



LIVING WELL NEWSLETTER

Issue 10 June/July 2025

North Yorkshire and York

LEARNING DISABILITY AWARENESS WEEK

16 to 22 June 2025 was Learning Disability Awareness Week which is led by MENCAP every year. The theme for this year was "Do you see me?"

This was about making sure that people with a learning disability are seen, heard, included and valued in all aspects of life and that we support them to live their best lives and have the relationships that they need.

Learning Disability Week was about:

- **Celebrating** the things that people with a learning disability do, and
- **Challenging** the barriers that people with a learning disability face

People with a learning disability can do anything they want to - see the links on the right - however:

- Only 26.7% of adults with a learning disability are employed
- 1 in 3 people with a learning disability spend less than 1 hour outside their home on a typical Saturday
- Over 2,00 people with a learning disability and / or autistic people are currently in mental health hospitals

Learning Disability Week in 2026 is from the 15th to the 21st June and we need to start planning it now. Please help us to celebrate all the great things that people with a learning disability do and have achieved across Humber and North Yorkshire by sending us your stories. We would also love to hear your ideas as to how we can make Learning Disability Week 2026 a really great event. Please email any stories and ideas to: hnyicb-ny.mhld@nhs.net

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

TO WATCH THIS VIDEO OF MODEL ELLIE GOLDSTEIN TALK ABOUT HER LIFE CLICK ON THE IMAGE BELOW:



TO LEARN ABOUT HEIDI'S GUINNESS WORLD RECORD CLICK ON THE IMAGE BELOW:



TO READ ABOUT SPAIN'S FIRST
PARLIAMENTARIAN WITH DOWN'S
SYNDROME CLICK ON THE IMAGE BELOW:



TO READ ABOUT LLOYD'S LONDON MARATHON RECORD CLICK ON THE IMAGE BELOW:



WE NEED TO TALK ABOUT...

ASPIRATION PNEUMONIA AND DYSPHAGIA

The recent LeDeR report found that Aspiration Pneumonia was one of the leading causes of death in people with a learning disability. People with a learning disability are 7 times more likely to die from Aspiration Pneumonia than people who do not have a learning disability.

What is Aspiration Pneumonia?

Aspiration Pneumonia is a type of pneumonia that is caused by bacteria entering the lungs and causing a severe infection, which can be life threatening.

What causes Aspiration Pneumonia?

Bacteria gets into the lungs when food, fluid or saliva is accidentally breathed into the lungs instead of being swallowed into the stomach.

People are most at risk of Aspiration Pneumonia if they have swallowing difficulties. This is called **Dysphagia**, which is when a person's swallow does not work properly and food and fluid goes into the person's lungs instead of the stomach. Some people also have difficulty swallowing their own saliva.

Common signs are:

- · Coughing during or just after meals and drinks
- Difficulty breathing, a person might breathe rapidly, gasp or wheeze
- They may have a wet or gurgly voice around mealtimes
- Watering eyes
- Raised temperature
- Change in skin colour
- Pain or discomfort when eating and drinking
- Weight loss
- Frequent cough

If you or someone you support has any of the symptoms above please make an appointment with your/their GP to get checked out and see if any medication is needed. They might also refer to a speech and language therapist who can help with eating and drinking. An easy read leaflet on Aspiration Pneumonia and Dysphagia is available on this link:

<u>https://www.happyhealthylives.uk/clientfiles/files/documen</u> t_library/AspPneuLeDeR%20V4-%2806.11.24%29.pdf

It is also important to have all flu and COVID vaccinations and may be worth talking to your GP about having the Pneumococcal Vaccine too but this is at the GP's discretion based on an individual's medical history.

Please see the resources section at the bottom for links to relevant information, including the full deep dive review, resources and easy read materials.

CLICK ON THE PICTURES BELOW FOR 4 VIDEOS WITH INFORMATION ON UNSAFE SWALLOWS AND HOW TO MANAGE THEM:









CLICK ON THE IMAGE BELOW FOR A VIDEO ON MINDFUL EATING:



CLICK ON THE IMAGE BELOW TO OPEN A PDF ON TREATMENT SCENARIOS:



CLICK ON THE IMAGE BELOW FOR MORE INFORMATION ON THE LEARNING DISABILITY REGISTER:





CLICK ON THE IMAGE BELOW FOR A VIDEO ON ANNUAL HEALTH CHECKS:



CLICK ON THE IMAGE BELOW FOR INCLUSION NORTH'S EASY READ GUIDE ON STAYING WELL IN HOT WEATHER



REMINDERS ABOUT...

The Learning Disability Register

If someone has a learning disability it is really important that they make sure to check with their GP that they are on their Learning Disability Register. This will make sure that they are invited for their annual health check.

Children who get extra help at nursery, school or college who find it hard to learn or do things for themselves may benefit from being on the Learning Disability Register to get extra health support from their GP practice. They will be invited for an annual health check from the age of 14 onwards, even if they are under the care of a paediatrician, as this will help them get to know their GP practice staff and help with their transition to adult services when they turn 18.

Having an Annual Health Check and Health Action Plan

People with a learning disability often have poorer physical and mental health than other people. This does not have to be the case. It has been shown that having an **annual health check** and a **health action plan** can improve the health outcomes of people with a learning disability.

It is really important that everyone over the age of 14 who is on their GP's Learning Disability Register has their annual health check and make sure to ask for a health action plan.

Remember to make sure your GP knows what **reasonable adjustments** you or the person you support may need too.

Stay well in hot weather

Now that the hot weather is upon us it's really important to keep cool and hydrated. Remember to:

- Stay indoors between 11am and 3pm when the sun is hottest
- Close windows and blinds to stop the sun heating up the room
- Drink plenty of water or squash, you can also eat ice lollies and ice cubes to keep cool, fruit like melon is also good
- Try not to drink alcohol or drinks with caffeine like coffee or cola
- Wear loose, light-weight clothes
- Wear a hat and sunglasses if you go outside
- Remember to use sun cream, SPF 30 or higher

GETTING MY HEALTH RIGHT FOR ME WORKSHOPS AND SURVEY

Our **Working Together Group** of self-advocates, people with lived experience and families and carers together with Inclusion North helped us to co-design and co-deliver a series of four Getting My Health Right For Me workshops.

To learn more, click here for a short film on our workshops

The workshops covered topics including annual health checks, being on the learning disability register, reasonable adjustments, eating healthily, dental health, mental health and constipation as well as body awareness and cancer screening.



The workshops were delivered in community groups across the county and the last one in July will be at Scarborough Mencap.

We would like to design more workshops for next year and would like to know which topics you and the people you support would like us to cover. Our Working Together Group and Inclusion North have created a short survey to get your views. Please fill in the survey by scanning the QR code on the right or by clicking on the link below: https://rixeasysurvey.org/kiosk/ZAqW

INCLUSION NORTH TAKE THE LEAD WORKSHOPS

Inclusion North are running **five free** online workshops for people with a learning disability and autistic people living in the North East or Yorkshire and Humberside.

The workshops all start at 10am and finish at 11.30am and are:

Thursday 10th July 2025: Confidence and Self-Esteem

We will work together to build confidence and feel good about who we are.

Tuesday 15th July 2025: Keeping Well

We will talk about how we look after our bodies and mental health so we can stay well and happy.

Thursday 24th July 2025: Staying safe at home and online

We will work together to learn about staying safe in our homes and online

Thursday 31st July 2025: Safeguarding

We will learn what safeguarding means and how to look after ourselves and each other

Thursday 7th August: Who we are and relationships

We will look at who we are (our identity) and talk about different relationships.

If you would like to find out more or **apply to join** a workshop please contact Maria Spadafora on 07483 340294 or email <u>maria.spadafora@inclusionnorth.org</u>

People will receive certificates for taking part and the workshops will be run again from Thursday 18th September 2025 if people cannot make the above dates.

THE MENTAL HEALTH, LEARNING DISABILITY AND AUTISM HEALTH INEQUALITIES TEAM AT NHS HUMBER AND NORTH YORKSHIRE HEALTH AND CARE PARTNERSHIP:

Who we are

We thought it was about time we introduced ourselves. Hakan is the Learning Disability Transformation Commissioning Manager and Tanja is the Learning Disability and Autism Project Support Officer in the NHS Humber and North Yorkshire Mental Health Learning Disability and Autism Health Inequalities Team at Humber and North Yorkshire Health and Care Partnership.

What we do

We work to address health inequalities for people with a learning disability and autistic people across North Yorkshire and York. Some of the things we do include working with GP practices to make sure they have the right people on their learning disability registers and to make sure that as many people as possible have their annual health checks.





We have also created a resources site for GP practices that has lots of easy read information they can download and send to or use with patients, families and carers. We have also set up a Community of Practice and have run training sessions which we have recorded to help GP practices train any new staff that start with them.

We also work with Inclusion North, self-advocates, people with lived experience, parents and carers across our areas and have formed our co-production Working Together Group. So far the Working Together Group have attended 3 of our Board and operational meetings where they have shared all the great things that they do and gave a presentation on the Getting My Health Right for Me workshops that were co-produced and co-delivered with them across North Yorkshire and York.

Why we do what we do

People with a learning disability die on average between 22 years (for males) and 26 years (for females) earlier than people who do not have a learning disability. We know that annual health checks can make all the difference in making sure that people keep healthy and get the right care as soon as they need it.

THE LIVING WELL NEWSLETTERS

Part of our work is writing and sending out the Living Well Newsletters to keep you informed about health issues and the groups across our areas that provide opportunities for people with learning disabilities and autistic people.

We would like to know if there are any topics that you would like to see in future editions of the newsletter and if you think there is anything we could improve. To give your feedback please complete this short survey: https://www.smartsurvey.co.uk/s/FIQRFB/

INFORMATION AND RESOURCES

Learning Disability Week

https://www.mencap.org.uk/learningdisabilityweek

https://youtu.be/jZvWecNsoBU

https://www.mencap.org.uk/blog/heidi-breaks-guinness-world-record

https://www.theguardian.com/world/2024/jan/09/mar-galceran-makes-history-spain-first-

parliamentarian-downs-syndrome

https://www.bbc.co.uk/news/uk-wales-68851567

https://www.mencap.org.uk/easyread/learning-disability-week-2025

https://register.enthuse.com/ps/event/OneBigWalk2025

Aspiration Pneumonia and Dysphagia (Unsafe Swallow)

Easy read leaflet on Aspiration Pneumonia:

https://www.happyhealthylives.uk/clientfiles/files/document_library/AspPneuLeDeR%20V4-%2806.11.24%29.pdf

All the Unsafe Swallow videos that are on page 2 of the newsletter, as well as more videos and resources can be found here:

https://necldnetwork.co.uk/work-programmes/health-inequalities/dysphagia-diamond-standards/resources/

Mindful eating video: https://www.youtube.com/watch?v=ZDtSEt8IF_c

NHS England RightCare Aspiration Pneumonia treatment scenarios:

https://www.england.nhs.uk/publication/rightcare-learning-disability-and-aspiration-pneumonia-scenario/

https://www.england.nhs.uk/wp-content/uploads/2023/06/20241402-Learning-disability-and-aspiration-pneumonia-scenario.pdf

Health Workshops Survey

https://rixeasysurvey.org/kiosk/ZAqW_

Inclusion North

To find out more about Inclusion North's work: https://inclusionnorth.org/our_work/
To join the **Take the Lead Workshops** email: maria.spadafora@inclusionnorth.org

Staying well in hot weather

https://inclusionnorth.org/wp-content/uploads/2024/05/Stay-Well-in-Extreme-Weather-Easy-Read-guide.pdf

Tell us what you would like to read about in the next Living Well Newsletter

https://www.smartsurvey.co.uk/s/FIQRFB/

Annual Health Checks and the Learning Disability Register

https://www.youtube.com/watch?v=zScJo1HbTK8

https://www.youtube.com/watch?v=IQynWG4LCnw

https://www.yumpu.com/en/document/read/68770906/lets-talk-about-annual-health-checks-easy-read-for-adults-with-downs-syndrome

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