



Easy Read Newsletter



Epilepsy care



**Extra help
from your GP**



The right home

and lots more information



Winter 2017-2018

Hello

Welcome to our latest easy read newsletter

It is for people with a **learning disability**
and **autistic** people

In this newsletter we just say **people**



A new look



This is the fifth easy read newsletter from NHS England. It is a bit different from our older newsletters. This time we are using photos.



What do you think?



- Is it easy to read?
- Do you like the pictures?
- Do you like the new **font**?

easy font
font **easy**



- Is there anything you would like to see in the next newsletter?



We would love to hear from you.
Our new email is engage@nhs.net

In this issue...

NHS
England



At NHS England we make big decisions about health care in England.



This newsletter tells you about our work. It tells you about ways you can get involved. You can read about :

Page **6**

Epilepsy care



It's not always easy to get the right help if you have epilepsy. Find out about some new work we are doing.

Page **10**

The right home can help



We have been sharing ideas to make sure there is a good choice of housing for everybody to live a happy and healthy life.



Your local doctor or GP can make sure you get extra help when you use NHS services.



Find the words in the box. In this issue the words are about health.



We have a plan to help people living in hospitals move back nearer their families. But how is it working?



Mary and Ted are helping us get better at supporting families and better at dealing with complaints.

Epilepsy :

By Jane Kachika
NHS England



Getting the right treatment



Lots of people with a learning disability have health issues.

Some people might need extra help to understand things and make sure they get the right care.



My name is Jane. My job is to help NHS services get better at giving this extra help.



In the last newsletter I wrote about my work with people who find it hard to swallow food.



Now I'd like to tell you about some work I am doing about **epilepsy**.



Epilepsy is a problem in the brain that causes a person to have **seizures**.

It is more common for people with a learning disability to have epilepsy.



Some people might fall over and start shaking.



Other people might have moments when they drift off and stare into space.



If you have epilepsy it can be hard to find out how to get the best treatment for you.



You might feel worried about what things are safe for you to do, even just going out on your own.





The law says NHS services must give you any extra help you need to get the right treatment.



This extra help is called **reasonable adjustments**. It can be anything you need to help you use NHS services :



You might need some extra time when you see your doctor

- so they can explain things clearly and give you time to think.



Or you might need easy read information about medicines or tests.



The important thing is NHS staff should work with each person to find out what support they need.



I am finding out how things are for people with a learning disability who use **NHS epilepsy services**.



I'm also working with families, carers and health care workers to find out what they think.



I want to find out if people are getting the extra help they need from epilepsy services.

- Do you get extra help?



- What things are good?

- What things could be better.?



Please email me if you would like to be a part of this work :

jane.kachika@nhs.net

The right home can help



We all need to find the house or home that makes us happy.

Some people live with their family.
Some people live on their own.
Some people live with other people.



People need the right support to live the life they choose.



But some people are not happy where they live - especially people who have lived in a hospital for a long time.

This can make them stressed and upset a lot of the time.



Moving to a different home can make a big difference for some people. It can make them feel happier, healthier and more relaxed.



It is really important to have different kinds of housing - so people can choose a home that suits them.



NHS England are working with a group of housing organisations called the **Housing Learning and Improvement Network**.



We have been sharing ideas to make sure there is a good choice of housing for everybody to live a happy and healthy life.



You can watch some videos about eight different people's housing stories here :

bit.ly/arealhome

Extra help from your GP



Did you know you can get extra help from your GP? Coming up we will find out about :



Annual health checks

Get a health check every year with your GP.



The learning disability register

This list helps doctors know which patients have a learning disability.



Reasonable adjustments

This is extra help you are allowed to get good health care.



Summary care records

Information about your health and how you like to be treated.

Annual health checks



If you are age 14 or older and are on the **learning disability register** you can get **annual health checks**.

These are meetings with your doctor or GP to check for any health problems, once a year.



The first part of the check might be with a nurse and the second part with the GP. Or the GP might do the whole check.



They will ask you questions and write things on their computer.



At the end of your check the GP will give you a printed **health action plan**.

You may want to put this information in your health book or **health passport** if you have one.

The learning disability register



To make sure you get your annual health check you need to be on a list called the **learning disability register**.

Only NHS staff at your **GP practice** can see this list. It tells them which patients have a learning disability.



We want to make sure everyone with a learning disability is on the list. So ask your GP if you're not sure.



Being on the list can help you get extra help called **reasonable adjustments**.



Reasonable adjustments



Reasonable adjustments can be anything that makes it easier for you to use health services.

You might want easy read letters and health information.



Maybe you need extra time and longer appointments - every person's needs are different.



Talk to your GP about any extra help you need. They will type this information into the computer - but only if you say it is ok.



The information on the computer is called your **summary care record**. It tells NHS staff about your health and how you like to be treated.



All NHS staff looking after you can see how best to support you.

Annual health checks

Sanjay & Michaela find out



1 Hello. We went to find out what happens at your annual health check.



2 You should get a letter asking you to come for an annual health check.



3 You might get a phone call or email - please come in for around 30 - 60 minutes.

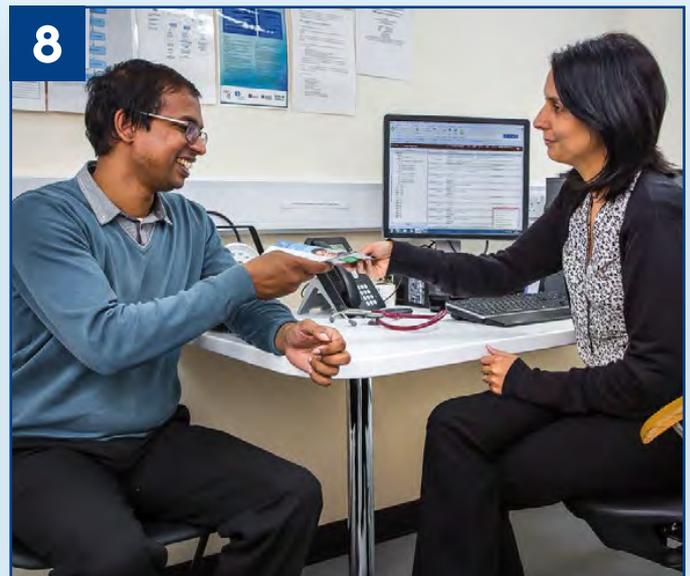


4 Annual health checks are usually at your health centre or GP Practice.



5
Just check in at reception.
You can bring someone with
you if you like.

6
Wait for your name to be
called - it might also show
on a screen.



7
The doctor (or a nurse) will
ask about your health.

8
Tell them about any extra
help you need - your
reasonable adjustments.

Annual health checks

Sanjay & Michaela find out



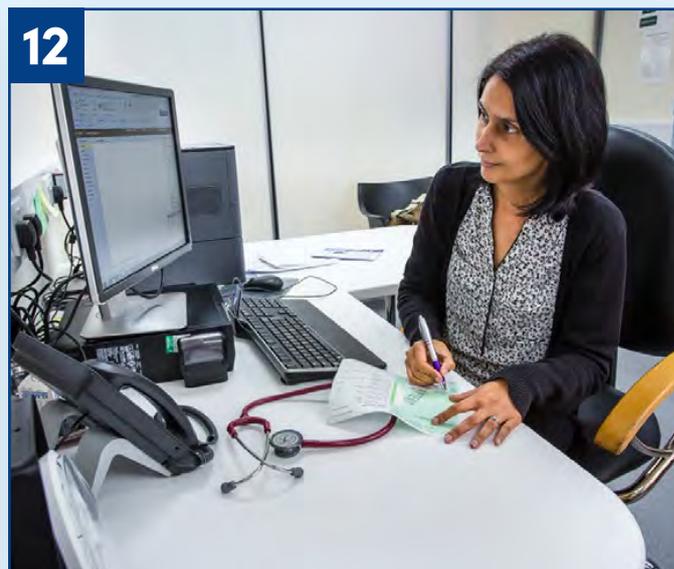
You might be asked to do some tests - you can ask to stop anytime.



The GP might check things like your height, weight, heart, tummy or feet.



You might need to give a sample of blood or wee.



The doctor will make a note of everything you talk about on the computer.

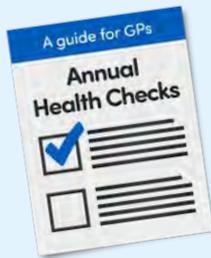


Lots of people still don't know about annual health checks. We are working hard to tell more people.



Find out more

You can watch a video by Mencap : bit.ly/dont-miss-out-mencap



Ask your GP if they know about the GP Toolkit guide : bit.ly/GP-toolkit

We love this video by The Misfits. You could watch it with your care staff - it shows how they can help too : bit.ly/misfits-video



Health is everybody's responsibility.

Word search



Can you find all these words in the box above?

bloodpressure

bone

cast

doctor

ears

flu

height

injection

nurse

weight

xray

Transforming Care Partnerships



Too many people are still being kept in hospitals and **assessment and treatment units**.

Some people have been there for years because they cannot get the support they need near home.



This is mostly people who have **behaviour that challenges** or serious mental health problems.



We have made a plan to get more people back home - with better support near where they live. It is called **Building the Right Support**.



Part of the plan was setting up groups across England called **Transforming Care Partnerships**.

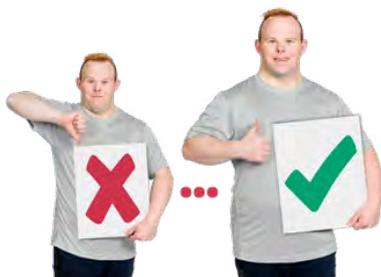
We call them **TCPs** for short. Everyone works together - NHS and council staff, people and families.

Transforming Care Partnerships

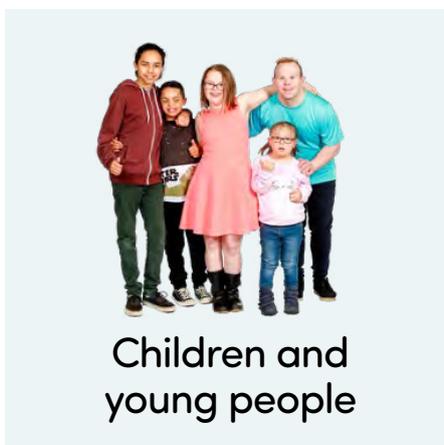


Right now we are looking at how well TCPs are working.

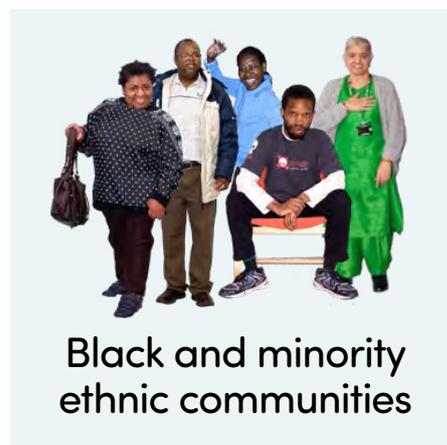
We know things are better in some places but not everywhere.



And we know we need to do more to support some groups :



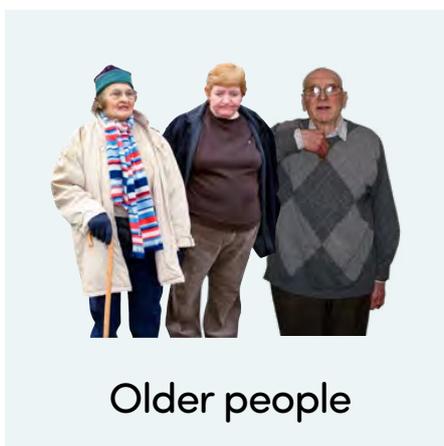
Children and young people



Black and minority ethnic communities



People who have been in trouble with the law



Older people



Autistic people



We have not been good at involving people and families.



And too many people are still stuck living in hospitals away from their family and friends.



Can you help us?

We want to know if TCPs are working well in your local area?

Have you been involved in your TCP?

Is there good support to help you take part?

Are people's lives getting better?



Please tell us what you think in our online easy read survey :

bit.ly/TCPeasyreadintro

Or email us for a copy :

TCPSurvey@icf.com

Working with family carers



Mary and Ted are the new **Family Carer Advisors** at NHS England.



Their job is to tell us how things affect families and carers.



As carers of people with a learning disability and autism they have learned a lot. We call this **lived experience**.





Ted and Mary are helping us get better at dealing with **complaints**.

And better at listening to ideas and **feedback** from people and their families and carers.



We had a big event about complaints and feedback. You can read our report about it here :

www.england.nhs.uk/learning-disabilities/get-involved/forum/

Mary says ...



“We want to make sure family carers voices are heard in the NHS. We want this to make things better for family carers and the people they support.”



If you would like to contact Mary or Ted please email :

england.improvinghealthquality@nhs.net

The last word

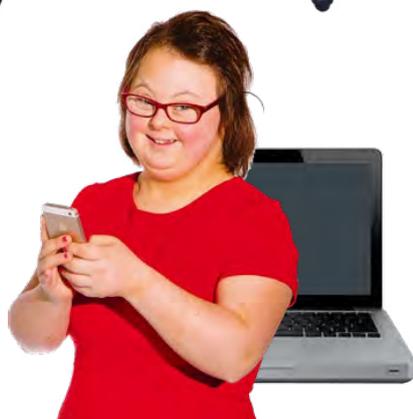
By Advocacy in Greenwich



That's the end of our winter newsletter. The next one will be out in Spring 2018.



We give the last word to members of **Advocacy in Greenwich** - who told us their experiences of annual health checks.



If you'd like to speak up about something that's important to you - please phone, write or email us.

Thank you to **Advocacy in Greenwich** and **Camden People First** for helping us make this newsletter.

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**My GP
made a time
to suit me**

**None of us
have ever been
given any easy read
information**

**My nurse
rings
and talks to my
mum not me**

**They took my
blood pressure
checked my oxygen level
and said it is done you
can go now**

**We like
easy read and
phone calls -
speak to us in
person**

**I have to
get my mum
to read stuff
for me**

**My nurse
checks in my black
book and talks
to me about my
medication**

**Some tell you
things politely, some
shout at you and tell
you what to do**



Contact us



The NHS England
Learning Disability and Autism
Engagement Team

Phone : **0113 824 9686**

Email : **engage@nhs.net**

Web : **[www.england.nhs.uk/
learning-disabilities/get-involved](http://www.england.nhs.uk/learning-disabilities/get-involved)**

Facebook :

**[NHS England Learning Disability
and Autism Engagement](#)**

Twitter : **[@NHSability](#)**

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