At the crossroads: Impact of transition specialist nurse (TSN) in care of children and young people with epilepsy undergoing transition process

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Introduction and Aims:

Young people living with epilepsy express a higher rate of satisfaction when using a patient-centred model of transition care, receiving the emotional and practical support from a skilled health professional. Those who experience a poorly planned and/or executed transition to adult services are at risk of increased dissatisfaction, morbidity and mortality including SUDEP.

A scoping exercise against national standards of healthcare transition for young people across the Northeast and North Cumbria highlighted the need for a robust transition process. This includes 10 stages of transition process and a key worker to support young people through the transition process in each trust. Although this role is usually provided by epilepsy specialist nurses, their busy workload often limits their involvement and delivery of the transition plan. Provision of a dedicated transition specialist nurse (TSN) can make significant improvement within the transition process and patient experiences.

We appointed a TSN in our trust in 2022 and she has been working with paediatric epilepsy services to provide transition care for young people with epilepsy.

The aim of our project is to determine whether there were differences in: the streamlining of the transition process, the patient experience of care and the service satisfaction for young people with epilepsy receiving care from the transition specialist nurse.

Methodology- Retrospective data collected from epilepsy database and patient's records.

Results- At time of TSN appointment in 2022:

No patient-centred formal transition process (Ready, Steady, Go)

No database of eligible young people for transition

Documentation on patient records patchy

Lack of training among staff

Patient education and information was lacking

Main interventions done by TSN:

Creating database, registering the RSG (ready, steady and go) plan in patient

record and alert on hospital record system

Training of staff about RSG and patient questionnaires

Meeting the patient and family in the epilepsy clinic