

MOVING ON UP TRANSITION BOOKLETS FOR PATIENTS

Context : To develop an effective epilepsy specific transition programme utilizing tools that improve the young person's experience of transition to adult services. We aimed to develop epilepsy specific transition leaflet with additional specific tool for young people with epilepsy and learning disability.

Action1: To consolidate the knowledge of the parent and child, with the emphasis on the child/young person working towards independence and understanding their condition. Separate areas of transition were identified and developed into 3 booklets which covered these aspects. These are written simply for the young person to read with blank spaces for them to answer questions (example below).

Action 2: A separate set of booklets for young people with a learning disability were developed using similar themes. Additional advice was obtained from local adult LD services and speech and language in developing these booklets (examples below).

4 Planning for the future; college and beyond



Epilepsy can affect your daily life and it can affect what job you do in the future. Plan ahead and discuss with your school, parents and epilepsy nurse what you want to do after school so you can get the best support.

If your seizures are well controlled, you will have more choices.

If you have epilepsy, colleges and universities should provide extra support to make sure you're not at a disadvantage because of your epilepsy.

What job would you like to do in the future?

On The Epilepsy Space website, you can hear about young people's experience of being a student with epilepsy.

Epilepsy is usually considered as a disability. The Equality Act 2010 protects your rights in work and education - www.gov.uk/rights-disabled-person

2. Asking questions and choosing



If you can it is important to learn about your epilepsy and learn how to make choices about how the doctor looks after your health.

You can practice this by telling your doctor or nurse something about your epilepsy or medication – like the time you had a seizure.

Can you ask a question or tell the nurse/doctor something about your epilepsy?

We also talked about being on the GP learning disability register and having yearly GP learning disability health checks.

Is your child registered at the GP as having a learning disability?

Are they getting a yearly GP learning disability health check?

And, we mentioned social workers. Transition social workers help you and your child with the move to adult council services, extra support and independence. Schools usually do the referral.

Does your child have a transition social worker?

Hull - www.hull.connectio.support.org then search the word 'transition'

East Yorkshire - Futures Plus - www.eastridinglocaloffer.org.uk

If able to, you could encourage your child to be even more involved in their epilepsy care. They can 'Ask 3 Questions'. This may be for a new treatment choice or to see if there's an alternative to the current treatment. As a parent/carer, you can also use these questions too.



- 1 - What are the choices?
- 2 - What's good and bad about the choices?
- 3 - Does your child know who ask to help them make the best choice?

Children's Epilepsy Nurse Transition Checklist 1

DISCUSSED	NEED TO REVISIT?
Y/N	Y/N
DATE:	
DISCUSSION POINTS:	
WHAT IS EPILEPSY?	
WHY DO I HAVE EPILEPSY?	
HOW WAS I DIAGNOSED WITH EPILEPSY?	
HOW IS EPILEPSY TREATED?	
WHAT MIGHT TRIGGER A SEIZURE TO HAPPEN?	
WHAT IS SUDEP?	
SEIZURE MANAGEMENT	
IF RECORDING 'NEED TO REVISIT' TO ANY OF THE ABOVE QUESTION PLEASE INDICATE REASON:	
ANY OTHER INFORMATION DISCUSSED?	
ACTIONS FOR PREPARING FOR FUTURE APPOINTMENTS?	

Future: We aim to obtain feedback from users and adult services.

We are developing a checklist that will facilitate electronic documentation of transition and also serve as an audit tool.

We will also modify the Learning disability version of the Transition tool.

DON'T BRING ME DOWN WELLBEING QUESTIONNAIRE

Context: Studies have indicated that 37% of 5-15 year olds with epilepsy have a co-existing mental health condition. An integrated approach with psychology is recommended with use of a screening tool for mental health difficulties as part of routine care.

Plan: We liaised with long-term conditions psychology team, to devise a 'Wellbeing screening tool' which was easy to use and could be completed in the waiting room before clinic. When there are concerns about mental health, users are supported via an agreed traffic light system. Options include sign posting to resources, discussing with the psychology team and referral to mental health services.

The Epilepsy Team would like to know how you have been feeling!

Name and Date of Birth: [Redacted] 02-05-2016

We would like to know how you have been feeling over the last few weeks, we have a few questions for you to think about and answer, and these can be discussed further during your appointment. These can be completed by yourself or with the help of the person who has brought you to clinic today, it's up to you!

We would also like to ask if you consent for this information to be discussed with our psychology colleagues within the Hull and East Riding Long Term Health Conditions (LTHC) Team if we feel this may be helpful. The Hull and East Riding LTHC Team help young people with epilepsy and their families to think about how they feel about their conditions and can provide advice or techniques to help.

Please tick the box if you are happy for this to happen.

How do you feel today?

On a scale of 1 - 5 how worried or concerned are you about the following:

Name: [Redacted]

1 2 3 4 5 (not worried at all) (very worried)

If you are worried, what are you particularly worried about?

What things make you happy? (Please circle the feeling which best with your response)

Happy Ok Sad

Angry Worried Confused

Please can you share a bit more about your feelings?

malin@hull.ac.uk

What would be helpful in relation to any worries you may have?

What things make you happy? (Please circle the feeling which best with your response)

Playing games, being with my peers (boys)

Thank you for taking the time to think about the questions, the epilepsy team are very happy to support you between appointments so please do get in touch if you need it.

Epilepsy

0 1 2 3 4 5 (not worried at all) (very worried)

If you are worried, what are you particularly worried about?

How does your epilepsy make you feel? (Please circle the feeling which best with your response)

Happy Ok Sad

Angry Worried Confused

Please can you share a bit more about your feelings?

malin@hull.ac.uk

What would be helpful in relation to any worries you may have?

What things make you happy? (Please circle the feeling which best with your response)

Playing games, being with my peers (boys)

Thank you for taking the time to think about the questions, the epilepsy team are very happy to support you between appointments so please do get in touch if you need it.

Future – Tool currently being audited.

Ref 1 - Davies S, Heyman I, Goodman R (2003) A population survey of mental health problems in children with epilepsy. Developmental Medicine and Child Neurology 49; 292-5

Remarkable people.
Extraordinary place.

Epilepsy team: F Lead, C Bennett, N Heenan, S Jose, V Mehta



Booklets 1-3 content – Transition Epilepsy Treatment Diagnosis Triggers Independence SUDEP General health Seizure diaries GP annual health checks Transition social worker Sleep Employment and education Bone health Best interest Sexual health Memory and learning Mental health Dentist Adult clinics Driving Alcohol and drugs Hospital passports LD liaison nurse LD red flag Parental responsibility