South
PAEDIATRIC NEUROSCIENCES
Operational Delivery Network

Best Practice Recommendations

# EPILEPSY TRANSITION

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| **SETTING** | South Paediatric Neurosciences Operational Delivery Network. |
| **FOR STAFF** | Staff involved in the pathways for young people (under 18 years) undergoing Transition within Epilepsy services. |
| **PATIENTS** | Young people who are with Epilepsy Services in organisations across the South region. |

## Guidance

### Summary.

Transition of a young person moving into adult health and social care is defined as “The purposeful planned process of transferring a young person’s healthcare from a child-centred to an adult orientated care setting that comprehensively addresses the medical, psychosocial, educational and vocational needs of that young person” (Inbetweeners full report, 2023).

The definition of transfer is the actual point when the responsibility of providing care and support to the young person moves from the children to adult services (NICE Guidelines, 2016).

World Health Organization refer to the adolescence phase of life between childhood and adulthood, from the ages of 10-19 years old. Transition should be undertaken in a person-centred way which reflects the rapid physical, cognitive and psychosocial growth of the adolescent years. It is critical that health services which the young person is accessing are equitable, appropriate and effective. (Adolescent health, 2024).

All young people with epilepsy under the care of secondary and tertiary services should be transitioned effectively and holistically within a planned pathway into the appropriate adult services for region. All centres offering Epilepsy services for young people should have in place appropriate transition pathways, policies, and facilities for the young person to ensure a timely personalised transition.

Trusts should ensure that transition and transfer are embedded into health care professional’s everyday practice. All health care professionals who are involved in transition should have access to transition training (Inbetweeners Full Report, 2023).

Education should be available to support professionals with a direct role and responsibility in transition. There is currently one online free course that be accessed on the following link: https://www.e-lfh.org.uk/programmes/adolescent-health/.

Trusts should ensure that all healthcare professionals involved in transition have this included in their job descriptions.

## Statistics

Young Epilepsy conducted a survey on the young person's changing experiences of epilepsy care in March 2021.

- 32% of young people said their experience of moving from children to adult epilepsy service had a negative impact on their mental health.
- 45% of young people said their treatment or diagnosis changed when they moved to adult epilepsy services.
- 39.5% of young people said they had no joint appointments with children's and adults' epilepsy services.
- 26.7% had more than 3 joint appointments (Young Epilepsy, 2021).

It is important for trusts to be aware of the inclusion of psychosocial, developmental, psychological, and medical barriers to transition:

- Providers to be aware of the inequalities within the population of young people with epilepsy, with the respect of their ability to access health services. In line with Core20PLUS5 (Core20PLUS5, 2023).
- Cognitive and developmental barriers including those with an identified learning disability and those with progressively apparent limitations in cognitive function.
- Complex mental health, mental health screening ensuring early planning is commenced (MICE,2021)..
- High risk of seizures i.e. drop attacks, which requires 1:1 supervision to ensure the young person's safety.

To also be mindful; of the challenges with parental adjustment and the parents/carers/guardians' anxiety over the transition journey. It is crucial that a plan is put into place to address and support these needs.

Link to Epilepsy 12 data: https://www.rcpch.ac.uk/work-we-do/clinical-audits/epilepsy12

It is widely acknowledged that offering an effective transition pathway for young people with Epilepsy has significant benefits to the patient, in terms of long-term outcomes concordance with care as well as having a positive impact on the Mental Health of the young person.

The following recommendations are designed to support the centres across the South in optimising transition pathways to achieve this. This document is intended to provide a reference for what is considered best practice across the South and should be viewed alongside locally agreed Standard Operating Procedures (SOPs) which should be followed at all times by local clinical teams.

## When to Transition?

- Healthcare trusts should have local pathway's/SOP for **ALL** young people transitioning with long term health conditions, including Epilepsy.
- Young person should be assessed by individuals with appropriate MDT expertise to ascertain the appropriate age/time to commence the transition discussions with young person and their parent/carer/guardian.
- It is recommended all hospitals in a region should have a policy regarding the acute admission of young people between the ages of 16-18 years old, which balances the health needs of the young person but also take into account the development and safeguarding needs of the young person. 16–17 year-olds can be admitted to an adult ward; however they are legally still children. To mitigate any risk to the young person local safeguarding policies should be in place for this age group.
- It is important to remember those young people who may benefit from greater time and resource to make an effective transition some additional time in paediatrics, to help develop those skills to make an effective transition at a developmentally appropriate time, which may be into early adulthood. It is paramount that both paediatric and adult services work in partnership to facilitate a smooth transition.

## Preparation prior to Transition Conversation

- It is pivotal to empower the young person including their parent/carer/guardian. It is also important to encourage the young person to become their own advocate; this right should be considered from diagnosis. This is likely to enhance effective seizure management and shared decision making. (Remembering to take into account the mental capacity act, consent and parental responsibility).
- Is the young person able to understand and communicate who is important to them (with support and appropriate adaptive communication methods).
- The young person and their parents/carers/guardians should be given appropriate information leaflets/electronic resources regarding the transition pathway.

## Initiating the first conversation with the YP and family

- The conversations should start at around the age of 13 years old. It is important to ensure that all the conversations and resources are developmentally appropriate for the young person.
- All young people with Epilepsy should have a designated named worker for initiating and planning their transition (NHS England 2023).
- Ensure the young person is involved in who they would like to be their named worker for initiating and planning the transition (NHS England 2023).

- If the young person is unable to verbalise this, then the parent/carer/guardian should be involved in this decision, also consider about enlisting an advocate if there are concerns about the young person's voice not being heard.

- To ensure the young person* is given a voice, who they would like involved in their transition, is it a parent/carer/guardian, friend or another relative (Inbetweeners Report 2023). "No decision about me, without me" (Department of Health 2012)". *To include looked after children.

- Ensure there is a clear list of all health, social and education professionals involved in transition.

- The most suitable transition pathway is chosen for that young person, ensuring the young person or parent/carer/guardian are involved in this.

- When trusts are developing transition pathways, specific consideration should be given to the added benefit of specific transition roles such as: Transition Specialist Nurse, Youth Workers, Adolescent Consultant, someone to oversee the young person through the transition pathway and beyond into adulthood.

- Liaising with primary care for young people with a learning disability. At the age of 14 years, they are eligible for an annual health assessment. To ensure a clinic letter is sent to the GP clearly stating that the young person is eligible for this (NHS England and Improvement, 2019) You can find a template in appendix V. It also important to ensure the correct SNOMED code is used.

- It Is also pivotal that GP's are included in MDT meetings and clinic letters relating to the young person's transition pathway are also sent to the GP.

- To ensure that the young person can be seen on their own for a period of the appointment.

- Local transition checklists must be completed.

- Ensure key professionals identified fluid may change over time, documentation is key to facilitate this.

- Clinic letters should include the young person.

- To approve and maintain attendance, consideration should be given to clinic times, venue, support options should be considered based on the child's age and consider other individual needs of the child such as co-morbidities, cognitive abilities, and anxiety levels.

- Members of the healthcare team should consider opportunities to 'make every contact count' (refer MECC) and consider health promotion opportunities during preparation discussions.

- Various methods and tools can be used to support children to have a successful transition. Examples of existing tools and resources used across the South can be found on the FutureNHS page https://future.nhs.uk/TVWPccodn/view?objectID=43867088.

## Commencing the Journey

- Ensure informed consent is an ongoing process.
- Any reasonable adjustments required should have been communicated across all stakeholders in preparation for the young person's appointment. i.e. appointment area, reception and wider department or nursing team. The young person, parent/carer/guardian should been involved in completion of the reasonable adjustments written within the clinic letter and should have a copy for reference.
- Understand/ take undertake the cognitive ability of the young person and make reasonable and appropriate adjustments for them.
- For those young people who have multiple professionals involved, an annual transition MDT meeting should take place. These should be coordinated by the Epilepsy Transition Specialist Nurse. Epilepsy Transition Specialist Nurse is to ensure minutes and actions are disturbed across the MDT.

**The following flow charts have been developed to support the individualised transition journey.**

Appendix I: Flow chart for young people with a low seizure burden.

Appendix II: Flow chart for young People with complex needs.

Appendix III: Flow chart young people with a life limiting/palliative diagnosis.

Appendix IV: Flow chart for young people with a learning disability.

## Pathway Audit and Review

- As part of the ODN, centres should participate in audits of their transition pathway for children; potentially but not inclusively to consider which inbetweeners recommendations.

### Table A

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**Authorising Body**

This document was approved through the Transition for Children with Epilepsy Working Group which is run by the South Paediatric Neurosciences ODN on 06/02/2024. For further information regarding this group please contact the ODN on cyp.odns@nhs.net.

**Queries & Contact**

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## Appendix I Flow Chart for Young People with a low seizure burden

Conversations start at 13 years of age, using Ready Steady Go. Discussions also around plan for adult services, to ensure expectations are set (potential discharge to GP)

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The young person is given the opportunity to be seen on their own from 13 years old. To start off with a small amount of time and then increase this time. To offer after school and virtual appointments.

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Once the young person turns 16 years old, they are to have two joint appointments with the paediatric epilepsy nurse specialist and the adult epilepsy nurse specialist.

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The young person is then seen by an adult neurologist, who can then decide at the appointment whether they follow up or GP or community epilepsy nurse.

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Discharge from adult neurology. A letter is sent to the young person and GP. Within this letter it clearly states the three reasons to referred into adult neurology. (Appendix VI)

## Appendix II Flow Chart for Young People with a complex health need

The transition conversation should ideally start around the age of 13 years of age. To ensure the young person (YP) and parent/carer/guardian are given opportunities to decide who they would like to be their keyworker throughout their transition journey. During this the YP and family are given opportunities to discuss future planning. (Explore the possible sharing of the keyworker role between Epilepsy Transition Specialist Nurse (ETSN) and Social Care Colleagues).

Ensure a list of current professionals is created and map to adult teams with the YP and family, to ensure good communication throughout the transition journey. A suitable transition pathway document is chosen, to ensure the YP and parent/carer/guardian are involved in this shared decision-making process.

Annual MDT transition meetings should take place. These should include the YP, parent/carer/guardian, key health, social and education professionals.

Keyworker to arrange and coordinate the annual meetings.

Keyworker to ensure minutes and actions are distributed across the MDT.

From the age of 15 years ensure conversations are had to identify when the young person turns 16 years they receive acute treatment in either a paediatric or adult ward.

To be also be mindful of the Mental Capacity Act when the young person turns 16 years and helping parents/carers to navigate this complex system (refer to your own mental capacity team).

Between the ages of 16 years -18 years old the YP and their family/carer/guardian to have at least two joint appointments with their ETSN, paediatrician and adult neurology prior to transfer. First appointment is led by the paediatrician and the second appointment is led by the adult neurologist, also the adult ESN should be present. Services are required to consider the physical environment and to make reasonable adjustments where necessary.

Transfer: prior to their 18th birthday.

It is paramount that both paediatric and adult services collaborate to ensure there is an overlap (Flex) of care planning and care provision from the age of 16 years and into early adulthood.

# Appendix III Flow Chart for Young People with a life limiting condition/palliative care diagnosis.

To start the transition conversation around the age of 13 years of age. To ensure the young person (YP) and parent/carer/guardian are given the opportunity to decide who they would like to be their keyworker throughout their transition journey. Also, the YP and their parent/carer/guardian are given the opportunity to talk about their needs and wishes for the future. (To explore the sharing of the keyworker role between Epilepsy Transition Specialist Nurse (ETSN) and the keyworker at the hospice.) It is important that a follow up meeting should be arranged within 3 months after these initial conversations.

To ensure a list of professionals is drawn up with the YP and parent/carer/guardian, to ensure good communication throughout the transition journey. A suitable transition pathway is chosen, to ensure the YP and parent/carer/guardian are involved in this shared decision-making process.

Parallel planning should take place for transition to adult services, though ensuring planning is made for deterioration through this process as well. Ensuring the MDT is involved in this parallel planning, including the hospice team.

Annual MDT transition meetings should take place, which include the YP and parent/carer/guardian. Keyworker to arrange these annual meetings.

Can virtual transition clinics be offered? to ensure the CYP and family are not having to take multiple visits to the hospital.

From the age of 15 years ensure conversations are had to see when the Young Person turns 16 years is it more suitable if they need acute treatment they are admitted to paediatric ward or adult wards.

It is paramount that both paediatric and adult services collaborate to ensure there is an overlap (flex) of care planning and care provision from the age of 16 years into early adulthood.

# Appendix IV Flow Chart for Young People with a learning disability

To start the transition conversation around the age of 13 years of age. To ensure the young person(YP) and parent/carer/guardian are given the opportunity, to decide who they would like to be their keyworker throughout their transition journey. Also, the young person and family are given the opportunity to talk about their needs and wishes for the future with the Epilepsy Transition Specialist Nurse (ETSN) and the wider MDT.

To ensure a list of professionals is drawn up with the YP parent/carer/guardian, to ensure good communication throughout the transition journey. A suitable transition pathway is chosen, to ensure the YP and family are involved in this shared decision-making process.

Annual MDT transition meetings should take place, which include the YP, parent/carer/guardian and key health, social and education professionals.

ETSN to arrange and coordinate the annual meetings.

ETSN to ensure minutes and actions are distributed across the MDT.

ETSN ensuring that conversations have taken place and clearly documented prior to the YP turning 16 years if they need acute treatment whether they would prefer to be admitted to paediatric ward or an adult ward.

To also be mindful of the Mental Capacity Act when the young person turns 16 years and helping parents/carers/guardian to navigate this complex system.

From the age of 16 years old the YP and their parents/carers/guardian to have two joint appointments with their ETSN, Paediatrician and adult neurology. First appointment is led by the paediatrician and the second appointment is led by the adult neurologist, also the adult ESN should be present. Services are required to consider the physical environment and to make reasonable adjustments where necessary.

The ETSN is responsible for ensuring that both paediatric and adult services collaborate to ensure there is an overlap (flex) of care planning and care provision from the age of 15 years and into early adulthood.

## Appendix V GP Template Letter

Dear GP,

Name:
Diagnosis:
SNOMED Code:

I am writing to inform you ……NAME…… is turning 14 years old on ……DATE….. We have informed …NAME….. and their parent/carer/guardian that they are eligible for an annual health check within primary care. We have asked them to contact the surgery to book in their annual health check.

Yours sincerely

## Appendix VI GP Template Letter for low seizure burden.

Dear Dr

……. has recently been transitioned from paediatric to adult services. ……. has been reviewed by the adult ……. Team and has been discharged from ongoing follow up due to stable seizure control.
We would be grateful for you ongoing support and management of …… epilepsy with prescribing continuation and review of epilepsy medications on an at least annual basis or more frequently if required.
Should you have any ongoing concerns including but not limited to:

- Recurrent seizures refractory to initial medication changes
- Discussion about coming off medications.
- Medication adverse effects
- preconceptual counselling

Kind regards