

For Young people with Muscle Disorders...

...SOME THINGS TO THINK ABOUT as you move from children's to adult services.

This leaflet has been written for young people with muscle disorders, and their family, to help them understand how health care might change as they move from children's to adult services. Your Paediatrician and other Health Professionals will discuss this move or 'transition' with you and make sure plans are in place before you leave the children's services. This leaflet has been written by the Scottish Muscle Network to help you understand and share in this planning.

Leaving school and moving into the adult world is an exciting time but there can be challenges. Adult health services are organised differently to children's. Outpatient clinics are often bigger and busier, and you might not be seen as often as in children's healthcare. You will get to know new doctors, nurses, therapists and other staff. This new team will need to know who you are, where you want to go and what you need to get there. It is important that you have support to start planning the move from children's to adult services in good time. You need to be involved in any decisions and be responsible for your health care as much as you are able

Preparing for the Transition: Before the transition to adult services actually begins professionals will begin to treat you as a young adult. This may involve giving you the opportunity to meet with a health care professional by yourself for a confidential appointment, often at the beginning of the clinic. Your parents will usually be invited to join in later. By having the opportunity of a joint appointment, your parents are still included in the consultation. As you grow older and more mature, your right to confidentiality and ability to consent to your own treatments should be respected*. Health care professionals will understand this, and respect the changing role and responsibilities of your parents.

To help you prepare for transition, and share in any decisions your care team might want to check a number of things:

- What you know about your condition and any treatment that you receive.
- That you know what to look out for and when to ask for help.
- That you know about keeping healthy.
- Your understanding of the role of the different health care professionals in helping you keep well, and how you can contact them.

They will also want to discuss your future hopes and plans, such as further education, employment or independent living, to help plan the support that you will need in the future.

The move between children and adult services happens at a time when many other changes are taking place. It is often helpful to agree a keyworker or co-ordinator to support you and your family, help make sure that you are involved in any decisions that affect you, and help coordinate the transition.

Making the Transition: The Paediatrician will agree a date with you, when you can begin the transfer to adult services. The health professionals will make referrals to adult colleagues and will plan a gradual transfer of care to the adult team. In many places joint clinics are held with the paediatrician and an adult physician. This gives you and your family the chance to meet the new specialist, and helps the health professionals hand over care. It is important that you get to know your new care team and how to contact them. Your Keyworker can help make sure that you continue to get the care and support that you need, and that this new team help you plan for the future.

Information and support: The information leaflets (appendix 1), self assessment plan (appendix 2) and person held records or care plans (appendix 3) can help you identify and communicate your needs and future plans, and help ease the move to adult services. The Muscular Dystrophy Campaign (MDC) has produced a folder, specifically to help this Transition. This is available by contacting MDC, or through the care advisors.

MDC contact details:

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*If a young person is over the age of 16 and has learning disabilities, or other problems affecting their mental capacity, they may be unlikely to take full responsibility for decisions about their health care, welfare and finances. In this situation parents, or other responsible adult, can apply for legal guardianship.