Young Epilepsy

Young people's changing experiences of epilepsy care

Summary of survey findings

March 2021

Key findings

Young Epilepsy surveyed young people with epilepsy (aged 11 to 25) about their experience of epilepsy care and how this has changed as they have grown older and transitioned to adult services. We found that:

- Most young people (77.5%) **transitioned to adult epilepsy care** at age 16, 17 or 18. (34.8% at age 16, 27.0% at age 18).
- The largest proportion of young people (39.5%) said they had no **joint appointments with children's and adults' epilepsy services** as part of the transitions process, whilst 26.7% had more than three joint appointments.
- Around 1 in 3 young people (32.3%) said their experience of moving from children's to adults' epilepsy services had a **negative impact on their mental health**.
- Nearly half of the young people (45.3%) said their **treatment or diagnosis changed** when they moved to adults' epilepsy services.
- More young people had contact with an **epilepsy specialist nurse** in children's services (79.4%) than in adult epilepsy care (73.1%).
- More young people **felt listened to** by their epilepsy nurse in paediatric care (72.3%) than by their adult epilepsy nurse (57.8%).
- More young people said their epilepsy nurse **explained things clearly** (66.4%), in comparison to their epilepsy doctor (59.9%).
- Only 39.4% of young people said their paediatric epilepsy doctor / nurse spent more time **talking to them directly** as they got older.
- Only 1 in 3 young people (29.0%) said they had more opportunities to **speak with their paediatric epilepsy doctor / nurse on their own** as they got older.
- Only 1 in 2 young people (51%) said their epilepsy doctor / nurse helped them to **understand and self-manage their epilepsy** more as they got older.
- Nearly 1 in 3 young people (29.7%) said their children's epilepsy doctor / nurse did not speak to them about **how epilepsy might impact on a range of life issues** (for adult care this was only 19.4%).

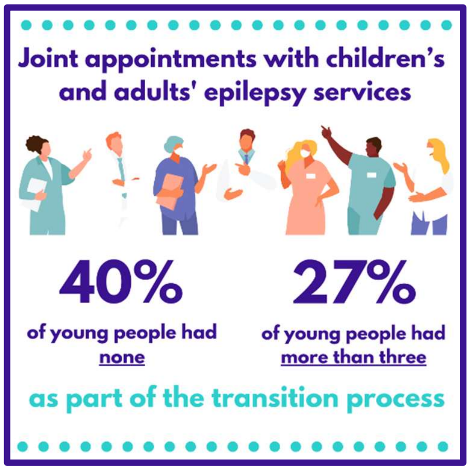
Age of transition to adult epilepsy care

Most young people (77.5%) transitioned to adult epilepsy care at age 16, 17 or 18 (34.8% at age 16, 27.0% at age 18).

- For those who transferred to adult epilepsy care at age 16:
    - 45.1% said their doctor / nurse started talking to them about their move to adult epilepsy care before they turned 16.
    - 54.8% said their epilepsy doctor / nurse started talking to them about this when they were 16.
- For those who transferred at age 18:
    - 62.5% said their epilepsy doctor / nurse started talking to them about their move to adult epilepsy care before they turned 18.
    - 37.5% said their epilepsy doctor / nurse started talking to them about this when they were 18.

Joint appointments with paediatric and adult epilepsy care

The largest proportion of young people who had transitioned to adult epilepsy care (39.5%) said they had no joint appointments with children's and adults' epilepsy services. However, 26.7% had more than three joint appointments.



Much fewer young people said they had one (9.3%) or two (3.5%) joint appointments.

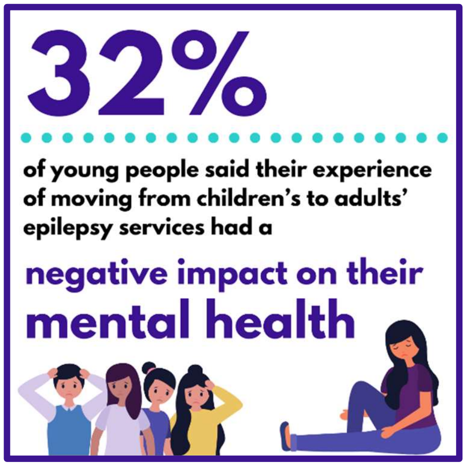
> *"Paediatric care was amazing but there wasn't a transition period. One day I was just handed off to a new service with no idea who I was seeing or what these people were like."*

Several young people highlighted the need more targeted services for young adults.

> *"I think there could be a transition period for young people turning 18 where if they feel they need to or want to talk with a specialist after they have been discharged from paediatrics this can be offered no matter how controlled their epilepsy is."*
>
> *"Once 17 I have to access adult A&E and be put on a ward with 100 year old patients with dementia."*

Impact of transition on mental health

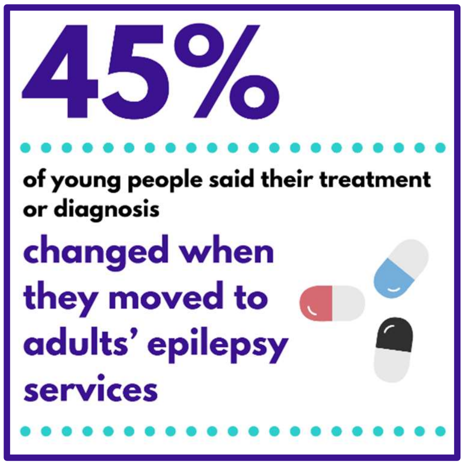
Around 1 in 3 young people (32.3%) said their experience of moving from children's to adults' epilepsy services had a negative impact on their mental health. 52.1% said that the process had no impact on their mental health.



> *"I feel forgotten within the system and very much alone."*
>
> *"I feel that I have been abandoned by the hospital after years of support as a child."*
>
> *"It wasn't a successful transition, which caused a lot of anxiety and stress."*
>
> *"I felt like there was less support for adults. Lots of things in life were changing that my epilepsy impacted upon and I had no idea how to handle it – still don't."*
>
> *"The transition needs to be less stressful. I formed a bond with my child epilepsy doctor and it was extremely confusing when I couldn't see him anymore. At the time it felt like a massive part of my support system had been taken away."*

Transition changes in treatment or diagnosis

Nearly half of the young people (45.3%) said their treatment or diagnosis changed when they moved to adults' epilepsy services.



45%

of young people said their treatment or diagnosis

changed when they moved to adults' epilepsy services

Some of this appeared to be due to different medication or an increased dosage being suitable in adulthood.

> *"Increase of medication due to increase in fits."*
>
> *"Taken off sodium valproate."*
>
> *"Keen to get me on different medication that couldn't have before because was under 16."*

Other changes appeared to mark a different approach to diagnosis or care.

> *"New medication, lots more testing, adjusted dose of existing AED."*
>
> *"Exploration of the possibility of surgery stopped for about a year and they just changed my meds before restarting looking into surgery."*
>
> *"I was diagnosed with JAE [juvenile absence epilepsy] whilst in the surgery process. Previous diagnosis was just generalised epilepsy."*
>
> *"Me, my mum and dad all had tests done on us and found out that I have a rare epileptic syndrome."*

Access to epilepsy professionals

More young people had contact with an epilepsy specialist nurse in children's services (79.4%) in comparison to adult epilepsy care (73.1%).

> "*My nurse was changed and I wasn't told of who the new nurse was until I turned up to the appointment I don't like meeting new people and this was ignored."*

Several young people said they had less support in adult services, in comparison to their experience of paediatric epilepsy care.

> *"My appointments have become less frequent and are now only brief 10/15 minute chats. My seizures are not controlled and my medication is just increasing."*
>
> *"I no longer have as much support now. If needed I'm told I can talk to my GP but I feel they don't know as much and that they also don't really care."*

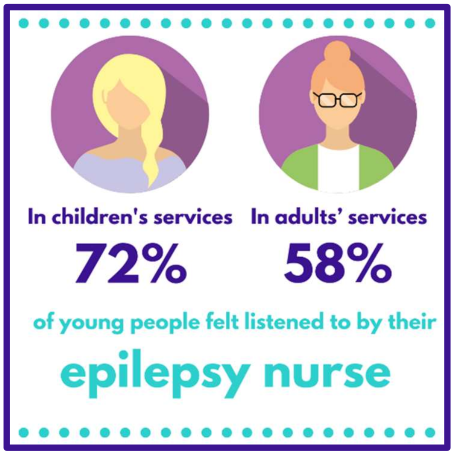
A significant number of young people suggested that more frequent contact from their epilepsy nurse / doctor would help them manage their epilepsy as they got older. Their recommendations included:

> *"Easier ways to contact epilepsy nurses or doctors."*
>
> *"Regular mini appointments just to check up and more help on how I can manage epilepsy in everyday life."*

Several young people mentioned the importance of having a healthcare professional who is the same gender, for discussing personal issues.

Being heard

More young people felt listened to by their epilepsy nurse in paediatric care (72.3%) than by their adult epilepsy nurse (57.8%).



In children's epilepsy care 58.9% said they felt listened to by their epilepsy doctor, significantly less than their epilepsy nurse. In adult services 56.3% felt listened to by their epilepsy doctor.

> *"As a child I was listened to, as an adult they try and tell me what to do."*
>
> *"There should be a young adult ward/service as in adult services I feel too young but in children's services they listened to me and I felt included in my care."*

There were mixed comments on the extent to which young people were listened to by their adult epilepsy professionals.

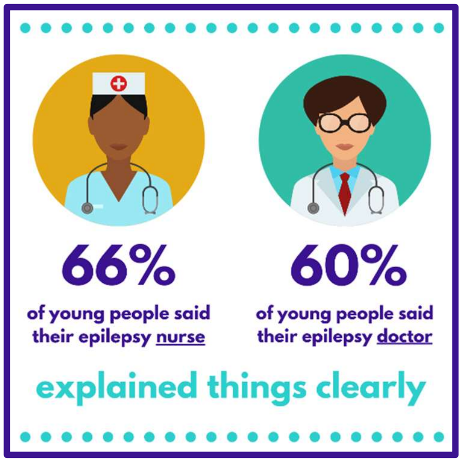
> *"The only reason I'm listened to now is because I'm not a child. Everything I said as a child I repeat as an adult and I'm listened to immediately."*
>
> *"I still feel like a child and I wish I was listened to more and had more control of my life rather than other people making decisions for me like I can't make them myself about MY life."*

Young people commented on what would help them manage their epilepsy as they got older:

> *"To have my concerns listened to."*
>
> *"Longer appointments! I have so many questions that just don't fit into the time!"*
>
> *"My appointments on time and me being listened to better. I struggle to understand things and what I am taking."*

Information being explained clearly

More young people said their epilepsy nurse explained things clearly (66.4%), in comparison to their epilepsy doctor (59.9%). There was not a significant difference between paediatric and adults' services.



In paediatric care 68.4% of young people said their epilepsy nurse explained things clearly, compared with 59.2% for their epilepsy doctor. In adult care, this was 64.0% for their epilepsy nurse and 60.8% for their epilepsy doctor.

Several young people commented on the need to have things explained more clearly to help them understand.

> *"Tell me in more details and maybe for me use pictures to help."*

> *"I just feel since my diagnoses, I've been seen by many different doctors who all tell me different things and have never been clear."*

Being spoken to directly

Only 39.4% of young people said their paediatric epilepsy doctor / nurse spent more time talking to them directly as they got older.

Young people commented on the difference in this area after moving from children's to adult epilepsy care.

> *"They're more direct and listen to me a lot more!"*

> "*It suddenly changed to the doctor only speaking to me and not my mum."*

One young person suggested that being more involved in their epilepsy care would help young people manage their condition as they got older.

Opportunities to speak in confidence

Only 1 in 3 young people (29.0%) said they had more opportunities to speak with their paediatric epilepsy doctor / nurse on their own as they got older.

29%

of young people in children's epilepsy care said they had more opportunities to

speak with their epilepsy doctor/ nurse on their own as they got older

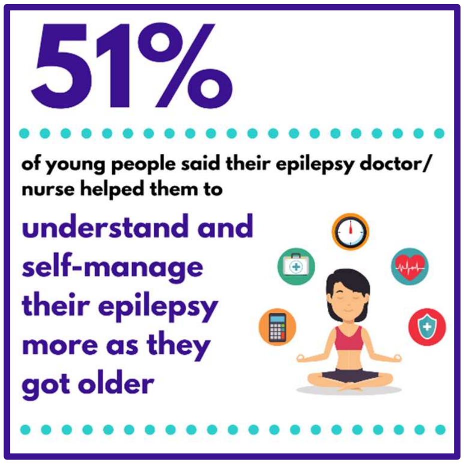
One young person commented on how things had changed for them:

> *"I have been able to speak privately about things with my doctor / nurse rather than have a parent present."*

Support with epilepsy self-management

Only 1 in 2 young people (51%) said their epilepsy doctor / nurse helped them to understand and self-manage their epilepsy more as they got older. Slightly more young people said this was true in adults' epilepsy services (53.0%), compared to paediatric services (49.7%).

> *"I have the freedom to choose my treatment! … I feel like I'm in control."*



A significant number of young people commented on how support with self-management could be improved. This included help to manage seizure triggers such as stress and tiredness, as well as support to manage medication routines and side effects.

> *"More interaction and support from people who know and understand epilepsy. Doctors / specialists teaching me more about what epilepsy affects etc."*

> *"Start talking one to one about getting older and wanting to get more independence, so I can be taken more seriously as a young adult."*

Several young people commented on how they would like better access to support as they get older because they are unable to live independently. Others spoke about the need for more epilepsy research and better treatments.

One young person spoke about withdrawing themselves from medical care, describing the side effects of medication as worse than the seizures:

> *"I discharged myself and lied about seizures stopping as I felt medical care no longer helped me."*

Epilepsy's broader impact on life

Nearly 1 in 3 young people (29.7%) said their children's epilepsy doctor / nurse did not speak to them about how epilepsy might impact on a range of life issues. For adult care this was only 19.4%.

The most likely topics mentioned were epilepsy's impact on driving, mental health and alcohol. Many young people said there should be more support on how epilepsy impacts on different areas of their lives as they get older. This could be support provided by their epilepsy team or signposting to other information sources or support groups.

Has your epilepsy doctor / nurse spoken to you about how your epilepsy might impact on any of the following (now or in the future)?

	Children's epilepsy care	**Adults' epilepsy care**
Mental health (e.g. worries and anxieties)	41.9%	48.5%
Exams	31.6%	20.9%
Studying at college or university	26.5%	30.6%
Moving away from home	12.9%	27.6%
Working	23.2%	34.3%
Alcohol	40.0%	50.7%
Driving	51.0%	67.9%
Travelling	12.9%	20.1%
Relationships	16.8%	30.6%
Your own life goals	16.8%	23.9%
None of these things	29.7%	19.4%

"I have been given lots of useful information about different issues as I've gone through university and into employment."

"I don't think there is much support as I would like to talk to someone as I get upset as I am not the same as my friends."

"I hate it. I can't drive, I messed up my GCSEs, I won't be able to get a job, I can't even shower without telling someone."

"It's made me less smart than I used to be and crushed everything I wanted to do at about the age I am now."

Many young people highlighted the need for more support with epilepsy's impact on mental health and suggested how this could be improved.

> *"Quicker access to mental health services.*
>
> *"Discussion of effect of diagnosis on mental health and regular mental health / general wellbeing check-up through later teen years."*
>
> *"Offering mental health support, because the stigma and misconceptions surrounding epilepsy are strong enough for people to leave you out of things in fear you'll have a seizure which can be really damaging mentally."*

Demographics

Young Epilepsy received 207 survey responses from young people with epilepsy across the UK, between 27 November 2020 and 18 January 2021.

The respondents ranged in age from 11 to 25 years old. Approximately 74.9% of the young people were female and 32.9% of the respondents had been diagnosed with a learning disability.

Most of the young people (78.2%) had been diagnosed with epilepsy before they turned 16. The current ages of the respondents were as follows:

- 11-15 (19.8%)
- 16-18 (15.0%)
- 19-21 (27.5%)
- 22-25 (37.7%)