

# What do Young People with Epilepsy approaching adult services want?

Hannah Gerrard, Roald Dahl Transition Epilepsy Specialist Nurse, Royal Berkshire Hospital Foundation Trust, Reading  
Dr Sarah Hughes, Paediatrician wsi Neurodisability/Epilepsy, Royal Berkshire Hospital Foundation Trust, Reading

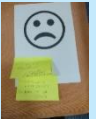
## Introduction and Aims

Adolescence is a stage when many young people (YP) become more independent and will want to make their own choices about their lives. Finding out what affects their epilepsy can be part of making informed choices. Part of the role of the Paediatric team working with YP with Epilepsy (YPwEp) includes preparing them for adult services and to be as independent as possible when managing their own health conditions.

For some YPwEp, the epilepsy may be their only health challenge. Many YPwEp will have comorbidities, which can require more complex planning for adult services and with variable independence. A Patient engagement/QI project, in line with the RCPCH&Us Engagement pilot programme 2021, aimed to review the current epilepsy transition service and gain the views on what the YPwEp and their families would like delivered and how. Within this review of transition, we have aimed to consider the transitioning of both those children in mainstream as well as those within specialist education provisions, whose needs may be different, due to their comorbid conditions.

Aim of the project to review three main areas of the epilepsy transition service:

1. Introduction and delivery of information about the move to adults and sharing risk information
2. Sharing information about things "outside" of the epilepsy eg preparing for college, driving, pregnancy, drugs and alcohol
3. What should the clinics look like? Do they want a teenager-specific clinic?



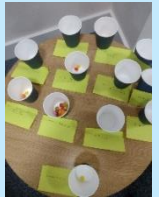
## Methodology

A four step approach was taken for this project: Planning was in line with the RCHP&Us engagement training pilot course and the project was registered with the RBHFT trust as a Quality Improvement project:

- **Stage 1: Patient engagement** – a series of events were planned in order to consider what the YPwEp wanted from their services, and how they would find it best to learn and develop their skills in self-management. This was held in person after school hours.
- **Stage 2: Parent engagement** – a series of events were planned in order to consider what their parents needed from transition services, including those families where their YPwEp had moderate/severe learning disability. This was held on teams due to parental commitments.
- **Stage 3: Clinician engagement** – the Paediatric Epilepsy team will meet to discuss the results from Stage 1+2, and to consider what might be possible within existing workforce
- **Stage 4: Review of resources** – a review was held to consider what resources currently exist to support individual learning.

YPwEp were recruited from Epilepsy clinics in sequential order and offered the chance to join an engagement event. Parents were separately asked to join the events.

Parents of YPwEp with mod/severe LD were invited to Stage 2 engagement events. A selection of Young Adults with Epilepsy were also individually asked about their experiences.



A range of tools were used including:

- Direct questioning and facilitated discussion between attendees.
- Using sweets to cast votes on personal preferences, such as timing of any training
- Using Post-its to comment on questions and the prioritise
- Review of existing knowledge and experiences of information shared about transition

## Results:

**Feedback on what is working well within the current epilepsy service:**

### YPwEP

- were clear that they were informed in their clinic appointments and understood the risks relating to epilepsy around water, heights, bikes, sports and sleep
- were clear that information on SUDEP was delivered in a sensitive way by the consultant and they understood how to minimise the risks
- 3/5 YPwEp felt they had been given sufficient information on their medication and medication management
- YPwEp were clear they did not want specific teenage epilepsy clinics

### Parents of YPwEP :

- felt risk and safety information was realistic, factual and informative
- felt there was a clear focus on what the young person could do after diagnosis
- were clear there was support outside of clinic appointments from consultants and epilepsy nurses to discuss information
- felt safe in the clinic to be able to be open with difficult topics

### Parents of YPwEP with LD

- felt the individual transition summaries were important so they knew who would be supporting their child's health needs



**Changes and improvement ideas which were shared by young people and families**

### YPwEP told us that they:

- would like further information on their diagnosis and how to inform others of their diagnosis
- would like more information delivered on the potential side effects of medication and information on how they know if the medication is effective
- would like further information on alternative treatments available when medications have not been effective
- would like more information on how alcohol will affect their epilepsy and the effect the alcohol will have on them

### Parents of YPwEP:

- feel drugs and alcohol risk information should be shared from 15 years old

### Meeting other YP with Epilepsy:

- YPwEp would like face to face group sessions without parents present after school to meet other young people with epilepsy and to have transition information delivered to them
- Parents of YPwEp were clear that risk information and medication management support would be best held as a group session with other young people with epilepsy delivered by the nurses/consultants. They felt a quarterly group session lasting 1-1/2 hours after school would work best

### Meeting other parents:

- Parents of YPwEp with LD did NOT report the opportunity to meet other parents would be something that would be important for them but would be happy to consider mentoring other parents who were earlier in the journey. Their YPwEp all attended specialist education provision, so already had peer support in place
- Parents of YPwEp without LD were observed to find it helpful to meet other parents as they reported they felt isolated in their journey

### Parent of YPwEP with LD

- would like the standard information shared with them for them to decide if it is relevant to their YP
- felt a transition was important to have for them to be informed of who will support them into adult services

### Contraception advice

- YPwEp would like contraception information from the age of 13 years old and further information on the effects their medication could have on the baby from 15 years old
- Parents of YPwEp feel contraception/pregnancy/sex/ alcohol risk information should be shared from 15 years old.

## Conclusions:

### Learning points:

- Service development WITH Young people involved can be rewarding and fun
- Young people are far more effective at teaching each other – we observed a superb discussion about SUDEP during one of the events
- Parents and YP valued meeting others in similar circumstances
- Parents of YPwEp and LD often already have peer networks established
- Despite the enquiry in annual Ep 12 audits, a teenager specific clinic is not current planned at this stage for our service, as our young people do not report finding this a helpful option.

### Next steps:

In line with the feedback from our YPwEp, and further to discussion within the Paediatric Epilepsy team, the following is planned:

- Three pilot sessions in evenings to share information on:
  - How do I tell my friends about my epilepsy? (including information on epilepsy, medications, first aid)
  - Wellbeing (mental health and adjustment, going to college)
  - Sex drugs rock and roll
- A parallel set of three sessions for parents is being offered as a pilot to share the same information
- Resources are noted to be tight within the service, but so these are being run as pilot sessions, pending feedback
- A further set of engagement sessions with parents of YPwEp and LD is planned, to look at Neurodisability and Learning disability aspects of transition, in order to plan for their training and support needs through the transition period

