observe.

If you want to find out more about the medication that your loved one is given, you could talk to their psychiatrist, their GP or even a pharmacist.

Medication should *not* be used simply to control someone's behaviour. This is called 'chemical restraint'. If your loved one presents behaviours that are really challenging, you should expect the hospital to be helping them by using positive behavioural supports (see below).

If you are concerned about the type or amount of medication that your loved one has been prescribed, or that it is not having any effect, talk to their psychiatrist. If you are still not happy, ask for a second opinion. A family member can ask for a second opinion on behalf of their relative, but only if their relative has said they can do so. There is no legal right to a second opinion, but a psychiatrist will normally arrange for a referral to another psychiatrist if asked.

The British Institute of Learning Disabilities has a free factsheet on 'chemical restraint'. Go to www.bild.org.uk/information/factsheets

Behavioural interventions

For people with learning disabilities who present behaviours that challenge, an approach called Positive Behavioural Support is viewed as good practice. It:

- focuses on changing the triggers for behaviour;
- uses teaching and development of skills as a central intervention;
- includes strategies for changing behaviour as well as strategies for managing behaviour when it occurs.

Look at the treatment and behavioural plan for your loved one (it will be part of their CPA care plan). It should say what staff will be doing to reduce and prevent your loved one's challenging behaviours. If it doesn't – if the plan is just about medication and what staff should do to deal with challenging behaviour when it happens – talk urgently to your loved one's Responsible Clinician.

The Challenging Behaviour Foundation is a helpful source of information, and has a range of free resources (leaflets, information packs and DVDs) for families. Go to www.challengingbehaviour.org.uk

Therapies

Many of the therapies available for people with mental health problems can be adapted for people with learning disabilities – psychotherapy, Cognitive Behaviour Therapy (CBT), Drama Therapy, group approaches. BUT access to the full range of mental health interventions for people with learning disabilities is limited and assumptions are often made that they will not benefit from such treatments. It may help to:

- ask the psychiatrist about the range of therapies available to patients at the hospital;
- ask which ones have been considered for your loved one.

If there is an issue about staff not having the skills to adapt such therapies to people with learning disabilities, remind the hospital of their duty under the Equalities Act to make 'reasonable adjustments'. You could suggest that a suitably skilled therapist (experienced in working with people with learning disabilities) is brought in on a sessional basis to work with your loved one.

You will find more detailed information about the assessment and treatment process in:

Standards for Adult Inpatient Learning Disability Units – Assessment and Treatment Units Royal College of Psychiatry 2010 Cresswell J, Bleksley S and Lemmey S

What does good look like?

The family members' advisory group identified a number of things that they expect a hospital to do, and family members to see:

- that the person's assessment draws on existing information and plans that are already in place, e.g. person-centred plans, Health Action Plans, positive behaviour support plans;
- that the assessment looks at triggers for the person's behavioural changes (leading to the admission) through discussion with the person, their family and supporters. The assessment records what has been learned from people and is based on evidence;
- the assessment and treatment plan is person-centred and clear about the results that treatment is aiming to achieve;
- positive behaviour support is used;
- the person and their family are given a copy of the assessment and treatment plan, and discuss it before treatment starts. The service welcomes families to have a copy so that they can monitor that the plans are happening;
- there is a structured plan ensuring that the person has the opportunity to engage in activities of their choice and is able to maintain and develop skills that will support their discharge;
- there is a structured plan for de-escalating behaviours that present challenges, it is clear if and when control, restraint, seclusion and PRN: Pro Re Nata (Latin: for the existing occasion; as matters are; as needed) medication would be used, and what form it would take. There is an agreement about how families will be informed if and when the above are used;
- risk assessments are not used to prevent people doing things; instead, they are used to ensure that people can participate in activities successfully;
- agreed actions happen, within the timeframe that has been agreed;
- proposed changes to the treatment plan are discussed with the person and their family, with reasons;
- the frequency of reviews is agreed with the person, and their family, and happen as planned.

What happens day to day

As well as good assessment and effective treatment, there are three main things that family members want their loved one to have whilst they are in hospital

- good quality day-to-day support
- a safe environment and safe support
- appropriate and interesting things to do with their time

The key to all of these is that support plans and activity programmes are **individualised and person-centred**. They should be about what's appropriate and right for the person you care about *as a unique individual*. You should be able to read their care plan and 'see your loved one in it'. In other words the plan should identify what they need support with day-to-day, their interests, their preferences, the risks, and it should say what will happen to address them.

Amongst other things, it should tell you:

- *how* their treatment plan will be delivered;
- *how* staff will respond to any challenging behaviours (see next page);
- *how* their independent living skills will be supported and maintained;
- *how* their cultural and spiritual requirements (e.g. food, skincare, dress customs, religious practices, etc) will be addressed;
- *how* their relationships with family and friends, and interests will be sustained;
- *how* their days will be structured and what they will do to stay active and prevent boredom;
- *what* your loved ones own views are about the plans;
- *who* has given consent to the plans.

How the person is treated, and what's done for them

The family members advisory group identified a number of things that they expect a hospital to do, and family members to see:

- a structured plan so that the person is actively engaged in meaningful activities during their period as an in-patient;
- the person's plan takes into account their potential for learning new behaviours from others, enabling them to take on positive roles and to have positive models whilst an in-patient;
- that everything – staff actions, recording, written plans, the environment - demonstrates people are treated with dignity and respect.

Responding to challenging behaviours

The term 'physical interventions' is used to mean responses to challenging behaviour that involve direct physical force to limit a person's movement:

- direct physical contact, such as holding down of arms;
- use of barriers to limit freedom of movement, e.g. locked doors and windows;
- use of materials or equipment to restrict or prevent movement, e.g. use of arm splints.

You should expect staff in the unit to use the **least restrictive practices** in all situations. It means they should be doing things in ways that prevent confrontational situations arising.

The Mental Capacity Act is clear that anything done for or on behalf of a person who lacks capacity should be the least restrictive of their basic rights and freedoms, and in their best interests (see page 19).

Every hospital will have a policy on use of control, restraint and seclusion. Ask for a copy. Above all, be vigilant. The criminal events at Winterbourne View reinforce that families have an important role to play in monitoring the way that people are treated day-to-day, and raising concerns in order to protect people's rights and safety.

Seclusion is not a treatment. It is used to manage people's behaviour. It is defined as: "… supervised confinement of a patient in a room, which may be locked. Its sole aim is to contain severely disturbed behaviour which is likely to cause harm to others." It should not be used as a punishment or threat, as part of a treatment programme, because of a shortage of staff, or where there is a risk of suicide or self-harm.

The Human Rights Act says that no one should be subjected to torture or inhumane and degrading treatment or punishment and states that any interventions that cannot be justified under therapeutic necessity will breach the law. In the absence of evidence that seclusion was unnecessary, it is presumed legal. It has been established in the courts that seclusion is justifiable if there is a threat to public safety, to prevent disorder or crime, to protect health and morals and to protect rights and freedom of others.

If your loved one has been secluded you should expect:

- the doctor to have been notified and that s/he attended immediately;
- a detailed record to have been made at the time it happened giving the reasons for use of seclusion, and what happened next. The entry should be made by the nurse in charge of the ward and the record should be countersigned by a doctor and a senior nurse;
- to be notified if you are the Nearest Relative.

The British Institute of Learning Disabilities has a number of helpful publications that can help you judge whether what's happening to your loved one is acceptable, or needs to be challenged, including –

- a free factsheet on timeout and exclusion. Go to: www.bild.org.uk/information/factsheets/
- BILD Code of Practice for the use and reduction of restrictive physical interventions. Go to: www.bild.org.uk/our-services/books/positive-behaviour-support/bild-code-of-practice

Physical interventions

British Institute of Learning Disabilities (BILD) guidance is that physical interventions should:

- only be used in the best interests of the person with learning disabilities;
- only be used alongside other strategies to help people learn to behave in non-challenging ways;
- be individualised and reviewed regularly;
- use minimal force and not cause pain.

Quality of support

Good quality day to day support:

- is respectful and compassionate;
- maintains people's dignity;
- is individualised;
- offers options and information so people can make choices;
- involves people in their own care and helps them develop their skills;
- is delivered by staff who are skilled in defusing situations and giving positive behavioural support;
- thinks about risks and plans things in ways that keep people safe from harm.

A hospital unit may have a culture in which blanket rules and 'common practices' act against the delivery of good quality support. If you are concerned that your loved one is not getting good quality day-to-day support, don't keep quiet. Raise it with the unit manager, and agree how support for your loved one will be improved.

If you don't get a satisfactory response, or you believe that support may even be neglectful or abusive, make sure that you have evidence to support your concerns, and:

- inform your loved one's Independent Mental Health Advocate, and ask for their support to;
- raise it with the hospital management team, as a written concern;
- copy the letter to the local social services department Adult Safeguarding team;
- contact your local HealthWatch for support.

HealthWatch support

From April 2013 the local HealthWatch will either directly provide NHS complaints advocacy i.e. support to make complaints about health services – or be able to signpost people to the local organisation providing the service.

Quality of delivery

The family members advisory group said you should expect the following standards to be met:

- staff show that they respect people and that they care about what happens to them;
- staff are trained in person-centred approaches, and positive behaviour support, and their performance is monitored to ensure they deliver support in a person-centred way;
- the service acts on the existing person-centred plan, positive behaviour support plan and/or Health Action Plan that's in place, and keeps them up-to-date;
- the service and its staff are organised around the needs of individuals;
- staff recognise when behavioural issues are emerging, and involve appropriate professionals so that the behaviours are analysed, and the service actively does something to address them;
- staff recognise when a person is developing health problems and ensure they see a GP in a timely manner;
- the service welcomes the person's own Personal Assistants as part of the team, and works with them to deliver the support;
- staff in the service are welcoming to family members and actively offer them their help;
- staff check out their impressions about what is happening with family members rather than making assumptions;
- there is dedicated time for staff to discuss the situation and plans for each person, away from patients;
- there is a clear, written plan about the medication that is prescribed for a person whilst they are an in-patient, which states why it is being prescribed and how it links to the overall treatment plan;
- the service can show that all staff on the unit have knowledge of behavioural assessment tools;
- the service deliberately matches staff to people - based on their skills, gender, ethnicity and interests – so that a person's needs are met;
- food and drink is appetising, people say it is good, and there are choices available that enable a person to adhere to cultural preferences/faith requirements.

Relationships on the unit

Living with a group of people that you don't choose to be with can be challenging, and your loved one may not like or get on with everyone on the ward. Equally, s/he may meet someone who becomes a friend during the period in hospital, which could help them a lot.

There are some important things to consider:

- Are any relationships hindering your loved one's 'recovery', perhaps provoking behaviours that are likely to extend their stay?
- Are there other people on the ward who are displaying behaviours that might harm your loved one?
- Are there any particular individuals on the ward who could be harmed by your loved one?

If the answer is 'yes' to any or all of these questions, talk to the ward manager about what you have observed and what you fear might happen.

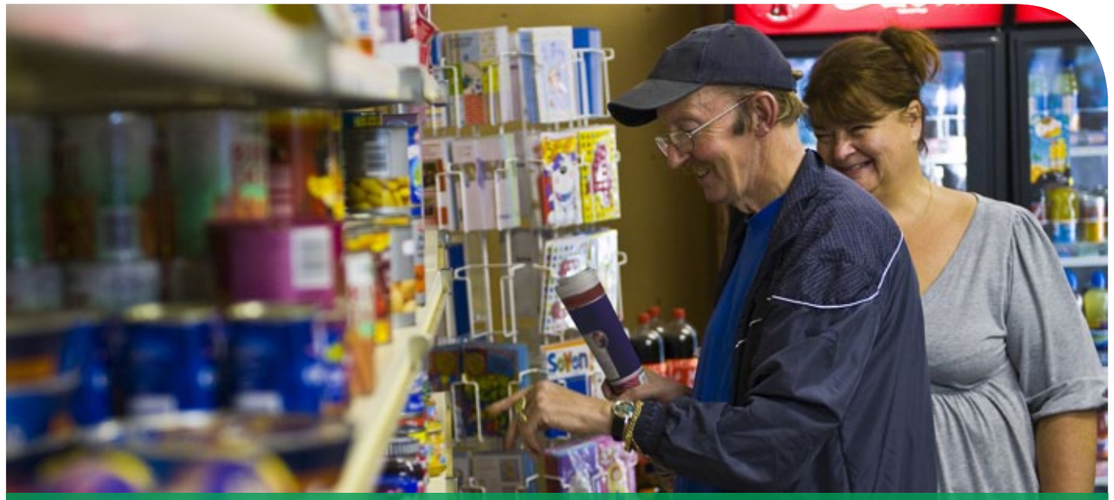
- Talk about the risks
- Ask them to make a plan to manage and minimise the risks, and to let you know what they will be doing
- Ask for your concerns to be recorded on file.

The issue of sexual relationships on hospital units is difficult. There are considerations about consent, privacy, informed choice and no easy answers. For patients who are unable to consent to sexual activity, it may be illegal. If you have any concerns at all about a relationship developing in a sexual or abusive way, raise it with the ward manager and request a meeting to discuss the issues and risks. If you think you have evidence that abuse has taken place, call the local Social Services office and give them the details. They will treat it as a 'safeguarding alert' and investigate.

Why not take a look at the helpful materials produced by the National Family Carer Network, especially their safeguarding resources. Go to: www.familycarers.org.uk and look for -

Making sure your relative is safe. Family carers' essential guide to 'safeguarding' adults with learning disabilities

Making sure your relative is safe. Top tips for family carers about 'safeguarding' adults with learning disabilities



Returning to community life

Whether the person you care about is in hospital as a voluntary or detained patient, the focus should be on helping them return to community life at the earliest appropriate time when they have recovered to a state of mental health and/or to behaviours that will no longer pose a risk to themselves or others. Pages 23 – 24 give information about how people can leave hospital, including how detention can be challenged.

Planning for discharge

Planning for discharge should start to be considered very early on after assessment, but is often left very late. This can mean that people with learning disabilities stay in hospital longer than needed because of the time it can take to organise community support, and to find accommodation if it is needed.

Don't let that happen to your loved one. You can help to make sure that it doesn't by:

- asking the unit to include a section on 'when I leave hospital', i.e. plans for discharge, in your loved one's care plan;
- asking the unit to discuss discharge plans at each CPA meeting (if it's not written on the agenda it may get overlooked – so just bring it up);
- asking your loved one's care coordinator from the community team to arrange a discharge planning meeting after your loved one's assessment and care plan has been drawn up, to develop an initial moving on plan, and then review and update it at regular intervals;
- making sure your loved one gets support to talk about what s/he wants when they leave hospital.

People who may not have decision-making capacity have the right to support from an Independent Mental Capacity Advocate (IMCA) when there is a question about where they move to from hospital and there is no family member who can be consulted. It is good practice for people who may be eligible for an IMCA – for accommodation decisions – to be identified on admission and a referral made.

If the person you care about has been detained under the Mental Health Act, they also have the right to support from an Independent Mental Health Advocate.

A discharge or moving on plan is about:

- where your loved one will live;
- what s/he will do each day;
- what their life will be like, and
- the support they will need and how they will get it.

An ‘All About Me’ profile

A profile that helps people understand your loved one, which includes how to communicate well with them, relationships with family and friends, important aspects of their history, their general health, likes, dislikes, preferences, cultural and language requirements, what they need help with day-to-day. The profile should help people to understand and treat your loved one as an individual.

Mental Health Tribunals and discharge planning

Starting discharge planning early means that the moving on plan can be presented to a person’s Mental Health Tribunal. The Tribunal may be more likely to discharge a person from detention if they see well thought out plans for post-hospital support.

A good moving on plan will include:

- an ‘All About Me’ profile;
- a clear picture of what s/he wants after leaving hospital, or – if they are unable to communicate this - what people who know him/her well are confident that s/he would want;
- where s/he will live after leaving hospital, and how they will be supported;
- their employment / daily activity after they leave, and how they will be supported;
- what will happen to help him/her learn and develop skills;
- what will happen to support friendships and relationships;
- what will happen to support their health and wellbeing – ongoing treatment, supporting behaviour change;
- what will happen to help him/her stay out of hospital, stay safe and to keep other people safe;
- what will happen to support them in their hobbies and interests;
- what will happen about money and belongings;
- any legal considerations (e.g. Community Treatment Order conditions);
- what will happen to support and involve family;
- how s/he will be prepared for their move out of hospital and how the move will be managed.

A good moving on plan will identify who will do what to make each part happen, and by when.

It is likely that a person with learning disabilities will have their initial support after discharge coordinated through the Care Programme Approach (see pages 20 – 21).

Carer’s assessment

If your loved one is going to live with a family carer after leaving hospital, that person’s needs should be assessed in their own right as part of the discharge planning. It is an assessment of their ‘ability to provide and to continue to provide care’. A care plan should be written that might include information on what to do in a crisis and what will be provided to meet their own needs, such as short breaks or money advice.

Ask your loved one’s care coordinator from the community team to organise the carer’s assessment.

Support after leaving hospital

Pages 23 – 24 give information and advice about how to ensure that your loved one gets the support they need after they leave hospital.

There are some things that you could do to ensure s/he gets the right support:

- support your loved one to make an early appointment with their GP to discuss any follow-up treatment;
- make sure his/her friends and relatives know about the discharge and make contact;
- ask the IMHA or IMCA to stay in touch with your loved one for a period of time to make sure the support is working well for them;
- make sure that reviews of your loved one’s community support arrangements happen as agreed in the ‘moving on plan’;
- keep in contact with their care coordinator from the community team and let them know quickly if there are any issues emerging.

Moving on

The family members’ advisory group gave a clear picture of what the moving on process should be like. Use these ‘standards’ as a checklist to make sure that the process works for your loved one.

- Moving on planning starts from when a person is admitted. There is a clear process. The person and their family are given verbal and written information about it on admission.
- The person and their family work with a group of professionals closely involved with the person to develop a person-centred moving on (discharge) plan. The plan identifies ‘essentials to, and for the person’ in relation to accommodation, lifestyle and support.
- It is demonstrated that employment, training and career advice are considered as part of the planning.
- A skilled and knowledgeable care coordinator from the placing authority facilitates the planning and produces a moving on plan that is agreed by the group.
- The planning process has clear stages and time limits. The plan details the support the person will get after discharge, including how it will be provided and who by.
- The person should return to their long-term home, where they were admitted to hospital from, unless it is not their wish or in their best interests to do so. If not returning to their home, the plan should identify more than one acceptable way forward and the person should make the final choice, with support.
- The placing authority has a clear and time-limited process to sign-off the person’s moving on plan and agree funding. It is part of the contract between the authority and the in-patient service.
- There is a route to ‘challenge’ decisions and resolve differences through an independent mediator.
- If there is no medical reason for detention in hospital to continue, the person’s order is discharged so that they can leave if they choose to. The service must have an agreed moving on plan ready and agreed with the person.

What to do if you have concerns

The simple advice is to speak up. Raise your concerns with the person responsible for the area that you have concerns about. For example, your loved one's Responsible Clinician if it is about their treatment plan; the unit manager if it is about the quality of day-to-day support.

If it feels hard to raise issues with professionals, or it makes you anxious, you could:

- ask your loved one's Independent Advocate if s/he can help;
- talk to an independent family advocate and ask for their help;
- take a friend with you to meetings;
- talk to HealthWatch in the local area;
- talk to your loved one's care coordinator from the community team.

Every local authority and health trust must publish details of its complaints policy. Administrative staff at the hospital will be able to give you information. There will be set timescales for the hospital to respond to you.

You could also contact any of the following organisations for help and advice:

- The **Care Quality Commission** advises that if you have a serious concern about quality of care you should contact the **social care department** at the local authority. If you think a crime has been committed, you should ring the police. You can also contact CQC itself by phone (03000 616161), email (enquiries@cqc.org.uk) or through a 'share your experience form' which can be found on their website (www.cqc.org.uk). Search by the name of the hospital and click on the 'tell us your experience' tab on its profile page. If you mark the concerns as urgent, your feedback will be prioritised – but they will not respond to individual complaints.
- CQC also has an easy to read leaflet on complaining about the use of the Mental Health Act. Go to: www.cqc.org.uk/organisations-we-regulate/mental-health-services/mental-health-act-guidance/second-opinion-appointed
- From April 2013 every local area has introduced a **HealthWatch** organisation – see page 31 for information about their role. You should be able to get their contact details from the hospital administration team or local social services department.
- Rethink – see next page. A factsheet on how to complain is available for free download from www.rethink.org/mental_health_shop/index.html (along with over 100 other factsheets)
- The National Family Carer Network. Go to: www.familycarers.org.uk They have a briefing on *when things go wrong* available at www.familycarers.org.uk/Libraries/Local/866/Docs/Resources/When_Things_Go_Wrong-3.8.12-1.pdf
- NHS England has useful information about how to make a complaint or compliment about a service and this can be found at www.england.nhs.uk/contact-us/complaint/

Organisations that can help

- **Rethink:** Telephone 0300 5000 927 (Monday to Friday 10am – 1pm) or email advice@rethink.org for mental health information and advice on practical problems.
- **Carers Direct:** Telephone 0808 802 0202 (9am to 8pm Monday to Friday, 11am to 4pm at weekends). Calls are free from UK landlines and mobiles or you can request a free call back. You can also ask for a call back in one of more than 170 languages.
- **National Family Carer Network:** Telephone 07747 460727 or e-mail info@familycarers.org.uk A network of organisations that support families of people with learning disabilities.
- **The Challenging Behaviour Foundation:** Telephone 0845 602 7885 or email support@thecbf. A support service for family carers and professionals caring for children and adults with severe learning disabilities and challenging behaviour. They have free information sheets and resources on lots of different topics related to challenging behaviour, including an information sheet about where to go for additional support.
- **NHS England:** For information and contact details go to www.england.nhs.uk/contact-us
- **Mind infoline:** For information and advice on a range of topics related to mental health. Telephone 0300 123 3393 (Monday to Friday, 9.00am to 6.00pm) or email info@mind.org.uk. They also send out printed information.
- **Mind's Legal Advice Service:** For information and advice on legal matters related to mental health. Telephone 0300 466 6463 or email legal@mind.org.uk
- **Mencap Direct helpline:** Telephone: 0808 808 1111 (Monday to Friday 9am - 5pm) or email help@mencap.org.uk. Advice and information on anything related to people with learning disabilities.
- **National Autistic Society helpline:** Call 0808 800 4104 (Monday to Friday10am-4pm, free from landlines and most mobiles). The Society has a list of law firms who have experience of working with, and representing, people with Autism.
- **The Tizard Centre:** The Centre provides consultancy to organisations supporting people who present challenging behaviours, as well as post-graduate study. It is recognised as a leader in the field. Telephone 01227 827373 or email tizard-info@kent.ac.uk

Other helpful things to read

- **The Mental Health Act: essential information for parents and carers**
  NIMHE / Rethink 2008. Available from Rethink www.rethink.org
- **The Mental Health Act Code of Practice:** Download from
  www.gov.uk/government/publications/mental-capacity-act-code-of-practice
- **Briefings about many different aspects of the Mental Health Act** are available from Rethink. Much recommended. Go to their website: www.rethink.org.uk
- **Mental health factsheets** written specifically for carers are available from
  www.carers.org/help-directory/mental-health-factsheets
- **The Mental Capacity Act: Making decisions: A guide for family, friends and other unpaid carers** OPG602 Office of the Public Guardian 2009 (4th edition)
  (Note: OPG 605 is an easy read version)
  www.justice.gov.uk/downloads/protecting-the-vulnerable/mca/opg-602-0409.pdf
- The National Institute for Health and Clinical Excellence **(NICE) has guidance on treatments and care** for many different mental health conditions. Go to
  www.nice.org.uk
- **Leaflets written for carers about learning disabilities and mental health**
  are available from the Royal College of Psychiatrists website:
  www.rcpsych.ac.uk For advice specific to family members of people who are in forensic units go to http://rcpsych.ac.uk/campaigns/partnersincare.aspx
- **There is a list of easy read information for people with learning disabilities, about all kinds of mental health matters:**
  Mental Health Services for People with Autism and People with Learning Disabilities.
  Go to www.ndti.org.uk
- **Information on Continuing Healthcare** can be found at
  www.learningdisabilities.org.uk/publications/continuing-healthcare