

Treat me well



How to meet the needs of people with **profound and multiple learning disabilities (PMLD)** in hospital

A guide for healthcare professionals, families and support staff

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How to use this guide

Throughout the guide, where we have used the term ‘person’ or ‘people’ we are referring to a person or people with profound and multiple learning disabilities (PMLD).

1. Introduction to this guide

Treat me well is Mencap's campaign to transform how the NHS treats people with a learning disability in hospital.

This guide is specifically to help healthcare professionals and families/support staff understand how to give people with profound and multiple learning disabilities (PMLD) the best possible care in hospital.

If hospital staff get things right for people with PMLD, whose combined needs are very complex, they should be able to get things right for everyone.

Mencap and PMLD Link, a charity with specific expertise around support for people with profound and multiple learning disabilities (PMLD), have developed this guide together with families.



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2. What does profound and multiple learning disabilities (PMLD) mean?

People with profound and multiple learning disabilities (PMLD) are, like everyone, unique individuals. Like everyone, they need to be included and respected, and with the right support are able to live a fulfilling life.

There are some things that all people with PMLD have in common:

- **They have a profound learning disability**
People with PMLD are likely to be using or developing skills that generally appear at a very early stage of development, for example learning about cause and effect, and turn-taking. They may show preferences of things they like or dislike in everyday situations as a form of simple choice making.
- **They have more than one disability. They may have sensory or physical disabilities, complex health needs or mental health difficulties and they may at times present with behaviours that challenge us.**
Many people may use a wheelchair. Others may have difficulty with movement, for example they may need support to control and vary their posture. They may experience the world in different ways because of sensory impairments, like vision or hearing loss, may have sensory processing difficulties, and may have complex health needs. They may be 'technology dependent', for example needing oxygen, tube feeding or suctioning equipment.



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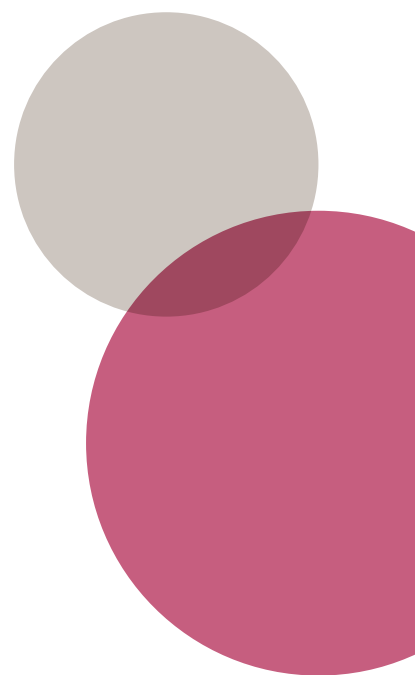
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- **Each person will have a unique way of communicating which may be difficult for others to understand**

Many people rely on facial expressions, vocal sounds, body language and behaviour to communicate. Some people may use a limited range of formal communication, such as a few words, symbols or signs. **People may not be able to communicate pain or their symptoms easily.** In most cases, they will need others such as family or support staff who know them well to interpret their unique ways of communicating and introduce hospital staff to the communication information, detailed in the person's hospital passport.

- **They have high support needs.**

It is likely that most people will need 24-hour-a-day support with all or most aspects of their daily life.



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3. What barriers can people with PMLD face in getting the right healthcare in hospital?

People with PMLD need particular support and attention to live as long and healthy a life as possible. Sometimes they don't get this support.

There are a number of key issues around getting the right healthcare in hospital:

- **Health complications.** As a result of their complex needs people can be at high risk of complications, even from common health issues, such as constipation or respiratory infections. It is vital they get the right support to help prevent these complications. If they do get ill it is essential that they get timely and high quality treatment, otherwise these health issues can become very serious and even life-threatening.
- **Treatment and recognition of pain.** Communicating they are unwell or in pain is difficult for many people with PMLD. Health professionals may mistakenly assume that a particular behaviour the person displays is just a characteristic of their disabilities, rather than realising it is their way of expressing pain or distress. Health conditions may be left undiagnosed and untreated as a result. This is called **diagnostic overshadowing**.
- **Poor partnership working between healthcare professionals and family/support staff.** Too often family and support staff who know the person well are not being listened to, or consulted with. They may have vital information about the person's needs and way of communicating, such as being able to:
 - Give important information about the person's medical history
 - Explain what the person's 'usual' communication and behaviour is when they are well, and how this differs when they are ill or in pain

Remember: Hospital staff should read a person's 'hospital passport' but we know that does not always happen – so be prepared to say how important it is and to read aloud key information.

- Give crucial advice to hospital staff about how best to support the person - what works and what doesn't.

In addition, where family/support staff are happy to be involved in providing care to the person in hospital, this is not always being facilitated. In other cases, they are being relied on too much to deliver basic care.

- **Negative assumptions about quality of life.** One of the greatest barriers that people face is the negative assumptions of others, for example about the meaning and quality of people's lives. This can be life-threatening as it can lead to inappropriate and discriminatory judgements about withholding treatment, what procedures and treatments the person can tolerate, and even whether their lives should be saved eg inappropriate use of Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) orders.
- **Avoidable deaths.** We know that some people with PMLD die because they do not get their basic health and care needs met. This can lead to deterioration in health conditions. This is happening in all types of settings, including **in hospitals**.



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Some examples of things that have gone wrong for people with a severe or profound learning disability in hospital:

- Receiving no sedation for painful procedures or no pain relief for fractures or post-surgery because hospital staff believed the person did not show the usual signs of pain or distress.
- Missing important signs or not being asked for crucial information to understand when people are very seriously ill – for example where someone with long term constipation actually has an impacted bowel.
- The person deteriorating and only the obvious health issue being treated rather than looking further. For example, where someone with asthma developed a chest infection, health professionals just treated the chest infection. Support staff had to really push for them to investigate further. When they did they found the person had a very large kidney stone, which had been impacting on her body and resulting in secondary infections occurring.
- Not being monitored effectively, with appropriate specialist input, to ensure the person receives nutrition and hydration. For example, some people have had difficulty tolerating a nasal feeding tube and this has not been addressed in a way that ensured they got the nutrition and hydration they needed. There have been cases where people with a learning disability have died due to starvation in hospital.

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4. How can families/support staff and health professionals in the community help someone prepare for going into hospital?

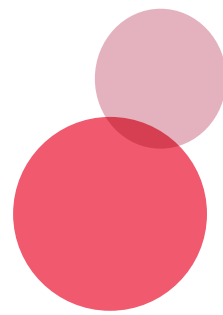
People may go into hospital for an appointment, a planned stay or in an emergency. It can be very helpful to prepare for all these situations.

- **Hospital passport.** Make sure the person has a detailed up-to-date 'hospital passport'. This is a document they can bring into hospital with them. It has key information about their communication, how they might express they are in pain, what their 'usual'/baseline presentation is, an overview of all their health needs, and what reasonable adjustments they may need in hospital.

You could ask any health professional who works with the person in the community (eg a community learning disability nurse or GP) to give you a template 'hospital passport' to fill in.

- **Summary Care Record.** Ask the person's GP to put key information from the hospital passport in the 'Additional Information' section of their electronic Summary Care Record. This means hospital staff can access this information on their computers when the person goes into hospital, and their learning disability is 'flagged'.
- **Learning Disability Liaison Nurse.** Contact the hospital's Learning Disability Liaison Nurse ahead of the person's admission, if their local hospital has one. They can valuably coordinate and prepare the necessary adjustments, including briefing hospital staff on the person's additional needs in advance. Check if the hospital has a Learning Disability Liaison Nurse and how to make contact by asking the person's local health professionals eg GP or community learning disability nurse. If there is no Learning Disability Liaison Nurse at the hospital their local health professional may help with this.

- **For a planned admission, where the person is going to have some sedation or anaesthetic for a procedure.** It may be that other more minor examinations or procedures could be undertaken whilst the opportunity is there. This could avoid the person having to return at a later date to be sedated or go under general anaesthetic again for these other procedures. However, it is important to remember that any decisions about treatment must be made in line with the Mental Capacity Act.
- **Support the person to prepare.** If the person you support benefits from sensory stories, create a personalised story to help the person prepare for the hospital environment (see Mencap’s guide with PAMIS on creating a multi-sensory story about going into hospital). The idea behind ‘preparing for a hospital visit’ is to prevent raised anxieties, so to be meaningful this will need to be very personalised to each individual. Some people get anxious if they know some change to routine is planned and it may be more appropriate to tell them at the time, not in advance.
- **Get a grab bag ready.** Prepare for emergency admissions by having a hospital bag already packed, ready to grab if you need to rush to hospital. Here are some specific things that may be relevant and helpful to include in a health file, in addition to the **Hospital passport**:
 - **A photo/‘pen portrait’** that shows the person well and happy – this can be a good talking point to introduce the person, and talking about their life can help reduce negative assumptions that can be made about people’s quality of life
 - **Distress recognition tools** eg the (DisDAT) to help identify when the person may be in pain
 - **A comprehensive up-to-date ‘Communication’ section within their hospital passport or a separate communication passport**
 - Copy of current **Medication Administration Records (MAR) chart**
 - **Protocols for medication** eg emergency protocol around use of PRN medication for epilepsy



- **Photos and descriptions of good sites to draw blood (cannulate)** eg if there can be difficulty finding suitable veins or the person is unable to stretch out their arm
- **Safe eating and drinking guidelines**
- **Postural care/ positioning guidelines** (seating and lying)
- **PEG passport** – which details how to use/care for a specific type of feeding tube and **enteral feeding guidelines**

The person should also take into hospital with them medications, feeds and spare equipment that they need eg gastrostomy tubes, stoma bags etc (as appropriate).

Medication and enteral feeds often take considerable time to be sourced causing a delay in being administered so it can be important these are brought in with the person on admission.

- **Reasonable adjustments.** Where appropriate, such as for an appointment or planned admission, consideration of what reasonable adjustments the person needs should be made prior to going to hospital and be part of planning the appointment or admission with hospital staff. Where it is an emergency situation it will be important to explain what reasonable adjustments need to be made when you get to hospital. **A key reasonable adjustment** needed will be for hospital staff to **work in partnership** with families and support staff who know the person best. See the next section for more information about reasonable adjustments.



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5. What are reasonable adjustments and where might they be made?

Adjustments may need to be made to the hospital environment or hospital procedures in order to enable people with PMLD to get the healthcare they need. This is not just good practice; it is the law. **Healthcare staff have a legal duty to make reasonable adjustments under the Equality Act 2010** and the **Accessible Information Standard**. This includes those working in A&E and ambulance staff.

Mencap's Treat me well campaign focuses on the importance of making reasonable adjustments for people with a learning disability in hospital.

The specific reasonable adjustments required by someone with PMLD will depend on the individual's needs. **But here are some of the common areas where reasonable adjustments may need to be made by hospital staff.** Many of these areas will be relevant to both planned and emergency admissions.

- **Take time to find out from family/support staff how you can involve the person as much as possible in their care and treatment**

Find out how you and other hospital staff can best introduce yourself to the person, for example through facial expressions or touching their hand. This information may be in their hospital passport as well. The person may also have a communication passport with valuable further detail about the person's ways of communicating. Find out how to involve the person in conversations as much as possible, remembering it is them you are treating. Use the person's communication style, for example this may be eye contact, facial expressions, body language.

Find out how best to prepare someone for a procedure and keep them as calm as possible, for example, they may have a favourite sensory object which is comforting. It may also be important for family or support staff to stay with them to provide physical and emotional support to the person during a scan, X-ray, blood test or any procedure. This may help



reduce anxiety for the person and help the person feel safe and secure. This could be discussed using the **Partnership checklist**.

- **Use the Partnership checklist to discuss and record how you will work together.**

Take time at the start of an admission, to discuss how health professionals, families and support staff, will work together – this includes how the person, family and support staff will be involved in decisions and how the person will be supported whilst they are in hospital. It is vital that everyone has a clear, shared understanding of the person’s health situation and can explore the options together and agree an appropriate plan of action for supporting and treating the person whilst they are in hospital.

It includes thinking about logistics to facilitate involvement. Where needed, for example, family and support staff may need extended visiting hours, the ability to stay overnight with the person, passes to enable them to access the hospital canteen, shower facilities and parking.

It is also important to plan for discharge together and identify what needs to be in place to meet the person’s needs once they leave hospital, including what follow-up there will be. These discussions will help clarify expectations (eg timescales, signs of recovery or when to seek help).

- **Read the person’s hospital passport and ‘Additional Information’ on the person’s Summary Care Record**

Make sure all ward staff working with the person, including any agency staff, carefully read the person’s hospital passport. Make sure they are aware of ‘additional information’ on the person’s Summary Care Record. The purpose of this is to understand important information about the person and their communication, health and care needs and the reasonable adjustments required.

- **Involve the Learning Disability Liaison Nurse, where available or the Community Learning Disability Team**

It is important professionals know who their liaison nurse is. They will be able to help hospital staff understand how to enable the person to access treatment or cope with being in

hospital. They can help identify how to make appropriate and essential reasonable adjustments for the individual. They can also signpost staff to documentation and processes (eg. around capacity assessments and making best interests decisions).

Learning Disability Liaison Nurses in the hospital will be able to help facilitate partnership working between ward staff and the family and support staff but there are often long periods of time, particularly at evenings and weekends when they may not be available, so it is vital the ward staff work in partnership directly with the family and support staff.

- **Take care to recognise and manage pain**

There are useful tools to assist staff in assessing the pain and distress of patients who cannot communicate verbally. Such tools, for example the Disability Distress Assessment Tool (DisDAT), used in conjunction with the knowledge of family and support staff who know the person well, and with the appropriate training, can be used to prevent unnecessary pain or distress.

Every member of staff whose role involves pain management needs to be aware of the potential difficulties in recognising pain in patients with a learning disability. It is important to understand what someone's usual behaviour is and how this may change when the person is in pain.

It is important healthcare professionals recognise and act on signs the person may be in pain as there could be serious underlying issues that need to be investigated and treated. It is also vital that the person receives appropriate pain relief.

- **Avoid delays in diagnosis and starting treatment**

Once pain or a health issue has been recognised, another concern is that people don't always get the investigations, treatment or intervention they need in a timely way, or even at all. Sometimes health professionals may believe that there are some procedures and treatments that the person would not be able to tolerate, based on unjustified assumptions relating to their profound learning disability and complex needs. Treatment and interventions for someone should be considered on a case-by-case basis and decision-



making must be in line with the Mental Capacity Act.

Where reasonable adjustments are given proper consideration and planning, it is possible for most treatments to be administered, so it is important these are properly explored.

- **Make sure basic care needs are met in hospital**

Make sure the person gets the right support in hospital for all their general care needs– including washing, personal care, eating, drinking and oral healthcare. Many people will need 1:1 care throughout their stay in hospital.

If families or support staff want to take on caring responsibilities in the hospital, hospital staff should support them to do so, but clear definitions of exactly what they are taking on must be drawn up. It is possible that a person's regular support staff want to provide care for the person in hospital but the care provider is not funded to enable this.

The hospital must make sure the person is getting the level of support they need and from someone with the right skills. They may need to organise and fund 1:1 support in hospital. It is most beneficial for the person to be supported by someone who knows them well.

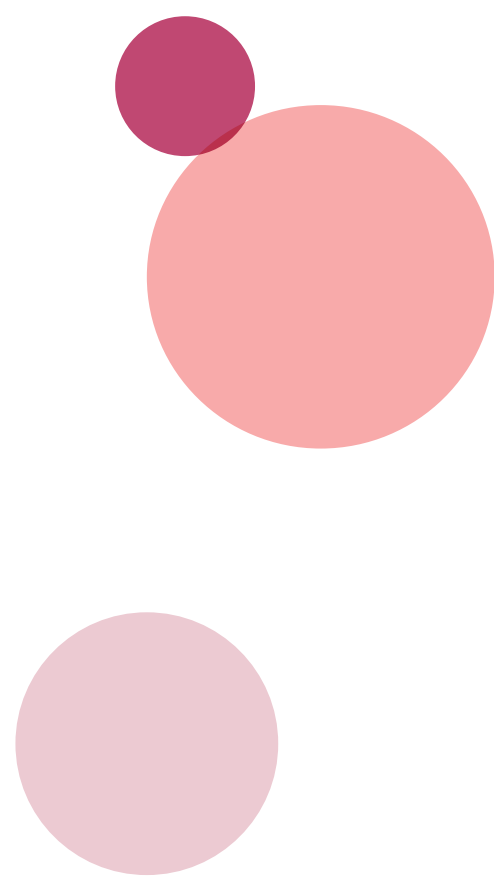
- **Eating and drinking**

Some people may have swallowing difficulties (dysphagia). They may need adaptations around mealtimes, for example, they may need their drinks thickened or their meals modified to be safe to eat, or they may need to be tube-fed.

It is very important to work in partnership with those who know the person well to fully understand the person's needs and how to support them. Input and advice from a speech and language therapist and assessments from a dietician may be required whilst the person is in hospital.

It needs to be clear:

- Who is supporting the person with nutrition and hydration (they must have the right skills)
- Who is responsible for checking the person is getting effective nutrition and organising (further) specialist



input in a timely way, and monitoring to ensure the person gets effective nutrition and hydration.

- **Consider how to make the environment as suitable as possible**

Hospital environments can be crowded, very noisy and bright, particularly in A&E. This can be particularly difficult for people whose senses may feel overwhelmed or who can get very anxious. It may help for them to have a quieter or less busy place to wait or stay. This may not always be possible, but hospital staff need to be aware of how the environment may impact on the wellbeing of the person, and discuss what adjustments they could make if someone comes into A&E, as well as for other admissions and outpatient appointments.

- **Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) orders**

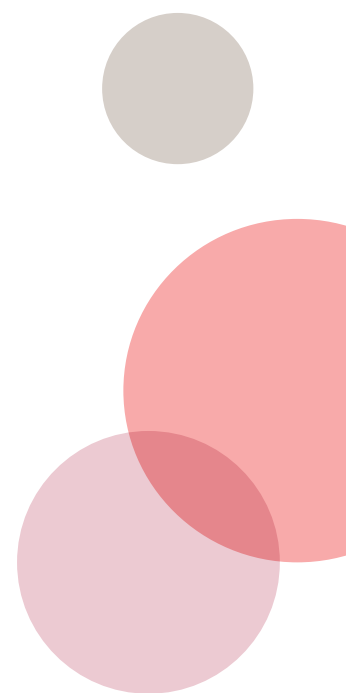
There have been circumstances where DNACPR orders have been applied to people who lack capacity to make this decision, without knowledge or involvement of family or the person's support team, and situations where DNACPR orders have been applied hastily in inappropriate situations, solely on the basis of the person's learning disability.

Be alert to the possibility that people with PMLD may have inappropriate DNACPR orders. They must only be in place if they have been appropriately agreed, in line with the law. This process must involve family and carers, where the person lacks capacity to make a decision themselves.

- **Postural care (protecting body shape) in hospital**

People who find it difficult to move or to change position without assistance, need personalised support to protect their body shape. In their day-to-day life this support may include a specially adapted wheelchair to support their posture and they may have a sleep system which helps protect their body shape whilst in bed.

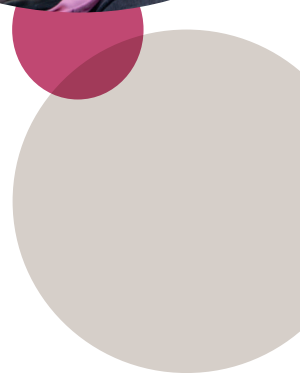
When in hospital, it is important the person gets the postural care they need. This may involve using their sleep system from home as well as support to change positions.



Without the postural care they need, people are at risk of pain and a number of health issues including bed sores and respiratory infections. Hospital staff should seek specialist advice from a physiotherapist or occupational therapist if necessary.

- **Support any long-term complex health needs and daily medication routine** which may be established as part of their normal day-to-day life. These needs must be supported when they are in hospital. Make sure it is clear what needs to happen and who is providing the necessary support for them.
- **The need to treat the person in a holistic way**
It is important to treat the person as a 'whole' person. Very often a person is seen by a number of different consultants because they have multiple conditions. Each consultant does not necessarily take into account the views of the other consultants and sometimes families/support staff find that the opinions are contradictory. There is a need for discussion between consultants, involving the person, family and support staff to ensure all aspects of the person's needs are addressed. Understanding what is wrong, when someone is not able to communicate symptoms, can require detective work together.
- **Plan discharge carefully**
Sometimes health professionals may think the person is returning to a 'nursing home' or a setting where there will be medical staff available, when in fact this is not the case. Discharge should be planned carefully to ensure the person's package of support in the community will meet their needs - this means the person may require extra input from community health professionals and/or additional funding in their care package if their needs have changed.

Discuss all these things, agree what reasonable adjustments are needed and put these in place.



Here are some examples of ‘reasonable adjustments’ that have been made for people with PMLD in hospital:

- ‘My brother needed to have a cannula inserted when he was in hospital. I told the doctor he finds it difficult to stretch his arm out and he doesn’t like his hands or arms being touched. The doctor said ‘right let’s look for other places’. He managed to use a vein in my brother’s foot instead. Since then, when the GP has needed to do a blood test he has taken blood from his foot as well.’
- ‘They used an ultrasound scanner for breast screening instead of a mammogram because the woman we were supporting was a wheelchair user who was unable to access this.’
- Some hospitals have installed a Changing Places toilet – a toilet with a hoist, height-adjustable changing bench. It means that people with PMLD have a toilet that meets their needs if they have to go into hospital.
- ‘My (adult) brother had an appointment at the Ophthalmology Clinic to diagnose his visual impairment. When I discussed his needs with the clinic staff we realised he needed to attend a different clinic – one where the hospital staff had paediatric expertise. My brother needed health specialists who were experienced in working with patients who, like him, are not able to speak, follow instructions, read or match pictures and letters. It was essential they had creative approaches to be able to assess his vision accurately.’
- ‘When my son had his hips in a plaster cast the hospital warned us about the high risk of pressure sores - because he couldn’t move himself. They put some protective cushioning around the top and bottom edges of his cast and gave us clear instructions about keeping pressure off his legs. He had his legs raised at an angle, supported on a pillow. We had to change his position frequently throughout the day and night. The nurse came every few days to check him out.’
- ‘My son needed a series of X-rays at 2-hour intervals over one day. They allowed us to visit the X-ray suite the week before, at a time when no other patients were there. He practised lying on the bed with firm straps round him - to ensure he would be still during the imaging. On the day itself, he really enjoyed himself! We played music, he was allowed to move his hands and play with his favourite toys, and he had two of us at his side throughout.’

6. What is the Mental Capacity Act* and how can it help save lives?

The **Mental Capacity Act** (MCA) is a law to protect people who may lack capacity to make a particular decision at a particular time. We know that people with a learning disability, including people with profound and multiple learning disabilities (PMLD), are dying avoidably because the MCA is not being followed.

Health professionals supporting people with a learning disability in hospital must follow the Mental Capacity Act. The law says they must start by assuming someone has capacity to make a decision and support the person to make their own decision where possible. If it is found that someone lacks capacity to make their own decision about care or treatment, then the law says a decision must be made in their 'best interests'. **The MCA has five principles that must be followed.** See the MCA Code of Practice for further information (link at the end of this booklet).

Note: Health professionals are required to involve an Independent Mental Capacity Advocate (IMCA) to represent the person, if a 'best interests' decision is being made about serious medical treatment and the person does not have a family member or friend who can be consulted.

For healthcare professionals who may be making a best interests decision about the person's care or treatment

The Mental Capacity Act has a checklist which must be followed when a '**best interests**' decision needs to be made. Not only is it the law to follow this 'best interests' checklist – it is extremely helpful– as it guides the person making the decision to do so with the person in mind, taking into account their wishes and feelings, avoiding discrimination, consulting with those who know the person well, exploring all the options, choosing the option that is less restrictive of the person's human rights.

* The Mental Capacity Act 2005 applies in England and Wales. There are different laws around mental capacity in Northern Ireland and Scotland. Therefore some of the content which relates specifically to the MCA 2005 may only be relevant for people in England and Wales.

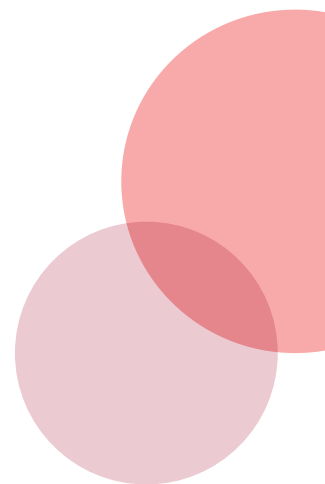
Here are some questions that may be helpful to consider in order to help ‘avoid discrimination’ (which can be unconscious) and ‘consult with others’, which are two of the things that must be done as part of the ‘best Interests’ checklist. **For the full best interests checklist see the MCA Code of Practice.**

Some questions to consider to help avoid discrimination:

- What would you do/ what course of action would you be considering in this situation - if the person **did not** have complex disabilities?
- If you are not considering this course of action for this person, why not?
- What assumptions are you making? Challenge yourself to consider if you might be making assumptions based on their disability, including assumptions about the quality and importance of their life.
- Check out those assumptions with colleagues who have expertise around learning disability, for example, a learning disability liaison nurse.
- Find out more about the person and their needs by spending time with the person and their family/support staff.

Some things to consider when consulting with others:

- Explore any assumptions and discuss adjustments that could be made or alternative ways that the person could get the treatment they need.
- Speak to family and the person’s familiar support staff who are likely to have lots of knowledge and expertise about the person and their needs. Take on board what they have said and ask further questions to understand why they are making their suggestions.
- Consider who else might be helpful to speak to or involve, such as:
 - Professionals in the community who know the person well – they are likely to be only a phone call away.
 - Hospital staff who may have looked after the person in the children’s hospital may be able to help.
 - A Learning Disability Liaison Nurse in the hospital will be able to help think about what reasonable adjustments might be effective.
 - Anyone who the family or regular support staff think is important to speak with.



7. I am a family member or support worker – how can I raise concerns?

If you are worried about the care or treatment the person is getting in hospital, you should always try, in the first instance, to explain your concerns to the health professionals involved in the person's care.

If you feel your concerns are not being addressed, then you can ask to speak to the Patient Advice Liaison Service (PALS) officer at the hospital. They may be able to help with your concern and/or give you information about the complaints process, including how to get independent help if you want to make a complaint. If you feel that the person is at risk of harm or deterioration due to the care or treatment they are receiving in hospital you can raise a safeguarding concern (during the day or 'out of hours') – the PALS team will be able to tell you how you can do this. If it is an urgent situation then your concern should be addressed as such, whatever route you choose.

If, for any reason, you are not able to speak to a PALS officer, any member of staff at the hospital should be able to signpost you to where you can make a complaint or raise a safeguarding concern.

If you disagree with a 'best interests' decision that hospital staff have made about the person's care or treatment, there are steps you can take, such as asking for a second opinion or for an independent advocate to be involved to represent the person. Ultimately, you can ask for the hospital to refer the decision to the Court of Protection to settle the matter.

Note: NHS England's 'Ask, Listen, Do' project is about making it easier for people with a learning disability and their families and support staff to raise a concern or complain about their care (further information at the end of this booklet).

8. Partnership checklist

Note: This checklist may help other people with a learning disability, not just those with profound and multiple learning disabilities (PMLD), get the right treatment in hospital.

This partnership checklist is to help everyone – **family members, support staff** and all **healthcare professionals** who may be involved in providing care for a patient with a learning disability – especially where the patient may be unable to make decisions about their care or treatment during a hospital stay.

This checklist is to use alongside the **hospital passport** (a document that has important information about the person's health and communication needs).

Whatever is agreed should be **recorded** in the patient's hospital notes and **communicated to all ward staff, including agency staff**.

This is important to ensure that hospital staff are clear how and when the patient's family or support staff from home need to be involved, and how to contact them urgently if necessary.

This partnership checklist will help hospital staff to fulfil their legal duty to make reasonable adjustments for people with a learning disability under the Equality Act.

Partnership checklist: key issues to discuss

1. Make sure hospital staff have the right contact details

- Name of family and/or the person's support staff
- Emergency contact number for family/support staff

2. Does the person have a hospital passport?

If not, provide a blank hospital passport and ask the person and their family/support staff from home to fill it out. Here is a link to a generic hospital passport template, which may be helpful: [www.easyhealth.org.uk/listing/hospital-passports-\(leaflets\)](http://www.easyhealth.org.uk/listing/hospital-passports-(leaflets)). Are there any other important documents that hospital staff need to look at? Make sure all hospital staff working with the person read the hospital passport, check their Summary Care Record for Additional Information and read any other important documents.

3. How will the person and family/support staff be involved in decisions about the person's care and treatment in hospital?

Hospital staff must always follow the Mental Capacity Act. Discuss how the person will be supported to make decisions in hospital, including the type of information and who will support them.

If the person is found to lack capacity to make a decision (after being given as much support as possible to help them make their own decision and there has been a capacity assessment), a decision will need to be made in the person's 'best interests'. Hospital staff must consult with those who know the person well such as family and support staff and involve the person themselves as much as possible. Find out how to involve the person as much as possible and how and when family and support staff want to be consulted.

Sometimes a family member may be a court-appointed Deputy/ have Lasting Power of Attorney for Health and Welfare. This means they will have the authority to make certain decisions on behalf of the person.

4. Will family/support staff be involved in providing aspects of care and support whilst the person is in hospital?

The person may need care and/or support such as:

- Personal care: washing, changing, oral healthcare
- Support with eating and drinking
- Support with complex needs, for example postural care
- Support with managing anxieties or sensory sensitivities
- Communication support
- Support to keep safe.

Be clear **who** is doing **what, when** and **how**.

Remember hospital staff have a responsibility to make sure all the person's health and care needs are met while they are in hospital. They may need to fund 1:1 care from someone with the right skills and expertise. It is most beneficial for the person to be supported by someone who knows them well.

5. Does the person need family/ support staff to be there to support and comfort them when difficult or painful procedures are happening, including surgery and post-surgery?

6. Does the person need family/ support staff to have extended visiting hours?

7. Does the person need family/ support staff to stay overnight?

If so, discuss what needs to be in place to enable this. For example:

- Where will family/ support staff sleep and on what
- Can they get a pass for parking, access to the hospital canteen, washing facilities or other support to stay close to the person?

8. Any other requirements for a successful partnership?

This checklist is based on an idea and the experience of Sue Jones. Her son Nick had a learning disability and autism. Sadly he died a preventable death in hospital. Nick's legacy is to help save lives by having excellent communication and partnership working between families/ support staff and healthcare professionals, to ensure patients receive the very best care and treatment.



Treat me well

How to meet the needs of people with profound and multiple learning disabilities (PMLD) in hospital

9. National guidance, further information and resources

National guidance around supporting people with PMLD

Supporting people with profound and multiple learning disabilities: Core and Essential Service Standards

The information in this booklet reflects the PMLD Core and Essential Service Standards, which aim to enhance quality of life for people with PMLD by ensuring high standards of care from all services, including hospitals. Following the standards will help maximise the health and wellbeing of people. The standards build on the elements of good support that Professor Jim Mansell set out in the report, Raising our Sights: services for people with profound intellectual and multiple disabilities (2010). The standards also respond to the findings of the Confidential Inquiry into premature deaths of people with a learning disability and the Learning from deaths (LeDeR) programme and reflect the recommendations in those reports.

www.pmlmlink.org.uk/wp-content/uploads/2017/11/Standards-PMLD-h-web.pdf

Learning Disability Capabilities Framework, Skills for Health

This sets out the knowledge and skills needed by health and social care staff supporting people with a learning disability. It includes a specific section on profound and multiple learning disabilities.

www.skillsforhealth.org.uk/images/resource-section/projects/learning-disabilities/Learning-Disabilities-CSTF.pdf

Further information and resources

- **East Midlands Top Tips for supporting people with PMLD**
<https://acppld.csp.org.uk/documents/top-tips-supporting-people-profound-multiple-learning-disabilities>
- **Template or examples of a hospital passport**
[www.easyhealth.org.uk/listing/hospital-passports-\(leaflets\)](http://www.easyhealth.org.uk/listing/hospital-passports-(leaflets))
- **Information about Summary Care Records and 'Additional Information'**
www.mencap.org.uk/treatmewell
- **Reasonable Adjustments for people with a learning disability – series of guidance, Public Health England**
www.gov.uk/government/collections/reasonable-adjustments-for-people-with-a-learning-disability
- **Postural care and people with learning disabilities: guidance, Public Health England**
www.gov.uk/government/publications/postural-care-services-making-reasonable-adjustments/postural-care-and-people-with-learning-disabilities

- **Makaton – key signs and symbols for the hospital**
www.makaton.org/shop/shopping/freeDownloadDetails/Lanyard-cards?fbclid=IwAR2Dnc8ngIHazCdPiUHAosNhSdgl3SKfNIiNmyquJo6Tklfzk_jlQUq7SMA
- **PMLD Link – Journal and health resources**
A charity with expertise around supporting people with PMLD. It shares information and good practice through PMLD Link Journal, a website and various social media channels.
www.pmldlink.co.uk
- **Mencap’s Treat me well campaign**
Mencap’s health campaign has information and resources that focus on health and people with PMLD, including a guide with PAMIS on making a multi-sensory story.
www.mencap.org.uk/treatmewell
- **Mencap’s advice and information service**
This includes factsheets, frequently asked questions and a learning disability helpline.
www.mencap.org.uk/advice-and-support
- **PAMIS resources**
An organisation in Scotland that works solely with people with profound and multiple learning disabilities and their families. It has number of resources around healthcare.
www.pamis.org.uk
- **Mental Capacity Act (MCA) Code of Practice**
www.gov.uk/government/publications/mental-capacity-act-code-of-practice
- **National Learning Disability Improvement Standards for all NHS Trusts**
NHS Improvement has developed new standards to help NHS trusts measure the quality of care they provide to people with learning disabilities, autism or both.
<https://improvement.nhs.uk/resources/learning-disability-improvement-standards-nhs-trusts/>
- **NHS England ‘Ask, Listen, Do’ project**
The aims of this project are that organisations, including hospitals: make sure people know how to raise concerns and complain, support people better when they do, really listen to what has been said without being defensive, and do something positive about it in good time and tell the person, family, paid staff, advocate what they are doing to put it right.
www.england.nhs.uk/publication/ask-listen-do-project-easy-read-leaflet/

Thank you to everyone who has contributed their time, expertise and experience to help develop this guide.

Find out more and join our campaign

www.mencap.org.uk/treatmewell
#TreatMeWell

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