

Transition from paediatric to adult epilepsy services: A patient centred approach

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Introduction

Epilepsy affects 0.5% to 1% of children and is one of the most frequent neurologic conditions in childhood.¹ Although remission can be achieved during childhood, in 40-50% of cases, young adults continue to have seizures, requiring their care transferred to adult services.¹ NICE quality standard (QS) cover diagnosing, treating and managing epilepsy both in children and young people (QS27) and adults (QS26).^{2,3} Both quality standards include an agreed transition plan into the adult service. "Transition from children to adult services for young people using health or social care services" offers a detailed guidance on this process. (QS140)⁴ This is an audit of our Epilepsy Transition Service against quality standards for Transition Services QS140.

Methods:

- ✓ We retrospectively analysed the clinical notes of the patients seen in the Epilepsy Transition Clinics (ETCs) at the Atkinson Morley Regional Neuroscience Centre St George's University Hospitals NHS Foundation Trust, between June 2015 and September 2017.
- ✓ We collected data on patient demographics, diagnosis and comorbidities.
- ✓ We also collected data on management, relevant clinical topics discussed during consultation as well as other significant issues, such as education, driving, employment, sexual health/contraception. Patients and parents/caregivers were asked to fill in an anonymised feedback form.

Results:

A total of 25 patients were identified, 19 males and 6 females, with a mean age of 17 years. Patient background epilepsy diagnosis and comorbidities are shown in graphs 1&2

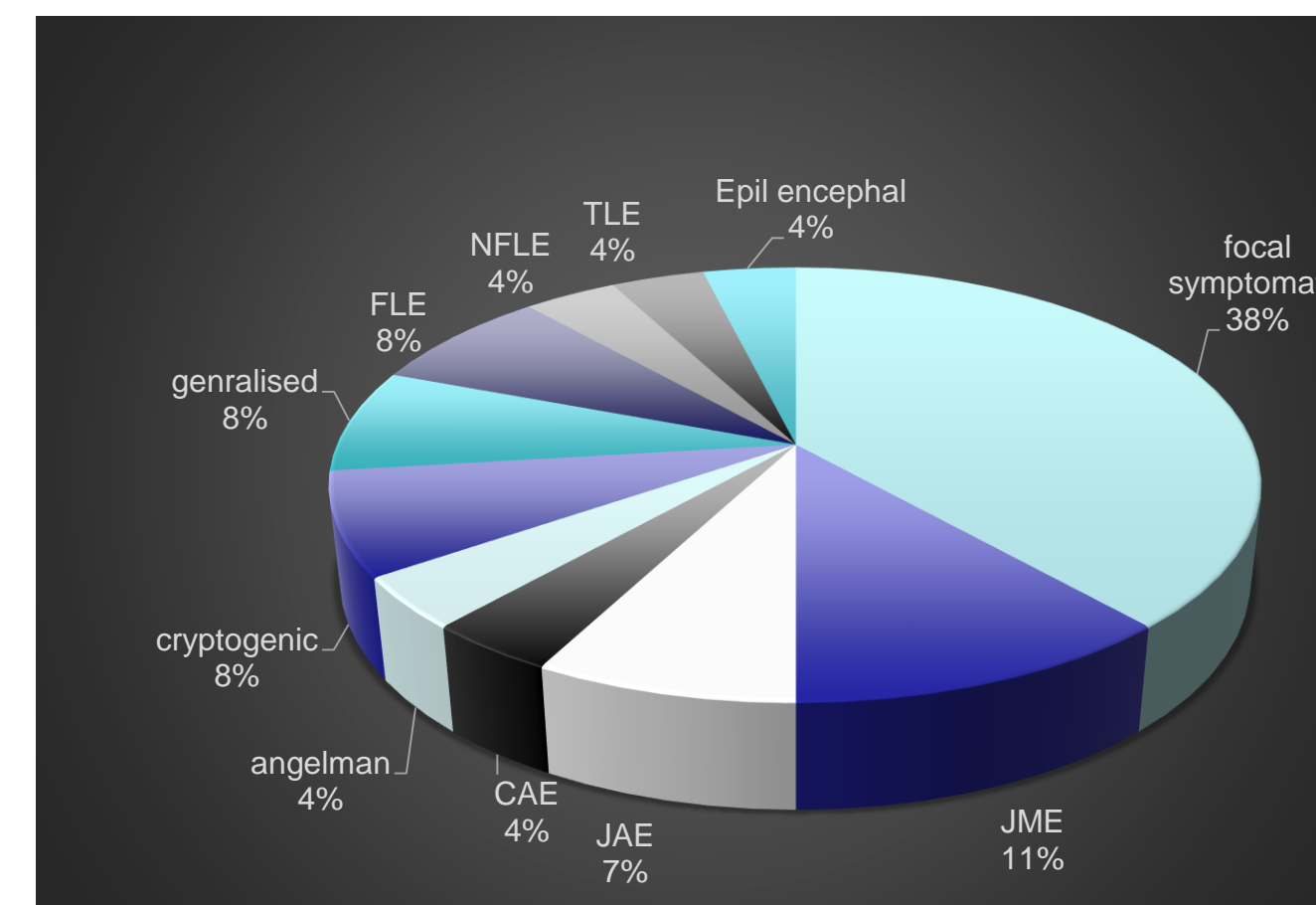
In the ETC, a consultant pediatrician with a special interest in epilepsy and a consultant epileptologist were always present. An epilepsy nurse was present in half of the clinics and a learning disability nurse in 16%.

i) Documentation

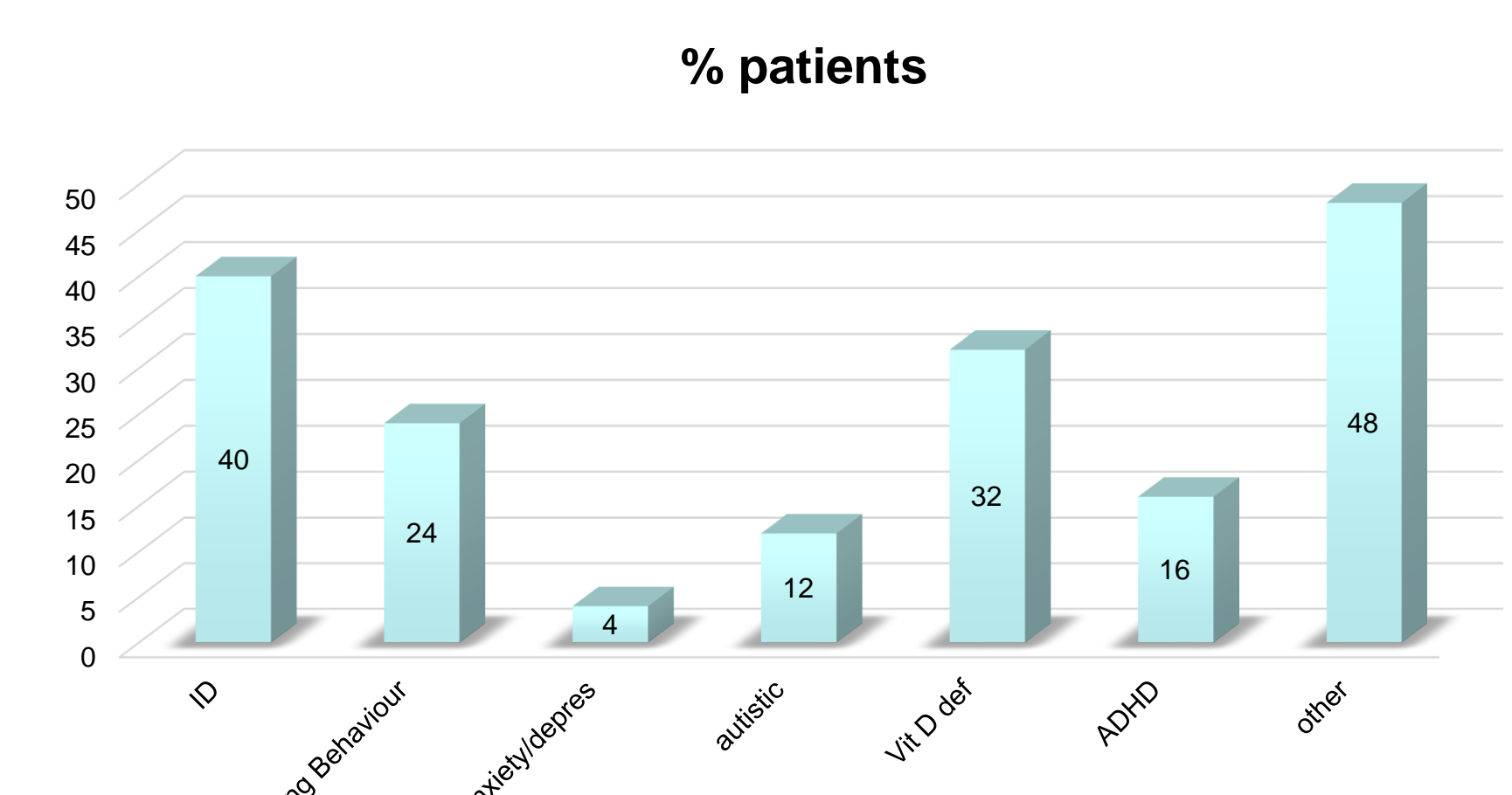
- ✓ Current antiepileptic drugs (AEDs) were documented in all cases and failed AEDs in 88%.
- ✓ Investigations were documented only if they were performed.
- ✓ Relevant topics were discussed in the majority of cases (clinical and background information 68% and 64% respectively).
- ✓ Most allied issues, such as driving, smoking, were discussed only in patients where it was felt appropriate. However, no patients received consultation on sexual health and contraception during the ETC. (Graph 4)

ii) Transition planning and feedback

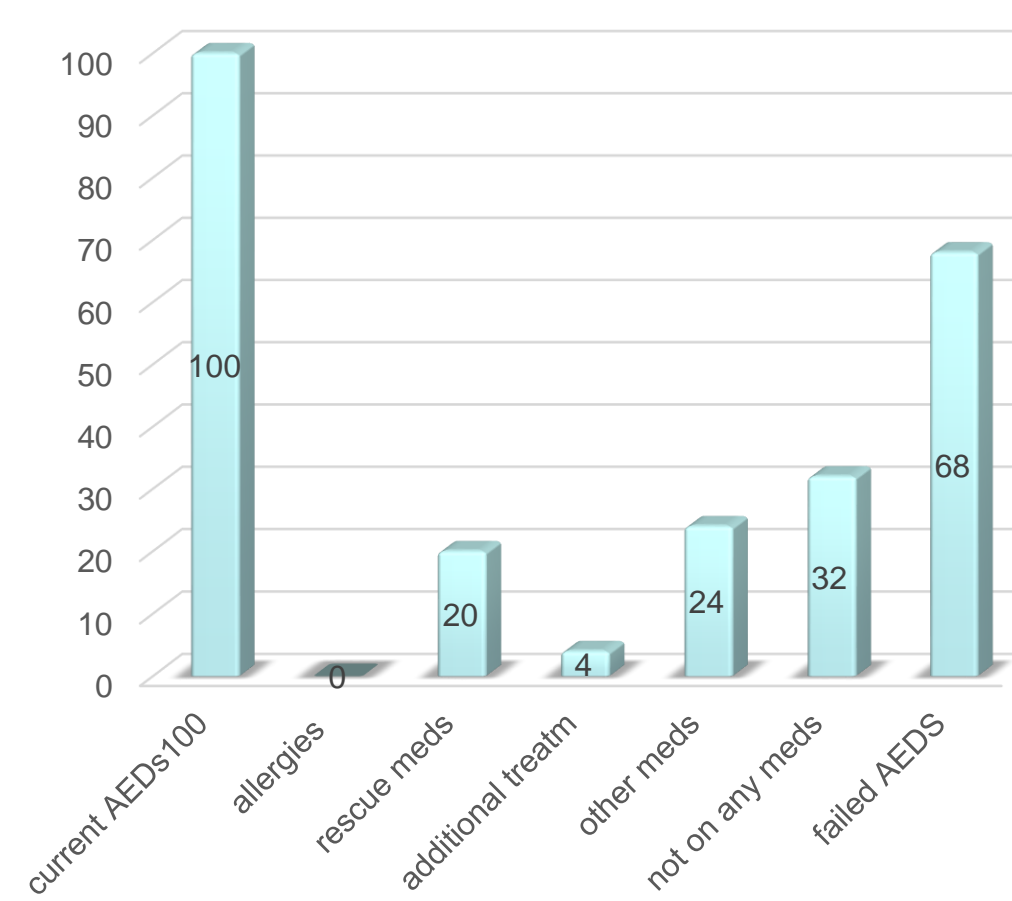
- ✓ All patients had planned transition and clinic review held by the paediatric team prior to transition.
- ✓ ETCs in our department received excellent feedback from patients and their parents/caregivers. All patients and caregivers felt they had received enough information during the clinical appointment, their concerns were heard and addressed and the clinic met their expectation.
- ✓ Only 14% did not attend the first follow up with the adult epileptologist and 27% with the adult epilepsy nurse.
- ✓ There is no Transition key worker in our service to coordinate care and support during transition and 56% of patients and parents/caregivers would have found a “transition nurse” very useful.



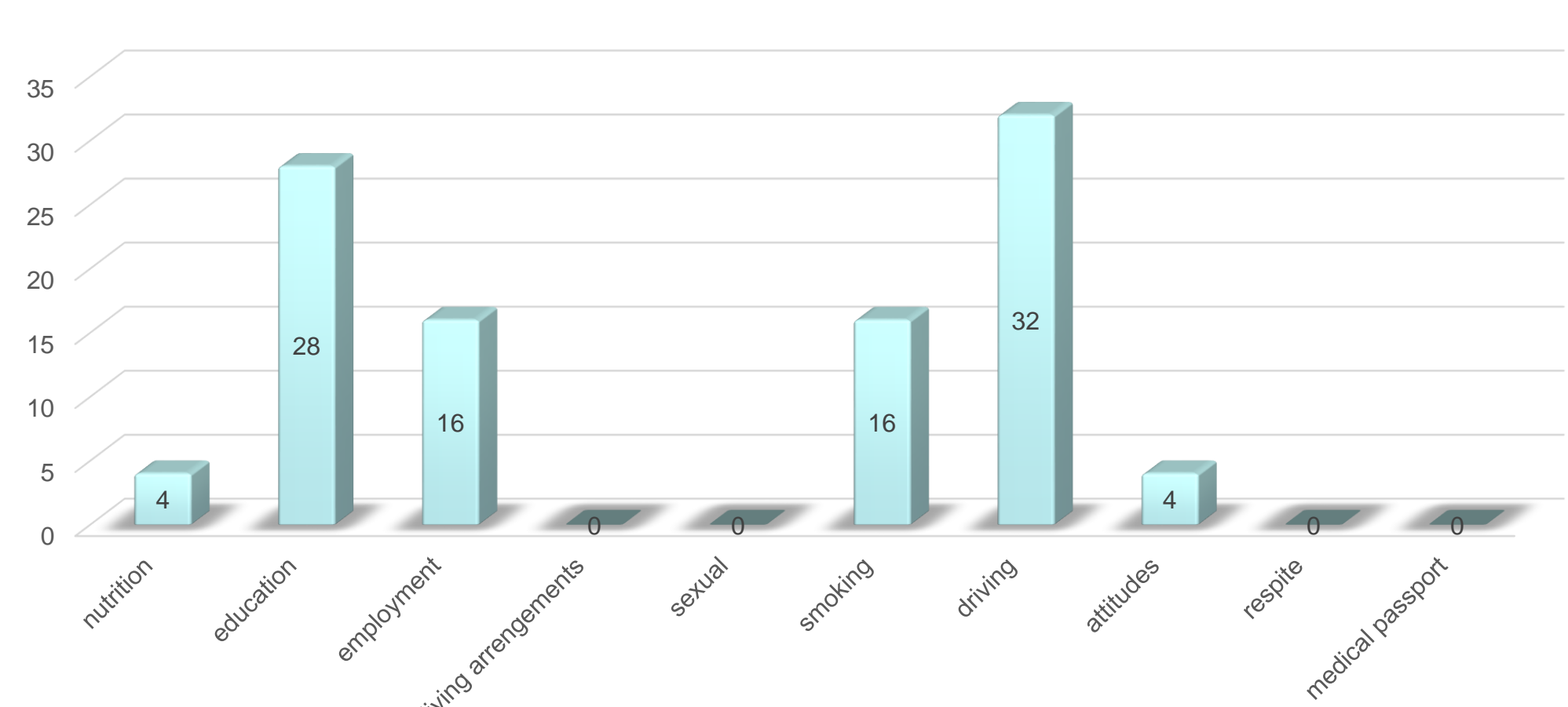
Graph 1: Epilepsy syndrome



Graph 2: Aetiology of epilepsy



Graph 3: Documentation of treatment



Graph 4: Documentation of allied issues discussed

Patient feedback form on transition epilepsy clinic service		Family/ carer feedback form on transition epilepsy clinic service	
1. Did you have any contact/ discussion with regards to what the transition clinic would involve?		1. Did you have any contact/ discussion/ information with regards to what the transition clinic would involve?	
Yes	<input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/>	Yes	<input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/>
2. Did you feel that you and I discussed your thoughts/ concerns about the transition clinic?		2. Did you feel that you and I discussed your thoughts/ concerns about the transition clinic?	
Yes	<input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/>	Yes	<input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/>
3. Did you feel you were involved in the decisions for your treatment in the transition clinic?		3. Did you feel you were involved in the decisions for your treatment in the transition clinic?	
Yes	<input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/>	Yes	<input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/>
4. Did you feel that your concerns and questions were answered in the transition clinic?		4. Did you feel that your concerns were listened to/ answered during the transition clinic?	
Yes	<input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/>	Yes	<input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/>
5. Did the transition clinic meet the expectations?		5. Did the transition clinic meet the expectations?	
Yes	<input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/>	Yes	<input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/>
6. Would it have been good to have a booklet for the transition services now that would list what you would be able to get at 15 and 18 transition appointments from adolescence and adulthood for continuity?		6. Would it have been good to have a booklet for the transition services now that would list what you would be able to get at 15 and 18 transition appointments from adolescence and adulthood to ensure continuity?	
Yes	<input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/>	Yes	<input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/>
7/ If you have answered "no", "unsure", could you please tell us why?		7/ If you have answered "no", "unsure", could you please tell us why?	
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8. Please write any comments on your experience in the transition clinic/ please use the back of the page if needed		8. Please write any comments on your experience in the transition clinic/ please use the back of the page if needed	

I am not sure if I was involved as mainly my father and my sister were talking

We are really happy with the service our son has received. Thank you for making his transition smooth

Very happy with the transition to adult services so far. My son's epilepsy is stable but I know who to call if I am concerned

The staff were really helpful and gave me the best advice and medications I am now

Transition was very smooth and we had a lot of support from doctors

Good because there was a common understanding of the situation making transition as easy as possible

quite friendly and got treated very well

If there have been more issues/seizures a transition nurse would have been useful

Patient and carer feedback forms

Patient and carer feedback

Quality standard [QS140] & Our Transition from children's to adults' services

Quality statements	
Quality statement 1: Planning transition	1. Transition planned by paediatric team
Quality statement 2: Annual meeting	2. Annual meeting took place
Quality statement 3: Named worker	3. Patients are under a named consultant but there is a need for a Transition Worker
Quality statement 4: Introduction to adults' services	4. Successful introduction to adult services through the Epilepsy transition clinic- Excellent feedback from the patients and their carers
Quality statement 5: Missed first appointments after transfer to adults' services	5. Only 14% DNA'd first follow up with consultant and 27% with the epilepsy nurse

Discussion:

Ensuring a smooth transition process is crucial for health and social related outcomes and engaging young people with adult services. Our practice meets most of the NICE quality statements and patients and parents/caregivers have a good experience of our services.

- ✓ To improve our documentation, we designed the "Referral Proforma for transition clinic" where all appropriate clinical and social information filled in by the paediatrician is available to the adult neurologist prior to the ETC.
- ✓ The paediatric epilepsy team has also created an information leaflet on the epilepsy transition process as part of the preparation of patients to this journey.
- ✓ The next step to improve our service would be to identify a "transition nurse" as the key worker and source of support prior, during and after their transition period.