



## Epilepsy Transition Guidelines

# Policy and Procedures for the transfer of Young People from Paediatric Epilepsy services to Adult Epilepsy Services

### Definition and overriding aims:

Transition is a period of planned and structured multidisciplinary review between both paediatric and adult teams with the aim of optimising the care and treatment of young people with epilepsy as they move from children's to adult services. Transition should be a smooth and gradual process that covers the period before, during and after a young person moves from children's to adult services. It should aim to address the individual medical and psychosocial needs of such young people and their families/carers in order to empower them with the skills necessary to manage their long-term condition.

### Rationale and evidence base:

“The need for continuity of care during transition from paediatric to adult services is particularly important for young people managing the physical and mental transition from adolescence to adulthood. Good management of this transition period by healthcare professionals is vital to develop and maintain the self-esteem and confidence of the adolescent with epilepsy. It also **provides an important opportunity to review the diagnosis, classification, cause and management of a young person's epilepsy before they enter adulthood**”<sup>[1]</sup>. The institute of public policy research have highlighted importance patient empowerment in improving outcomes and reducing long-term cost to the NHS.<sup>[2]</sup>

Children with epilepsy have been shown to have worse social outcomes in adult life including lower levels of academic achievement and employment, higher levels of alcohol misuse and mental health service engagement. This remains the case when compared to both healthy controls and to children with other non-epilepsy chronic conditions such as JIA.<sup>[3][4][5]</sup> Transition clinics have been shown to reduce AED poly-therapy, reduce the number of patients on AEDs, improve AED compliance and improve overall social outcome in terms of education, employment, independence and overall psychosocial outcome<sup>[6]</sup>. Studies have highlighted that effective transition improves long term outcomes in chronic conditions and improves service experience for young persons and their carers<sup>[7]</sup>. A recent Cochrane review has highlighted that the available body of evidence to evaluate the impact of transitional care programmes is small however three studies did highlight improvement in transitional readiness in young people, enabling them to better self-manage and adjust to using adult health services.<sup>[8]</sup>



## **NICE quality standards of transition:**<sup>[7]</sup>

1. Young people who will move from children's to adults' services start planning their transition with health and social care practitioners by school year 9 (aged 13 to 14 years), or immediately if they enter children's services after school year 9.
  - Allows for better planning and a more gradual process with more time for the young person to become involved in decisions and with the aim of reducing disengagement with services.
2. Young people who will move from children's to adults' services have an annual meeting to review transition planning.
  - Allows for regular review of a young person's changing needs through adolescence and into adulthood.
3. Young people who are moving from children's to adults' services have a named worker to coordinate care and support before, during and after transfer.
  - A single point of contact (ideally someone the person knows and trusts) serves to co-ordinate care and signpost to appropriate support amongst the multiple services and professionals the young person comes into contact with. The aim of this is to increase attendance in adult services and to generate a better experience of care and better outcomes.
4. Young people who will move from children's to adults' services meet a practitioner from each adults' service they will move to before they transfer.
  - Provide an opportunity to build a young person's confidence, reduce their concerns and increase their willingness to have new practitioners involved in their care. This can lead to a smoother transition for the young person and more regular attendance at appointments in adults' services, with better outcomes.
5. Young people who have moved from children's to adults' services but do not attend their first meeting or appointment are contacted by adults' services and given further opportunities to engage.
  - Disengagement with adult services may have an adverse impact of their future health, mental health and social care needs and thus every effort should be made to encourage engagement of the young person with adult services.

## **Implementation of the transition process:**

The implementation of a transition process at an individual hospital level will inevitably vary based upon the local availability of funding and resources such as epilepsy specialist nurses, psychological input, clinic space and inter-departmental co-operation between adult and children's services. The following is one proposed model.

1. Annual review in a designated MDT transition clinic for all patients with known epilepsy from the age of 12 years.
2. The composition of the transition MDT should ideally consist of a paediatrician with expertise in epilepsy, epilepsy specialist nurse, clinical psychologist, disability lead nurse



and charity representative such as epilepsy action. Presence of these professionals may vary across hospitals in the region based on their local availability.

3. One member of the MDT should be named as the care co-ordinator throughout the transition process (paediatric epilepsy nurse(s) are most often best positioned for this role).
4. Pre-appointment questionnaires should be sent out to the young persons and their families to help identify key areas of importance to them (paper based or online survey). These questionnaires should be mindful to address additional social issues relevant to adolescents such as alcohol consumption, clubbing, contraception, pregnancy and driving. Some units may be able to offer pre-appointment virtual clinics, which can be used to identify these issues. Parent and Young person questionnaires are freely available as part of the “Ready, Steady, Go” program.<sup>[10]</sup>
5. A QOL scoring system should be implemented as an objective measure of progress, to highlight short-term issues and to help with long-term evaluation of local service performance.
6. A standardised model of transition such as the “Ready, Steady, Go”<sup>[10]</sup> program should be considered as a framework for clinicians to use throughout the transition process.
7. From 16 years of age (this will be dependant on the developmental level of the young person and the clinicians assessment of their readiness for transition to adult services) at least one annual joint MDT to include a neurologist and specialist nurse from adult services should ideally take place prior to care being taken over by the adult services team. If joint MDT is not possible then the young person should have met members of the adult services team prior to full transition under their care.
8. Transition to adult services should be achieved prior to their 18<sup>th</sup> birthday (although the optimal age will vary between young persons).
9. Regular audit of the process should be undertaken to assess adherence to NICE standards and to assess the impact of the service on measureable outcomes such as attendance, compliance, AED polypharmacy and QOL measures.

## **References:**

[1] Epilepsy in children and young people. NICE quality standard[QS27] February 2013.

[2] Patients in control. Why people with long-term conditions must be empowered. Institute for public policy research. September 2014.

[3] Juvenile myoclonic epilepsy 25 years after seizure onset: A population-based study. Camfield CS, Camfield PR. *Neurology*. 2009;73:1041–1045.

[4] Idiopathic generalized epilepsy with generalized tonic-clonic seizures (IGE-GTC): A population-based cohort with >20 year follow up for medical and social outcome. Camfield P, Camfield C. *Epilepsy Behav*. 2010;18:61–63.

[5] Transition from pediatric to adult epilepsy care: a difficult process marked by medical and social crisis. Camfield P1, Camfield C, Pohlmann-Eden B. *Epilepsy Curr*. 2012 Jul;12(Suppl 3):13-21.



[6] Long-term effects of a multidisciplinary transition intervention from paediatric to adult care in patients with epilepsy R.P.J. Geerlings et al. *Seizure* 38(2016)46–53

[7] Bridging the gap: an integrated paediatric to adult clinical service for young adults with kidney failure P N Harden et al. *BMJ* 2012;344:e3718

[8] Interventions to improve the care of adolescents with long-term health conditions as they transfer from child to adult health services. Campbell F et al. *Cochrane Database of Systematic Reviews* 2016, Issue 4. Art. No.: CD009794.

[9] Transition from children's to adults' services. NICE quality standard [QS140] December 2016.

[10] Dr Arvind Nagra. University Hospital Southampton. NHS Foundation Trust.

<http://www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx>

*Guideline developed by Dr Luke Perry and Dr Muhammed Ottayil. July 2018, Ratified on 11<sup>th</sup> October 2018; Next review July 2021*