

# Plain English newsletter

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#### 1. Who should read the newsletter

- people with a learning disability and autistic people with or without a learning disability
- families, carers, and advocates
- community groups, charities and advocacy groups who can explain to their members any difficult ideas and use these for information sessions

You may find some of the information in this newsletter upsetting, so please make sure you can talk to someone, if you need to.

We have included links to webpages so you can find out more.

#### 2. Words we use

The newsletter is for people who have different needs and skills.

It can be difficult for some people to understand health services.

We try our best to use words that people know.

Hard words are in **bold** and **purple**. We explain the hard words.

If you don't understand any words, ask someone to explain them to you.

# 3. Constipation

**Constipation** is when you find it hard to poo or poo less often than you normally do.

People with a learning disability are much more likely to:

- get constipation
- have their symptoms missed
- die from constipation

Taking some types of medication mean you may be more likely to get constipation.

These are some of the signs you may be constipated:

- sore tummy when you try to poo
- it hurts when you poo or try to poo
- hard or lumpy poo
- runny poo
- pooing less than usual

If you are worried you may have constipation, speak to your GP.

You can keep your poo healthy by:

- eating a mixture of different foods, including fruit and vegetables, if you can
- drinking plenty of water and exercising

# 4. Eating disorders in autistic people

Many autistic people find food and eating difficult.

An eating disorder is when you have a difficult relationship with food which can affect and be caused by your mental health.

Autistic people can get eating disorders and need hospital treatment more than people who are not autistic.

Some autistic traits might mean that autistic people are more likely to have eating disorders, these include:

 sensory differences, preferences for routines and difficulties identifying emotions and body signals like hunger

Autistic people might also be more likely to have eating disorders because they:

- have stomach problems
- may be very strict about following rules about healthy eating. This is called orthorexia
- may use hunger to cope with stress from things happening around them

Some autistic people may have avoidant restrictive food intake disorder (ARFID).

**ARFID** is when you avoid certain types of food. This can lead to eating very little or not eating at all.

It is important to tell your GP or doctor if you think you have an eating disorder.

However, many autistic people can find it harder to get treatment.

Services should provide reasonable adjustments.

A **reasonable adjustment** is a change that a service can make to help someone with a disability.

The PEACE Pathway (pathway for eating disorders and autism developed from clinical experience) can help with eating disorder treatment for autistic people.

You can see their free resources on their website: <u>PEACE Pathway - resources</u>

# 5. Lung cancer

We have 2 lungs in our chest to help us breathe.

Your body is made up of lots of tiny pieces called cells.

Sometimes these cells go wrong. They can grow into a lump called a tumour.

Lung cancer is one of the most common types of cancer.

Lung cancer is often caused by smoking but a small number of people get lung cancer even though they have never smoked.

For help to stop smoking, see the <u>quit smoking information</u> on the NHS website.

You cannot catch lung cancer from anyone else, and you cannot give it to anyone.

For more information about lung cancer, see the NHS website on lung cancer

Some signs of lung cancer are:

- a cough that does not go away
- finding it harder to breathe or it hurts when you breathe
- losing weight without trying
- seeing some blood on your tissue when you cough

If you are worried that you may have the signs of lung cancer, speak to your GP.

GPs may ask you to have some tests.

There are treatments that can help, especially if lung cancer is found early.

#### 6. Pneumonia

Pneumonia can be more serious for people with a learning disability than people who don't have a learning disability.

Pneumonia is a type of chest infection that makes it hard to breathe.

You are more likely to get pneumonia in the winter and if you get the flu first.

For more information on the signs of pneumonia, see the NHS website on pneumonia

If you are worried you may have the symptoms of pneumonia, speak to your GP.

How to help avoid pneumonia:

- don't smoke
- keep active
- wash your hands often
- get your flu vaccine
- get your pneumococcal vaccine if you are 65, or older and have not had it before

The pneumococcal vaccine is a vaccine that is used to help protect against pneumonia and some other illnesses.

You may also be able to have the pneumococcal vaccine at any age.

This is if you have another illness that makes you more likely to be very poorly if you get pneumonia.

If you are not sure, ask your GP (doctor).

# 7. How to get support and speak up

If you are worried about the care and treatment the NHS is giving you, tell someone you trust straight away.

The NHS has made an easy-read form. It helps you tell staff or a service what you think could be done better.

Find the form by visiting <a href="www.speakup.org.uk">www.speakup.org.uk</a> and click on projects and search for 'Ask, Listen, Do'.

Ask someone to help you fill in the form if you need to.

# 8. People who can help you

An **advocate** can help you to tell people what you need to try and get you the right health and social care support.

Find out more about advocates on the NHS website.

The NHS Patient Advice and Liaison Service (PALS) can support with healthcare queries or problems. If you are in hospital, you can ask staff how to contact PALS.

Or visit the What is PALS (Patient Advice and Liaison Service)? webpage to find out more and your nearest PALS office.

Your local Healthwatch can help with questions about your GP, hospitals, dentists, pharmacies, care homes or other support services.

To find out more about Healthwatch visit www.healthwatch.co.uk

If you are a parent carer, you can contact your <u>local parent carer forum</u>. Parent carer forums can help services in their area meet the needs of disabled children and young people and their families.

# 9. Keep updated

This newsletter was created by the NHS England Learning Disability and Autism Programme, with member representatives from our <u>Advisory Group</u>.

Get in touch if you want to tell us anything about this newsletter.

You can either phone us on 0113 824 9686 or email us at engage@nhs.net

#### Update email

Sign up for our monthly learning disability and autism update email which includes important health information.

Already shared on our social media pages, the update email provides this information, all in one place.

To register to receive this, email us at <a href="mailto:engage@nhs.net">engage@nhs.net</a>

#### 10. Connect with us

- Facebook: NHS England Learning Disability and Autism Programme
- X (was called Twitter): @NHSAbility
- Email: engage@nhs.net