

**Learning
Byte**

Living healthy, living well

Supporting the physical health and well-being of
people with profound and multiple learning disabilities



Contents

Welcome to this Learning Byte!	4
What is a Learning Byte?	4
Who's it for?	4
What will it give me?	4
What is profound and multiple learning disability?	5
What is the prevalence of PMLD?	7
What is physical health and well-being?	8
What physical health and well-being challenges do people with PMLD face?	9
Inequalities	12
Promoting good health and well-being	13
Accessing health care	14
Specific physical health and well-being issues for people with PMLD	17
Mobility and positioning problems: postural care	17
Epilepsy	18
Eating and drinking	22
Communication	24
Mental and emotional well-being	25
Oral health	27
Overcoming sensory loss	28
Bowel management and incontinence	31
Promoting meaningful activity	31
Medical consent	32
Summary and conclusion	33
References	34
Further reading	35



Welcome to this Learning Byte!

This Learning Byte draws on information from a range of sources on the physical health and well-being needs of people with profound and multiple learning disability (PMLD). It looks at the physical health and well-being issues people with PMLD often experience.

What is a Learning Byte?

It's an alternative to a traditional, structured, beginning-to-end course that is available in bite-sized chunks in the workplace. You can access it in different ways – on a PC or mobile device, for instance – and at any time.

Who's it for?

We've developed this Learning Byte for students not only of learning disabilities nursing, but also those from all other fields of nursing – adult, mental health and children's. It will also be relevant for any staff who work with people with PMLD.

What will it give me?

The Learning Byte provides you with a brief guide to physical health and well-being of people with PMLD. By the time you've completed it, you will:

- understand the increased and different health needs of people with PMLD and critically reflect on their health promotion needs
- reflect on health inequalities for people with learning disabilities and explore strategies to minimise them
- understand how people with learning disabilities may experience barriers to accessing mainstream health and care services
- recognise a range of health needs experienced by people with PMLD.

What is profound and multiple learning disability?

People with profound multiple and learning disability (PMLD) are a diverse group of individuals with their own personalities, preferences and ways of communicating. The abilities of those described as having PMLD vary considerably, not least because of the varied life experiences they may or may not have had. They are one of the most marginalised groups of people in society and are often excluded from playing their full role, primarily because our communities are not inclusive, or not inclusive enough.

Profound means deep, intense, wise, requiring great insight or knowledge. Although many people with PMLD have significant areas of disability (as described below), they also have unique characteristics that never cease to surprise those who care for and work with them. This Learning Byte, with its focus on physical health and well-being, reflects a scientific, medical approach, but the experience of being a part of their lives is something very different. The concentration on physical health and well-being issues means we tend not to highlight the unique contribution they make to the lives of others, not least in what they are able to teach us about how to care, how to act with compassion and how to make human connections. While not reflected extensively in the text, we should keep this very much in mind as we read through the Learning Byte.

People with PMLD clinically share a number of characteristics that make this term appropriate and which lead to challenges for them and those who support them. Their prime disability will be profound learning disability, the causes of which are many and varied. All have had some form of damage to their brain and central nervous system. This may have been caused by injury

before, during or after birth or by genetic factors, infections, or accidental or non-accidental injury. Whatever the cause, which sometimes goes undiagnosed, their development as children and adults is severely constrained.

Few achieve the cognitive and communicative abilities of a 2-year-old and clinically are described as having an intelligence quotient less than 20 (IQ<20) (hence the “profound learning disability” term). The physical and sensory disabilities that arise from damaged brain function (the “multiple disabilities” reference) also restrict their interaction with the world, making them highly dependent on others to ensure they have the opportunity to experience the valuable things of life that others take for granted. The majority will be life-long wheelchair users. The combination of intellectual, physical and sensory difficulties is often compounded by significant health problems, including epilepsy and respiratory and nutritional difficulties, resulting in many being fed non-orally.

Most people with profound and multiple disabilities live at home with their parents. Research has shown that family carers spend on average 8.5 hours per day on basic caring tasks. It is difficult for people with PMLD to access activities in their communities because many facilities are neither accessible nor inclusive, but with the correct help and support, and with true access to lifelong education and resources, people with PMLD can and do take an active role as participants in their communities.

What is the prevalence of PMLD?

In 2012, 26,236 adults with learning disabilities were known to local authorities across Scotland. Estimates suggest the prevalence of people with mild-to-moderate learning disabilities in Scotland is around 20 in every 1,000 population, and for people with PMLD in the region of 3-4 in every 1,000.

Pause for reflection



Spend a few minutes identifying your existing knowledge, skills and areas for development in relation to supporting people with PMLD to manage their physical health and well-being – make some notes below.

Existing knowledge:

Existing skills:

Areas for development:

What is physical health and well-being?

The World Health Organization defines good health as:

... a state of complete physical, social and mental well-being, and not merely the absence of disease or infirmity.¹

The WHO definition recognises that health should be viewed in a wider context than simply physical health and includes the idea of well-being. Health therefore has physical, emotional, social and spiritual factors. This reminds us of the importance of individual empowerment and the right to make choices to the development of good health and well-being among people with PMLD.

Pause for reflection



Think for a little while about what having good physical health and well-being means to you. What factors have to be in place to support your own physical health and well-being? What similarities and differences might a person with PMLD find?

What physical health and well-being challenges do people with PMLD face?

People with a learning disability in general have a higher prevalence of health challenges and a particularly high level of unmet health needs compared to their peers in all age groups. The pattern and types of health needs experienced by people with PMLD differs from that of the general population, as do the main causes of death. This has important public health implications and influences the kind of community and service responses that need to be in place.

Activity: Health challenges for people with PMLD



Make a short list of health challenges that people with PMLD may face more commonly than others in the population, then check your notes against the text that follows.

People with PMLD have higher levels of:

- particular cancers (for instance, they are three times more likely to develop gastrointestinal cancer and people with Down syndrome have a higher risk of leukaemia)
- coronary heart disease, with approximately 50% of people with Down syndrome having congenital heart defects
- respiratory disease, the leading cause of death in people with learning disabilities
- mental health conditions, but many mental health conditions can go undiagnosed due to communication difficulties
- dementia, particularly in people with Down syndrome (the age of onset being 30-40 years), augmented by the fact that people with PMLD are now commonly living longer due to advances in medical technology
- health concerns in relation to mobility, epilepsy, sensory impairment, physical impairment, musculoskeletal conditions, oral health, dysphagia, diabetes, constipation, osteoporosis, endocrine disorders and accidents/injuries/falls
- gastro-oesophageal reflux disease (GORD), which has been identified as a significant contributor to sleep and behavioural problems, anaemia and oesophageal cancer.

Pause for reflection



Can you come up with some reasons why people with PMLD face these health challenges on such a scale?

You might have concluded that there are many reasons for people with PMLD to experience increased health challenges. Here are just a few.

- Some of the causes of learning disability have associated health needs. Tuberosus sclerosis, for instance, is associated with epilepsy, Down syndrome with dementia, congenital rubella with sensory impairments, and perinatal trauma (often leading to cerebral palsy) may result in musculoskeletal problems and impaired mobility.
- Musculoskeletal problems (such as changes in muscle tone) may lead to contractures and scoliosis, which can impact on the ability of internal organs to function properly.
- Adults with PMLD are more likely to be prescribed multiple drug treatments that can adversely affect health through side-effects and medication interactions.
- Obesity is more prevalent in people with learning disabilities than the general population, contributing to higher risk of cardiovascular and cerebrovascular disease.
- Conversely, people with PMLD may struggle to maintain a healthy weight and sustain adequate nutrition and hydration due to problems with eating and drinking and impaired ability to swallow (dysphagia). They may also be at high risk of aspirating food and fluids, leading to frequent chest infections and episodes of pneumonia.
- People with PMLD will be reliant on others for support, so the attitudes towards health and healthy activities of paid carers, which vary according to background, training, motivation and understanding, are vital.

The cumulative effects of these issues can be serious. Increased health challenges and unmet needs in people with PMLD can lead to shorter life expectancy than that of the general population, poorer quality of life, increased risk of exclusion and a greater chance that health conditions go undetected and therefore untreated.

Inequalities

Pause for reflection



How can we use what we know about the different health needs of people with PMLD and the health challenges they face to improve their health outcomes and increase their sense of well-being?

You may have mentioned that having detailed information about health needs, supports, service planning, delivery and allocation of resources. This is particularly important where inequalities in health exist. For example, recognition of the prevalence of breast and lung cancer in the general population has led to increased resources being spent on research, treatment and health promotion in this area. No one would suggest this is not positive, but people with a learning disability are less likely to develop breast and lung cancer than the rest of the population. Gastrointestinal and oesophageal cancers are much more common, but significantly less is spent on raising awareness about, and taking measures to avoid, these cancers.

Inequality in health patterns in these areas leads to potential inequality in meeting health needs.

Promoting good health and well-being

At the beginning of this Learning Byte, we asked you to think for a little while about what good physical health and well-being means to you. Many people who answer this question focus more on physical health than the social, emotional and mental health issues that influence our sense of well-being, but we need to recognise the impacts on all aspects of our lives.

This is what we do when we think about promoting good health and well-being. It is about enabling people to increase control over and improve their health by moving beyond an exclusive focus on individual behaviour towards an understanding of the impacts of a wide range of social and environmental factors.

There's much we can do to promote the health and well-being of people with PMLD. We could, for instance, provide opportunities for activities that promote good health, act as role models and ensure we know about the range of local services available that could help with people with PMLD and their families and carers to access relevant health promotion activities.

Promoting good health and well-being, however, is everybody's business, not just that of health professionals. Carers and family members providing support on a daily basis are in the strongest position to influence positive choices and maximise opportunities around health.

Pause for reflection



Reflect on your current role – what can you do to promote health for the people you support?

You may have mentioned the importance of promoting and ensuring:

- a well balanced eating plan
- opportunities for physical activity
- access to regular health checks, eye tests and dental check-ups
- good postural care
- maintenance of skin integrity
- effective management of epilepsy
- strategies for communication
- identification and management of pain.

It is particularly important to get to know the person with PMLD well, as a simple change may indicate that something is wrong.

Accessing health care

The Scottish Government's strategy for people with learning disabilities, *The Keys to Life*,² states that people with learning disabilities want, and should be able to use, the same services as anyone else in society. It emphasises that specialist services should be available for people with learning disabilities when required, but that they should add to, and not replace, existing services.

But we know from research and day-to-day experience that people with learning disabilities often experience barriers to accessing health and care services and to getting the care and treatment they need.

These barriers may represent services' inability to interpret people's needs, a lack of understanding of environmental issues that might help or hinder people with learning disabilities from accessing a service, or even a failure to tackle what amounts to discrimination. Here are some examples of issues that make access difficult.

People with learning disabilities and those with PMLD may have limited or no verbal communication. It is therefore difficult for them to communicate pain, distress or symptoms. This can lead to delayed intervention and further complications. The Breaking the Barriers: communication with people with profound and multiple learning disabilities Learning Byte³ identified that using the Disability Distress Assessment Tool (DisDAT)⁴ can be helpful in identifying the person's level of distress.

Health needs can be overlooked by paid carers and professionals or be wrongly attributed to the person's learning disability or associated condition: for example, a person with a learning disability and cerebral palsy whose increasing falls are attributed to his limited mobility rather than a potential visual or auditory impairment.

Health information materials are often presented in formats that are inappropriate for people with learning disabilities, or focus on health issues that may not be of particular relevance to them.

GP appointment times may be too short to allow a thorough assessment and additional preparation that may be required is not given due consideration. In addition, some GPs and practice nurses have little knowledge about the needs of people with learning disabilities.

Perfectly laudable concepts about people having freedom to make their own choices on issues such as taking a prescribed medication may be applied indiscriminately to people with learning disabilities, leading to the person's unwillingness to accept the medication not being explored and a possible compromise solution not being found.

Institutional discrimination against people with learning disabilities has been reported in the NHS. One tragic impact is when a decision is made not to treat a person with PMLD or to withdraw treatment early due to the health team making inappropriate decisions on the person's quality of life that are based on little or no understanding of his or her perceptions.

Pause for reflection



Have you witnessed barriers being placed before people with PMLD that restricted their access to information, care or treatment? If so, what were they?

What could you do to minimise these barriers in the future?

The cumulative effects of these issues can be serious. Increased health challenges and unmet needs in people with PMLD can lead to a shorter life expectancy than that of the general population, poorer quality of life, increased risk of exclusion and a greater chance that health conditions go undetected and therefore untreated.



Specific physical health and well-being issues for people with PMLD

Mobility and positioning problems: postural care

Postural care is about protecting a person's body shape. It is very simple and gentle. People are at risk of developing changes in body shape if they find it difficult to move independently, spend lots of time in a limited number of positions, experience other difficulties such as hypermobility (which means they have very flexible joints), or have low muscle tone. Children are at greater risk than adults because they are growing so quickly.

The gold standard for assessment of body shape is the Goldsmith Indices of Body Symmetry,⁵ which is an objective and validated measure of a person's structure and movement. It is not routinely available in all parts of the country, however.

Postural care is a fundamental aspect of a person's physical health care. The way in which the body responds to the effects of gravity is predictable, so we are able to use equipment and positioning strategies to prevent changes in body shape and their associated secondary complications. Common difficulties experienced by people who do not have access to postural care include hip pain, structural problems at the hip (such as dysplasia, subluxation and dislocation), seating difficulties, communication problems, swallowing, feeding or digestive difficulties, increased risk of chest infection and skin problems, and pain and discomfort.

Some people need postural care for a short period of time (when recovering after surgery, for example), but others will need it for longer periods, perhaps their whole life, to be protected from the harmful effects of gravity. If you have concerns for your own postural care or that of a loved one, consider where the person is spending most of his or her time. Appropriate seating and supportive night-time positioning are essential elements of a person's postural care simply because they are used for thousands of hours during the course of the year. An occupational therapist or physiotherapist may be able to offer specialist advice and support in relation to seating and use of equipment.

Epilepsy

Epilepsy is one of the most common and persistent health problems in people with PMLD, with over 60% affected. The more severe the developmental delay, the higher the risk of epilepsy. The risk is also increased if there is associated cerebral palsy.

Epilepsy is often misdiagnosed because the symptoms resemble a number of other conditions. Repetitive behaviours, muscular movements and apparent unresponsiveness are often interpreted as epileptic seizures when there is no evidence of epileptic discharges.

Seizures are not only frightening for the person experiencing them, but also cause great anxiety for families and carers. It is very important that carers have appropriate support so they can understand what is happening, recognise the symptoms and keep a detailed history of the person's epileptic events. This history, which could include video recordings from a mobile phone, is essential in supporting health professionals to make correct diagnoses and prescribe the right treatment.

Epilepsy is usually controlled with appropriate medication, but control can be more difficult for people with PMLD due to the severity of the epilepsy and the effects of other health problems. Epilepsy medication can have severe side-effects, so it is important to achieve a balance between reducing the frequency and severity of seizures and maintaining or improving quality of life for individuals, their families and carers.

When a seizure starts**DO:**

- note the time
- clear a space around the person
- cushion the head to prevent head and facial injury
- loosen tight neckwear
- loosen chest and leg safety straps on wheelchairs
- remove spectacles, if worn
- turn on side if possible, to aid drainage (recovery position)
- reassure others and explain what you are doing.

DO NOT:

- put anything in the person's mouth
- restrain or restrict movement during the seizure
- give anything to eat or drink
- move the person unless he or she is in danger.

Treatment

Anti-epileptic drugs (AEDs) are available to treat different types of seizures and syndromes. For generalised seizures, the first line of treatment is usually sodium valproate (Epilim) or lamotrigine (Lamictal), while for partial seizures, sodium valproate (Epilim), carbamazepine (Tegretol) or lamotrigine (Lamictal) are commonly prescribed. People with PMLD may not be able to be completely seizure-free with the use of just one drug, and a combination is usually prescribed. It is often a case of trial and error, with different dosages of drugs tried until the combination that has the best result is found. This can be a long process, as introducing and withdrawing AEDs has to be done slowly and in a controlled way.

Some factors that can trigger seizures

- Missed medication
- Illness/infections (such as urinary tract infections)
- Lack of sleep
- Heat
- Stress (including that caused by constipation or pain)
- Menstrual cycle

A care plan for use by all carers should be drawn up in consultation with the person's GP and/or specialist service. This should include:

- a record of triggers that cause seizures and seizure warning signs
- descriptions of seizures, including length, frequency and recovery
- pattern – for instance, whether they occur mostly at night or during the day, or are linked to events such as menstruation
- prescribed medication
- seizure-recording sheets (including annual charts)
- who records the seizure
- protocols (see below)
- who should be contacted afterwards
- all relevant correspondence from GP, hospital and other services.

Emergency medication

Most seizures last less than two minutes. A prolonged seizure lasting more than five minutes or a series of seizures are more likely to progress to status epilepticus (or 'status' for short). Status during a tonic-clonic (convulsive) seizure is a medical emergency that requires emergency treatment, such as rectal diazepam (note that large doses of diazepam may cause breathing difficulties, or have the opposite effect in causing the person to become alert or hyperactive) or buccal midazolam. It is important that there is an individual protocol for carers to follow for such emergencies and that carers are given the necessary training (updated every two years) to safely administer these medicines.

The protocol should include:

- exact instructions on when to administer medication
- dosage, strength and route of administration
- details of dose and timing of any second dose that is necessary
- actions if the seizures do not stop.

Activity: Finding out about epilepsy



Click on this *link* (or go to <http://www.epilepsysociety.org.uk/what-epilepsy#.VhUYOFRwYdU>) to view a video from the Epilepsy Society that will help you understand what epilepsy is, how it is diagnosed and how you should respond when someone is having a seizure.

You will find specific information on epilepsy and people with PMLD *here* (or go to: http://pamis.org.uk/cms/files/leaflets/epilepsy_leaflet.pdf).

Eating and drinking

Children and adults with PMLD often have difficulties with eating, drinking and swallowing as a consequence of their physical and health impairments. Eating, drinking and swallowing may appear abnormal, but may not be pathological. Instead, many people with PMLD often adapt to their physical and functional difficulties through atypical eating, drinking and swallowing patterns and behaviours to maximise efficiency.

Many people with PMLD nevertheless have disordered eating, drinking or swallowing – dysphagia – that can lead to life-threatening conditions such as choking, pneumonia, malnutrition and dehydration. Respiratory illness (including pneumonia and pneumonitis) is the principal immediate cause of death in people with learning disabilities across all age ranges.⁶

Causes and signs of dysphagia

Dysphagia simply means difficulty in swallowing. The causes and severity are often influenced by the psychomotor impairments and multiple co-morbidities associated with PMLD and cerebral palsy, and how they may change with age. These include cardiopulmonary problems, neuromotor dysfunction, seizure disorders, anatomical abnormalities, scoliosis, kyphosis and abnormal tone of the oropharyngeal musculature.⁷ It might also be caused by less obvious factors like medications, polypharmacy and community-acquired infections.

Common signs of dysphagia in people with PMLD include poor sucking, swallowing and chewing, food/drink/saliva falling out of the mouth, oral hypersensitivity, persistent coughing and vomiting. A large majority of people with cerebral palsy also suffer from chronic gastrointestinal problems such as GORD.^{7,8}

Assessment

Dysphagia and its potential consequences are often assessed and managed by a qualified dysphagia practitioner, typically a speech and language therapist. A combination of instrumental techniques (such as videofluoroscopic swallow study and fiberoptic endoscopic evaluation of swallowing) and non-instrumental methods (case history or observation at mealtimes) are used to assess the potential role of dysphagia in causing certain health conditions.

Treatment

Treatments for dysphagia vary widely, from surgical interventions to environmental manipulation through using specialised utensils, positioning, sensory modification and texture modification of food and fluids. Using texture modification and thickened fluids to treat dysphagia has become increasingly controversial in recent years, with increased risks of dehydration, urinary tract infection, fever and pneumonia associated with the use of thickened fluids.⁹

Helicobacter pylori

The bacterium *Helicobacter pylori* is often found in the stomachs of people with PMLD. It can cause gastric ulcers: families and carers need to be aware of this as it might explain changes in behaviour such as irritability or self-injurious and challenging behaviours. *Helicobacter pylori* can be treated with antibiotics.

Communication

The Breaking the Barriers Learning Byte³ showed that people with PMLD have difficulties:

- receiving communication messages due to visual, hearing or attention problems
- understanding or interpreting messages they are given because of their cognitive impairment
- working out what messages they want to convey because, for example, they find it difficult to correctly interpret their body's needs, such as hunger or thirst
- expressing due to a lack of speech and/or other means of getting their message across
- engaging in opportunities to communicate because they appear to choose to engage in repetitive self-stimulating behaviours rather than being sociable.

The Learning Byte sets out a number of strategies for enhancing communication, including:

- getting to know the person
- reading his or her non-verbal communication
- intensive interaction
- the use of objects of reference
- the use of the Disability Distress Assessment Tool (DisDAT)
- the use of personal communication passports.

Activity: Focusing on communication



If you haven't already done so, access the Breaking the Barriers Learning Byte *here* (or go to www.nes.scot.nhs.uk/media/3224238/learning_byte_communication__final_.pdf) and familiarise or refresh yourself on the issues around communication with people with PMLD.

Mental and emotional well-being

Awareness that people with PMLD suffer from depression, anxiety and stress, just as many other people do, is growing. We also know that people with PMLD experience more health and sensory problems, which can have a direct effect on their well-being. Despite this, signs may be easily overlooked by carers because the person cannot talk about his or her difficulties.

Mental health is as important as physical health and is central to well-being. Good mental health helps people manage day-to-day living, enjoy life and cope with pain and sadness. Everyone has unique mental health needs. When these needs go unmet, individuals are susceptible to developing problems. So all families and carers who support people with PMLD should be able to recognise the importance of good mental health and the impact it has on overall well-being and quality of life.

Diagnosing mental health problems in people with PMLD is extremely difficult. It is not easy to determine what a person with PMLD is feeling to assess his or her mental state. It can also be difficult to distinguish challenging behaviour from mental ill-health, or to see the link between poor mental health and its expression through challenging behaviour.

Diagnosing mental health difficulties in people with PMLD requires consultation with families, carers and others who know the person well; only they can tell you about the changes in the person's mood or behaviour that may indicate a mental health problem.

Recognising mental health problems in people with PMLD

Mental health problems in people with PMLD may be diagnosed by recognising:

- changes in appetite – increased or lessened
- changes in sleeping pattern – someone might sleep more or less than usual
- changes in facial expression – frowning, not smiling, not making eye contact
- changes in posture – perhaps sitting with the head down
- withdrawing or being unresponsive – someone who appears quieter than usual or does not respond in the usual manner
- increased crying – particularly in situations where the person had previously been comfortable or happy
- self-injurious behaviour – biting (thumb, hand), nipping, grinding teeth (if this is not the person’s usual behaviour)
- increase or decrease in normal vocalisation
- disruptive behaviour – this can result from changes in emotional and mental well-being and it is important to recognise and respond to any changes noticed
- increase in seizure activity – this may be attributed to changes in emotional and mental well-being for some people.

There may also be an increase in sexual behaviour as a result of changes in emotional and mental well-being. Sex is a difficult topic to discuss, and you should ensure that you observe people’s cultural and religious values when supporting individuals, their families and carers. It is not unusual for sexual expression shown by people with learning disabilities to be seen as a problem: rarely is it celebrated as an aspect of normal development.

Oral health

Good oral hygiene is essential for enjoying mealtimes and maintaining good health. Considerable evidence shows that people with PMLD have a higher level of dental decay and mouth infections than the general population, so teeth should be cleaned twice a day with fluoride toothpaste and regular visits to the dentist arranged.

Good oral health care is very important to the health, dignity, self-esteem, social integration and quality of life of people with PMLD. They nevertheless experience more problems with their oral health than the general population for a number of reasons, including oral and facial developmental abnormalities, various medical conditions, the effects of medication and the consequences of challenging behaviour. Poor oral hygiene further exacerbates these inherent problems.

The key to a healthy mouth is the day-to-day care provided in the home environment by families and carers. People with PMLD rely on their families and carers for toothbrushing, so it is important they have the knowledge and skill to manage the person's oral health care. They will also need to ensure that the person has a healthy diet and arrange regular contact with dental services. It is also important when helping to brush the teeth of a person with PMLD that you listen to and follow the advice of their parents or carers. You may find relevant and helpful information in the person's health passport.

Health passports

You can access further information on health passports on the PAMIS website *here* (or go to www.pamis.org.uk).

Overcoming sensory loss

Sight

Sight helps us to:

- communicate with others
- develop and maintain relationships
- move safely around and make sense of our world
- take part in leisure and recreation activities
- learn skills and take part in education and work activities
- maintain our independence.

One in three people with learning disabilities has a sight problem, many of which could be correctable. Up to 90% of people with Down syndrome and 70% of people with cerebral palsy may have significant sight impairments.

Many people have lived for many years, even their whole lives, without knowing they have a sight problem, and families and carers may not know how to recognise difficulties. Unrecognised or uncorrected sight problems may disincline people to learn new skills or do things they used to enjoy. This might be put down to the person's PMLD rather than a correctable sight problem, such as a cataract or simply the person's eyesight deteriorating with age.

Undiagnosed or unnoticed sight problems can lead to people becoming:

- distressed and angry
- anxious and frustrated
- withdrawn and frightened
- deskilled and demotivated
- prone to self-harming (eye-poking or self-injury to the head and eyes).

Accessible information and skilled support from others can prevent these from occurring and ensure that people with PMLD can access quality eye care.

Pause for reflection

A person with PMLD may not be able to tell you that he or she has a sight problem. What signs that the person is having visual problems could you look out for?

You might have mentioned some of the following:

- the person’s eyes might look sore or blood-shot, or cloudy
- the person might start squinting or moving his or her head to “odd” positions when looking at, or looking for, things
- the person might start to become disoriented
- he or she might no longer enjoy TV or looking at photos
- familiar faces or places may be unrecognised
- the person might become tentative or fearful in twilight or in shadows, or be disoriented in bright sunlight.

Hearing

The term “hearing impairment” applies when an individual’s hearing is affected by a physical condition or injury. People can be born with hearing loss, or it may develop with age.

Around 40% (exact estimates vary) of adults with learning disabilities experience moderate-to-severe hearing loss. In some cases, it may exacerbate the effects of an individual’s learning disability: behaviours can be considered part of the learning disability rather than associated with hearing loss if unrecognised or undiagnosed.

Untreated hearing loss can contribute to delayed speech and language development, difficulties with learning and problems communicating with others. Early diagnosis is therefore vital, especially for people who may already experience difficulties in these areas.

Hearing problems are particularly common among people with Down syndrome and, as with the general population, become more likely and more extensive as people age.

Help and advice on hearing loss

Action on Hearing Loss (formerly known as the Royal National Institute for Deaf People) (access *here* or go to <http://www.actiononhearingloss.org.uk/>) provides support for people with hearing loss and tinnitus. They do this through day-to-day care, supplying communication services and training, providing practical advice to protect hearing, campaigning to change public policy around hearing-loss issues and supporting research into a cure for hearing loss and tinnitus.

SENSE (access *here* or go to <https://www.sense.org.uk/>) is a national charity that supports and campaigns for children and adults who are deaf, blind or have associated disabilities.

The National Deaf Children's Society (NDCS) (access *here* or go to <http://www.ndcs.org.uk/>) works to break down barriers faced by deaf children and their families.

Bowel management and incontinence

People with PMLD are extremely likely to have continence issues due to impaired neurological development, but other factors – medical problems, the effects of medication, behavioural, dietary and emotional issues – can also impact on an individual's bowel and bladder control.

Continence is both a health and quality-of-life issue. It is therefore extremely important that people with PMLD get the right kind of individual support to meet their circumstances, while upholding their dignity and privacy and maintaining good health.

All people with continence problems are entitled to a continence assessment to identify the underlying causes and contributory factors. The key aspects of a continence assessment include:

- taking a history
- performing a physical examination
- testing the urine for indicators of conditions such as diabetes and infections and to assess the level of hydration in the body.

Once a diagnosis is made, a treatment plan can be developed. The most suitable method of management for many people with PMLD is through containment, using pads that are available from continence services.

Promoting meaningful activity

It is important that people with PMLD are engaged in meaningful activities, both indoor and outdoor. PAMIS (<http://www.pamis.org.uk/>) has a range of resources that can be used when planning these activities.

Medical consent

In Scotland, you are legally an adult when over the age of 16. The law assumes you can then make decisions about your medical treatment.

People with PMLD may not be capable of giving informed consent. Under the Adults with Incapacity Act (Scotland) Act 2000,¹⁰ parents (and others) are able to apply to become welfare guardians. This involves an assessment of the ability of the adult concerned to make informed decisions and an application to the Sheriff Court for a guardianship order to authorise a particular person to make decisions on his or her behalf.

Summary and conclusion

This Learning Byte has given you a brief guide to the physical health and well-being of people with PMLD. You should now understand the increased and different health needs of people with PMLD and how people with a learning disability may experience barriers to accessing mainstream health and care services. You should also have the ability to recognise a range of health needs experienced by people with PMLD. Importantly, the Learning Byte has also given you an opportunity to reflect on health inequalities for people with learning disabilities and explore strategies to minimise them. We hope you will now be able to embed your new knowledge and insights into your practice with people with learning disabilities, those with PMLD, and their families and carers.

Activity: Paper to practice



Well done for completing the Learning Byte!

Reflect on your learning. Identify five key areas in which your knowledge has developed, then write one objective for each, outlining how you can implement some of what you've learned in practice. It might be about developing yourself or your service to provide good care and support. Discuss it with your lecturer, supervisor, mentor or manager.

Key learning – I have learned about:	To develop this area of practice, I will:
1.	
2.	
3.	
4.	
5.	

References

1. Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19–22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948. Geneva, WHO.
2. Scottish Government, (2015), The keys to life. Scottish Government, Edinburgh <http://www.gov.scot/resource/0042/00424389.pdf>, accessed 16 March 2016).
3. NES, (2015), Breaking the barriers: communication with people with profound and multiple learning disabilities NES, Edinburgh (http://www.nes.scot.nhs.uk/media/3224238/learning_byte_communication__final_.pdf, accessed 16 March 2016).
4. Regnard C., Matthews D., Gibson L., & Clarke C., (2003), Difficulties in identifying distress and its causes in people with severe communication problems. *International Journal of Palliative Nursing* 9(3): 173–6.
5. Access at: <http://www.simplestuffworks.co.uk/downloads> (accessed 16 March 2016).
6. Glover G., & Ayub M., (2010), How people with learning disabilities die. London, Learning Disabilities Observatory.
7. Field D., Garland M. and Williams K.J., (2003), Correlates of specific childhood feeding problems. *Paediatric Child Health*. May-Jun;39(4):299-304.
8. Del Giudice E., Staiano A., Capano G., Romano A., Florimonte L., Miele E., Ciarla C., Campanozzi A., Crisanti AF., (1999), Gastrointestinal manifestations in children with cerebral palsy. *Brain Development*. Jul;21(5):307-11.
9. Robbins J., Gensler G., Hind J., Logemann J. A., Lindblad A. S., Brand D., Baum H., Lilienfeld D., Kosek S., Lundy D., Dikeman K., Kazandjian M., Gramigna G. D., McGarvey-Toler S., Miller P.J. and Gardner, J.D., (2008), Comparison of 2 Interventions for Liquid Aspiration on Pneumonia Incidence A Randomized Trial. *Ann Intern Med*. Apr 1; 148(7): 509–518.
10. Scottish Government, (2000), Adults with Incapacity (Scotland) Act 2000. Edinburgh, Scottish Government.

© NHS Education for Scotland 2016. You can copy or reproduce the information in this document for use within NHSScotland and for non-commercial educational purposes. Use of this document for commercial purposes is permitted only with the written permission of NES.



NHS Education for Scotland
Westport 102
West Port
Edinburgh
EH3 9DN
www.nes.scot.nhs.uk