

Transition from Paediatric to Adult Neuromuscular Services



What is transition?

At the moment your child is looked after by a children's (Paediatric) Neuromuscular team, but they will be transferred to the adult service as they become older.

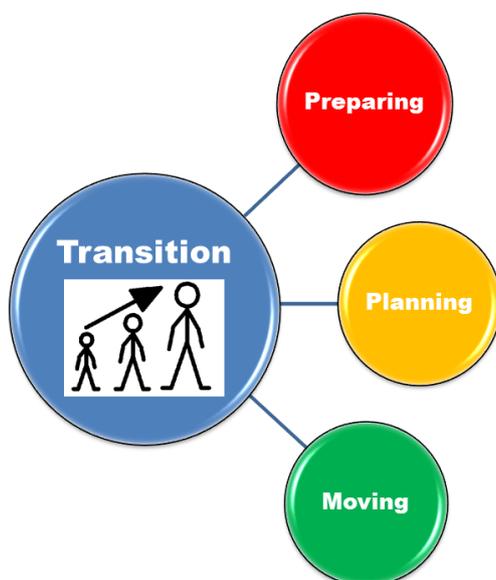
Transition is a process of preparing, planning and moving to adult services. It marks the time when your child can start to be more involved in managing their neuromuscular condition.

This leaflet aims to explain why it is helpful to start considering Transition when your child is aged 11-14yrs and the process involved.

Transition will be a gradual process that gives you, your child and everyone involved in their care, time to prepare for the transfer to adult neuromuscular services.

In general, your child's care will formally transfer from paediatric to adult services between the ages of 17 and 19 years of age. However, we will be guided by you, your child, their understanding of their condition and local health service policies in place in your area to determine the most appropriate time to transfer care to the adult Neuromuscular Service.

We know from Research and our own past experience that if we don't take time to discuss the transition the change to adult service can be an unnecessarily complicated and stressful process. That is why the neuromuscular service has adopted the **Ready Steady Go Framework** developed in Southampton Children's Hospital¹ and adopted by NHS England.



Ready Steady Go is designed to enable us to support your child in becoming an independent adult by working with you to give them the confidence, knowledge and skills to manage their condition when they become adults.

Ready Steady Go is based on a series of structured questions designed to facilitate discussion with the NM team, you and your child about their knowledge of their health condition and plans for the future.

Your Neuromuscular Advisor will meet with you and your child at home to discuss the Ready Steady Go paperwork and support you and your child during the Transition from Paediatric to Adult Neuromuscular care.

Depending on the complexity of your child's neuromuscular condition, your Neuromuscular Advisor may meet with you and your child up to three times to go through the **Ready Steady Go** paperwork.

The completed **Ready Steady Go** paperwork will be routinely shared with you and your child as well as other services involved unless you request otherwise.

Below is a list of the main topics covered by **Ready Steady Go**

- **Knowledge**
 - * Supporting your child to describe their condition and understand its management
 - * Knowledge of their medications - what they take and why
 - * Explaining differences between adult and paediatric services and information about the adult Neuromuscular team
 - * Discussing how NM Transition links with into Transition in other services
 - * Provision of useful links to support groups/resources
- **Health and lifestyle**
 - * Discuss and share information about the benefits of a healthy lifestyle in relation to exercise, diet, relationships and their condition
- **Daily living**
 - * Considering, within the limits of their condition, how to promote independence
 - * Finances/Benefits in adulthood
- **School, Further Education and Work**
 - * Thinking about opportunities after school
 - * Considering if extra support in school, equipment, grants are needed

- **Leisure**

- * Sporting activities
- * Life skills including use of public transport, accessing shops, leisure facilities
- * Socialising

- **Encouraging independence / self-advocacy**

- * Building up your child's confidence to ask questions and make decisions about their healthcare depending on their age and level of understanding
- * At clinic appointments providing your child with opportunities to speak privately, if they wish, to the neuromuscular team.
- * **"Ask 3 Questions"** ²

Ask 3 Questions



- **Managing emotions**

- * Allowing your child opportunities to consider how their condition may affect their emotional well-being
- * Considering who can help them to manage their feelings when they feel sad/fed up /angry, anxious

- **Preparation for adult services**

- * Explaining the differences between Adult and Children services and consider practical issues such as getting to appointments, frequency of appointment, obtaining repeat prescriptions and possibility of having to pay for medicines or applying for exemptions
- * Ensuring your child knows when and where to get help and who to contact in an emergency
- * When your child moves to adult service, their opinion and consent will be sought by members of the neuromuscular team and other healthcare professionals

Further support and Information

You and your child can find out more about some of the things mentioned in this leaflet via the following links.

1. **Ready Steady Go paperwork** — <http://www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx>
2. **Ask 3 Questions**—<http://www.pat.nhs.uk/downloads/patient-information-leaflets/other/Ask%203%20Questions%20Leaflet.pdf>
3. **Hello to Adult Services**—<http://www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Hello-to-adult-services.aspx>
4. **Muscular Dystrophy UK Transition information page**—<https://www.muscular dystrophyuk.org/news/news/hear-my-voice-transition-guide/>
5. **UHBristol Transition Website for Neuromuscular Patients** - <http://www.uhbristol.nhs.uk/transition/neuromuscular/>
6. **NICE Guidelines on Transition** - <https://www.nice.org.uk/guidance/ng43>

Your Named Worker for neuromuscular transition is:

Name:

Tel:

Email:

My notes / questions



South West Neuromuscular Operational Delivery Network

The South West Neuromuscular Operational Delivery Network is hosted by North Bristol NHS Trust.

Specialist clinics are held at the following Trusts:

- North Bristol NHS Trust
- University Hospitals Plymouth NHS Trust
- University Hospitals Bristol NHS Foundation Trust
- Royal Cornwall Hospitals NHS Trust
- Cornwall Partnership NHS Foundation Trust
- Gloucestershire Hospitals NHS Foundation Trust
- Taunton and Somerset NHS Foundation Trust
- Royal Devon and Exeter NHS Foundation Trust
- Torbay and South Devon NHS Foundation Trust

If you would like further information, please contact us:

Post: South West Neuromuscular ODN, Office 7, Gate 18, Level 1,
Brunel Building, Southmead Hospital Bristol, Westbury-on-Trym,
BRISTOL, BS10 5NB

Tel: 0117 414 1184 / **E-mail:** swneuromuscularodn@nbt.nhs.uk

Web: www.swneuromuscularodn.nhs.uk

Twitter: [@SWNODN](https://twitter.com/SWNODN)