



Northumbria Healthcare
NHS Foundation Trust

Transition of young people with epilepsy to adult services

Issued by Northumbria Healthcare NHS Foundation Trust

What is transition?

Transition is another word for change. It is the term we use for the planned process of moving your epilepsy care from children's services to adult health services or the GP and helps prepare you and your parents / carers for the move.

Most young people will move to adult services at the age of 16 but for others it may be a little later.

The main difference between children's and adult services is that you will be making your own decisions about your condition in adult services, with the support of your family if you would like it.

In the case of young people who do not have the capacity to make their own decisions, the healthcare team will discuss the Mental Capacity Act with you and explain the role families take in contributing to decisions about the young person's healthcare from the age of 16.

More information about the Mental Capacity Act can be found at: <https://www.mencap.org.uk/advice-and-support/mental-capacity-act>

A video explaining this further can be found at: <https://learningdisabilitymatters.co.uk/resources-to-support-the-rights-of-children-and-young-people-with-learning-disabilities-to-reasonable-adjustments-across-settings-so-they-can-enjoy-the-best-of-life-and-reach-their-full-potential/>

You will be offered an appointment in the transition clinic with your paediatric epilepsy team twice a year from the age of 13 and more often if necessary.

Do I have to transition?

Yes. Your current paediatric epilepsy team are experts at looking after children and young people with epilepsy however as you grow older your needs will change and adult services and / or your GP will be able to support you better.

You may also find that you would prefer to be seen in a more grown-up environment, rather than the children's departments or wards.

Age 13-14 (year 9)

This is an opportunity to discuss issues relating to your epilepsy such as independence, safety, leisure activities and medication.

We will offer you the opportunity to meet with your epilepsy nurse independently for part of your appointment. Like all medical consultations this part of the appointment is confidential and if information needed to be shared with other professionals, this would be discussed with you first.

Age 15-16 and above

This is an opportunity to discuss issues relating to education, careers, driving, independence, drugs, alcohol, sleep, sexual health etc. You may want to spend part, or all of this appointment without your parents / carers.

What can I do to get ready for the transition?

- Learn about your condition and treatment
- Practise asking and answering questions about your condition
- Take some responsibility for your medication, what you need, when and how much
- Learn how to order prescriptions from your GP
- Practise making appointments with your consultant / GP / epilepsy nurse
- Keep a list of important phone numbers
- Have time in clinic with the nurse or doctor without your parents / carers
- Find out what changes in your condition need urgent attention
- Find out who to contact in an emergency
- Keep to agreed treatment plans

After transition

It can be difficult for some families to break contact with the children's service once transition to the adult service or GP has taken place, however it is important that the adult teams are the first point of contact for any questions or concerns about your health once you have been discharged from the children's service.

Keeping safe when out with friends

It is important that you go out, see friends and enjoy life however the following safety tips are issues you need to consider:

- Plan ahead – if you do have a seizure would the people around you know what to do?
- Get your friends to reassure your parents or carers that they know what to do if you have a seizure
- When you go out, agree to check in with your parents or carers by phone – even just a quick text will let your family worry less
- We advise you to wear medical identification jewellery and carry an identification card (available from Epilepsy Action or Young Epilepsy). This should contain details of medication you take, how long your seizures normally last and your emergency contact.

Contraception

Some antiepileptic drugs (AEDs) can make the contraceptive pill and emergency contraception (morning after pill) work less effectively which could lead to an unplanned pregnancy. When you are ready to become sexually active make sure to arrange an appointment with your GP or local sexual health clinic to discuss sexual health including contraception.

Barrier methods such as condoms are not affected by epilepsy medicines and also protect against unwanted sexually transmitted infections so we always advise using a barrier method alongside other methods of contraception.

Cigarettes and alcohol

We do not advise anyone to smoke. The younger you start smoking, the more damage there'll be to your body as an adult.

If you are smoking during a seizure you are at risk of burning yourself and / or starting a fire.

Drinking too much alcohol may stop your AEDs from working effectively and can seriously increase the risk of a seizure. It is recommended that you should not drink more than 2 units of alcohol a day – as a rough guide a pint of beer is 2.5 units and a small glass of wine is 1.5 units.

For more information on units of alcohol please visit <https://www.nhs.uk/live-well/alcohol-support/calculating-alcohol-units/>

After heavy drinking, the risk of a seizure is highest when the alcohol is leaving your body. This risk is usually between 6 and 48 hours after you've stopped drinking. Vomiting (being sick) after heavy drinking may reduce the level of AEDs in your system and affect seizure control.

If you are going out, set an alarm on your phone to remind you to take your medication at the usual time.

Recreational drugs

Amphetamines, PCP, cannabis, spice, ecstasy / MDMA, cocaine and heroin all increase the risk of having a seizure and can interact with AEDs. For more information about drug use visit www.talktofrank.com

Managing your epilepsy at school or college

- If you have friends that you trust, you may want to talk to them about your epilepsy and seizures.
- Make sure teachers and close friends know what to do if you have a seizure.
- If you feel tired following a seizure you could negotiate a plan with the school or college where you could have a short rest away from the classroom until you feel better.
- There are some subjects that require additional safety precautions for young people with epilepsy. Discuss your subjects with your epilepsy team who will be able to advise the school or college.
- School work and exams can be adjusted to take account of your epilepsy – perhaps by having longer to complete your coursework or having supervised rest breaks or additional time during an exam.

Further education and careers guidance

North Tyneside Connexions service provide information, advice, guidance and support for 13-19 year olds to help them make choices for careers and learning. They can be contacted by telephone on 0191 643 6965 or via their website connexions.nt@northtyneside.gov.uk

In Northumberland, careers advice is available to 16-18 year olds by Northumberland County Council Careers Guidance Team. They can be contacted by telephone on 01670 622 799 or text 07827244027 and their email address is careersteam@northumberland.gov.uk

Information about epilepsy and university can be found at www.epilepsysociety.org.uk/university-and-epilepsy

Transition support for young people with a learning disability:

Northumbria Healthcare NHS Trust has a transition pathway for young people with very complex health needs and the Special School Nurse and / or Children's Community Nurse will support the young person and their family / carers through the transition process.

The 'Preparing for Adulthood' website

<https://www.preparingforadulthood.org.uk/> offers information and advice which aims to ensure young people with SEN / disabilities have equal life chances as they move into adulthood.

The information they provide includes:

- Information on Education and Health Care Plans (EdHCP)
- Information on transition
- Information especially for young people

If you need to be admitted to hospital it can be helpful to complete a 'hospital passport' so that hospital staff know more about your needs to make your admission easier. Your healthcare team can provide you with a hospital passport.

In North Tyneside, 'preparing for adulthood' information can be found on the council website at:

<https://my.northtyneside.gov.uk/category/1248/preparing-adulthood>

In Northumberland, advice about transition and 'preparing for adulthood' can be found through the council website at:

<https://www.northumberland.gov.uk/Children/Northumberland-Local-Offer-SEND-0-to-25-years/Preparing-for-adulthood.aspx>

Annual health check

Anyone aged 14 or over who is on their GP's learning disability register can have a free health check once a year. This health check helps you stay well by talking about your health and finding any problems early, so you get the right care. More information about the annual health check can be found here:

<https://www.youtube.com/watch?v=e3ZSPDyBAVA>

Useful websites

North East and Cumbria learning disability network:

<https://neclidnetwork.co.uk/>

Learning disability matters: <https://learningdisabilitymatters.co.uk/>

Patient advice and liaison service (PALS)

If you have a compliment, concern or complaint please contact our PALS team on 0800 032 0202 or

northoftynepals@northumbria.nhs.uk

Contact us

If you need to contact us you can speak to one of our Paediatric Epilepsy specialist nurses on the numbers listed below:

Andrea Irlam – available Monday to Friday from 08.30am to 4.30pm.
Telephone: 0777502947

Sophie Gilmour-Ivens - available Monday to Thursday from 08.30am to 4.30pm.

Telephone: 07814652086

Alternative Formats

If you would like a copy of this information in large print, another language, audio tape or other format please call the Contact Centre on 03 44 811 8118.

Other sources of information

NHS 111

NHS Choices

www.nhs.uk/pages/homepage.aspx

NICE (National Institute for Health and Clinical Excellence)

www.nice.org.uk

Patient Advice and Liaison Service (PALS)

Freephone: 0800 032 0202

Text: 07815 500015

Email: northoftynepals@nhct.nhs.uk

Northumbria Healthcare NHS Foundation Trust

General Enquiries 03 44 811 8111

www.northumbria.nhs.uk



PIN 959/V1

Review date: January 2024

© This material is the copyright of the Northumbria Healthcare NHS Foundation Trust.