



LIVING WELL NEWSLETTER

Issue 6 June/July 2024

North Yorkshire and York

PROFOUND AND MULTIPLE LEARNING DISABILITIES

A profound and multiple learning disability (PMLD) is when a person has a severe learning disability and other disabilities that significantly affect their ability to communicate and be independent.

Someone with a profound and multiple learning disability might have difficulties seeing, hearing, speaking and moving. They may have complicated health and social care needs due to these or other conditions.

People with a profound and multiple learning disability need support to help them with some areas of their life, such as eating, washing or personal care. Lots of people with a profound and multiple learning disability can still be involved in decisions about themselves, do things they enjoy and be independent.

PMLD and Postural Care: People who find it hard to move are most at risk of developing body shape distortions. This is because they often sit and lie in limited positions. Postural care is about using the right equipment and positioning techniques to help protect and restore body shape.

Failure to protect body shape can have serious consequences for a person's health. It can even cause premature death.

PMLD and Communication: Many people with PMLD do not use formal communication, such as speech, symbols or signs. Instead they tend to rely on facial expressions, vocal sounds, body language and behaviour to communicate.

PMLD and Lung Care: Respiratory disease is consistently shown to be the leading cause of death for people with PMLD, especially pneumonia. This is not the case in the general population and suggests that signs of respiratory disease are not being picked up early enough in this group of people. This may be partly due to difficulties in communication with people with PMLD and partly due to their susceptibility to respiratory infection.

Please see the resources section at the end for links to relevant information and easy read materials on PMLD – Postural Care, Communication and Lung Care.

POSTURE CARE - MILLY'S STORY VIDEO BELOW



"IF YOU LISTEN, YOU WILL HEAR US" VIDEO BELOW



LIAM'S WHEELCHAIR VIDEO BELOW



WE HAVE TO TALK ABOUT...DIABETES!

According to Diabetes UK People with a learning disability are more likely to have diabetes than the general population.

Adults with a learning disability have much higher levels of multi-morbidity than the general population, with health problems starting at an earlier age; this includes diabetes.

Prevalence of diabetes in people with a learning disability is unknown, but recent data indicate it is around 10% - nearly double the rate of the general population. In most cases this is Type 2 diabetes.

The reasons for higher estimates being based on the following:

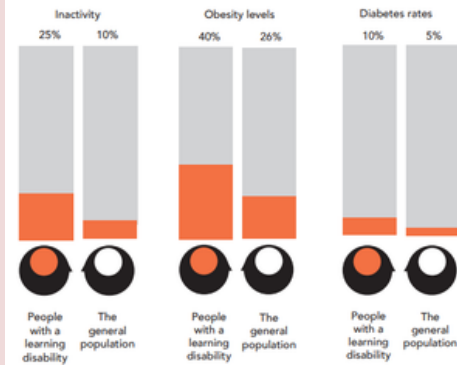
- People with learning disabilities leading a more sedentary lifestyle, undertaking low levels of exercise
- Consuming high fat diets
- Being prescribed high levels of antipsychotic medications, all of which can contribute to obesity

Improving the care of people with diabetes and a learning disability

- Improved testing and diagnosis
- Promoting Diabetes Self-management
- Weight management, healthy eating and regular exercise

Please see the resources section at the end for links to relevant information and easy read materials on managing Diabetes.

DIABETES AND LEARNING DISABILITY - A COMPARISON



CLICK BELOW TO FIND OUT

Top Tips Talking to People with a Learning Disability About Diabetes

HAVING DIABETES AND LEARNING DISABILITY VIDEO BELOW



INTRODUCING ... RESPECT

RESPECT
Recommended Summary Plan for
Emergency Care and Treatment

All health and social care providers in York and North Yorkshire are working together to introduce the ReSPECT process.

- ReSPECT stands for **Recommended Summary Plan for Emergency Care and Treatment**.
- It is a short plan about what should happen if a person needs healthcare or treatment in an emergency, based on what is important to a person and what choices there may be.
- ReSPECT is a way of making sure that healthcare workers know what is important to you in an emergency, when choices may have to be made very quickly.
- Everyone will have different care and wishes for how they want to be treated in an emergency. Making a ReSPECT plan will help people think about the kind of care and treatment they want before an emergency happens, and anyone can make a plan.
- You should get all the support you need from health and care workers to complete a ReSPECT form.
- If someone is not able to make decisions for themselves, the ReSPECT process will make sure those decisions are made in the person's best interests. You can ask your healthcare worker any questions about what is on the plan.
- When you are finished, the healthcare worker will sign the plan. You can keep the plan with you but let your family or care staff know where it is.
- A copy will also go in your medical notes. You can find out more at <https://letsgetbetter.co.uk/respect/>
- There is a survey on this site to give your feedback about the ReSPECT process.

More information is also available at www.respectprocess.org.uk

LEARNING DISABILITY AND DEMENTIA

People with a learning disability are more likely to get dementia at a younger age. About 1 in 5 people with learning disabilities who are over the age of 65 will develop dementia. People with Down's syndrome have an even higher risk, with about 2 in 3 people over the age of 60 developing dementia, usually Alzheimer's disease.

People with learning disabilities may find that their dementia gets worse more quickly than someone without a learning disability. This can be due to delays in getting a diagnosis because, by the time their condition is diagnosed, the person's symptoms have worsened. They are also more likely to have existing health conditions that aren't well-managed. This makes it even more important to get the right care and support.

The following tips may help to make life easier for the person with the learning disability and their family.

- Support the person in eating and drinking well, getting enough sleep, and taking part in physical activity if possible
- Keep up with their health appointments, including optician, dentist and hearing checks. Things like hearing and sight problems can make confusion worse
- Try to remove safety hazards from the person's home so they can live as safely and independently as possible
- Request a Needs Assessment from Social Services to establish any new care and support needs
- Help the person remain in their usual routine and carry on with activities they enjoy, with adaptations and support if necessary
- Be aware of the person's feelings and emotions. It is often assumed that people with dementia cannot experience anxiety and depression, but this is not the case
- Spend time together doing activities you both enjoy to maintain a connection between you

HAVE YOU HAD YOUR ANNUAL HEALTH CHECK AND HEALTH ACTION PLAN YET?

People with a learning disability often have poorer physical and mental health than other people. This does not need to be the case.

It is important that everyone over the age of 14 who is on their doctor's learning disability register has an annual health check.

Please see the resources section at the bottom for link to relevant easy read materials on Annual Health Checks including a video clip.

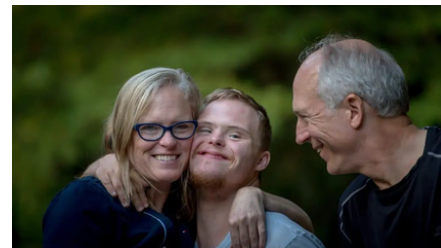


IMAGE FROM DEMENTIA UK

USEFUL WEBSITES LINKS ON LEARNING DISABILITIES AND DEMENTIA
JUST CLICK ON ICONS



Guidance
Dementia and people
with learning disabilities:
making reasonable
adjustments – guidance



OUR COMMUNITY: NORTHALLERTON MENCAP - TREAT ME WELL GROUP

WHO ARE WE?

Northallerton Treat Me Well Group was set up to support a campaign that Royal Mencap was doing across the country about better and equal healthcare for people who have a Learning Disability.

Members of the group are from local organisations who work with people who have a Learning Disability, people who have a Learning Disability and family Carers. We meet in the Goosecroft Centre, Northallerton every two months and we are always looking for new members who might be interested in joining.

CAMPAIGNING

The first campaign we did was to ask for a dedicated Learning Disability Nurse to work at the Friarage Hospital, Northallerton.

Liz Dixon is a Learning Disability Nurse based at James Cook Hospital, Middlesbrough. We found out that her time was very limited to do all the tasks involved in her job at both hospitals. We did some research about the national issue regarding specialist nurses, we found out that this was a national issue and that it was recognised as a problem. We held an activism day and invited people in to take part. We made fridge magnets to highlight the issues and to make sure people knew how important the role is to support people when they are in hospital and also for other admissions for medical procedures. We wrote to the Chairman of the South Tees Trust who replied and liked the fridge magnet idea.

Eventually Liz came to report to us that our campaign had helped to make her job better. Liz now works across both hospitals in Children's and Adults health services for people who have a Learning Disability, she also has an assistant who attends our Treat Me Well meetings and administration support too.

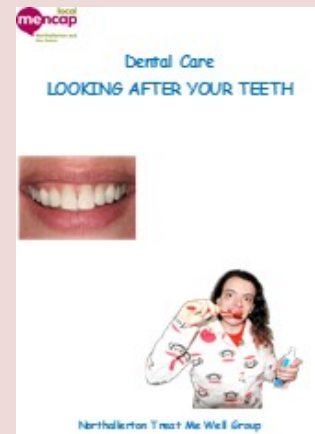
QUALITY CHECK SURVEY AT FRIARGATE HOSPITAL AND EASY READ INFORMATION ON DENTAL HYGIENE

We work closely with Liz even though she cannot attend all of our meetings. Our local group has been involved in a quality check survey about access and how staff in all departments of the Friarage Hospital treat people who have a Learning Disability, reviewing the James Cook website, is a member of the Learning Disability Partnership Group which covers both hospitals.

We also share good and bad practice when people have told us about their experiences to try and improve services and also praise them when good things have happened as a result of speaking up.



Members of the group wanted to do something about dental hygiene as they said that they could not find any easy read information about this. We decided to write an easy read leaflet so that everyone could use it to understand how to keep their teeth healthy. We did some more research to decide what to include in it. We also had advice from local dentists to make sure our facts were correct. It took a while but we managed to publish the leaflet. This has been distributed across Hambleton and Richmondshire.



GUESTS

We invite guest speakers to tell us about their work, for example we recently had a presentation about the case of Oliver McGowan and the mandatory training that health staff have to do to make sure bad practice that happened to him does not happen again.

Other things we have talked about are continuing healthcare, reasonable adjustments and annual health checks.

The Royal Mencap Treat Me Well campaign has finished but our local group decided to carry on and look at other issues that might need to be looked at in more detail to make sure people who have a learning disability get equal treatment in all areas of their lives.



One area we are looking in to is independent living and supported living accommodation. We are waiting for the results of a national survey carried out by Learning Disability England before we go ahead.

WHAT DID OUR MEMBERS SAY?

We asked members of the group for quotes about how they feel being a member, here are some of them:

“ helping me to understand other peoples point of view”

“being listened to”

“finding out information that helps me when I go to appointments”

“supporting people to speak up”

“we share experiences”

“working together”



**If you are interested in joining the Northallerton Treat Me Well Group please contact:
Sue Lear, B.E.M. Telephone: 01609 778894 or email: admin@northallertonmencap.org.uk**

INFORMATION AND RESOURCES

Profound and Multiple learning disabilities

- [People with profound and multiple learning disabilities \(PMLD\) - Mencap](#) (Links to many information and resources).
- [PMLD - Postural Care - Mencap](#)
- [Respiratory Health for People with Profound and Multiple Learning Disabilities - PAMIS \(Promoting a More Inclusive Society\)](#)
- [Your guide to Communicating with people with profound and multiple learning disabilities \(PMLD\) - \(Mencap\)](#)
- [Top Tips for supporting and meeting the needs of people with Profound and Multiple Learning Disabilities \(PMLD\) - Midlands and East NHS](#)

Diabetes

- [Improving care for people with diabetes and a learning disability - Diabetes UK](#) (Numerous tools and resources including easy read and videos).
- [Making a decision about managing type 1 diabetes - NHS England](#) (Easy read document)
- [Easy Read information about Diabetes Type 2 - Knowdiabetes](#) (Easy Read Leaflets)
- [Learning Zone - Discover more about your diabetes - Diabetes UK](#) (Videos, quizzes and interactive tools).

Dementia

- [Learning disabilities and dementia: How to support someone with a learning disability and dementia - Dementia UK](#) (Numerous resources).
- [Learning Disabilities and Dementia - Alzheimer's Society](#) (Easy read leaflets).
- [Learning disabilities and Dementia - Alzheimer's Society](#) (A useful guide for carers).
- [Easy Read NHS Health Check-Dementia Leaflet](#)

Annual Health Checks

- [Mencap Annual Health Check Easy Read Guide](#)
- [NHS England - Harshi's Annual Health Check and Health Action Plan \(Video\)](#)

Contact: If you have any queries about this newsletter or any of the topics raised here you can contact us on hnyicb-ny.mhld@nhs.net