

Epilepsy12 Quality Improvement Case Studies 2023

South Tees Hospitals NHS Foundation Trust

Transition to adult epilepsy services is a key step in the management of children and young people with epilepsy. In the past, we had an informal arrangement around transition which was not consistently applied. Our trust-wide transition steering group supported a focus and formalisation of a clear transition pathway between child and adult epilepsy services.

Our aims were:

- To raise awareness on the importance of transition planning
- To formalise a clear transition pathway using a recognised model
- To improve patient and parent carer experience around the progression from child to adult epilepsy services.

A trust transition nurse was appointed to work with the epilepsy team and staff were educated on the Ready, Steady, Go transition programme. Electronic transition forms were also made available.

We identified all the patients who were entering the transition phase and enrolled them on the Ready, Steady, Go pathway. We established a specific transition nurse-led transition clinic to enable time and space for questions and support, separate to clinical needs, with both paediatric and adult epilepsy nurses present. Young people were seen for some of the appointment on their own. Older young people started with the 'Go' aspect of the programme to offer at least some preparation and empowerment.

Outcomes

As a result of the project, we were able to empower and prepare young people and their families/carers. The approach enabled discussion on care and safety risks, such as alcohol, sex and relationships. Relations between paediatrics and adult services improved as well.

However, young people and families were often wanted to use these appointments to discuss non-transition related items, such as their symptoms and medication.

Next Steps

We will continue to roll out the Ready, Steady, Go programme with more focus on the 'Ready' and 'Steady' at earlier points in the patient pathway, as 'Go' will always be covered in the transition clinic. We also plan to offer further joint clinics with adult services and sharing a '3 Questions' leaflet with patients to encourage shared decision making. To evaluate the project, we developed a patient experience questionnaire.

