PAEDIATRIC AND ADOLESCENT EPILEPSY

TRANSITION GUIDANCE
Paediatric and Adolescent Epilepsy Transition Guidance

**Executive Summary:**
This document outlines the pathway of transition for children and young people with epilepsy from paediatrics to adult care. The transition process encompasses the planning, education, nurturing, support and organisation required for the young person and their family to move into adult services at a pace that is tailored to the individual child. Responsibilities and timings for the stages of transition are identified within this document.

**Supersedes:** New guidance

**This guidance will impact on:** Paediatric epilepsy services, Adult epilepsy services

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SECTION 1: INTRODUCTION

Epilepsy is a common neurological disorder characterised by recurring seizures. Different types of epilepsy have different causes. Caring for children and young people with epilepsy is a complex process which must be firmly focused on the child or young person and their family and other carers supported by health care professionals who have skills and expertise in all aspects of epilepsy management.

The Royal College of nursing (2013) states that young people aged 10 - 19 account for over 12 per cent of the UK’s total population in 2003. An increasing number of children with long-term conditions and complex needs are surviving into young adulthood. With over 85 per cent of children with chronic illnesses (Betz, 1999) and 90 per cent of those with disabilities surviving into adulthood, there is a growing need for specialized care to ensure a seamless transfer and transition from children’s to adult health care services.

A smooth transition is further supported by the intercollegiate report “Bridging the Gaps: Health Care for Adolescents” [2003], guidelines from the Royal College of Nursing [2004], “You’re Welcome” standards for adolescent-friendly services [DoH 2005] and is in keeping with the objectives of “Every Child Matters” [DfES 2004] and “Every Young Person with Diabetes Matters” (DOH 2007)

Definition of transition

Transition is a “planned, purposeful movement of the young person from a child centred to an adult orientated health care system”. It is a process which evolves over a considerable period of time and should not be considered an event. (Blum 1993)

Transitional care is a multi-dimensional, multi-disciplinary process that addresses not only the medical needs of young people as they move from a children’s service to a young persons services but also their psychosocial, educational and vocational needs and the needs of their parents.

The aims of transitional care are to:

1. Provide high quality, co-ordinated, uninterrupted health-care that is patient-centred, age and developmentally appropriate and culturally competent, flexible, responsive and comprehensive with respect to all persons involved;
2. Promote skills in communication, decision-making, assertiveness and self-care, self-determination and self-advocacy;
3. Enhance the young person’s sense of control and move towards independence
4. Provide support for the parent(s)/guardian(s) of the young person during this process
5. Maximise life long functioning and potential [McDonagh 2003,2005a].
SECTION 2: Key elements for an effective transition programme

1. A written policy (the trust has produced this guidance document to support staff to provide personalised care and support in line with individual transition needs of patients).
2. A preparation period and education programme with an individualised approach, which addresses psychosocial and educational/vocational needs, provides opportunities for adolescents to express opinions and make informed decisions and gives them the option of being seen by professionals without their parents.
3. A co-ordinated transfer process with a named co-ordinator and continuity in health personnel when possible.
4. Administrative support
5. Primary health care and social care involvement.

SECTION 3: Purpose

This guidance provides framework to ensure that the trust is effective in making suitable arrangements for the transition of young people with epilepsy from a paediatric to adult /young person’s service. It aims to ensure that children and families are fully involved in the process of transition and that all staff are aware of the process.

All staff must ensure that all aspects of equality and diversity (E&D) are considered in order to ensure the child and their family/carer receives appropriate care and treatment and should include:
- interpreters (for non-English speakers or hearing impaired),
- access, aids and adaptations (for physical, sensory and learning disabled people) and
- religious and cultural factors – for example, ensuring specific dietary advice is provided.

These should be considered prior to any decision relating to transition.

For further information about E&D issues, please refer to the Equality and Human Rights Policy and Interpretation and Translation Policy

Safeguarding children and young people

- All those who come into contact with children, young people and their families in their everyday work, including staff who do not have a specific role in relation to safeguarding children, have a duty to safeguard and promote the wellbeing of children.
- All staff should be familiar with the trust policy and procedure for safeguarding children and young people, ‘what to do if you are worried a child is being abused’
- All health professionals working directly with children should ensure that safeguarding and promoting their welfare forms an integral part of all stages of care.
- All staff should be alert to the potential indicators of abuse and neglect in children, know how to act on their concerns and fulfill their responsibilities. A range of single and inter-agency training courses are available. Individual staff members and their managers will need to identify the correct level of training to enable the individual to fulfill their roles and responsibilities.
Where there is a current safeguarding concern consideration should be given during the transition period as to whether this will continue to be a concern into young adulthood and to whether referrals to the Trust Adult Safeguarding team and Adult Social Care are required.

All trust policies, procedures and advice on training is available on the Trust intranet or from Melanie Barker.

References/ related documents:
- Lost in Transition – key objectives, RCN

SECTION 4: Roles and Responsibilities

Clinical Matron

- The role of the clinical matron is to support and oversee the Paediatric Epilepsy team in the management of the service, act as an advocate for the service and ensure the team has adequate skills and knowledge to manage transition.

Paediatric Epilepsy Nurse

- The role of the paediatric epilepsy nurse is to ensure there is appropriate individualized transition for patients in adherence to this guideline.

SECTION 5: Background to the service

Currently there is no formal process for the transition of young people from paediatric to adult services. Whilst we accept that this is unsatisfactory, we are working hard to ensure that the patients have informal contact with us in regards to transition and their options, whilst hoping that a formal process will be up and running very soon.

The current paediatrician with specialist interest in epilepsy does discuss transition with the young people in their clinic appointments from around 16 years onwards.

The specialist epilepsy nurse has adopted a transition model which is used nationwide with all types of conditions, to create an interim process to support the young people and their families through the transition period. The model is called ‘Ready Steady Go!’ and uses three colour coded questionnaires to assess a young person’s knowledge of their own epilepsy and its management. This should be started from age 13 years and then completed before they move over to adult services. Parents also get the opportunity to voice their hopes through the transition process.
SECTION 6: Age ranges and clinics.

There must be a flexible approach to transition which takes into account developmental readiness and links to other social transitions such as leaving school. However for the purpose of the document age ranges and movement through the clinics have been defined as follow:

- Paediatric up to 16 years old
- Teenager 13/16 years old
- Young Person 16/19 years old
- Adult 19

SECTION 7: Philosophy of Transition

Aim of the service

East Cheshire Trust wishes to offer an excellent service to all children and young people with epilepsy and their parents and carers. We will do this by delivering good quality care that delivers excellent clinical outcomes that are provided by a multidisciplinary team that empowers the patient and their parents and carers.

- A transition programme is an essential part of quality care for adolescents with epilepsy.
- Effective transition must recognise that transition in health care is only one part of the wider transition from dependent child to independent adult.
- Transition services must also address the needs of the parent/guardian(s) whose role is evolving at this time in their son/daughter’s life and health-care.
- In moving from child-centred to adult health services, adolescents undergo a change that is cultural as well as clinical.
- Transition services must be multidisciplinary and involve both paediatric and young person’s epilepsy teams and any other parties involved in the care of the adolescent.
- Transition services should also include education, social services and voluntary agencies. Service development must be undertaken in collaboration with the adolescent involved, enhancing their sense of control and independence in their healthcare.
- Coordination of transitional care is critical and a key worker should be identified for each adolescent to oversee his or her transition who links with a counterpart within the young persons service to ensure seamless transition.
- Transition is NOT synonymous with transfer. Transition is an active process and not a single event like transfer. Transition must begin early, be planned and regularly reviewed and be age and developmentally appropriate.
- Transition services must undergo continued evaluation.

SECTION 8: Preparation for Transition

- Both the teenager/adolescent and their parent(s) are prepared for transition and eventual transfer to the young person’s service.
- Adolescents are only transferred to the young persons service when they have completed growth and puberty and have the necessary skills to function in a young persons service largely independent of parents and staff e.g. decision-making, communication, self-care, assertiveness. When this is not possible due to cognitive impairment and/or severe
disability, appropriate advocacy, preparation and developmentally appropriate care in the young persons service should be ensured prior to transfer.

- Transition planning is instigated well before the anticipated transfer time – in early adolescence when a series of educational interventions discuss understandings of their condition, the rationale of therapy, source of symptoms, recognising deterioration and taking appropriate action, and most importantly, how to seek help from health professionals and how to operate within the medical system, including primary and emergency care.
- Adolescents are helped to take appropriate responsibility for their epilepsy from as early an age as possible. Furthermore, their parents are encouraged to help them to do so.
- The concept of independent visits is introduced well in advance the aim being to see the teenager/adolescent by themselves for some time during clinic visits from approximately age 13-14 years. NB Parents must remain involved and should be seen with the adolescent at some time during the session (note research into this by Weissberg-Benchell, Wolpert and Anderson, 2007)
- However an informal or formal chaperone must be present for any physical examination. Any intimate examination must be carried out in the presence of a formal chaperone, an informal chaperone parent / carer or someone already known and trusted by the child/young person may also be present for reassurance and to minimise any distress caused by the procedure. Adolescents/Parents or guardians must receive an appropriate explanation of the procedure in order to obtain their informed consent to examination. (See trust Chaperone Policy)
- In preparation for adolescents to be seen independently, the paediatric clinic will provide continuity of professionals at each visit. The adolescent and young person is also be given (where possible) the option of seeing a professional of preferred gender if necessary. Team members (including departmental visitors’ e.g. medical students) are kept to a minimum in these individual consultations i.e. a maximum of 1 extra.
- A schedule of likely timings and events is given in early adolescence and they should be involved in developing detailed timings for their own transition. Details are documented in the notes to ensure continuity especially if seen by different members of the multi-disciplinary team.
- Leaflets and material about the young persons clinic and transition process is provided in clinic settings from early adolescence.

### SECTION 9. Timings and age

Timing of transition MUST be flexible and not restricted to age criteria only. Timing of transition and transfer depends on

- chronological age,
- maturity,
- adherence,
- independence,
- adolescent readiness,
- parental readiness.

Flexibility will also be required depending on the adolescent’s medical status.
1. **Earliest discussion of transition to adult care**

This should take place at 10 or 11 years during their last year at primary school. A transition plan for ALL teenagers/adolescents should be in place by the age of 14 years and reviewed at least annually thereafter.

2. **Age of effective transfer to young persons service**

Aged 16-18 years.

3. **Age of effective transfer to adult service.**

Aged 18 years.

4. **Exceptions to above timing**

Whilst a young person may be transitioned from a paediatrician to an adult doctor at the age of 16 years old, the nursing care will remain within the paediatric epilepsy team until that person reaches the age of 18 years old when they will be fully transitioned to the adult epilepsy team. In the 2 years prior to full transition to adult nursing services, the paediatric epilepsy nurse will involve the adult epilepsy in the young person’s care so to ensure that there is good communication between the two services and familiarity between the family and the adult epilepsy nurse prior to full transition. Whilst the adult epilepsy nurse will become involved around the age of 17 years old, the nursing responsibility will remain with the paediatric epilepsy nurse until the young person is 18 years old.

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**SECTION 10. Process of transition**

**Preparation for Transition**

**Initiation & co-ordination of transition**

Every consultant and nurse seeing children and young people in the clinic is responsible for ensuring discussion of transition when they see a patient aged 13-14 years old. Full documentation that this has taken place must be recorded on the patient’s notes and the diabetes database.

**First discussion of transition**

Adolescents will be identified at pre clinic meetings that they will begin transition at that appointment and a member of staff named as the key worker for the patient. This will ensure transition is discussed with every patient and identify the key worker responsible for the process.

**Educational programme**

- Gradual increasing emphasis on increasing self advocacy for the adolescent patients in clinic. This includes involvement in decision making, being seen alone and other issues which impact on their life.
• The competency checklist that is used by the paediatric diabetes department will transfer with the young person as they move into the adult service.

**Assessment of readiness for transition**

This will involve individual discussion with the adolescent and their parents with the epilepsy team. The ultimate decision to move to the young person service lies with the adolescent. This will be assessed at each appointment following completion of the GCSE’s.

**Transfer Process to Young Persons Service**

The Paediatrician writes a letter of referral requesting an appointment in the young person’s clinic and an appointment is given within 3 months. Issues of confidentiality must be considered in the young persons clinic letters are addressed to the young person, parents are seen with the young person if they wish.

**Transfer Process to Adult Services**

Transfer to the adult service will be at 18 years. This service currently involves a change of staff and venue. Consideration needs to be given to transport issue, how to avoid non attendance and identification of key personnel.

**Involvement of GP in transfer process**

The GP needs to be sent a copy of the transition plan.

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**SECTION 11: Audit**

This effectiveness of this guidance and the quality and effectiveness of service provided to children and young people transitioning and their families will be monitored via SQS Sub-committee via complaints/ PALS, incidents and survey data

Any learning/recommendations will be discussed and agreed by the Paediatric Clinical Governance Committee.

**SECTION 12: References**

Blum RW. Garell D, Hadgman CH et al. Transition from child-centred to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. *J Adol Health* 1993; **14**: 570-6


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