Transition
A guide

Muscular Dystrophy UK
Fighting muscle-wasting conditions

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What is transition?

This is a big question. And something people often ask us. Also, when do I need to start thinking about it? What do I need to be aware of?

Transition in healthcare means moving from children’s services to adult services. That means you’ll move to a whole new team of doctors and health professionals. Sometimes you may have to go to a different hospital for your appointments. But that isn’t always the case.

People most often move to adult services between the ages of 16 and 18. There isn’t really a set time when you have to make the move but it will have to happen at some point. You may find that some of the services you use do have strict age limits while others don’t. This is why it’s best to start having those very first discussions about transition with your doctors as soon as you can. Your healthcare team will then help you to figure out when it’s the right time for you to fully transition.

Transition should be a gradual process. There is no fixed schedule for changes. During transition, you’ll learn much more about your muscle-wasting condition. You’ll also become more responsible for managing it.
After transition, you may find that you’ll now:

▶ book and organise your own medical appointments
▶ see new healthcare professionals, such as consultants or physios
▶ talk directly to your consultants
▶ talk to your GP more – he or she will take on a bigger role in your care
▶ move from your current paediatric hospital for your appointments
▶ know more about all the medications you’re on – what they do, what they’re for, how often you need to take them
▶ go on your own to some clinic appointments
▶ get an emergency care plan so you’ll know who to contact and what to do in an emergency
▶ use different healthcare services more or less often than before
Transition top tips

Here’s what some young people have to say about it:

“You have the right to be involved in discussions and to make informed decisions about your care. So find out if meetings are taking place without your knowledge and involvement. (I had no idea this was happening.) Insist on shaping your own future and being consulted about all decisions, especially life-changing ones.”

Karis Williamson, Inverness

“You have the right to choose the hospital that will be right for you. Make sure you’re happy with the doctors that you’re referred to. It’s really not too scary.”

Laura Bizzey, Snape
“Ask questions. Lots of them. There is no such thing as a silly question. Ask about your future and possibilities or eventualities and how these will be addressed. It’s not easy to think about your future but sometimes it’s as simple as having a name and a number of someone who you can contact when you start facing difficulties.”

Matilda Ibini, London

“Start thinking about what you’d like to do when you’re older. Not just in terms of learning or working. Where do you want to live? What are your dreams?”

Fleur Perry, Swindon

“Independence is important but there are many forms of it. Think about both your physical and mental independence.”

Vivek Gohil, Leicester
“Ask for every piece of information possible. Tell them you need to know you’ll be cared for.”

Ryan Worth, Crewe

“Write a list of all the professionals and organisations that you rely on. Put a tick next to all the ones who have given you information about what is going to happen when you reach your mid to late teens. Ring all the others and ask for written information about their transition process.”

Fleur Perry, Swindon

“If you (or your parents) are having to chase people to get things sorted, contact your local MP to get things rolling for you. And make sure you ask for as much advice as possible and get to know who is there to help.”

Oliver Mason, Chesham
Plan the stages of your transition. Ideally it should be a gradual process giving you and your family plenty of time to prepare for the move to adult services. The more planning you do, the better the transition process will be.

Focus on what you want to achieve in the future. Then make sure the care and support you get is also focused on that.

Make sure you are included in conversations about your care. The doctors and other members of the team need to make plans with you, not about you.

Speak with your healthcare team about what support is in place to help you through the transition process. Tell them if you are worried about it. They need to work with you to make sure the transition process is right for you.
Get involved in the process. It can help you to feel happier and more confident about what’s happening. Don’t be afraid to speak to your doctors about anything.

Ask your hospital what their transition process is. Each hospital does transition differently and some use a general check-list called “Ready Steady Go”. This is to see if you’re ready to move to adult services.

Take a look at the Muscular Dystrophy UK care plan. When you feel confident to fill this in with the help of your healthcare team, it could be a good indication that you’re ready for the move to adult services.

If you feel like the care you’re receiving isn’t good enough, talk to someone at Muscular Dystrophy UK. There is official guidance about what your transition process should look like, so get in touch to find out what your rights are and what you’re entitled to.

If your clinic holds a ‘transition day’, go along to it. You’ll find out what to expect and get to meet your adult services team.

And just remember – this is a process. Not everything will be completely new. This is just the next step.
So what next?

**Young people with muscle-wasting conditions tell us how patchy and inconsistent transition in the UK can be. Some people have really positive experiences. Others don’t feel at all supported by their doctors and healthcare team. We’re here to help you make your experience as positive as possible.**

**Talk to us**

You may feel anxious, or worried about transition. Sometimes talking to someone really helps. And getting the right info does too. If you don’t feel comfortable talking to your doctors or other specialists, our friendly care and support team is here for you. They are always happy to listen and offer guidance. If you* have any questions, give them a call.

**Speak to someone who’s been through it**

If you’d prefer to speak to someone who’s been through transition, we can put you in touch. We have a team of people who know what it’s like to live with a muscle-wasting condition. Talk to them about anything you might be worrying about. They probably felt the same way too.

*Unfortunately we aren’t able to take calls and offer support to young people aged under 18 themselves, but we can support you if a parent, guardian or other adult family member or carer contacts us on your behalf.*
Get information

It always helps to have the right info about things, and we have loads on our website. Among other things, you’ll find:

- factsheets about the different muscle-wasting conditions
- the Muscular Dystrophy UK care plan
- a range of top tips about things like learning to drive, going to university, going on holiday.

There’s also a new section on our website especially for you
www.musculardystrophyuk.org/youngpeople

Join Trailblazers

Would you like to campaign for change for young disabled people? Join Trailblazers, and help do just that. Along with about 700 young disabled people, you can challenge the barriers in society that prevent you from living full and independent lives. You’ll also get the chance to meet other young people who can relate to what you’re going through.

Find Trailblazers on Facebook and follow them on Twitter:
www.musculardystrophyuk.org/trailblazers
@MDUK_Trailblazers
Muscular Dystrophy UK is the charity bringing individuals, families and professionals together to beat muscle-wasting conditions. We’re providing a range of services and opportunities to help people live as independently as possible.

We’re here for you at the point of diagnosis and at every stage thereafter, and can:

- give you accurate and up-to-date information about your muscle-wasting condition, and let you know of progress in research
- give you tips and advice about day-to-day life, written by people who know exactly what it’s like to live with a muscle-wasting condition
- put you in touch with others living with the same condition, who can tell you about their experiences
- tell you about the services, equipment and support you’re entitled to.