

**Mapping Transition
to make it
Personalised and
Holistic**

**RCPCH EQIP QI
Project**



**Hull University
Teaching Hospitals**
NHS Trust

Aim



To develop and implement a personalised transition plan for CYP with epilepsy for 40% of my caseload



Map transition care pathways in line with the National Epilepsy Care Bundle

Learning Points

1. Data
2. Family and young person engagement
3. Transition in young people with additional needs
4. Know your tribe
5. Know your area

DATA

Primary Drivers

CYP are better equipped for adult life with epilepsy and have a plan that is personal to them and useful.

Paediatric and adult buy in and support for the project from HUTH

CYP have better health outcomes post transition

Enable equality and reduced variability in the transition pathway between different patient groups and trusts.

Secondary Drivers

- Offer mix of face to face, online, questionnaires.
- Engagement day.
- Meet face to face with cyp with different abilities and ages

- Arrange an initial meeting with adults to discuss the project and plan activity..
- What transition information is currently given and how it is given. HUTH

- To set a baseline, pick 20 sets of notes from HUTH of 16-19 year olds who have moved to adults early 2023 and review what transition information was given by paediatrics and adults.

Ideas for change

- Contact local youth worker groups especially those involved in health work.
- Bribery
- create pamphlets/QR codes/leaflets/links to material already existing.
- Keep QI team updated.
- Identify venues for meetings and develop range of questions we need to explore.
- Separate groups/work with parents.
- Identify any budget from health that can be used to fund the groups/encourage participation/spend on materials or finished product.
- Identify mixed group from 12- 17
- Piggyback notes audit onto other audit work using Epilepsy bundle appendix 10

To develop and implement a personalised transition plan and transition pathway for CYP with epilepsy and a hand held transition plan for 40% my caseload

Data: What did our test reveal?

- 65% had a hand held transition plan in the form of a GP letter, but plans were not SMART
- 25% had not made a first appointment with adult neurology and had no follow up
- 0% had consent documented for sharing information
- 0% CYP with LD/ASD had hospital passport completed
- 17% of those in the questionnaire round wanted a clinic letter written to the YP
- 100% of those in the focus group wanted a CYP specific written transition plan

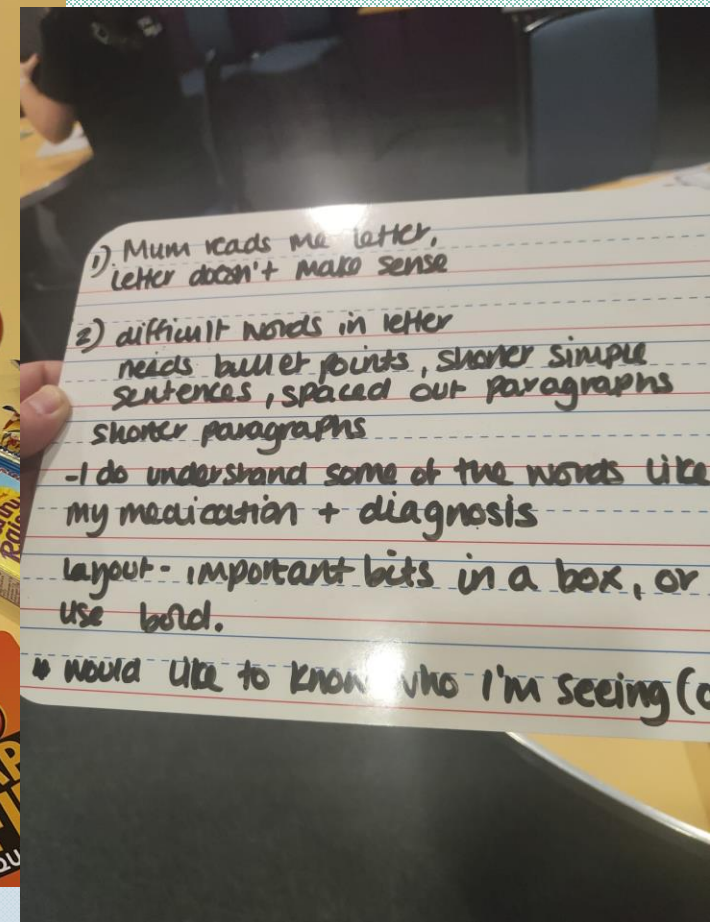
YP and Family Engagement

ENGAGEMENT:

- Formal family and CYP engagement– questionnaires, small YP focus group, clinic discussions
- Informal – direct contact with certain families (eg who's children had autism and LD) to discuss specific issues (F2F, phone, home visit)

HOW:

- Questionnaires (18 completed) after clinics, F2F with small group CYP, in clinic
- Mapping the transition pathway. (SEND, TS, Dravets , complex epilepsy)



1) Mum reads me letter,
letter doesn't make sense

2) difficult words in letter
needs bullet points, shorter simple
sentences, spaced out paragraphs
shorter paragraphs

- I do understand some of the words like
my medication + diagnosis

layout - important bits in a box, or
use bold.

• would like to know who I'm seeing (c)

Communication with CYP: Feedback from Youth group and parents

- Loved the £10 gift voucher
- Be friendly. Make the YP feel at ease. Smile 😊
- Talk to the YP. Even if they can't answer you back
- Get the YP to join in the consultation
- Short simple sentences. Don't rush. Pause between sentences. Don't waffle.
- Don't expect quick answers. Give time think and weight up the options
- Give longer appointments. Repeat important information on another day
- Chose a quiet clinic room without distractions – don't make people wait
- Use information the YP might understand

3. Why do I have epilepsy?

Epilepsy is a common condition. 1 in 240 children have epilepsy. It is even more common in adults. We only know what causes epilepsy in 4 out of 10 children. If we know the cause, it's often genetic or due to some sort of change or damage in your brain.



My epilepsy was caused by

Sometimes it helps to know why you have epilepsy so the doctors know what medication to use, or you might be able try another sort of treatment.

4. How was I diagnosed with epilepsy?

Your epilepsy diagnosis was made by a discussion with yourself, your parents, carers, or your teachers who might have witnessed you having a seizure. We often ask your carers to make a video of your seizures so we can use that we can pick out all the little details that are important.

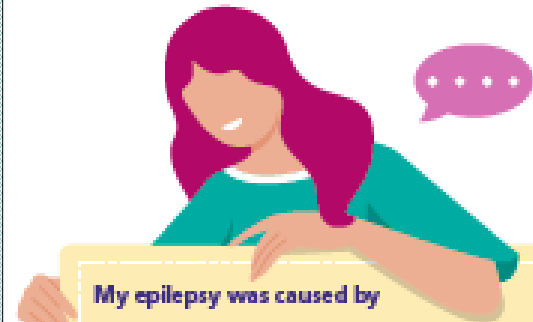


The doctors may ask for other tests to help them try and make sure they have your diagnosis of epilepsy correct. These tests may be a EEG, an MRI, an ECG or blood tests to test for genetic condition.

My epilepsy was diagnosed by.....

2 Why do I have epilepsy?

Epilepsy is a common condition. 1 in 240 children have epilepsy. It is even more common in adults. We only know what causes epilepsy in 4 out of 10 children.



My epilepsy was caused by

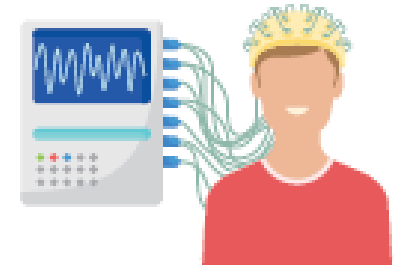
Sometimes it helps to know why you have epilepsy so the doctors know what medication to use, or they might try another sort of treatment. Knowing why you have epilepsy also help us decide if you will still have epilepsy as an adult.

3 How was I diagnosed with epilepsy?

Your epilepsy diagnosis was made by:

A discussion with yourself, your parents, carers, or your teachers who might have witnessed you having a seizure. We often ask your carers to make a video of your seizures so we can use that we can pick out all the little details that are important.

The doctors or nurse may ask for other tests to help them try and make sure they have your diagnosis of epilepsy correct. These tests may be a EEG, an MRI, an ECG or blood tests to test for genetic condition.



My epilepsy was diagnosed by

Transition in CYP with SEND / LD/ Autism



EDUCATION and EMPLOYMENT - Clarify SEND needs/ Diagnosis
EHCP reviews Future plans, Work experience



SOCIAL CARE SUPPORT, CONSENT - Parental Responsibility, Mental capacity, Best, Interest, DLA – PIP, Transition Social Workers, Care Packages, Independence



LD HEALTH SUPPORT – LD liaison nurses, LD flag, Hospital Passports, GP LD register, LD 14+ health checks, Wellbeing Service, Community Team for Learning Disabilities, PMLD/ Complex Neurodisability: Home visits, MDT, joint home visits



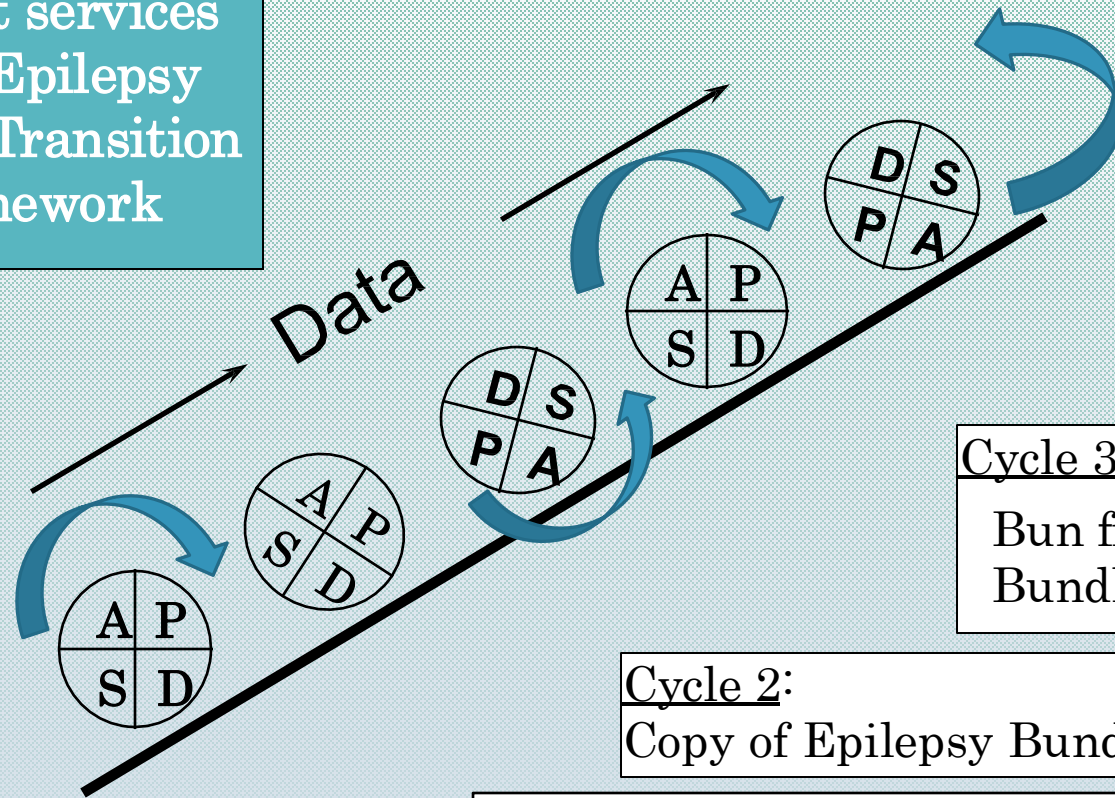
LIFESTYLE - Friends and relationships, Drugs and alcohol, Sexual Health and Pregnancy, Stress and emotional wellbeing, Living Well



Know your tribe - Engaging with Adult services

Mapping transition
to adult services
using Epilepsy
Bundle Transition
Framework

PDSA cycles



Cycle 5
To re-audit records

Cycle 4
Processes clarified and changes
agreed on

Cycle 3:
Bun fight in the board room to map the
Bundle against what was happening

Cycle 2:
Copy of Epilepsy Bundle framework emailed to adults

Cycle 1
Invite to the adult team to request we map the service

Initiate Transition: from 13 YO

DURING Transition: 13 – 16 YO

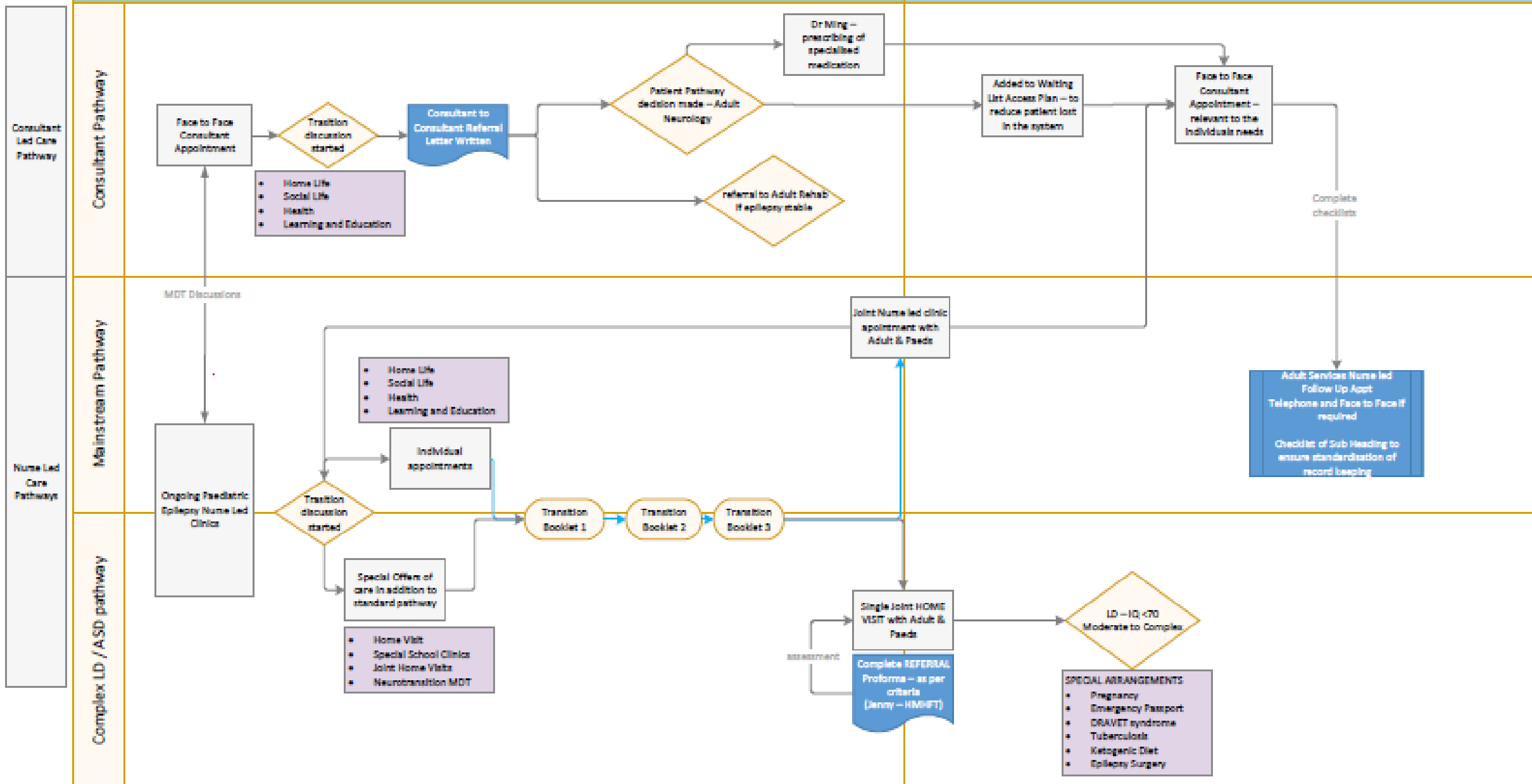
16-18 YO

POST Transition: Up to 25 YO

Epilepsy Transition Pathway

Paediatric Services

Adult Services



Know your Area

Education

Local SEND team, EHCPs
Hospital SEND teams
Connexions
SENCO / Special schools
Local offer

Community Health services

Continuing care
Learning disability teams
GP
Wellbeing service
Palliative care teams
ICB



Social Care

Mainstream
Disability – OT, home care
Transition/adults S/W

Hospital based services

Learning disability team
QI
Communications teams
Digital team
Other subspecialties
ED



Service impact

- Collation of resources for signposting for CYP with diverse needs(heath, lifestyle, education, employment, community inclusion)
- Transition letters to be addressed to CYP and include domains in the National Epilepsy Care Bundle
- Better equipped at developing individual personalised transition plan (develop SMART goals consistently)
- Develop transition specific clinics with longer appointments to maintain focus
- Continue with youth engagement and patient feedback