



NHS

Midlands and East

Top Tips for supporting and meeting the needs of people with Profound and Multiple Learning Disabilities (PMLD)



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Useful resources

Health:

- **UK health and learning disability network**
www.jan-net.co.uk
- **Department of Health**
www.dh.gov.uk/health/search/?searchTerms=learning+disability+publications
- **RCGPs**
www.rcgp.org.uk/clinical_and_research/circ/innovation_evaluation/learning_disabilities_resource.aspx
- **Learning Disabilities Observatory**
www.improvinghealthandlives.org.uk/

PMLD specific:

- **Raising our Sights**
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114346
- **PAMIS**
www.pamis.org.uk/
- **PMLD network**
www.pmldnetwork.org/
- **PMLD link**
www.pmldlink.org.uk/

- **PMLD fact sheet**
www.pmldnetwork.org/pmld%20definition%20factsheet%20-%20standard.pdf
- **Mencap's PMLD Communications Guide**
www.mencap.org.uk/page.asp?id=1539

Easy read:

- **Easy Health**
www.easyhealth.org.uk
- **CHANGE**
www.changepeople.co.uk

Multi media:

- www.multi-me.com

Research:

- **Centre for disability research**
www.lancs.ac.uk/cedr/
- **Norah Fry research centre**
www.bristol.ac.uk/norahfry/



Introduction

Top Tips for supporting and meeting the needs of people with Profound and Multiple Learning Disabilities (PMLD)

People with Profound and Multiple Learning Disabilities (PMLD) are amongst the most disabled individuals in our community.

They have a profound learning disability which means that their intelligence quotient is estimated to be under 20 and therefore have severely limited understanding.

In addition they have multiple disabilities, which may include impairments of vision, hearing and movement as well as other problems like epilepsy or autism.

Most people in this group are unable to walk unaided and many have complex health needs requiring extensive help. People with PMLD have greater difficulty with communicating: they typically have very limited understanding and express themselves through non – verbal means or at most through using a few words and symbols.

This means that people with PMLD need high levels of support from others with most aspects of daily living: help to eat, to wash, to dress, to use the toilet, to move about and to participate in any aspect of everyday life.

All children and adults who have profound and multiple learning disabilities will have greater difficulty communicating. Many people will have additional sensory or physical disabilities, complex health needs or mental health difficulties.

People with profound and multiple learning disabilities have more than one disability.

Their main disability is a profound learning disability. This means they need lots of support.

They might have these other disabilities as well.

- Physical disabilities. This is a disability to do with the body
- People who use a wheelchair have a physical disability
- Sensory disabilities. This is when people find it difficult to see or hear
- Lots of health problems
- Mental health problems
- Autism
- People with profound and multiple learning disabilities need a lot of support: They also find it very difficult to communicate



Despite such serious impairments, people with PMLD can form relationships, make choices and enjoy activities. The people who love and care for them can often understand their personality, their mood and their preferences.

These Top Ten Tips have been developed to support everyone, professionals and carers alike to help the person with PMLD live a fulfilling, happy and healthy life.

It is important that everyone understands that people with profound and multiple learning disabilities have the same rights as every other citizen. We must enable each individual to engage with their world and achieve their potential so that their lives go beyond being 'cared for' to be valued for who they are as people. www.pmldnetwork.org/

In the words of a family carer:

"People with PMLD are just that: PEOPLE and supporting them to live a fulfilling, happy and healthy life is everybody's responsibility."

It is acknowledged that there are a number of definitions used world wide, for example Profound Intellectual and Multiple Disabilities (PIMD) (Reference: 'Raising our Sights: Services for Adults with Profound Intellectual and Multiple Disabilities', Professor Jim Mansell 2010).

PMLD Network (2002) 'Valuing People with Profound and Multiple Learning Disabilities (PMLD)'

www.pmldnetwork.org/

Department of Health (2001) 'Valuing people: a New Strategy for Learning Disability for the 21st Century'.

Further reading

Bellamy, G Croot L, Bush, A, Berry H. Smith A (2010) A study to define profound and multiple learning disabilities (PMLD) Journal of intellectual disabilities, September 2010, Vol. 14, 3:pp.221-235



Basic Health Needs

10 Top Tips for supporting the basic health needs of people with PMLD

- 1** **People with Profound and Multiple Learning Disabilities have greater health needs than the general population. They are more likely to have the following conditions;**
Respiratory Disease, Epilepsy, Coronary heart disease, Gastrointestinal reflux, Diabetes, Helicobacter pylori, Osteoporosis.
<http://www.advocacyresource.org.uk/LD> (Raising Our Sights report)
- 2** **It is important to recognise when someone with PMLD is in pain and to manage this effectively**
Listen to those who know the person well, ask about any changes in behaviour and interactions, facial expressions and gestures, reduction in appetite.
- 3** **There should be an annual health check and assessment**
The GP and/or community nurse will arrange this, always involve the carers.
[www.rcgp.org.uk/pdf/CIRC_A%20Step%20by%20Step%20Guide%20for%20Practices%20\(October%202010\).pdf](http://www.rcgp.org.uk/pdf/CIRC_A%20Step%20by%20Step%20Guide%20for%20Practices%20(October%202010).pdf) - When page open use search tool, entering 'Annual health checks for people with learning disabilities' to find step by step guide.
- 4** **Involve professionals who can offer support and advice in the community and hospital**
Community learning disability nurse, health liaison/facilitator, acute liaison/facilitator, dietitian, physiotherapist, speech and language therapist.
- 5** **Don't make assumptions about the person's symptoms, quality of life**
Listen to those who know the person well, read their Health Action Plan (HAP)/ Person Centred Plan (PCP).



6

Adjustments should be made to ensure that people with PMLD can access services

e.g. longer appointment times, ensure equipment such as hoists are available
Organisations have to make sure that there is equal access to services.

Visit: www.equalityhumanrights.com

<http://www.improvinghealthandlives.org.uk/publications>

Click on the 'Reasonable Adjustments' link

7

Use resources to help people with PMLD have a positive experience in hospital settings

Communication tool/passport, traffic light assessment, health action plan.

An example can be found on: www.easyhealth.org.uk

8

Be aware of good dental and oral hygiene, weight changes, appetite, and skin integrity

www.dentalhealth.org.uk

9

Be aware of the importance of eye care and vision

Visit your local optician

or visit www.lookupinfo.org

10

It is essential to know and follow the principles of the Mental Capacity Act

The law says that people must be supported as much as possible to make their own decision before anyone concludes they lack capacity to make that decision. Best interests should be followed when a person lacks capacity.

Communication

10 Top Tips for supporting the communication needs of people with PMLD

- 1** Gain information about communication from a parent, key worker or paid carer with a long relationship with the person

Mencap's PMLD communication guide has useful hints and tips
www.mencap.org.uk/page.asp?id=1539

- 2** Key Information about the individual's communication needs should be found in: communication tool/passport, traffic light assessment or health action plan

www.totalcommunication.org.uk or www.scope.org.uk or
local speech and language therapist (SALT) www.rcslit.org

- 3** Hearing and or vision can impact upon communication

Visit www.lookupinfo.org to find a local optician who makes adaptations to their eye tests for people with learning disabilities. A hearing test can be arranged through the individual's GP.

- 4** Objects or photographs can help the person to understand what is happening

For more information on objects of reference visit
www.totalcommunication.org.uk or contact your local SALT.

- 5** Allow more time for the person to process what is being said and what is happening

Allow plenty of time for conversations and reduce distractions.



6

A person may be trying to tell you something through their facial expression and body language

Talk to someone who knows the person well or refer to information on/in the individual's communication tool to ensure you interpret their non-verbal communication accurately.

7

The person may have a communication aid

Can the person use a BIGmack switch or another electronic device to make requests? Visit www.ace-centre.org.uk for more information or contact local SALT.

8

Make sure that you help the person have a chat/tell their story

Intensive interaction www.intensiveinteraction.co.uk and interactive story telling www.bagbooks.org offer ideas on how to approach interaction.

9

Make sure the environment encourages communication and interaction

Exploring different sensory experiences together promotes shared communication e.g. objects to touch, sounds, things to look at or watch, opportunities for movement, things to taste and or smell.

10

Follow the principles of the Mental Capacity Act to support someone to make a decision or if they lack capacity, act in their best interests

It may be beneficial for the person to have an advocate who can make sure that everyone who knows the person well is involved, communication tools, HAP's and person centred plans are followed.

Eating & Drinking

10 Top Tips for supporting the eating and drinking needs of people with PMLD

1 Supporting eating & drinking needs falls within the expertise of a range of different professionals and agencies

Visit: www.rcplondon.ac.uk www.npsa.nhs.uk
www.cwt.org.uk/publications.html?ewld

2 Good nutrition is vital for good health

Look out for:

- Visible weight loss
- Changes in appetite
- Changes in behaviour at mealtimes

Dietitians provide support for both oral and non-oral feeding regimes.
www.bda.uk.com

The MUST is a useful screening tool for malnutrition. www.bapen.org.uk

3 Adequate hydration is vital

Fluid can be given in a range of forms such as puddings, jellies, soups and smoothies.

4 Chewing and swallowing can be problematic and coughing/ choking at drink/mealtimes can lead to chest infections

Contact Speech and Language Therapy service so that a Dysphagia assessment can be carried out. Advice will be given re. best techniques and safest food/ drink textures.

To find a speech and language therapist visit: www.rcslt.org.uk

5 A good posture must be achieved during mealtimes

Contact local Physiotherapy service for advice.
To find a Physio visit: www.csp.org.uk

8

6 Adaptive crockery or cutlery or other mealtime aids can be beneficial

Contact local Occupational Therapy service for advice.

To find an OT visit: www.cot.co.uk

7

7 Good oral hygiene can help prevent chest infections

A Specialist Dentist or Oral Health Advisor can help. Contact local community dental service or visit: www.dentalhealth.org.uk

8

8 Medication may be given in tablet/syrup/jelly or suspension form to assist swallowing

Contact local GP or local Pharmacist for advice.

9

9 Communicate information

Ensure ALL available advice is readily accessible to everyone involved in mealtimes and that a copy of guidelines is in the Health Action Plan.

10

When giving food/drink to someone:

- Give choices wherever possible
- Use the right utensils
- Check the textures are correct
- Consider the best environment for the person
- Adjust your rhythm and pacing to suit the individual

NB Find out what it feels like to be assisted by another person when eating/drinking!

Posture & Mobility

10 Top Tips for supporting the postural and mobility needs of people with PMLD

1

A 24-hour approach to postural-care

It is vital to consistently support posture throughout the day and night in order to reduce the risk of complications associated with severe physical disability e.g. pain, pressure sores, spinal deformity, joint contractures and respiratory infection.

www.posturalcareskills.com

2

Details of local specialist postural-care therapists and other professionals involved in care should be identified in the person's Health Action Plan (HAP)

This will include:

Physiotherapist/OT

Wheelchair therapist/services

District nurse

3

Postural-care guidelines and equipment should be agreed before they are issued

Client and carers should be involved with assessment, selection and issue of equipment and review to ensure equipment and guidelines are acceptable and 'fit' with family life.

4

Clear photographic postural-care guidelines should be issued along with training and support

Ask the specialist therapist about this.

5

Contact a specialist therapist to support training in 24-hour postural-care



6

Make sure that postural-care guidelines and equipment are reviewed as part of an annual review of health needs

In order to reduce risk of complications, annual reviews should be arranged with your specialist therapist to establish whether equipment and guidelines remain appropriate.

7

Be aware of any gain or loss of weight or a change in body shape

“Made to measure” supportive equipment may no longer be appropriate and could increase the risk of complications (see 1.)

Arrange a review with a specialist therapist.

8

Be aware of skin integrity, don't ignore areas of reddened, blistered or broken skin. If you have concerns:

- Contact a district nurse immediately for assessment, treatment and advice
- Contact a specialist physiotherapist or occupational therapist as an urgent review of postural-care and seating / lying equipment may be indicated.

9

The prescribed equipment should improve quality of life

Equipment should be comfortable, enable purposeful activity and should not cause harm. Contact a specialist if concerned.

10

Hospital staff need to be aware of postural-care guidelines for any admission, this includes bathing and toileting needs