

## Transition from children's to adults' health services

**Calum:** Hi, I'm Calum. I'm an MS reporter for the MS Trust. In this video I'm finding out about moving from children's to adult health services. This process is called transition, but what exactly is transition and what does it involve?

Transition basically means making plans so you're prepared to move to adult MS services when the time is right for you. To find out more about what happens during the transition period and who will support you, I spoke to two MS nurses to ask them some questions.

**Mary:** Hello, my name's Mary.

**Sharon:** Hello, my name is Sharon.

**Mary:** We're both nurses that care for people with MS.

**Sharon:** I work in the children's neurology service here at Addenbrooke's so I often see young people who have MS.

**Mary:** And I support adults living with MS but I do see young people who've recently moved over from children's services.

**Calum:** Great, so my first question is, why do young people with MS have to move to adult services in the first place?

**Mary:** The main reason is to make sure you're getting care that's right for you and your needs. The health professionals that make up your new adult team will have more experience caring for young adults and will be more suitable supporting you as you grow up.

**Sharon:** As well as this, your teenage years are a big time of change both mentally and physically. You may feel like you're beginning to outgrow children's services so an adult setting may suit you better as you get older and become more independent.

**Calum:** OK, so it's all part of growing up and becoming more responsible for yourself. So when does transition start? Will it be at a certain age?

**Mary:** OK, so there's not a strict timeline. Often it might depend on the things to do with you and what's going on in your life, like exams or whether you're on medication or not, so there's no set age.

**Sharon:** Your health professionals might start talking about transition when you're about 12 or 13, but the actual transfer will usually be a few years later when the time is right for you. Usually you will have transferred to adult services by the time you're 18, but it might be earlier for some and later for others.

**Calum:** That's good to hear that it can be fairly flexible to suit you. So who will be there to support you through the transition process?

**Sharon:** You should be given a specific person to help you through transition from start to finish. They're often known as your named worker or key worker. They'll be

there to help you get prepared before you transfer and will also be there if you need any support in the months after you've moved to adult services.

**Mary:** Your named worker should be a health professional in your team who you already have a good relationship with, such as your current MS nurse.

**Calum:** What kind of things will they do to help you prepare for the changes?

**Mary:** There are lots of ways your named worker can support you. They can help you learn more about your MS and the medication you're on.

**Sharon:** They can help you build up your confidence so you feel comfortable taking a more active role in your appointments and maybe even attending them on your own.

**Mary:** They can help you to get to know the adult service team before you transfer. This might include visits to the adult service and joint appointments with a health professional from your current team and someone from your new team.

**Sharon:** They may encourage you to create a folder about yourself and share it with your new team so they can get to know about you, your MS and your goals for the future.

**Mary:** They'll go through the help and support that's available to you, including how you can get in touch with the health professionals in your new team when you transfer.

**Sharon:** They may be able to direct you to peer support groups or put you in touch with other young people who are going through or have recently been through transition.

**Mary:** Finally they may talk to you about living a healthy lifestyle as you begin to make more choices for yourself. This includes things like eating a healthy diet, taking lots of exercise, not smoking, not drinking very much and sexual health.

**Calum:** All of that support sounds great! Will you have to go to a different hospital?

**Mary:** Well, you might not have to. It really depends on the services at your current hospital and in the rest of your area. It also depends on where your needs will be best met. You might choose to go to a specialist hospital that's further away from home, rather than one which is closer but has less expertise in MS.

**Sharon:** If you do have more than one choice, it can be useful to ask your named worker if it is possible to arrange to meet the different teams. If that's not possible, it's worth visiting the hospital or looking at their webpages to get a feel for them.

**Calum:** OK, so you might not have to move hospital. Meeting the new team sounds like a good idea. How will the new service be different?

**Mary:** In adult services there'll be more emphasis on you taking responsibility for your own care. You'll notice that letters are addressed to you rather than your parents and your team will talk to you directly in appointments and you'll be the one asking the questions. You'll also have to start organising your own appointments.

**Sharon:** You'll probably also notice a difference in the environment. There may be older people in the waiting room who've been living with MS for a long time. It will also generally be busier. There are more adults with MS than children.

**Mary:** Because it's busier they may take a little longer to get an appointment and it might not be possible to speak to your MS nurse or neurologist straightaway. You may have to be a little bit more flexible when booking appointments. They may not be able to arrange them around school holidays like they did before.

**Sharon:** You may need to get your first appointment with your adult team booked in around six months in advance to make sure there is no gap in the care that you receive. When you move to adult services, you'll get to choose who you want in your appointments. Adult services will welcome whoever you want with you. You might want your mum or dad to be there or your partner or a friend. Going on your own is fine too.

**Mary:** Overall it'll be a big change. There'll be lots of new people in your team and it may take a little while to get used to them all. You might also have to get used to finding your way around a different hospital. But remember, however scary it may seem at first your new adult team are still there to look after you and your health.

**Calum:** Quite a lot to take in then! How involved would a young person's parents be in the transition process?

**Mary:** Transition is all about you but your family can still be involved.

**Sharon:** It's a gradual process with you slowly taking more responsibility and your parents taking more of a backseat. It can be a difficult time for them too. They've been used to being in control and it can be hard for them to let go and get used to being less involved in your care.

**Mary:** Remember, although you're starting to take more responsibility you can still ask your parents for advice along the way. It can be helpful for you all to talk about how you're feeling and any worries you have.

**Calum:** Thanks Mary and Sharon – that was really helpful. Here are the main things I've learnt about transition.

Number one – transition involves being more in control of your own healthcare. It's all about being treated more like an adult, as well as feeling and acting like one.

Number two – there's no set age when transition happens. It depends on you, what's going on in your life and the services in your area.

Number three – you might have to change hospital but you might be able to stay where you are.

Number four – you'll have plenty of support along the way, mainly from your named worker but also from other health professionals, peer support groups and your parents.

And finally, number five – let's be honest, it's a big change and you'll have to get used to new people but that's all part of growing up.

So Mary and Sharon were really helpful but I thought it'd be good to speak someone who's actually been through it all. To finish off the video, here's Abigail talking about her transition journey with her mum, Nicola.

**Abbie:** I'm Abigail. I was diagnosed three years ago when I was 14. For the process of going to adult services pretty much I was told by one of the nurses that for my first course of Lemtrada treatment that I was going to be on the children's ward and then for my second course of treatment I was going to be on the adult ward. So I was kind of slowly introduced to it through that.

During my first course of treatment, the MS nurse came to me to obviously tell me what was going to happen for my second course and explained obviously about the process of moving from children to adult. She'd tried to gently like reassure me and make sure that I was okay to move, rather than just kind of throwing it at me. I was gently reassured through being told that I'd have a room by myself so that obviously it wouldn't be so frightening having to be moved.

I was, when I was diagnosed I was kind of in between two hospitals. When I was getting better I got the choice to obviously which hospital I wanted to stay at. But they are both amazing, they were both absolutely incredible. They were such a nice team, both of them, and it just felt quite nice having the choice because I mean because I was considered a child at the time so it felt quite nice to get a say, rather than obviously having the decision being made for me.

I do miss, I do miss the, like even though I know I'm a child I miss like the special stuff in the child ward. It felt nice because obviously they were making such a big deal and, you know, obviously I'm a teenager – I'm fully grown! – but it did feel nice to be made like quite a big fuss over.

It may seem incredibly scary but once obviously you're there it's not that terrifying. I mean you are still in an adult ward even though you do consider yourself quite young. Obviously you are there but it's not too terrifying because you do know more, depending on whether you want to know more.

**Nicola:** I'm Abbie's mum. I'm not going to say my age! My daughter was diagnosed three years ago so we've been supporting her through her MS from child services to adult services since.

We met the MS nurse from the children's team and then one of the MS nurses we hadn't met before from the adult team and she explained exactly what would happen and what she could do because obviously it was a bit daunting for Abbie to move from children's to adults'. There were certain things they could do to help support us through it.

Going into adult services Abbie was 16, not quite 17. It's quite daunting to suddenly go from being on a children's ward where there's lots of things, lots of children, you're busy, there's things going on all day, to suddenly be on an adult ward. She was in a little room on her own but they managed to sort of do it so she wasn't with

other people, especially people that were further on maybe with their MS which could have been quite scary for somebody who's quite newly diagnosed.

We would be there with her for any of the chats with the nurses just so we would remember because Abbie would sometimes struggle to remember the things she needed to remember or would get muddled with the things she needed to remember and then we'd just go over things with her again or clarify things for her that she wasn't sure about and just be there for her. Bring the tea and coffee, you know, and things when she was having treatment and so she wasn't on her own. I was there the whole time.

If you're not sure ask and if you're still not sure ask again. There's nothing, it's never too much trouble. But just ask questions and it's not as scary as you think.