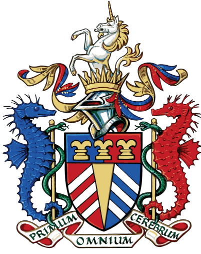
Recommendations for the Transition of Children and Young People with Neurological Conditions to Adult Services

Association of British Neurologists

BPNA
British Paediatric Neurology Association



Recommendations for the transition of Children and Young People with neurological conditions to adult services

This document has been developed jointly by the Association of British Neurologists (ABN) and the British Paediatric Neurology Association (BPNA) to provide guidance for **Paediatricians**, **Paediatric Neurologists** and **Adult Neurologists** in the UK on the transition and transfer of Children and Young People (CYP) with neurological conditions to adult services. The document is also intended to support CYP and their families/carers in preparing for transition.

Examples are provided on the typical situations where transfer after adequate transition from children's services would be expected to be to:

- General Practice [gold - block line]
- Local Neurology Service [blue - dashed line]
- Specialist Neurology services [grey - dotted line]

These services have been coded to enhance understanding.

It is recommended that the process of transition begins not later than 16 years of age, and has been completed by 18 years of age. Decision making, including the exact timing of transfer, should be shared between paediatric and adult services, the young person and their carers/family. Decisions should take into account local resources, including mental health service provision and inpatient services, and their criteria for treating CYP. Paediatric services should continue to lead on the care of CYP until the process of transition has been completed.

It should be noted that this guidance is limited to the transition period, and in many cases it should be anticipated that follow up within adult neurology services will be time limited (could be discharged to primary care after a period of monitoring as per Getting It Right First Time (GIRFT) Southampton guidance[1]) – this should be explained to CYP during transition. Where CYP are transferred to General Practice, referral from General Practice to adult neurology services in the future for further neurological review should be considered if there is a change in clinical circumstances.

This guidance may be superseded by local pathways. If this document does not provide guidance about the clinical scenario in question, the paediatrician can consider "advice and guidance" from neurologists rather than setting the expectation that the CYP will be reviewed in clinic.

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[1] https://cdn.ymaws.com/www.theabn.org/resource/resmgr/files/services/neurology_-_developing_a_reg.pdf

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Epilepsy

The guidance below is based on information on CYP with epilepsy from the NHS England bundle of care.[2]

Where a CYP has been seizure free for >1 year following transfer, GIRFT Guidance recommends referral back to GP led care.[1]

Examples of CYP expected to transition to GP services:
- CYP seizure free and not on antiseizure medications (ASMs).

Examples of CYP expected to transition to local adult neurology services:
- CYP seizure free but to remain on ASMs (including where trial of weaning of ASMs has been unsuccessful). If ASMs do not include valproate or topiramate, can transition to adult Epilepsy Nurse service if available.

Examples of CYP expected to transition to specialist adult epilepsy services:
- CYP with complex epilepsy (trialled 2 or more ASMs).
- CYP with moderate – profound intellectual disability and ongoing comorbidities should additionally be referred to the local adult learning disability team.
- CYP with VNS.

CYP with intellectual disability and ongoing additional comorbidities but where epilepsy is not an active issue can be transitioned to the local adult learning disability team, the GP and other specialist clinics if necessary, according to co-morbidities.

[2] https://www.england.nhs.uk/long-read/national-bundle-of-care-for-children-and-young-people-with-epilepsy/

Headache

Examples of CYP expected to transition to GP services:

- Most CYP affected by headaches receiving standard prophylactic agents would be transitioned to GP services.
- CYP with a history of Idiopathic Intracranial Hypertension that is well controlled or in remission.
- CYP with cluster headache which is well controlled on treatment.
- CYP with New Daily Persistent headache for whom a secondary cause had been excluded.

Examples of CYP expected to transition to local adult neurology services:

- CYP with ongoing disabling headache who have failed three prophylactic treatments in the absence of Medication Overuse Headache.
- CYP with Idiopathic Intracranial Hypertension requiring active monitoring.
- CYP Receiving cGRP Monoclonal antibody treatment or Gepants (this depends on local pathways).
- CYP with New Daily Persistent Headache not yet fully investigated.

Examples of CYP expected to transition to a specialist adult headache service (it is noted that some local neurology services may provide this):

- CYP potentially in need of GON blocks*, Botulinum Toxin injections or Eptinezumab infusions.
- CYP under tertiary services needing full MDT not available outside of specialist centres (e.g. refractory chronic migraine or cluster headache).

**NB No evidence to support use outside of acute treatment.*

Neuroinflammation

Examples of CYP expected to transition to GP services:

- Previous monophasic neuroinflammatory episodes or previous relapsing neuroinflammatory disorder but no relapses for several years and not receiving any immunomodulatory treatment – excluding multiple sclerosis.
- Rare resolved neuroinflammatory disorder with no ongoing intervention - e.g. CYP experiencing Opsoclonus Myoclonus Syndrome in early childhood.

Examples of CYP expected to transition to local adult neurology services:

- Monophasic neuroinflammatory disorder with no ongoing inflammation but residual neurology – e.g. limbic encephalitis/NMDAR with secondary seizures, or Acute Necrotising Encephalitis of Childhood (ANEC) with ongoing neurological deficit/dystonia.

Examples of CYP expected to transition to a specialist adult neuroinflammatory services (some local neurology services may provide this):

- Ongoing relapsing demyelination – e.g. multiple sclerosis, relapsing MOGAD, NMSOD etc.

Movement Disorders

Examples of CYP expected to transition to GP services:

- CYP with static well controlled movement disorders e.g. well controlled essential tremor, paroxysmal kinesigenic dyskinesia controlled with carbamazepine, motor tics on no medication, stable levodopa responsive dystonia.

Examples of CYP expected to transition to local adult neurology services:

- CYP with progressive movement disorders due to conditions likely to progress over time, generally well controlled on a limited number of medications, e.g. slowly progressive neurodegenerative disorders, motor tics.

Examples of CYP expected to transition to a specialist adult movement disorder services:

- CYP receiving invasive neuromodulation with intrathecal baclofen or Deep Brain Stimulation.
- CYP receiving botulinum toxin treatment for dystonia or other movement disorders
- CYP with neurotransmitter disorder – jointly to neurology and adult inherited metabolic disorders.
- CYP with juvenile Parkinsonism.
- CYP with rapidly progressing neurodegenerative disorders with complex motor disorder, e.g. pantothenate kinase associated neurodegeneration.

For CYP with cerebral palsy, particularly those receiving regular botulinum toxin injections transition in most cases would be to local adult spasticity services or neurorehabilitation services depending upon local arrangements.

Neuromuscular Disorders

Given the progressive nature of most neuromuscular disorders affecting CYP, onward referral to specialist adult neuromuscular services (with input from cardiac and respiratory services as appropriate) is recommended.

Genetic Inherited White Matter Disorders

It is recommended that all CYP with confirmed or suspected inherited white matter diseases are referred both to local adult neurology services and the national Inherited White Matter Diseases services (for England only). The majority of CYP in England with suspected/confirmed Inherited White Matter Diseases should already be known to commissioned white matter disorder services, facilitating transition to adult services.

CYP with non-specific white matter changes, e.g. identified when investigating developmental issues, would not typically be expected to be transitioned to neurological services (unless they experienced an additional neurological issue, e.g. epilepsy, which would warrant referral).

Cerebrovascular Disorders

Examples of CYP expected to transition to GP services:

- Stroke in CYP with no further events and not on medication with stable imaging and stable clinical picture for longer than 3 years.
- CYP with focal cerebral arteriopathy.
- CYP who have experienced post varicella vasculitis.
- CYP who have experienced neonatal stroke.
- Some CYP receiving a single antithrombotic may not need follow up with adult neurology – decide case by case.

Examples of CYP expected to transition to local adult neurology services:

- CYP with CNS vasculitis

Examples of CYP expected to transition to a specialist adult neurovascular and/or Stroke services:

- CYP on dual antithrombotic for any cause.
- CYP with moyamoya disease.
- CYP with genetic vascular diseases where new lesions can emerge – either known to emerge or if cause unknown in someone with multiple vascular lesions.
- Tumour related vascular disease/Neurovascular disease of the brain or spinal cord due to radiotherapy in childhood (e.g. SMART syndrome).

Neurocutaneous Disorders

Examples of CYP expected to transition to GP services:

- CYP with neurocutaneous disorder without epilepsy, or intrusive focal neurology

Examples of CYP expected to transition to local adult neurology services:

- CYP with neurocutaneous disorders and epilepsy.

Examples of CYP expected to transition to a specialist adult neurocutaneous services:

- CYP with complex presentations requiring ongoing specialist monitoring and MDT review (e.g. NF1 with complex plexiform lesions).

Authors & Acknowledgements

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Acknowledgements

BPNA
British Paediatric Epilepsy Group
Movement Disorder Specialist Interest Group
Children’s Headache Network
Genetic White Matter Disorders SIG
Neurocutaneous SIG
Cerebrovascular SIG
Muscle Interest Groups

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ABN
Epilepsy Advisory Group
Headache Advisory Group
Movement Disorder Advisory Group
Neuroinflammation Advisory Group
Neuromuscular Advisory Group
Services Committee
Stroke Advisory Group

ABN Executive Council Approved March 2026

Next review due 2029

This guidance from the ABN and BPNA outlines how children and young people (CYP) with neurological conditions can move safely from paediatric to adult care. It is aimed at paediatricians, paediatric neurologists and adult neurologists, as well supporting CYP and their families/carers during this transition. The document provides condition-specific recommendations indicating whether ongoing care is best delivered by GPs, local adult neurology, or specialist services.

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