

GUIDE FOR YOUNG MEN WITH DUCHENNE MUSCULAR DYSTROPHY

*Preparing for a
successful transition
to adult care*

Key steps to ensure a smooth transition



WHY IT IS IMPORTANT TO TRANSITION TO ADULT CARE

As you enter young adulthood, there will be many changes in your life, including the care you receive for Duchenne muscular dystrophy (also called DMD or just Duchenne).

You will transition to an Adult Neurologist, who will be vital in providing you with adult DMD care. Adult Neurologists are experts in nervous system disorders and are well positioned to help you manage your neuromuscular disease as an adult.

You may also transition from a paediatric to an adult multidisciplinary team, in which different adult specialists work together to provide comprehensive care. These specialists are better equipped to manage the progression of DMD as you grow into adulthood.

To achieve independence and get the healthcare support you need, your active involvement throughout the transition process is important. By communicating with your care team and building a transition plan, you may have the opportunity to take more responsibility for managing your own healthcare. Staying on your personalised treatment plan will be the best way to delay disease progression.

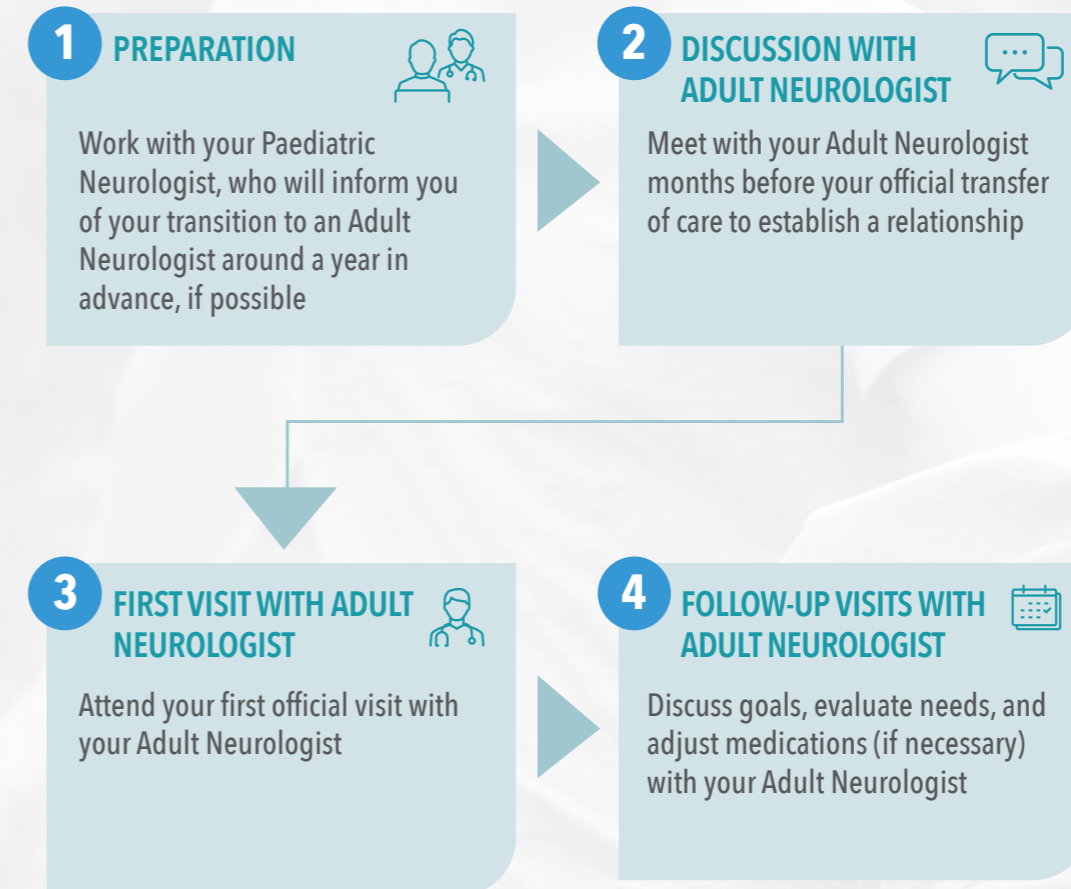
PREPARING FOR A SMOOTH TRANSITION

For your transition to be as smooth as possible, you should know what to expect. To keep your healthcare uninterrupted, it is important to begin talking about the transition to adult healthcare with your Paediatric Neurologist as soon as you can.

Entering adulthood can be a rewarding time as you plan for your future. You may have goals for higher education or work, managing your own relationships with others, deciding where to live, and finding safe transportation options for getting around. It is never too early to start thinking about the goals you would like to set for yourself and talk about them with your healthcare providers.

Remember: as you transition to adulthood, your adult care team, social workers, educators, and family members can offer you support.

AN IDEAL TRANSITION FROM PAEDIATRIC TO ADULT CARE



TAKE THESE EARLY STEPS TO HELP MAKE YOUR TRANSITION SUCCESSFUL

- Learn as much as you can about DMD
- Think about the goals you would like to set for yourself and start talking about them with your healthcare providers
- Get to know your Adult Neurologist in advance of the official transition
- Meet with other members of your adult healthcare team early, if possible
- Ask whether dosing adjustments may be needed for any medications you are taking

CHECKLIST OF ACTION ITEMS YOU CAN TAKE AT EACH KEY STAGE OF THE TRANSITION PROCESS

1 PREPARATION

Work with your Paediatric Neurologist, who will inform you of your transition to an Adult Neurologist around a year in advance, if possible

- Understand why it is important to transition to adult care
- Learn more about how to manage DMD as an adult and other adult specialists you may need to see
- Build a transition plan around your individual goals, as well as the community services and providers you need to achieve these goals, which may include social workers, educators, your adult care team, and family members

2 DISCUSSION WITH ADULT NEUROLOGIST

Meet with your Adult Neurologist months before your official transfer of care to establish a relationship

- Decide whether you want to attend this meeting on your own, without parents or caregivers
- Read through the **DMD Overview for Patients** before the meeting to review important information about DMD
- Write down any questions you may have about adult care before the meeting
- Ask your Adult Neurologist what he or she expects of you in the adult care setting
- Discuss your goals and needs, such as independence, education, or relationships

3 FIRST VISIT WITH ADULT NEUROLOGIST

Attend your first official visit with your Adult Neurologist

- Ask any follow-up questions from your introductory meeting
- Talk about medicines you are taking and whether additional treatment or changes may be necessary
- Ask about seeing the other adult specialists in your multidisciplinary team

4 FOLLOW-UP VISITS WITH ADULT NEUROLOGIST

Discuss goals, evaluate needs, and adjust medications (if necessary) with your Adult Neurologist

- Stay involved in decisions about your care and any changes to medicines
- Continue to discuss your goals and needs


WHY ADULT CARE FROM DIFFERENT SPECIALISTS IS IMPORTANT

As you grow into adulthood, you will need an adult treatment plan that includes a multidisciplinary team made up of many different adult specialists. You may need to visit these specialists more frequently than you had before the transition.

In addition to your Adult Neurologist, who helps support your nerve and muscle health, your care team will include a Respiratory Specialist for your lungs, a Cardiologist for your heart, and a Nephrologist for your kidneys. You may need other specialists who can help you preserve movement, make a diet plan, check for bone health, or help with your emotional and social needs. Talk with your Adult Neurologist about which specialists you need to see and how often you need to see them.

Staying on the multidisciplinary treatment plan designed specifically for you by these specialists will be the best way to maintain your health.

IMPORTANT: DO NOT STOP OR MAKE A CHANGE TO ANY TREATMENT FOR YOUR DMD WITHOUT FIRST CHECKING WITH YOUR DOCTORS.



*You can play an active
role in your transition
to adult care*

By planning for the future, you can empower yourself to take more responsibility for your own healthcare, get the support you need, and successfully transition to adult care.

- Talking about the transition with your Paediatric Neurologist as soon as you can is an important first step
- Communicating with your care team and building a transition plan can help you take more responsibility for managing your own healthcare
- Getting to know your Adult Neurologist months before the official transition of care can help establish a relationship
- Checking with your doctors before stopping or making any changes to your treatment is important
- Maintaining your health involves an adult multidisciplinary team, in which different adult specialists work together to create a treatment plan designed specifically for you