



# How-to guide 2

## clinical procedures

For people with profound and multiple learning disabilities

**Raising**  
our Sights



# Raising our Sights guide to clinical procedures

*Raising our Sights*, by Professor Jim Mansell, was published in March 2010 with recommendations that aim to make sure people with profound and multiple learning disabilities (PMLD)<sup>1</sup> and their families get the support and services they need, and do not miss out on opportunities for more choice and control over their lives.

Some local areas have started to carry out recommendations from the report. However, many areas have yet to begin and have asked for further guidance on how to do this.

Now that local health and wellbeing boards are starting to lead the commissioning of health and social care services, it is a good time to think about what good support for people with PMLD looks like. It is an opportunity to make sure the right services are commissioned to meet the needs of a group of people who have so often been left out.

These how-to guides were commissioned by the Department of Health, and produced by Mencap and the PMLD Network, to help local areas implement the *Raising our Sights* recommendations, which are aimed at the local level. It does not focus on recommendations aimed at government and national bodies.

## About this guide

This guide to clinical procedures is one of 11 guides designed to help local areas implement the *Raising our Sights* recommendations. It is for both families and commissioners.

For more information about Raising our Sights, and to download all the guides, go to:

[www.mencap.org.uk/raisingoursights](http://www.mencap.org.uk/raisingoursights)

## Sections in this guide

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<sup>1</sup> Read the PMLD Network definition of profound and multiple learning disabilities at [www.pmldnetwork.org](http://www.pmldnetwork.org)

## **What are clinical procedures?**

‘Clinical procedures’ is a term used to describe certain processes or procedures which an individual with complex health needs may require, either as part of their routine care or within an expected emergency situation in order to maintain their optimal health or sustain their life. These procedures are sometimes referred to as ‘invasive clinical procedures’.

Clinical procedures cover the support required by individuals who depend on a medical device to sustain their life. Within care services, this support is usually provided by a non-health qualified person who has been trained and assessed as competent to provide it.

Routine and regular clinical procedures may include nasogastric, gastrostomy and jejunostomy feeding, oxygen dependency, catheterisation, nebulising and suction processes, tracheotomy and stoma care. Procedures required in an emergency include the administration of rectal Valium or Diazepam, the administration of Buccal Midazolam or the reinsertion of a tracheotomy tube.

# 1. What Raising our Sights says about clinical procedures

There are three recommendations:

## Recommendation 29.

The Department of Health should lead an initiative to adapt policies and procedures used in children's services for use in services for adults, involving representative bodies of the relevant professions and agencies.

## Recommendation 30.

Local policies should be based on the principles that (i) arrangements will be designed so that they sustain and enhance the quality of life of the disabled person by enabling clinical procedures to be carried out when and where needed, and (ii) arrangements will be coordinated and consistent between agencies, avoiding unilateral exclusions and consequent service gaps.

## Recommendation 31.

Local policies should focus on procedures identified by families as currently problematic, including all relevant care settings, such as hospitals, community services and people's own homes. These policies should specify who is responsible for carrying out clinical procedures in different situations and should deal with issues of clinical governance, legal liability and insurance.

*Raising our Sights* identified that many adults with profound and multiple learning disabilities (PMLD) are being denied services or access to certain opportunities and activities, because some agencies are preventing their staff from undertaking clinical procedures or using medical devices to sustain or support life. For example, administering rectal Diazepam or Buccal Midazolam, tube feeding, suctioning or administering oxygen. This situation can arise for a number of reasons including a lack of agreed local and national guidelines, organisational policies and procedures, fear of litigation, lack of adequate insurance cover for

clinical tasks and a lack of clarity about training and support for staff and carers.

Professor Mansell highlighted the progress which had been made in children's disability services to deal with these issues, and to develop a model which could be used across the board to ensure the inclusion of disabled children with complex health needs. *Raising our Sights* recommended that a similar initiative was required in adult services.

This clinical procedures guide will help local areas implement these recommendations and ensure the inclusion of people with PMLD. It focuses on what 'good' looks like and what needs to be in place to meet the needs of people with PMLD.

## 2. What does 'good' look like?

- **Families, friends** (and other local campaigners) understand the type of support adults with profound and multiple learning disabilities (PMLD) should be receiving for any complex health need they may have. This will ensure people are included in both specialist and universal services in a way that is safe and respects their dignity.
- **Commissioners and** support brokers plan and commission services that support and sustain the health of people with PMLD who require clinical procedures while that individual is receiving activities and services, in the same way as other disabled people.
- **Service providers** work through a process which ensures the safe inclusion of adults with PMLD who also have complex health needs, by training and supporting their own staff to carry out clinical procedures.

### 3. What needs to be in place to ensure the inclusion of people with profound and multiple learning disabilities

Many adults with profound and multiple learning disabilities (PMLD) who also have complex health needs are being denied access to opportunities and services because service providers refuse to support their health needs while they are attending the service. *Raising Our Sights* found that people with PMLD were often seen as ‘too disabled’ for disability services.

This clinical procedures guide uses a process which was developed in children’s disability services in 2004 (Dignity of Risk), and has been disseminated through a number of publications and training courses. It is based on the recognition that disabled people have rights to access services, while acknowledging that the support required to enable this to happen does carry a number of mainly manageable risks. The model explained in this guide attempts to balance those rights and risks.

In addition, there is a recognition that the number of disabled adults who now require clinical procedures has increased over the past ten years. If this group of adults is to access the same services – either specialist or universal – accessed by other people, as is their right, it is essential that there is an agreed procedure for staff to be trained to support people who require clinical procedures. For staff working in services, it is evident that more disabled adults have PMLD and their needs are changing. For example, the number of people who require nasogastric, gastrostomy or jejunostomy feeding shows a significant increase when compared with the figures for five or ten years ago.

This information about how to include disabled adults with complex health needs has been written using the experience and protocols of two local authorities: Kirklees Council and Leicestershire County Council.

The process, which is outlined in Section 7 of this guide, covers ten areas. These areas should form a checklist for service providers

and commissioners to ensure that everything is in place to ensure support is provided in a way that is safe and respects the dignity of the person.

#### **The ten areas are:**

1. joint working arrangements – local policies and procedures
2. information on the person
3. developing a partnership with the person
4. issues of consent
5. positive risk management
6. plan outlining health needs
7. training and support of staff
8. written information
9. written records
10. review and monitoring.

This process is equally applicable to adults who manage and arrange their own services and support through individual budgets and direct payments. The arrangements for risk

assessments to be carried out and support staff to be trained must be as robust as those for directly provided services when they are employed by the disabled person.

The process is outlined in more detail in the next section of this guide. There is a checklist that summarises the key points of the process in the **guide for commissioners**.

The local authority must take into account issues of safety when agreeing a direct payment for a disabled person who requires clinical procedures as part of their support. It would not be acceptable in law for direct payments to be refused to adults requiring support for clinical procedures because a local area is unable to put in place procedures that meet the necessary requirements.

## Policy and legislation – rights and risks

In order to ensure that disabled adults with PMLD can be safely supported, services need to achieve a balance between managing the risks involved in undertaking clinical procedures and ensuring this group of adults can exercise their right to access services.

All service providers, ie employers, have a duty to ensure that people using their services are not exposed to unacceptable risks, and that their staff are not being either reckless or negligent when they provide that service. This is achieved through effective risk management. (Risk assessment is described in more detail later in this guide.)

### Risks



### Rights

Services need to assess the potential risks and hazards associated with clinical procedures and avoid them if they are unnecessary, or minimise them if they cannot be avoided. Many risks cannot be eliminated but controls can be put in place to reduce risk to a level which is 'reasonably practicable'.

It is important to bear in mind that risk taking can be positive – we all take risks which may benefit and improve the quality of our lives. Assessing risk needs to occur in all settings, including an individual's home if that person is supported by a personal assistant in their home or the family home. Positive risk enablement should encourage people to take more control of their lives and manage the tensions between choice, risk and safeguarding.

One of the ways to control risk in relation to clinical procedures is to have in place a process of care planning, training and support to the staff who are administering those procedures. In law, service providers need to be able to demonstrate that risks have been assessed and managed correctly if anything went wrong. If a service provider cannot demonstrate that reasonable steps were taken to avoid an accident or incident, there are two charges that may be brought against them:

- Negligence - where staff failed to do something which it was their duty to do, and a foreseeable loss happened as a result.
- Recklessness - where staff knew there was a risk but either did not manage that risk or deliberately allowed the situation to occur in spite of the risk.

On the other side of the scale, disabled adults with PMLD who require clinical procedures have the same human rights as anyone else to pursue a fulfilling life. These are set out in the **Human Rights Act 1998**. Disabled adults with PMLD therefore have a right to access the same services as other disabled people, as well as local services in their community. This right is protected by the **Equality Act 2010**.

Prior to the mid-1990s when the Disability Discrimination Act was passed, many services were ‘risk averse’ and disabled adults with high support needs were seen as ‘too disabled’ for disability services. Service providers attempted to manage risk by trying to eliminate it. A turning point came with the **East Sussex judgement** in 2003. Although this judgement was in relation to moving and handling, it established the important principle that blanket bans were unlawful and that services needed to assess risk on an individual basis. In other words, services could not adopt a ‘no lift policy’ or state that all individuals requiring a specific clinical procedure could not use a service. A risk assessment must take into account the impact on the disabled person, their wishes, feelings and human rights, it said.

The judge emphasised the need for a balanced approach to the rights of the disabled person and the rights of workers to be protected by

health and safety regulations. The judgement further clarified that disabled people have the right to participate in community life and access activities in their community.

**The Equality Act 2010** created a legal framework to help achieve equality for disabled people. For the first time it brings together all the legal requirements on equality that the private, public and third sectors need to follow.

The Act protects disabled adults from discrimination which includes:

- Treating a person worse than someone else because they are disabled. This is known as direct discrimination.
- Putting in place a rule or way of doing things that has a worse impact on someone with a disability than someone without one, when this cannot be justified. This is known as indirect discrimination.
- Treating a disabled person unfavourably because of something connected with their disability when this cannot be justified. This is known as discrimination arising from disability.
- Failing to make reasonable adjustments.

## If the person can't access the services they need

There may be some situations where you feel a person with PMLD is either being denied access to services because their health needs are considered ‘too complex’, or are unable to access services because the right clinical procedures are not in place to adequately support their complex health needs. In these cases you may want to challenge or campaign.

Your local Learning Disability Partnership Board (LDPB) can be a good place to get advice or support and link up with other people to campaign. Many now have a PMLD champion or PMLD sub-group. Carers groups, local Mencap groups or advocacy organisations can also be good places to bring people together to support each other and campaign.

## Challenging

Sometimes you may just be trying to change things just for the person with PMLD who you support rather than trying to get wider change.

Some tips:

- Use the information in this guide, including what ‘good’ looks like, legal rights and policy information, to support your challenge.
- If the person’s needs are not being met, say so in a letter to the lead person at social services or the Clinical Commissioning Group (CCG). Let them know you will campaign publically against their decision if they do not listen to what you have to say.
- Get your local councillor or MP involved. You could ask them to write a letter of support.
- If you are not listened to, you might want to make a complaint or seek legal advice.
- If there are other people with PMLD in the area facing similar issues you may want to get together to campaign publically!

## Campaigning

If a particular issue is affecting more than one person with PMLD in your area, you may want to work with others to raise awareness about this and campaign publically for change. An example of an issue that many local areas have successfully campaigned against is the lack of appropriate changing facilities for people with PMLD. Thanks to campaigning, many local areas now have Changing Places toilets.

Some tips:

- Organise a campaign for people in your area to send an email or letter to their councillors.
- Launch a petition explaining what you are campaigning for.
- Hold a public meeting to tell people about the campaign and how they can get involved. You could invite a local newspaper or radio station along to cover the story.
- Organise a rally by inviting members of the public to a significant place, such as a town hall, to publicise the issue. Again, your local media might want to cover this.
- Gathering real stories and using photos and film can be very powerful. Social media can be a useful tool to share these.
- Don’t forget to plan your campaign!

## To help you challenge and campaign, see:

The Challenging Behaviour Foundation information sheet **Ten Top Tips**, by **Luke Clements**, which sets out the legal rights to community care services, has a template letter to follow if you want to challenge a community care decision. See <http://www.thecbf.org.uk>

**Mencap’s Know your rights local campaigns guide** (this is specifically about cuts, but it

has some useful general information about campaigning). See [www.mencap.org.uk/node/14506](http://www.mencap.org.uk/node/14506)

The **KnowHow NonProfit** website, which is part of the National Council for Voluntary Organisations, has lots of useful ideas about campaigning, including how to plan a campaign. See <http://knowhownonprofit.org/campaigns/campaigning/planning-and-carrying-out-campaigns/planning/planning>

## Complaints or legal action

Some people may choose to go down the complaints or legal route if their challenging or campaigning is not successful.

### Complaints

See our factsheet about making a complaint. It includes some specific information about making complaints in relation to each of the topics in the *Raising our Sights* how-to guides. See: <http://www.mencap.org.uk/raisingoursights/complaintsfactsheet>

### Legal action

Getting legal advice can be helpful. It is useful to do this sooner rather than later as some sorts of cases, such those involving the Human Rights Act or the Equality Act, have time limits on them. It doesn't necessarily need to cost you anything because you might be entitled to legal aid or be able to get a law firm to take on your case for free. For further information, or to find a solicitor, contact the Disability Law Service on 020 7791 9800 or email [advice@dls.org.uk](mailto:advice@dls.org.uk)

## 4. Detailed case study

### Natasha

Natasha is 19 years old and has profound and multiple learning disabilities and complex health needs. She requires assistance with moving and handling, is regularly hoisted and has been fed via a gastrostomy tube for the past four years. Natasha takes regular medication four times a day to control her seizures. She also has a VNS (Vagal Nerve Stimulator) in place and carers are required to use the 'magnet' when a seizure starts. In an emergency, Buccal Midazolam is administered to control a particularly severe and long seizure.

Natasha requires support to help her access the world around her. She understands very little verbal language and uses non-verbal communication and behaviour to make her needs known. A communication passport is used to ensure that everyone who supports Natasha understands her communication.

Natasha left school a few months ago. A comprehensive assessment was carried out prior to putting in place a support package jointly funded by social care and

health services. Natasha's parents both work and their needs were assessed as carers so that Natasha could continue to live at home, but in a way that means she is as independent as possible. Her parents have chosen to continue to provide some of her support.

Natasha's support is provided using a mixture of direct services and support purchased via a direct payment. She attends the local authority day service from Monday to Thursday. On Fridays she has a personal assistant, paid for by a direct payment. In the mornings a private care agency helps her get up and be washed, dressed and fed. When she returns home from the day service, Natasha is supported by a personal assistant until 6pm when her parents return from work. This arrangement is funded through a direct payment. She attends a residential respite unit on alternate weekends and receives some support, provided using a direct payment, on weekends she is at home.

Natasha's local authority and health trust have in place a joint policy which details

how adults like Natasha who require clinical procedures will be supported, so that they can be included in services in the same way as other disabled adults. The policy and procedures have been agreed by all agencies working in the area.

Representatives from adult social care services started attending Natasha's reviews two years prior to her leaving school. This meant that they have a comprehensive understanding of her needs and the support she is likely to require. The information about Natasha has been written up, agreed with her parents and is shared with all the services that she uses. This has meant that Natasha's parents have not had to repeatedly provide this information to a number of different services.

Prior to Natasha moving into adult services, risk assessments were carried out by the day service. Risk assessments of the clinical procedures were undertaken by a registered nurse from the Community Team Learning Disabilities (CTLD). The risk assessments were shared with the respite unit, the private care agency and

Natasha's parents who will be employing the personal assistants to work in the home. Where additional risk assessments were required, the local authority ensured the care agency and parents had the skills to carry these out.

The risk assessments on the clinical procedures all specifically address Natasha's needs and were written in plain English so that they can be understood and followed by all her carers. Additional risk assessments were carried out on the moving and handling required by Natasha.

The local authority assessment officer held a meeting attended by all the agencies that would be working with Natasha in adult services, together with her parents. It was agreed that the Community Team Learning Disabilities (CTLD) nurse and the assessment officer would complete a Health Action Plan (HAP) using the information already obtained during the assessment and risk assessment processes. The HAP would then be shared with the agencies and the family, who could then use it to ensure Natasha's needs were met by support staff.

A second meeting was held to look at issues regarding the training and support of staff carrying out clinical procedures and administering medication. This addressed concerns about the number of staff that could potentially be carrying out personal care tasks. It looked at how this number could be minimised. It was agreed that the CTLD nurse could train the non-health qualified staff to carry out tube feeding, the giving of Buccal Midazolam and the use of the VNS magnet, and sign those staff off as competent. The CLDT nurse would then offer support where necessary.

Natasha's family asked to be included in the training for the personal assistants as they will be the employers and it was a useful opportunity to update their knowledge and skills.

Attendees also discussed ways of ensuring that all support staff were kept up to date about changes. It was agreed that a single medication sheet would be used, which would be kept in Natasha's wheelchair bag. This would be updated by the family and the CTLD nurse. The sheet would inform staff about the medication Natasha needed and would record that it had been given. In addition a diary would be kept

with Natasha and support staff would be encouraged to write in it, so that Natasha's care would be co-ordinated.

Natasha's case study is a good example of joint working with the person at the centre.

## 5. Film

See how Kirklees council has put in place necessary clinical procedures to help ensure adults with PMLD, who have complex health needs, can access and enjoy the same activities and services as other disabled people.

[www.mencap.org.uk/raisingoursights](http://www.mencap.org.uk/raisingoursights)

## 6. The process

### Area 1. Joint working arrangements – local policies and procedures

**“The strength of partnership working has been that the organisation we work for has not been the primary issue – but we have been able to put the clients first. We have all brought different skill sets to the table and learnt a lot from each other.”**

**(From Kirklees Council and South West Yorkshire Partnership Foundation Trust)**

The inclusion in all services of adults with profound and multiple learning disabilities (PMLD) who have additional health needs cannot be achieved by any single agency or organisation working on its own. It is essential that all agencies in any geographic area work together to create partnership arrangements so that all services in an area follow the same protocols and policies to ensure the inclusion of adults who require clinical procedures in all universal and specialist services.

This partnership arrangement will lead to greater clarity on how each service can, for example, ensure that its staff are properly trained and supported. Service providers should not be in the position of having to negotiate funding to train staff each time an individual

with complex health needs wants to access their services. All areas should have joint policies and protocols in place that outline the process in that area. Some areas may draw on Continuing Healthcare (CHC) funding or core health funding to support this group of disabled adults.

The use of health funding varies across the country. In Leicestershire, for example, individuals requiring clinical procedures may be either 100% funded or part-funded by CHC funding. This arrangement is outlined in the revised *National Framework for NHS Continuing Healthcare and NHS Funded Nursing Care (2012)*. The key thing is that, in all local areas, there is clarity on how this funding is accessed and the criteria for drawing on it is outlined in the clinical procedures protocol.

Areas may decide that their protocol for clinical procedures should be part of a wider policy. For example, included in their protocol for the administration of medication (Kirklees Council), or in a wider health and social care protocol outlining the delegation of tasks across agencies (Leicestershire County Council). Where the policy and procedures sits in any local area will depend on its particular history and local arrangements. (See example below.)

Protocols for clinical procedures form part of Kirklees’ Policy and Procedures for the Safe and Appropriate Handling of Medicines. This followed concern expressed by managers in the Day Opportunities department of the local authority about the giving of medication to individuals, particularly when it was required by individuals away from their usual day service base (for example when they were out doing activities in the community). Additionally, the department needed to review the role of, and tasks being carried out by, the learning disability nurses employed within day services and ensure the most effective use of their skills.

Following an audit of adult learning disability services, a joint working group was set up to establish the medication policy across adult services to cover residential (including respite) and day opportunities/services. The carrying out of clinical procedures formed part of the ‘level three’ tasks outlined in that procedure. Although the giving of medication through a feeding tube forms part of that policy, enteral feeding - which is not classed as medication - is covered by a separate policy which sits alongside the medication policy.

The protocol in Leicestershire County Council, which has been in place since 2005, is similar in its process to that of Kirklees but forms part of a joint health and social care protocol which looks at the delegation of tasks between the local authority and health. The background to this arrangement is that a joint protocol of many years' standing had outlined tasks that staff from each agency would carry out when going into someone's home. This document was very rigid in its delineation of tasks which often meant staff from each agency were in the client's home at the same time. Recognition of the ineffective use of staff time resulted in agreement for a new protocol to consider which tasks could be delegated to the other agency so that only one staff member was sent to support an individual.

The result was a 'protocol' which now covers the carrying out of clinical procedures by local authority-employed staff who have been risk assessed and trained by a registered nurse. Like the Kirklees process, clinical procedures form part of 'level three tasks' requiring training and assessment of competence.

The two local areas both have protocols in place which, in terms of impact on processes, are very similar but due to their history and local circumstances are part of very different wider policies.

### **Having a jointly-agreed arrangement will:**

- **provide consistency** of approach across an area and give status to that approach
- **ensure the** commitment of all agencies to providing shared governance and shared ownership of the process
- **draw on** the expertise and knowledge of staff in all agencies
- **ensure that** the roles and responsibilities of all agencies are clearly defined
- **lessen confusion** for carers and families about what tasks services can and cannot take on
- **help to** clarify entitlement to a level of support that adults with complex health needs may expect
- **clarify the** funding arrangements for support to the individual.

### **Who should be involved in developing the joint arrangements?**

If possible, all agencies should come together in a partnership group and be involved in drawing up the policies and protocols. It is useful to involve some carers who have sons and daughters with PMLD and complex health needs. Although the partnership group may be large, once the basic outline for the policy is agreed most of the work can be done in smaller task groups.

Smaller task groups can benefit from the wider involvement of front-line professionals, such as Community Team Learning Disability (CTLD) nurses, to maximise the sharing of knowledge and expertise across sectors and professional groups. It is vital to involve unions and professional organisations at an early stage in the development of the policies rather than consulting them at the end of the process.

The life of the partnership group should not be limited to the development of the arrangements but should continue in order to monitor and update the protocols.

### **Monitoring and updating the protocols and procedures.**

Once the local protocol has been agreed it should be rolled out to organisations and agencies across the area through training days, presentations and other one off events. It is important to include families in this roll-out so that they know what they can expect. It is also essential to find ways to ensure the protocol is understood by those with responsibility for organisations offering services to this group of adults. For example, local councillors, trustees of third sector organisations and management boards of private organisations.

Once a local area has an agreed arrangement

in place, each organisation or agency needs to incorporate it into their individual policies and procedures.

### **Adopting organisational policies and procedures**

The joint working arrangement or protocols in any area forms the main umbrella under which each organisation or agency will write their own protocol, appropriate to their operation and the activities they provide. An organisation's policy and procedures should be in line with the joint working arrangements in that area. For services that are part of a national third sector or private organisation, the policies and procedures may need to be in line with both the local area arrangements as well as the policies of the national organisation. Where there are differences, these will need to be resolved in the service level agreement or contract.

An organisation's protocols may form a stand-alone document or it may be part of a wider policy, such as the medication protocol. The document needs to be appropriate to the size and complexity of the organisation, and the type of activities that are offered.

#### **Having an individual policy will:**

- **demonstrate the** commitment to positively promote the inclusion of adults with PMLD

and complex health needs

- **lead to** a clear understanding of the roles and responsibilities of staff, paid carers and other personal assistants
- **clarify what** families and carers can expect from a service, and what is expected of them.

Carrying out clinical procedures will mean that staff and other carers are involved in providing personal or intimate care. Intimate care is one of the factors which increase the vulnerability of disabled adults. Often this care is given by many different carers and staff each day. Therefore when writing the protocol, organisations or agencies should consider linking their protocol to existing policies for the safeguarding of vulnerable adults at both an area and organisational level.

#### **A policy should include information on:**

- **The roles** and responsibilities of staff and other paid carers for the support of an individual with complex health needs. Some services may employ specific support staff to carry out clinical procedures as part of their duties.
- **Duty of** care. Anyone caring for another has a common law requirement to act responsibly and ensure the individual is healthy and safe.
- **What the** service expects from families in terms of being kept informed about an

individual's needs.

- **The training** that staff and carers can expect to receive prior to supporting an individual who requires clinical procedures.
- **Indemnity or** insurance arrangements. All employers should make sure that their insurance covers actions that could be taken by staff in the course of their employment. It is the employer's responsibility to ensure that proper procedures are in place, that staff are aware of the procedures and are fully trained. Staff may be anxious about taking responsibility for supporting an individual with complex health needs because they fear something may go wrong. They can be reassured that, in the event of a successful claim for alleged negligence, it is the local authority or employer, not the employee, who is held responsible and would meet the cost for damages - unless that staff member had not followed their employer's policy.
- **Risk management**, record keeping and protocols to be followed.
- **Responses to** emergency situations.
- **Any additional** arrangements which need to be in place for activities which take place away from the usual base or site.

## Area 2. Information on the person

The organisation offering a service will need to hold information about a person with profound and multiple learning disabilities (PMLD), including details about their disability, medical condition and support needs. This information is required to plan a service or activity so that it is inclusive and minimises risks to the disabled person and staff.

### Obtaining information

Information about a person with PMLD is usually held by their primary carers. This may be their family if they live at home, or a residential home or support service. It is important that the service obtains as much information as possible in order to plan safe and appropriate support. If a service is committed to the inclusion of people with high support needs, it will need to take a proactive role by promoting an atmosphere which is open and in which families feel comfortable to disclose information, safe in the knowledge that such information:

- will be used sensitively to help the disabled person make the most of their time
- will be communicated to staff who need to know that information
- will not be used to bar a family member from the service or specific activities.

Some of the required medical information will need to be verified by a medical practitioner. For example, if a service is required to administer medication, the dosages will need to be verified by a GP or other key medical staff. All information on a person with PMLD will need to be regularly updated as needs change and develop. The review process in social services is often an appropriate time to ensure that information is up to date.

### Information sharing and confidentiality

One of the dilemmas facing any service is how much of the information about the person should be shared and with whom, and how much should remain confidential. The service needs to weigh up the rights and risks, taking into account the views of the family carers and, in some instances, those of the person, and make a decision for each individual. The decision may depend, for example, on a particular condition. If the person is allergic to certain foods and likely to go into anaphylactic shock, the information about allergies will need to be shared with both staff and other service users. On the other hand, if a person with PMLD has a bowel condition, information may be shared only with those that need that information. The individual's safety will always be the first consideration.

### Passing on information

Information should be shared and passed on well in advance from one service to another, particularly if the person is moving into new or different services. For example, information should be passed on from children's services at the time of preparation for adulthood, or when a person is going to live in a residential home. Meeting the needs of adults who require clinical procedures may require time to plan and make reasonable adjustments or to put into place support arrangements.

### Providing information to staff

It is important that general information should be provided to give staff an understanding about a particular condition as well as how that condition is likely to affect the person. This type of information should not be viewed as replacing training which staff may require, nor replacing the need to get information about the person's particular needs from a health professional. However, general information can be found on the websites of all the national organisations supporting people with specific conditions.

### Area 3. Developing a partnership with the person

If a service is to support a person with profound and multiple learning disabilities (PMLD) in a person-centred way they should consider and promote the following principles:

- **Independence.** People should be encouraged to do as much for themselves as they are able to.
- **Communication.** Disabled adults should have as much say as possible in the way their care is given. It is therefore essential that their method of communication is understood and documented, and knowledge of it is shared among carers. The guide on communication has lots of ideas and suggestions.
- **Dignity.** The person's dignity and right to privacy should be respected at all times.

All services should identify and adopt methods of working that encourage adults who require support with clinical procedures to be as independent as possible, while still receiving the necessary support and care. For people with PMLD, this will often include helping them take part in decisions which affect them and making sure their wishes and feelings are communicated and understood. For example, by understanding a person's non-verbal communication, staff will know whether that

person is comfortable in the way they are being lifted or being supported with their enteral feeding.

Most disabled adults with PMLD will communicate through non-verbal behaviour, using body movements, eye contact, noises and mood changes. **Communication passports** are increasingly used with adults who have PMLD as a way of documenting and sharing understanding of a person's non-verbal communication. The passports include information about the person, how they communicate and how to interpret their communication. These documents are often developed by speech and language therapists based in the Community Team Learning Disabilities (CTLD) team. However, if a person does not have one, the service can develop a simple passport to ensure all staff understand the individual's non-verbal communicative behaviours.

#### Developing a simple communication passport

A passport details the communicative behaviours of a person, suggesting what they might mean and explaining how staff should respond.

1. Draw up a list of the most important and appropriate needs and feelings staff need to

know to support an individual. For example, feelings of comfort, distress, hunger, thirst, anxiety and pain.

2. Speak to at least one person, but preferably two or three people who know the individual well and ask how they communicate these basic needs. How does the individual indicate that they are happy or enjoying something? How do they indicate unhappiness or distress? How do they indicate that they are hungry, thirsty or in pain? Information could be gathered using the table, on the next page.

How does the person tell you when they:	What does the person say? What noises do they make? What signs do they use?	What does the person do with their hands, feet, body language, etc? Or how does the person behave?
Are hungry		
Are thirsty		
Are comfortable		
Are in pain		
Are uncomfortable		
Like someone		

Put this information into a passport format shown in the example, below.

When I do this	People think I mean	You should do
Kick my legs out, smile, laugh and blow kisses	I am happy and enjoying what I am doing	I would like you to let me continue what I am doing or do this activity again
Make a long moaning sound, bite my hand or cry	I am distressed or not enjoying what I am doing	I would like you to stop this activity
Bang my hand on my leg	I am hungry and would like something to eat	I would like you to give me some food
Stick my tongue out	I am thirsty	I would like you to give me a drink
Make eye contact with you	I am showing you that I know you and like you	I would like you to interact with me

## Area 4. Issues of consent

The Lord Chancellor described the Mental Capacity Act (2005) in the following words:

***“It will empower people to make decisions for themselves whenever possible, and protect people who lack capacity by providing a flexible framework that places individuals at the very heart of the decision-making process. It will ensure that they participate as much as possible in any decisions made on their behalf and that these are made in their best interests.”***

Adults with profound and multiple learning disabilities (PMLD) have the same rights as anyone else to take part in decisions that affect them and, where possible, give consent for a clinical procedure to be carried out. Decision making and consent falls within the legal framework of the Mental Capacity Act (2005).

### **The decision-making process for most decisions consists of the following elements:**

- **information** to understand what has happened, or information on which to base a decision (informed choice)
- **cognitive process** - weighing up different options and making a choice
- **expression** of one’s decision or views

- **action feedback** - receiving acknowledgement or feedback on one’s views or decisions, or having one’s decisions acted upon.

### **This means that making decisions is affected by three processes:**

- **comprehension** - ability to understand and retain information
- **cognitive ability** - ability to weigh up information and reach a decision
- **communication** - ability to communicate the decision made.

It is these abilities that are assessed when mental capacity is considered in relation to a particular decision. In practice, making decisions will be beyond the ability of many disabled adults with PMLD. This means service providers will need to find more creative ways of obtaining their views and preferences. They need to find ways of breaking down the elements or doing things differently, to ensure that all individuals can take part in decisions and have a say in the way their support is given. **Involve Me**, a Mencap project looking at creative ways to do this, is discussed in the guides on **personalisation** and **advocacy**.

### **The key principles of the Mental Capacity Act are:**

- a presumption of capacity – a person is assumed to have capacity unless it is established that they lack it
- individuals should be helped to make decisions
- a decision deemed unwise does not mean a person lacks capacity to make that decision
- all decisions made on behalf of a person who lacks capacity must be in their best interests
- decisions made on behalf of a person should always consider the least restrictive option in terms of their freedom.

The code of practice for the Act outlines a two-stage capacity test to determine if a person can make their own decisions:

#### **Stage one**

This asks if the person has an impairment of, or disturbance in, the functioning of the brain. If so, does that impairment or disturbance make the person unable to make a particular decision?

If the answer to both these questions is ‘yes’, then the assessment can proceed to Stage two.

## Stage two

This stage asks the following questions:

- does the person understand the information given to them?
- do they retain that information long enough to be able to make a decision?
- do they weigh up the information available to make the decision?
- does the person then communicate that decision?

When deciding whether a person has the capacity to make a decision it must be remembered that this is a time- and decision-specific test. The individual may be able to make some decisions and not others, or may be able to make a decision one day but not the next. Assessing their capacity is based on whether or not they can understand and retain the information relevant to the decision, their ability to use or weigh up that information and their ability to communicate their decision.

Many people with PMLD will not have the capacity to make a decision or give consent to the support required for a clinical procedure, so a best interest decision should be made to cover that support. This decision should be made by someone who knows the person well; a health professional, family and the service

involved in giving the support. The factors which will be taken into account are the need for the procedure and support, the benefits of the procedure and consideration of what is the least restrictive intervention. Best interest decisions need to be recorded and shared with those working with the person.



### Sam's story

Sam has a profound learning disability and diabetes. He does not like needles and drew back when anyone tried to test his blood. The medical team treating him took his behaviour to mean that he was refusing treatment. This was worrying because regular blood tests are required for diabetes to be monitored and treated properly, to avoid it leading to further disability such as sight loss or even death. Sam's mother was very concerned.

The medical team involved knew what they should do in an emergency but were not clear about a more routine situation like this. They were worried that restraining him could contravene the Human Rights Act.

This situation took place before the Mental Capacity Act came into force. However, if the Act had applied then, the doctors would have found out that Sam lacked the capacity to consent to blood tests, and that they therefore needed to act in his best interests. This would have involved holding a meeting with his mother and those who knew him well.

Mencap got involved in Sam's case and made sure such a meeting was held.

Doctors should now know what is permitted under the Mental Capacity Act, and that they need to make reasonable adjustments under the provisions of the Equality Act 2010.

## Area 5. Positive risk management

There is an element of risk involved in many tasks carried out to support adults requiring clinical procedures. These risks cannot be removed completely but it is possible to manage them. All services and organisations are likely to have their own policies and procedures for carrying out risk assessments. This section will therefore outline the basic principles and focus on risk management in relation to clinical procedures.

### The basic elements in positive risk management

- **Risk** refers to the possibility of a situation occurring which would involve exposure to the possibility of something harmful happening.
- Risk is a combination of the **likelihood** of something harmful happening and the **seriousness** of the potential injury.
- A hazard is less likely to cause harm if certain **controls** are in place. Controls are the steps taken either to eliminate the hazard or reduce the associated risk to an acceptably low level.
- Risk is managed by **assessing it**, avoiding it if it is unnecessary or otherwise reducing it to a level which is **‘reasonably practicable’**.
- When considering what is **‘reasonably practicable’**, the needs of the disabled adult

and those of the staff should be taken into account.

- The Health and Safety Executive defines reasonably practicable as:  
***“An employee has satisfied his/her duty if he/she can show that any further preventative steps would be grossly disproportionate to the further benefit which would accrue from their introduction.”***

All service providers need to agree who is responsible for carrying out risk assessments, ensure those individuals are trained, and have in place procedures and paperwork in order to carry out the risk assessment. All risk assessments should be reviewed on a regular basis.

Risk assessments of clinical procedures should be carried out with input from a health professional who is familiar with both that procedure and the person with PMLD. However, all staff working with that person should have sufficient basic training to recognise what might pose a risk to them. The risk assessment should be specific both to the person and the procedure. This means that if a service provider has four people requiring Buccal Midazolam, a risk assessment is carried out for each.

All risk assessments should be written in plain

English rather than health and safety jargon so that they can be understood by all staff and easily put into practice. The risk assessment should be person-centred and take into account the dignity and rights of the person.

There are some areas of risk connected to certain procedures which have specific regulations and guidance, and which are likely to be covered in the health and safety policy of the organisation. These include:

- control of Substances Hazardous to Health regulations 2002. (COSHH)
- clinical waste
- infection control.

All services working with disabled adults should have in place policies and procedures relating to the administration of medication.

## Area 6. Plan outlining health needs

An adult with profound and multiple learning disabilities (PMLD) and high support needs should have an individual plan which covers their general health care needs as well as their clinical procedures. Local practice will differ from one area to another; some areas may have a single plan and others may have separate plans for each type of specialist support. These local arrangements will usually have developed in a specific way due to historical and practical factors. Many areas use **Health Action Plans** (HAPs) and the information contained in these may be used to write a shorter and more specific health care plan for services. See the **health guide** for information about HAPs.

Whatever the local arrangement, it is important that if a person needs additional assistance in specific areas of care, the information explaining how the support should be given needs to be recorded and shared with all those who are providing this support. Each person should have an individual plan which is specific to their particular needs. Plans will vary in length and complexity depending on the person's needs. As these plans will be read and used by a range of staff, they should be written in clear English, avoiding jargon and medical terms, so it is easy to understand.

A plan outlining health needs should be holistic,

person-centred and should cover the individual's condition, medicines and support required. This should cover:

- particular procedures that should be carried out, by whom and the ongoing training and competency checks they can expect
- protocols for exchanging information between agencies, with clearly defined lines of responsibility and named contacts
- additional risk assessments required for that particular person, and who is responsible for completing them
- any special health care needs that may affect the person's use of services such as transport or implementation of therapy programmes, etc
- the use, storage and maintenance of any equipment
- information on the manner in which the person prefers any clinical task to be carried out, in order to ensure consistency
- any anticipated changes in the person's condition or care routine
- arrangements for reviewing the plan
- clear supply route for any medical equipment such as tracheotomy tubes.

The plan should be drawn up prior to the person starting in a new service by people who know

them well, including family, health professionals and staff working in the service. Plans covering health care needs should be live documents which can be altered if the person's needs change. The plan should be reviewed as part of the annual review process and kept in a place which is accessible to staff, but which takes into account the need for confidentiality.

Smaller services (for example respite services or activity based services) should be able to access and adapt health plans from larger services (for example day services). This means there will be a consistent approach in the way healthcare needs are met, and avoids health professionals being asked to attend multiple meetings to draw up new plans for each service.

Many people who require clinical procedures will need an emergency plan as part of their health plan. This will cover likely emergency situations such as seizures or respiratory problems. The emergency plan should be easily accessible and written in a way that is easy to follow at a time of crisis, for example in the form of a flow chart. All staff should be familiar with emergency procedures, who they should call for help and how to access emergency services.

A number of **plans used in Kirklees** outlining specific areas of support are included at the end of this guide.

## Area 7. Training and support of staff

**“Staff in Day Opportunities have found that working alongside health staff has increased their understanding of why things need to be done in a certain way and they are also confident to go to the nurses and question things they do not understand.”** Service manager, Kirklees Council

**General training.** Many services may undertake general training that will give all staff a good understanding of certain conditions. For example, staff in a day service or residential home may attend general training on epilepsy which will cover the need for rescue medication. However, only those working with people who require rescue medication will receive specific training on administering the medication.

**Specific training.** Training on a specific clinical procedure will need to be carried out on an individual basis for everyone supporting a person. This training cannot be cascaded by someone who has attended a course to other staff, nor can training to meet the needs of one person be generalised to meet the needs of another. In general, staff supporting disabled adults with profound and multiple learning disabilities (PMLD) who require clinical procedures, are unlikely to have any health qualifications and are not usually registered

nurses. Training of support staff to carry out a clinical procedure must be carried out by a registered nurse or medical practitioner. Although it is good practice to invite families to attend the training, they should not train the support staff.

The protocol should clearly state the arrangement of delegated tasks, as in the example below from Leicestershire County Council.

**“Healthcare remains the responsibility of the NHS but some tasks (as defined within this protocol) may be delegated to care workers by NHS health professionals who will provide the training and supervision to ensure the care worker has the appropriate knowledge, skill and competence to carry out the task/function.”**

In June 2005, the Royal College of Nursing (RCN) developed an advisory list of procedures that may be safely taught and delegated to unregistered health- and non-health qualified staff. This list appears on the RCN website and although it was initially written for children, it is equally applicable to adults and is regularly updated as medical procedures develop.

The list of procedures which can be safely taught and delegated to unregistered health-

and non-health qualified staff includes, for example, injections, suppositories, tracheostomy care, administering oxygen, tube feeding and stoma care. The tasks that should not be undertaken by unregistered or non-health qualified carers include procedures such as the reinsertion of nasogastric or gastrostomy tubes, programming syringe drivers, deep suctioning and the giving of medicines not prescribed or included in a care plan.

Link to the Royal College of Nursing website on delegation of clinical procedures:  
[http://www.rcn.org.uk/development/communities/rcn\\_forum\\_communities/children\\_and\\_young\\_people\\_field\\_of\\_practice/cyp\\_continuing\\_care/news\\_stories/managing\\_children\\_with\\_health\\_care\\_needs\\_delegation\\_of\\_clinical\\_procedures\\_training\\_and\\_accountability\\_issues](http://www.rcn.org.uk/development/communities/rcn_forum_communities/children_and_young_people_field_of_practice/cyp_continuing_care/news_stories/managing_children_with_health_care_needs_delegation_of_clinical_procedures_training_and_accountability_issues)

**The trainer.** Training must be carried out by a registered nurse or medical practitioner. It has become common practice for registered nurses working for enteral feed companies to carry out the training of staff. While it is acknowledged that they have expert knowledge about their particular product, they very seldom know the particular disabled person. It is preferable for support staff to be trained in clinical procedures by nurses who know the person as this provides a more person-centred, holistic approach.

It also means both the person and their support staff are offered ongoing support and monitoring.

Under Kirklees Council procedures, the training of support staff in enteral feeding is a joint process. The nurses employed by the 'feed company' conduct the knowledge-based part of the training, while individual specific training is carried out by learning disability nurses employed by the health authority and based within day opportunities centres. These nurses know the individual, offer ongoing support for all the health needs of that person and are on hand to resolve problems as they arise.

**Assessed as competent.** Health professionals who have conducted training must sign a competency form confirming trainees are able to carry out a particular procedure, and agree when their training should be updated. Until this form is signed the training is not deemed complete.

There has been some reluctance in the past among registered nurses to carry out the training and then sign the competency form because the Nursing and Midwifery Council Code of Practice (2008) holds them responsible for the delegation of the tasks.

A solution was found in the development of

competency-based training which clarified for both the health professional and the person being trained what new knowledge they had acquired, what practical tasks they had been trained to do and what they were being considered as competent to do. Competency-based training contains elements of both theoretical knowledge and practical training.

**Support staff.** Experience in children's services with children who require virtually 24-hour support, such as those on long term ventilation or with tracheostomies, has shown that it is more cost effective and the care provided is more consistent, if the team supporting the child is built around the needs of the child rather than the service. It is common practice in cases of children requiring smaller support packages for each service to recruit or train their own support staff. However, because of the cost and time involved in training support staff for children with very high levels of support, it has become evident that a team of staff should be recruited and trained for a particular child. This means that one member of that team will support the child across all the services they access.

Although the number of adults with very large support packages is still relatively small compared to children, it will increase as more young people requiring 24-hour support survive

into adulthood. This is an issue which adult services can address through the use of good practice models from children's services, to provide a more cost effective and consistent package of support.

The issue of vicarious liability is raised when support staff 'follow' an individual to different services, instead of their being supported by staff from that service. This might be the case, for example, where individuals are supported by staff employed by them or their family through a direct payment or individual budget arrangement. In this situation, that staff member would be on the premises of a service provider who is not their employer, so it is essential to establish who will take legal responsibility for their actions.

**On-going support and monitoring.** Support staff who have recently completed training should be offered on-going support and monitoring by the health professional who delivered it. This is one reason why it is preferable to use registered nurses employed by a health trust rather than the registered nurse employed by the feed or equipment company, or an independent nurse. It means support is offered within a holistic and person-centred context and can focus on the whole person, rather than the clinical procedure.

## Area 8. Written information

Services should hold written information about the person detailing their disabilities, health conditions, likes and dislikes, preferred method of communication, and contact details for family members and key professionals to be called in an emergency. This may be in the form of a communication passport. Services also need to hold written information about clinical procedures, usually in the form of a health care plan or a plan relating to a specific procedure.

If medication is administered either orally or via an enteral feeding tube, or rescue medication such as Buccal Midazolam or rectal Diazepam is required, the information on dosage must be in writing and verified by the GP or consultant. If dosages are changed, services need to be notified in writing.

This may cause difficulty when dosages are changed with immediate effect at medical appointments. However, this can be resolved by using a pro-forma letter which the individual takes with them to all medical appointments. The letter is signed by the GP or consultant if the medication has been changed and given to the service to allow an immediate change of medication.

A service should also have information on the clinical procedure written in plain English in a

way that is easy to follow, such as a flow chart. This is usually documented as part of the care plan. Written instructions given to staff should be clear and unambiguous.

See an example of a **form used to administer Buccal Midazolam** at the end of this guide.

## Area 9. Written records

Services need to record the routine giving of medication, whether orally or via an enteral tube. People who take a number of medicines at different times of the day could have a single drug sheet or record of medication which stays with them. It is important to obtain the agreement of all services and the family to use the same recording system. This should record the administration of rescue medication, such as Buccal Midazolam, or the use of a VNS (vagus nerve stimulator) magnet or an epipen. When an epipen is used for a severe allergic reaction, or Buccal Midazolam is given, and an ambulance is then called, the epipen or syringe should be given to ambulance staff. The dose given is then recorded by the ambulance staff and relayed to the staff in the hospital emergency department.

If a person refuses medication or spits it out, this should be recorded. If medication is not taken or an error is made in giving medication

(giving the wrong dosages or the incorrect medication) this needs to be documented and will usually require more senior staff or health staff to be notified. Support staff should be encouraged to report any errors and not attempt to cover them up.

It is important that frontline staff do not spend excessive amounts of time completing paperwork at the expense of supporting people. This means thought needs to be given to what records frontline staff are required to complete, and a principle of 'proportionality' should be applied.

Training on clinical procedures and evidence of competence needs to be updated on an annual basis. The service should hold records detailing the initial training of staff members, when the training has been updated and when it is next due.

## Area 10. Review and monitoring

As with any process it is essential to complete the circle by building in a system of reviews and monitoring. This should include:

- Review of the person. Reviewing the clinical procedures should be a part of the person's annual review so that the procedure is seen within the context of the whole person.

- Review of support staff. The employer and the health professional responsible for carrying out training need to review the training and competencies of the support staff annually.
- Review the plans. This should be linked into the person's annual review. The health care plan and the risk assessments specific to that person must be reviewed and updated.

## 7. Share good practice!

We know there is already good practice out there and some examples are referred to in these *Raising our Sights* how-to guides. But we would like to hear of more examples and share them so other local areas are inspired to develop good support and services for people with PMLD too.

Please tell us about any good practice in your local area relating to support or services for people with PMLD:

Email [pmlidnetwork@mencap.org.uk](mailto:pmlidnetwork@mencap.org.uk)  
Call 020 7696 5549



### The Lambeth PMLD project

This project aimed to show what life was like for people with PMLD in Lambeth, and use the information to better plan to meet their needs. It was initiated by family carers of people with PMLD on the Lambeth learning disability partnership board and run in partnership with Lambeth Council, NHS Lambeth, 'I Count' Register Services, National Mencap and Lambeth Mencap.

The project identified people with PMLD on the learning disability register using criteria developed from the PMLD Network definition. Information was also collected through surveys and interviews with families and support staff.

Priority areas for change were identified and, two years on, there is an active PMLD sub-group committed to take these forward. The focus is currently on developing meaningful activities for people with PMLD in Lambeth. There is a case study and film of Lambeth's work on meaningful activities work in the *What people do in the day* guide.

For more information about the Lambeth PMLD project see:  
[www.mencap.org.uk/Lambethpmlid](http://www.mencap.org.uk/Lambethpmlid)

## 8. Templates

We would like to thank Kirklees Council, the South West Yorkshire Partnership Foundation Trust, Leicestershire County Council and the Leicester Primary Care Trust for sharing their experience and protocols.

We include templates from Kirklees Council and the South West Yorkshire Partnership Foundation Trust on the following pages.

Kirklees Day Opportunities - LD

Administration of Buccal Midazolam

This plan can only be implemented by staff who have received training on the administration of buccal midazolam and feel competent to administer the medication.

Date of Plan:

Name of client:

Date of Birth:

Address:

Next of Kin:

Prescribing Medic:

<b>Description of seizure:</b>

**Administration Plan:** - Prescribed dose of      mg/      ml of **Buccal Midazolam** to be given **via the buccal cavity** (space between jaws and cheeks) if ..... has a seizure as described above which lasts for ..... **minutes** **OR** a period of ..... **minutes** of almost continual seizure activity with breaks between. **This is given in      doses set out below.**

**1<sup>st</sup> dose**

**1<sup>st</sup> dose to be given after ..... minutes**



**If seizure continues after 1<sup>st</sup> dose and there are signs of breathing difficulties dial 999.**  
**If there are no signs of breathing difficulties and seizure continues for a further .....minutes administer 2<sup>nd</sup> dose.**

**2<sup>nd</sup> dose**

**If seizure continues after 2<sup>nd</sup> dose and there are no signs of recovery or there are signs of breathing difficulties dial 999.**

**If there are no signs of breathing difficulties follow recovery below.**

**After administering Buccal Midazolam/recovery:**

**Any concerns with administration and/or recovery an ambulance must be called immediately and no further doses to be given.**

All observations and recovery time must be recorded accordingly in the:

1. Daily notes
2. Epilepsy diary/chart.

Plan written by:

Signature:

Designation:



With all of us in mind

## Kirklees Day Opportunities - LD Epilepsy Nursing Support Plan:

<b>CLIENT NAME:</b>	<b>Date:</b>	<b>Named Nurse:</b>

<b>Classification of seizures:</b>
<b>Type of seizure(s):</b> e.g. tonic clonic, absence seizure if known .....
<b>Description and duration of seizure(s):</b>

<b>Possible seizure triggers</b> e.g. flashing lights, loud noises, heat, stress

<b>Warning signs</b> e.g. stage in menstrual cycle, twitching, mood changes
---



With all of us in mind

**Pre (leading up to a seizure):**

**Imminent (directly before a seizure):**

**NB: not all warning signs will be displayed prior to every seizure.**

**Medication:**

**Anti epileptic medication:**

Ensure that medication which is prescribed to be given at the Day Centre is taken. If not taken, record the omission.

**Action to be taken during seizure:**

**First Aid Measures:**

Observe breathing rate or pattern and eye appearances (e.g. eye rolling, pupil size); and observe for signs of cyanosis (a blue colour to the lips and nails) and warning signs that may indicate another seizure.

**Specify usual recovery pattern:**

**Action to be taken if seizure continues:** include details of rescue medication



With all of us in mind

(including route) if applicable and link to rescue medication plan

Continue to monitor breathing rate/pattern and eye appearances and observe for signs of cyanosis and warning signs that may indicate another seizure. If another seizure occurs apply first aid measures as previously specified.

**When emergency services should be contacted:**

**Monitoring seizure recovery and after care:**

**Documentation:**

Document the following in the daily notes:

- Time and length of seizure
- Anything unusual prior to seizure
- Any potential triggers
- How the seizure started
- Description of the seizure
- What the person was like after the seizure (recovery)
- What actions were taken including administration of buccal midazolam or rectal diazepam
- Any injuries
- Any other related health issues

Complete epilepsy diary/chart

**Contact:**

Inform family members/carers about the seizure(s) and make enquiries about medication being taken/ new medication; regular bowel movements and general health.



With all of us in mind

<b>Other contacts (if applicable):</b>
<b>Consultant Neurologist:</b> Name: Telephone Number:
<b>Epilepsy Nurse:</b> Name: Telephone Number:

<b>Evidence base:</b>
Joint Epilepsy Council (2004) A Guideline on Training Standards For The Administration of Rectal Diazepam Joint Epilepsy Council (2008) A Guideline on Training Standards For The Administration of Buccal Midazolam

Care plan written by:..... Signature:.....

Designation:..... Date: .....

Will be reviewed: .....

<b>Review date:</b>
<b>Review findings and action:</b>
<b>Reviewed by:</b> <span style="float: right;"><b>Signature:</b></span> <b>Designation:</b>

<b>Review date:</b>
<b>Review findings and action:</b>
<b>Reviewed by:</b> <span style="float: right;"><b>Signature:</b></span> <b>Designation:</b>



## Jejunostomy Plan

**Name:**

**DOB:**

<p><b>Pump and Feeding regime:</b></p>	<p>Please note .....has a gastrostomy tube inserted into a jejunostomy site.</p> <p>..... is fed over night via her jejunostomy.</p> <p>..... can eat small amounts of liquidised food during the day.</p>
<p><b><u>Feeding Tube Details;</u></b></p> <p><b>Currently in situ;</b></p> <p><b>Size;</b></p> <p><b>Date of last insertion;</b></p> <p><b>Emergency replacement tube;</b></p> <p><b>Location;</b></p> <p><b>Expiry date;</b></p>	<p><b>CAPSULE MONARCH Trans-shaping G tube. (in situ permanently)</b></p> <p><b>12 French</b></p> <p><b>13/06/2011</b></p> <p><b>12 French Corflo expanded gastrostomy tube with 5cc balloon.</b></p> <p><b>TO BE KEPT AT ALL TIMES IN ..... BAG ON THE BACK OF HER WHEELCHAIR.</b></p> <p><b>November 2013</b></p>
<p><b>Equipment</b></p> <p><b>Syringes</b></p>	<p><b>50ml Female luer lock syringe/enteral (purple for administration of water and medication)</b></p> <p><b>Syringes are <u>SINGLE USE ONLY</u></b></p>



<b>Additional flushes/water</b>	<p>200mls of sterile water at 9.30am and 200mls of sterile water at 2.00pm.</p> <p>Refer to support plan 2. Sterile water via jejunostomy.</p>
<b>Administration of medication</b>	<p>See support plans</p> <p>5. Administration of Movicol via jejunostomy.</p> <p>6. Administration of chlorphenamine maleate via jejunostomy.</p>
<b>Infection Control</b>	<ul style="list-style-type: none"><li>• Wear clean non sterile gloves.</li><li>• Wash and dry hands</li><li>• Apron if required.</li><li>• Dispose of soiled items in clinical waste.</li><li>• Always use sterile water for jejunostomy.</li><li>• The syringes are <b>SINGLE USE ONLY</b>.</li><li>• Check date and time of water if open. If unopened date and sign the water bottle with time of opening. (water must be disposed of after 24hrs of opening)</li></ul>
<b>Stoma /tube care</b>	<p>See support plans 1. Care of the jejunostomy site. Also see care plan 8 (personal care) this states how to position tube correctly to prevent the tube being displaced or coming out completely.</p>



**Trouble shooting**

**Blocked tube**

**See support plan 4. Unblocking gastrostomy tube.**

**Accidental removal/displacement/Blocked tube**

**If tube comes out or it is not able to be unblocked it can be replaced Monday to Friday 9am to 5pm in out patients clinic- please ring ahead and take the spare tube (corflo) and information , this is carried in her cool bag on the back of her wheelchair. Out of these hours please contact A&E. If..... has to visit A&E out of hours then the carers/staff who accompany her must ensure that they ring secretary with in normal working hours to make an outpatients appointment. (Dietician) also need informing if the tube needs replacing.**

**Excessive bile.**

**If there is excessive bile coming back into tube, then refer to appropriate health professional to arrange for tube to be assessed in clinic. When ..... is in respite contact details for OPC are below.**

**(add further issues where needed)**



With all of us in mind

<b>Contact Details</b>	
<b>GP</b>	
<b>District Nurses</b>	
<b>Dietician</b>	
<b>Nutricia</b>	
<b>HRI</b>	
<b>Named Nurse</b>	
<b>Signature</b>	

## Acknowledgements

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