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Guide to Transition for 13-25 Year Olds with Muscle Disease

Published April 2010 Edition 1



# **Guide to transition**

## **Foreword**

The Muscular Dystrophy Campaign is delighted to provide you with this groundbreaking **guide to transition to adulthood**.

Whether you are a young adult living with muscle disease, a parent or professional involved in their care, we hope that you find the guide helpful in advising you further about the services, entitlements and places to go for further information and support.

This publication has been produced as part of the Muscular Dystrophy Campaign's ongoing commitment to providing free and expert information to all those affected by muscle disease.

Our thanks go to Bupa Giving for its support in funding this important project, and to the large number of individuals with muscle disease, their families and the professionals who gave their time and expertise to help make this project a success.



**Philip Butcher**  
**Chief Executive**  
**Muscular Dystrophy Campaign**

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Edwina Perkins (Project Manager)

Julie Cassell

Martin Chainani

Tamsin Coade

Sue Manning

Sue Gallagher

Gill O'Neill

Alison Brown

Shirley Crosby

Jan Smith

Jane Stein

Wilma Stewart

# Guide to transition

## Introduction

This **guide to transition services** is aimed at young people aged 13-25 affected by muscle disease, their families and the professionals involved in their care. It provides advice about services and entitlements and signposts where to go for further information and support.

### **The guide is divided into three sections:**

1. Young peoples' perspective – feedback and recommendations from young people with muscle disease on their experiences of becoming an adult.
2. For professionals – transition between health, education and care services, models of transition and details of useful legislation and guidance.
3. General guidance for everyone – this section is divided into key areas which include funding, lifestyle, medical, practical, social support and relationships.

We would like to update you with any new information and factsheets as they are produced, and welcome your feedback on this pack along with any suggestions which you may have for new materials.

To help us keep in touch and update you with news, updates and information on events which may be of interest to you, please ensure that you have given us permission to store your contact details on our secure database.

Should you have any further questions or concerns, please do not hesitate to contact our Information Service:

**0800 652 6352** (freephone)  
info@muscular-dystrophy.org  
www.muscular-dystrophy.org



Emma Mowat  
Head of Support Services  
Muscular Dystrophy Campaign





# Guide to transition

## About muscle disease

Muscle disease causes muscles to waste and weaken. It doesn't just affect the muscles in the arms and legs but the heart and respiratory muscles too.

Muscle disease does not discriminate – it can affect females and males of any age and any race.

More than 70,000 babies, children and adults in the UK are affected by one of the 60 conditions which the Muscular Dystrophy Campaign supports. Most conditions result from a genetic fault which stops the body from producing proteins that the muscles and nerves need to work properly.

Most of these conditions are progressive, causing the muscles to gradually weaken and waste over time. Mobility is affected and most conditions lead to some sort of disability, however the severity of conditions and how they affect people varies greatly.

Many conditions are inherited – they can be passed from parent to child – but other conditions, like myasthenia gravis, are acquired during a person's lifetime.

There are no cures and many of the conditions are life-limiting.

### The Muscular Dystrophy Campaign

- We provide free practical and emotional support.
- We fund world-class research to find effective treatments and cures.
- We campaign to raise awareness, improve care and support, and bring about change.
- We award grants towards the cost of specialist equipment, such as powered wheelchairs.
- We lead the fight against muscle disease in the UK.

*Please note, muscular dystrophy, neuromuscular conditions and allied disorders are collectively referred to throughout this guide as 'muscle disease'.*



# Guide to transition

## Definitions of transition

Before we begin to explore the specifics of transition for young people with muscle disease we must clarify what is meant by the term 'transition'.

Put simply, transition is **the process of changing or moving from one state, condition, form, stage, activity or place to another.**

So how does transition relate to young people with muscle disease? It refers to **a move** from being a child to a young adult:

- in relation to law, education, health and social care services
- in the eyes of society – friends and partners, employers and community.

So transition to adulthood for young people with muscle disease involves navigating a vast range of subjects, services, professionals and individuals, in a field which is already complex, and at a time of life which is already vulnerable for most, whether living with muscle disease or not.

## Transition to adulthood

*"Ultimately an effective transition serves as a bridge – from adolescence to young adulthood. What lies at the end of this bridge is critical, for a 'good transition' will count for nothing if there are no real choices about future transition."*

Hudson (2006)

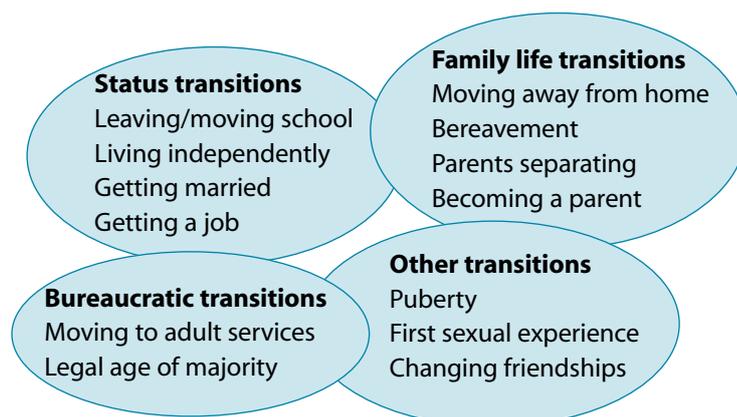
*"Transitions occur throughout life and are faced by all young people as they progress, from childhood through puberty and adolescence to adulthood; from immaturity to maturity and from dependence to independence. In addition, some young people experience extra transitions as a result of other life events, for example, bereavement, separation of parents, and being placed in care."*

Transition: Getting it Right for Young People, Department of Health/Child Health and Maternity Services Branch (2006)

*"Times of transition bring with them various other opportunities including the opportunity to reflect on and be proud of achievements...to be hopeful for the future."*

National Children's Bureau (2005)

Transition can be seen to affect an individual's status, family life and other aspects of their lives as illustrated in figure 1 below



Transition marks a time where an individual gains greater choice and autonomy as they become independent. This can be a source of great anxiety for parents and carers when deciding how best to manage future risk. There is a marked discrepancy between the risk perceived by young people with physical disabilities and that perceived by their carers/parents. It is important to adopt the right strategy to reduce risk in a way that doesn't restrict an individual's autonomy or access to opportunities that are available to their peers. A large part of the process is to provide the relevant life skills training during the transition period.

Young people have to manage transitions within education from pre- to post-16, whether that is moving into a school sixth form or from school to further education or training. They may be:

- leaving education and going out to work
- leaving home to move into their own accommodation
- moving on to adult social services provision.

Key stages are illustrated in figure 2 below

Stage of transition	Difference
Leaving home	This may occur later in the life of someone with physical disabilities.
Managing money	Young people with physical disabilities may not have had any experience of managing their own money, or knowledge of what they may need to budget to live independently.
Independent social life	Young people with physical disabilities can face barriers when establishing independent social lives, such as lack of access to transport or communication technology, needing carer/ family support, and lack of access to a peer group.
Finding employment	Young people with physical disabilities are likely to find it more difficult to gain paid employment or need more help to access work.

## Transition and disability

Young disabled people and their families often find the transition to adulthood both stressful and difficult. For many, there is a lack of co-ordination between the relevant agencies and little involvement from the young person. Some young people are not transferred from childrens' to adults' services with adequate health care plans, which results in exclusion from adults' services. This is likely to affect young people with severe learning disabilities and complex health needs in particular.

## Summary

With support and good planning, young people can actively participate in the transition process – making it a successful and empowering experience for all involved.



# Guide to transition

## 1. Young peoples' experiences of transition

This guide aims to support those young people and families who are going through transition from childhood into adulthood, and the professionals involved in supporting them through this. This section focuses specifically on feedback and recommendations from young people themselves.

Those going through the process often describe transition as a time of sadness, which involves breaking emotional ties with the services they have become used to as children and moving on to adults' services.

To produce this guide we drew on consultation exercises and ran groups with young people, reflecting on their thoughts, experiences, needs and priorities. In summary, the factors identified as most important were for young people to be able to:

- develop practical experience and skills
- enjoy leisure activities
- gain a range of information about their condition
- gain emotional support and discuss their concerns in confidence/private
- have a say in the content of their transition plan
- have hopes and dreams (like having their own home, a job, partner, children)
- make informed choices and decisions about their own care
- plan transition on the basis of strengths rather than their disability.

### Issues facing young people

The young people whose views were incorporated into this guide had concerns about lack of suitable health services and felt they had been provided with inadequate information. They had also had problems accessing education, employment, housing and benefits.

Problems experienced during transition made it difficult for them to achieve their long-term goals for education, independence and employment. This left young people bewildered about what services and choices were available to them when entering adulthood.

Thanks to improvements in condition management and medical care, children with muscle disease are now living longer. However, surveys have highlighted inadequate provision of care to adults with muscle disease, combined with lack of care available during the transition stage. Young adults should be able to expect the same high level of services which are now increasingly being received by children with muscle disease.

Young people and their families face a number of issues as they move from childhood to adulthood, including:

- lack of funding, information and expertise in adult clinical services
- limited access to education and employment opportunities
- challenges in their social lives, particularly when forming relationships
- limited access to appropriate equipment and support for independent living.

## Recommendations from young people and their families

Overall, this project highlighted the need for some simple standards of care which support the priorities identified by young people themselves, and help guide those professionals working with them through the transition process. Young people would appreciate implementation of the following:

### **1. Care must be consistent and responsive to individual need**

Young people should have standard access to ACT (Association for Children's palliative care) pathways, hospices, transition guidance and regional care advisors/coordinators. They appreciate continuity of contact with people they can get to know and see regularly. As parents often feel responsibility for co-ordinating service delivery themselves, and feel that care giving lies with them alone, they welcomed the concept of a 'health portfolio' which encourages effective information sharing between different agencies. There should also be a formal process which helps young people with disabilities to identify what support they need, according to their own ability and desired independence and helps to achieve this.

### **2. A change in the responsibility for care**

The young person should be supported towards taking charge of their own routine treatments, dealing with problems and gaining independence. This will help equip them with the skills to manage adult life and fully enjoy activities such as employment, going away to college or living with a partner.

### **3. Access to a range of information must be available**

Young people want a say in how much information they receive about their condition and when they receive it. Information should be made available in a variety of formats and from a range of sources to ensure maximum accessibility.

### **4. The process of transition should happen over a number of years**

Transition should start while the young person is still under children's services. The paediatric team should outline a 'timetable' of transition, including when the last paediatric clinic or admission will take place. This should be between the ages of 16 and 18, but currently varies in different locations. All young people with learning difficulties should have a transition plan as set out in 'Valuing People' (the Government's three year strategy for people with learning disabilities).

### **5. Young people should be encouraged to fully participate in their own care**

It's important to empower people with muscle disease from an early age. Parents could encourage their children to meet the care team at clinics on their own for the first part of the consultation. Young people want the opportunity to be involved in all decisions about their treatment, and consulted, rather than being 'told' what is going to happen or communicated with through their parents.

### **6. Young people with muscle disease need contact with one another**

Peer support programmes can be very helpful in coping with the uncertainties of adolescence and reducing the sense of isolation felt by many people with muscle disease of all ages. Mentoring programmes offer an opportunity for young people to build relationships, and develop skills and independence, while using their personal experiences to support one another. Informal care strategies which are flexible and tailored according to individual needs are preferred.

## Summary

These views and experiences of young people in transition and their families were expressed in focus groups. They highlight problems which individuals have experienced along with suggested solutions. The general section of the guide signposts to solutions, suggestions on best practice and organisations to approach for further help.



# Guide to transition

## 2. Becoming a man: Life with Duchenne muscular dystrophy

### Introduction

This factsheet is based on discussions between two researchers and 40 young men with Duchenne muscular dystrophy. Our thanks to David Abbott for allowing us to reproduce the following feedback.

In 2007 and 2008, David Abbott and Professor John Carpenter of Bristol University met with young men aged between 15 and 33-years-old, and their families, from the West Midlands, South West and the North East of England. Topics they discussed included:

- What experiences people had of school, college and university.
- What support people got and what support they wanted.
- What happens to services as young people with muscle disease get older.
- What people do with their social lives.
- What it's like to live with Duchenne.

A summary of the feedback which was shared by the young men and their families is shown below.

### School, college and next steps

People had good and bad things to say about what school and college were like. They found things like helpful staff, on-site physiotherapy, having friends and more independence positive, but found access, transport, getting around, being left out of things and even being bullied problematic.

Steve wanted to leave school after his exams and get a job; Jim wanted to leave college and do something else (but wasn't sure what) and Nick wanted to go to university. It was acknowledged that big decisions can mean a lot of change.

### A transition plan

If you're provided with a statement of special educational needs at school you should have a meeting every year from the age of 14 until you leave school, which helps you plan what you do next. This is a part of the **transition plan**.

*'It does seem to be that before you're 16 there is a plan – this happens, then that happens, and it's smooth. Then you hit a certain age and no-one's thought about what happens next!'*

You can invite people who you think will be helpful or might have good ideas about what you do next to the meeting. It is your right to be able to access the right help and support to make choices as you get older and it is your school's job to organise this meeting. You have a right to be as involved as you want to be.

### What happens to services as you get older?

You probably know that when you get to a certain age, the doctors and other people you see might change. You might move from childrens' services to adults' services. Some people said this was stressful and that they did not always know what to expect.

Charlie was concerned about what it would mean to go to adult services; Lee had moved from seeing a consultant in childrens services to one in adults' services and Omar quite liked adults' services because he felt more in charge of what was going on. Jack said that when he moved to adults' services he felt there were too many doctors to see and he made his own choice about what to do. A lot of people said that when they got older they didn't have things like physiotherapy or hydrotherapy. Iain said, *"Like physio, you get it till you're 16 and then, no idea what happens next. I don't get it anymore"*

## Having a social life

There were lots of things that people were into – music, computers, art, cars, TV, sport. A couple of young men said how much they wanted to have and drive a car. One 17-year-old had been through a driving assessment and got his provisional driving licence.

*"Everyone wants to have a good social life: friends, places to go, things to do. It's no surprise that young men with Duchenne in this research wanted all these things too."*

Everyone wants to do things with their friends which don't involve their parents - it's an important part of getting older. Not everyone was happy with having enough friends or having a good enough social life especially people who had finished school or college.

Jack,22, had finished college and lived at home. He said: *"I don't really have anyone to go out with or anything."*

Quite a lot of people were in Jack's position.

Some people lived away from home at residential college or university. They said that their social lives were pretty good and that they had quite a lot of independence. Four people had girlfriends and said this had made a big difference.

## Living with Duchenne

When people did want to talk about living with Duchenne, they usually talked to parents or friends, but it wasn't always easy. Some people said it was hard to talk to their parents because they wanted to protect them – they didn't want their parents to get upset. Jake said he talked to his mum if he had worries about his condition. Simon said he'd been part of a small group of other guys with Duchenne, which helped a lot: *"A while ago a couple of friends of mine had md and we used to go to this meeting where we'd just go and talk about anything – like stuff we couldn't talk to mum and dad about. I mean we could talk about a really depressing subject but we'd have a laugh about it. And I'd come out of it feeling loads better."*

It maybe that you can talk to friends and family about how you feel. But if there are times you want to talk to someone else outside of your family and friends, you could talk to someone like a counsellor – lots of people talk to counsellors when they have feelings or problems that they want to share with someone else. Your GP may be able to refer you to someone. Or you could talk to a professional you get on with and ask them for help organising this.

## Having a job

Only one person in the research had ever had a job. There were lots of different views about employment. Some people were not sure if they could get a job. Those people who did want to get a job said they expected it would make them feel more independent and help them meet more people.

Some people had been actively looking for work and found it very hard.

*Craig and Liam said: "We think this is a big topic. We've both been looking for work and it's been difficult. And it seems to be difficult for other people too. We think that people with Duchenne can get a job if they get the right support. We know it's difficult but keep trying and think positive."*

## Becoming a man

## Information about options post school/college

People wanted general and specific information about courses, work and daytime activities which they could get to and which took place in buildings they could access. *"I'd like to go to like a place – like a youth club where they MC (Master of Ceremonies) and stuff like that – I'd go and listen and watch."*

## Being talked to like a real person

People didn't like going to appointments where professionals only talked to their parents. Young people naturally preferred it when they were treated as young adults and involved in decisions about their care: *"Some staff at places like hospitals can be great at patronising you. They're like, 'Is he alright?' and they talk to my parents. My mum says, 'Ask him yourself!'"*

## Being supported by friendly professionals

Young men liked professionals who were friendly and interested in them – not just their condition – and treated them as a 'normal person' too. They preferred established relationships where they were able to build up trust: *"You need continuity and you need some person almost to make a friendship with you before you're going to tell them things."*

## Good care

People had lots of different types of care. Some people's parents provided most of it while others had people coming from agencies into their home or employed personal assistants. Young people said their ideal supporter/carer would be quite close to their own age and someone who they could build up a relationship with over time. Trust and confidence were really important. One man described an ideal carer: *"Someone you can joke with, someone who knows what they're doing and someone my mum can get on with."*

## Chances to talk when people want to

When it comes to talking about Duchenne, there isn't just one way or answer. Everyone's different – some people don't want to talk about it and some people do. Many people had problems accessing information.

## Time away from family

It's good for everyone in every family to have time apart. Young people said they appreciated opportunities for time alone: *"You do spend a lot of time with your parents. I think sometimes it'd be nice to have a bit more time to myself and for my mum and dad to have a rest too."*

## Further information

- **Services which help with transition** – [www.transitioninfonetwork.org.uk](http://www.transitioninfonetwork.org.uk)
- **Duchenne muscular dystrophy** – [www.muscular-dystrophy.org/about\\_muscular\\_dystrophy/conditions](http://www.muscular-dystrophy.org/about_muscular_dystrophy/conditions)
- **Support for families affected by Duchenne muscular dystrophy** – [www.muscular-dystrophy.org](http://www.muscular-dystrophy.org)  
[www.dfsg.org.uk](http://www.dfsg.org.uk) [www.actionduchenne.org](http://www.actionduchenne.org)
- **Campaign for equal rights and make friends** – [www.muscular-dystrophy.org/trailblazers](http://www.muscular-dystrophy.org/trailblazers)
- **Direct payments** – [www.bristol.ac.uk/norahfry/research/completed-projects/livingitup.pdf](http://www.bristol.ac.uk/norahfry/research/completed-projects/livingitup.pdf)
- **Help with how things should work if you're aged 13-19** – [www.connexions-direct.com](http://www.connexions-direct.com)
- **Information and support if you have left school or college** – Muscular Dystrophy Campaign's Information service 0800 652 6352 (freephone) or [info@muscular-dystrophy.org](mailto:info@muscular-dystrophy.org)





# Guide to transition

## 3. Transition between health, education and care services

**Transition can be a time of fear and uncertainty about the future, and concern about lack of social opportunities. Recognising that these are common feelings and getting help to deal with concerns can help to make transition a positive time of progress, development and achievement of independence.**

**This section may be of particular interest to professionals involved in the care of young adults with muscle disease.**

### Problematic transition – issues

Feedback from young people and their families has highlighted a variety of difficulties in navigating services within the current health, education, care and support systems.

#### 1. Variation in services and support

Despite the existence of legislative guidance about transition in the UK, there continues to be marked variation in the transition arrangements available to young people. Topics often raised by young people and their families, which restrict their independence, focused on personal safety and risk, money matters (including benefits) and transport.

#### 2. Lack of planning

A fifth of young people leave school without a transition plan and lack of planning leads to uncertainty and stress for families. The quality of transition planning varies widely - in some cases it is ad hoc, confused and uncoordinated, in others, good and well planned. For many young people, key issues (e.g. transfer to adult health or social services) have not been addressed by the time they leave school.

#### 3. Lack of client involvement

Almost half of all young people asked said that they had little or no involvement in planning for their future. The topics covered in transition planning are often quite different from those identified as important by families. Whether young people received transition planning or not made little difference to what happened to some of them after leaving school.

#### 4. Lack of appropriate information and support

There is a lack of easily accessible information for young people and their parents about the future and there are few post-school options available to young people, particularly in relation to housing and employment.

### Successful transition

It is apparent, from the issues identified above, that transition is a complex area both from the perspective of the young person and that of the service provider. To resolve the issues identified, the following are needed:

### **1. A cohesive approach to service provision**

Effective inter-agency working, and joint assessment and training initiatives between health, education, statutory and voluntary services are crucial. Open, honest and respectful communication must be fostered between agencies and families with independent advocacy for young people.

### **2. An effective transition plan**

It is essential for all young people to have a transition plan. All staff working with them must have appropriate race and disability equality training. Young people with learning difficulties must have access to the same opportunities to realise the same aspirations as their peers. A statutory transition planning process begins during Year 9 of school. Connexions must attend the Year 9 'transition' review which results in a Transition Plan. If the young person's needs call for provision from a number of agencies this should be a multi-agency meeting.

### **3. A 'holistic' approach**

A unified approach to transition planning, which focuses on managing transition at a number of levels, not just between health and related services, is key. A multi-agency approach greatly enhances the success of transition. Young people need a complete package of service provision combined with the opportunity for regular reviews.

### **4. Dedicated key workers**

Key workers who can offer support and guidance to individual youngsters and their families, throughout the transition process, are needed. This support will enable a seamless transition from children's to adults' services and ensure a range of options are available for young people.

### **5. Involvement of young people**

It is essential that young people and their families are involved in the transition process and have easy access to appropriate information about local post-school alternatives in housing and employment.

### **6. Specific contribution from health professionals**

Health professionals can provide crucial benefit to the development of long-term plans for education, employment and social support in a variety of ways, depending on the nature of the young person's condition. Their input could include things like interpreting the person's clinical diagnosis, explaining likelihood of improvement or deterioration, giving information and guidance on treatment options, and the risks of various courses of action.

## **Services involved in transition**

Various services and systems, which will help provide best practice, in supporting young people through transition are available.

### **1. Connexions**

Connexions is an advice and guidance service for young people aged 13 to 19, and available to young people with learning difficulties and disabilities up to the age of 25. It provides support to all young people with additional needs during their transition to adulthood and can act as the lead in promoting this multi-agency approach.

For those with learning difficulties or disabilities who are thinking of going on to further education or training, Connexions can assess their needs and the provision which will be required to meet their needs (under Section 140 of the Learning and Skills Act 2000). Connexions also has an important role in transferring information about a young person's individual needs.

### **2. The National Service Framework for Children, Young People and Maternity Services**

The Children's National Service Framework sets standards for children's health and social services, and explains the relationship between those services and children's education.

### **3. Statements**

Known as a statement of special educational needs (SEN) in England, Wales and Northern Ireland and a review and assessment of special educational needs in Scotland. Many young people with disabilities or long-term conditions may require one of these to ensure a clear education pathway and that the right support is available.

### **4. The Special Educational Needs (SEN) Code of Practice**

This code of practice gives Connexions responsibility for overseeing implementation of the transition plan and co-ordinating its delivery with relevant agencies. This code of practice also encourages (but does not require) schools to consider transition planning for young people with SEN and disabilities.

### **5. Care Co-ordination Network UK (CCNUK)**

This networking organisation promotes and supports care co-ordination or key working for disabled children and their families in England, Northern Ireland, Scotland and Wales. They work in partnership with disabled children, their families and professionals to ensure that all families across the UK have access to high-quality care co-ordination or key worker services.

#### **CCNUK**

Head Office- Tower House,  
Fishergate,  
York YO10 4UA  
01904 567303  
info@ccnuk.org.uk

#### **CCNUK Scotland**

The Melting Pot  
5 Rose Street  
Edinburgh EH2 2PR  
0131 243 2634  
scotland@ccnuk.org.uk

#### **CCNUK Wales**

The Ebenezer Centre- Thorn House  
Crane Street  
Cefn Mawr  
Wrexham LL14 3AB  
01978 821 324  
wales@ccnuk.org.uk

#### **Disability Action**

Portside Business Park  
189 Airport Rd West  
Belfast BT3 9ED  
028 90297880



## 4. Models of transition explained

Model	Description	Pros	Cons
Dedicated follow-up service	Service provided within the adult setting without a combined paediatric-adult clinic and with no direct input or continuity from paediatric services.	Simplest model.	Requires professionally qualified specialists to help young people attend adult clinics and arrange meetings with paediatric services. Lacks continuity.
Seamless clinic	A clinic which begins in childhood or adolescence and continues into adulthood, with both child and adult professionals providing ongoing care as appropriate. Duration of joint care can vary from individual to individual.	Allows access to experts in both paediatric and appropriate adult specialties. Enables professionals to learn from one another. Allows some continuity of care.	Requires resources, including additional administration and clinic time. Geographical constraints may limit the availability of such a service.
Lifelong follow-up within the paediatric setting	The default model often adopted by disability services, for example for people with cerebral palsy, Duchenne muscular dystrophy or Down's Syndrome.	Ensures continuity of care.	Staff may encounter difficulties gaining expertise in more traditionally adult issues such as vocational, employment, benefits, independent living skills, contraception.
Generic transition team within a children's hospital	It involves having one or two dedicated nurse specialists who can ensure that all young people have appropriate transition support.	Named identification contact point	Requires nurse specialists and services will need to be shared between the number of young people requiring transition support at any time.
Generic transition co-ordinators for larger geographical areas	Developed by the Department of Health in Australia to cover a large area. This model may be appropriate for conditions which are relatively rare, or for co-ordinating links between Children's Hospitals and local General Hospitals.	Good approach where large geographical areas need to be covered or where a condition is relatively rare.	





# Guide to transition

## 5. Legislation and guidance

Below is a list of good practice guidance and legislation relating to the process of transition. These may be useful for those involved in delivering care.

- National Service Framework (NSF) for Children Young people and Maternity Services standards on Transition
- National Assistance Act 1948
- Chronically Sick and Disabled Persons Act 1970
- Disability Discrimination Act 2005
- Fair Access to Care Guidance 2003
- Children's Act 2004
- Health and Social Services and Social Security Adjudications Act 1983
- Disabled Persons (Services, Consultation and Representation) Act 1986
- National Health Service and Community Care Act 1990
- The Carers (Recognition and Services) Act 1995
- The Education Act 1996
- Special Education Needs and Disability Act 2001
- DDA 1995 (Further and Higher Education) Regulations 2006
- Welsh Assembly Government Section 7 Guidance: Service Principles and Service Responses 2004
- Welsh Assembly Government Statement of Policy and Practice for Adults with a Learning Disability 2007 (Section 7(1) of the Local Authority Social Services Act 1970)
- Better Care, Better lives-improving outcomes and experiences for children, young people and their families living with life limiting and life threatening conditions (DOH Scotland 2008)
- Aiming High for Disabled Children (HM Treasury 2007)
- Getting it right for every child (Scottish Government 2008)



# Guide to transition

## 6. State benefits

The benefits and tax credits system is complex and ever-changing. This factsheet provides a check list of benefits currently applicable to disabled people and advice on things to consider in respect of benefit applications. Advice on sources of information is given in the 'Further Information' section.

**Ensuring that you are in receipt of the right benefits is important. As well as maximising income they can be a passport to other schemes or services. Review your situation whenever government changes to benefits are announced or your personal circumstances change.**

## Professionals and their area of expertise

It is unlikely that benefit advisers and staff in government agencies will be familiar with the nature or rate of progression of neuromuscular conditions, due to their rarity and complexity. Disabled people applying for benefits are advised to explain their situation in detail, giving supporting evidence from staff at their specialist neuromuscular clinic or from other medical/therapeutic staff working with them.

## General information and advice

As state benefits are liable to change there are agencies (including the Citizens Advice Bureaux – [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk) or the Welfare Rights Officer found at your local Council Offices) who can provide good, independent, up-to-date advice. Specific benefits will not be discussed.

Anyone uncertain as to whether they might be entitled to benefits should consider the following questions – benefits may be payable in these cases:

- Does my disability affect my mobility e.g. walking, standing, falling, pain levels?
- Does my disability affect my ability to do certain tasks? (e.g. to cook a meal or to manage personal care routines)
- Does my disability affect my ability to work?
- Have I had to make (or do I need to consider making) adaptations to my home because of my disability?
- Does my disability affect anyone else? (e.g. is a family member/friend having to assist me with certain tasks or take on additional responsibilities?)
- Do I have dependents I am responsible for? (children, elderly relatives etc)
- Have my living arrangements changed? (e.g. have I moved out of the family home/ college or university?)

## Remember the following

- Not all benefits are means tested but some are paid specifically to those on a low income
- Not all benefits are adversely affected by savings
- Some benefits are payable regardless of whether you are in employment and some may be payable specifically to those in employment
- Benefits to help offset the additional mobility and/or care costs of being disabled may be payable (e.g. Disability Living Allowance known as DLA)
- The fact that the care/support you need is provided by a family member (e.g. a partner or parent) does not necessarily exclude a benefit from being paid and, in fact, such carers may be entitled to benefits in their own right. i.e. Carers Allowance
- Help is available to ensure you can access college and/or university. Ask to speak to the student disability officer and Social Services for any care needs

- Help is available to start work, remain in work or to retrain (talk to the Disability Employment adviser at the Job Centre Plus)
- Help may be available towards the cost of housing and council tax (and, via your occupational therapist/council, with housing adaptations)
- Extra benefit may be payable if you have dependents
- If your situation changes in any way either physically (e.g. your condition progresses and you need more help) or in a practical way (e.g. you get married, have a child, someone moves in/out of your family home, you start work or find work more difficult) be aware that it is your responsibility to tell the authorities as soon as possible as your benefits may be affected
- Benefits can not usually be backdated so if you think you may be entitled, make a claim as soon as possible
- Overpayments will usually have to be repaid.

### **When making a claim, ensure that:**

- you get accurate, impartial advice from an expert (e.g. an adviser at the Citizens Advice Bureau or Welfare Rights Officer at your local Council Office)
- you apply for any benefit that may be applicable – as long as you fill in the forms honestly the decision as to whether or not you are eligible is with the authorities, not you
- you try to include all the information asked for (but if you do not have the information available do not delay putting in the claim – you can send the information later)
- you provide as much relevant information as possible (e.g. when applying for DLA keep a diary for a week showing what help you needed and remember to think about the variability in your condition and how things are on a “difficult day”). This is not always easy and recording all the help you need may be hard. Do try to be explicit about all the help others give you and the things you find hard/impossible – this will help the right decision to be made
- any supporting letters are specific (e.g. when applying for DLA a letter of support from a physiotherapist outlining your difficulties in walking is far more helpful than a letter from the GP stating only that they think you should be entitled to the benefit)
- you put your name, date of birth and National Insurance number on all letters or documents you send
- you keep accurate records (with dates), of claims made, advisers spoken to etc. Try to keep copies of any completed claim forms you send in.

### **If you think the wrong decision has been made about a claim:**

- read through the correspondence sent with the notification of the decision as soon as possible. There is often a time limit on challenging decisions
- follow the procedure detailed in the correspondence for challenging a decision. Put your request to challenge the decision in writing and keep a copy
- take expert advice as to whether the decision is reasonable and what chance of success there may be in taking it further (usually there is more chance of success than you might expect)
- ask what supporting evidence is required and gather it in advance
- if you are attending a tribunal, prepare thoroughly with an expert adviser if possible. Take someone with you who knows about your condition and how it affects you.

### **Benefit advice is available from the Government**

- You can apply for many benefits online – visit **[www.direct.gov.uk](http://www.direct.gov.uk)**
- Benefits Enquiry Line on **0800 88 22 00** (this is for general advice only – they cannot chase up existing claims)
- The Department of Work and Pensions – visit **[www.dwp.gov.uk](http://www.dwp.gov.uk)**
- Job Centre Plus advisers can give information on some benefits – visit **[www.jobcentreplus.gov.uk](http://www.jobcentreplus.gov.uk)** or contact your local Job Centre Plus
- In some areas there may also be welfare rights agencies with specialist workers – your local library or Social Services will be able to tell you about such services.

**You can also find information via the following organisations:**

Citizens Advice Bureau

Will be able to provide you with details of your local bureau.

**[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)**

The Disability Alliance

Publishes the Disability Rights Handbook annually in April/May.

**020 7247 8776**

**[www.disabilityalliance.org](http://www.disabilityalliance.org)**



# Guide to transition

## 7. Disabled Facilities Grants

### What are they?

Disabled Facilities Grants (DFGs) are mandatory financial grants run by local authorities to help meet the cost of adapting properties where a disabled adult or child lives (this can include mobile homes or houseboats). The scheme operates in England, Northern Ireland and Wales.

DFGs are 'means tested' for adults. This means the Government assesses and decides what level of benefit should be received. However, this is not the case for children. Local authorities also have discretionary powers which allow them to provide assistance to families.

### Mandatory DFGs

Mandatory DFGs help ensure a person with a disability has adequate access into and around their home, and that there are adequate facilities within the home. Grants are given to install or make adaptation to provide:

- ramps, widening external/internal doors or shallow steps;
- suitable washing/bathing/showering/toilet facilities;
- a stair lift or a 'through the floor' lift;
- improved controls for heating or lighting;
- facilities for the preparation of food and cooking in the kitchen.

Grants are also given to ensure that there is:

- adequate access to a shared family room;
- access to, or provision of, a room used to sleep in;
- room for the disabled person to move around and ability to access parts of the home so they can look after someone else;
- a safer environment for the disabled person and others living in the home.

Occasionally an extension to the property might be suggested to ensure needs are met.

### Available grants

(this information is subject to change)

In England the maximum grant available is £30,000.

In Northern Ireland the maximum grant available is £25,000.

In Wales the maximum grant available is £36,000.

### Discretionary powers of local authorities

Local authorities can use discretionary powers to meet additional costs (there is no maximum to discretionary grants). Assistance can be in the form of:

- a grant;
- a loan;
- provision of materials, labour or advice.

**Adaptations must meet the specific needs of the disabled person. They must be assessed, usually by an occupational therapist, and justified to be necessary and appropriate, and reasonable and practicable in relation to the property.**

These discretionary powers also allow a local authority to provide help in other ways, for example the:

- acquisition of accommodation which might meet someone's needs better than adapting an existing property;
- provision of small scale adaptations either not covered by a DFG or to get urgent adaptations done more quickly.

Local authorities may also take security, including putting a charge on someone's home. This can mean a local authority can recoup their loan when the house is sold.

## Who is considered to have a disability?

Someone who:

- has substantial impairment to sight, hearing or speech;
- has a mental disorder or impairment of any kind;
- is substantially physically disabled by illness, injury, impairment since birth, or otherwise;
- is registered, or could be registered with the social services department as being disabled.

## Who is eligible to apply?

The applicant must be:

- an owner-occupier;
- a private tenant;
- a landlord with a tenant who has a disability;
- a local authority tenant;
- a housing association tenant.

The applicant need not be the disabled person so, for example, a parent, guardian or foster parent might apply on behalf of a child.

## How do I apply?

Check first with your local authority as to how they initiate and process applications.

Initially, you can ask social services or the housing department for an application form. The relevant department cannot refuse to give you a form. Some authorities offer the services of an agency that will oversee the process from beginning to end – this can cost money though. If the disabled person lives in a local authority or housing association property, or is a tenant of a registered social landlord, some local authorities have different ways of processing requests. In this instance the applicant should contact the landlord first.

**N.B.** An application will not be accepted once any work has started; nor will a grant be offered if work is started before approval is given.

## Who decides what adaptations are needed?

Once the initial application form has been completed, arrangements will be made for someone (usually an occupational therapist) to visit the home so they can carry out an assessment.

## What should you consider?

Prior to the visit, it is useful to have a good idea of what adaptations are necessary to help ensure nothing is inadvertently overlooked. It is also important to plan ahead. Remember to consider a child's future needs as it may not be possible to secure another grant a few years later.

Are there any cultural or religious considerations to be taken into account? How might other family members be affected? For example, if a disabled young person needs attention regularly during the night, it is probably important they are not sharing a bedroom with a sibling.

The best assessments usually happen where there is good working partnership between the occupational therapist and the family. A word of warning – in some areas there may be a long waiting list to get an appointment with an occupational therapist.

## What happens next?

It is important to be aware that the whole process can be very lengthy. While there may be variation from one authority to another, an example of the process is:

### 1. A preliminary 'test of resources'

This is the 'means test', which will indicate how much the applicant might have to pay. The test will involve the checking all financial and benefits information provided by the applicant. Where the disabled person is over 18 years of age the circumstances of both the disabled adult and their spouse or partner (if applicable) will be taken into account. If it is a disabled child the financial circumstances of the parent(s) will be assessed. The purpose of the means test is to determine how much (if anything) the applicant will have to pay towards the cost of the work.

### 2. Plans and specifications will be drawn up

For major work it is advisable to involve a qualified architect or surveyor. Their fees can be included in the cost of the work.

### 3. Agreements

Agreements will be made on the plans and specification and then estimates to get the work undertaken will be obtained (at least two quotes are required).

### 4. Submitting the grant application

The grant application is submitted together with any supporting documents requested. It is important to make a formal application because the local authority has to give a decision within six months of receiving one. They cannot refuse to accept a formal application however this does not mean the application will necessarily be successful.

### 5. Financial contribution

The financial contribution, if any, will be determined.

### 6. Work starts

Assuming the application is successful the work can begin. It must be completed within 12 months of grant approval.

### 7. Project assessment

Once completed the work is checked to ensure it is satisfactory.

### 8. Payment made

At this point any financial contribution from the occupant will be paid with the authority paying the balance.

## Conditions of accepting the grant

The grant conditions are supplied with the grant approval. For most people the main one relates to a certificate, which will have already been signed, stating that the intention is that the property being adapted will be the main residence of the disabled person for (usually) five years. It can be shorter if there are health problems or other special reasons.

## Policies and procedures

- DFGs should not be used for minor adaptations where the cost would be less than £1,000.
- Some authorities will not use the DFG, for local authority tenants where the cost is less than £2,000.
- The process and local prioritisation for administering DFGs can vary from one local authority to another. It is therefore important to ask your local authority what its policies and procedures are.
- Some authorities will have one department or agency that oversees the whole procedure from the outset, which means the applicant has only has one point of contact. Others will not.

## Further information

**DIAL UK** (Disability Information & Advice Line)

St. Catherine's

Tickhill Road

Doncaster

South Yorkshire DN4 8QN

**01302 310123**

**information@dialuk.org.uk**

**www.dialuk.org.uk**

DIAL offers free, independent advice on all aspects of disability and has over 140 local centres. Home visits can be arranged.



# Guide to transition

## 8. Charitable grants

### Introduction

This is one of a series of factsheets which look at how to source additional funds from charitable sources.

Charities or grant-giving trusts rarely give money for things that might reasonably be expected to be obtained from, or funded by, statutory sources, so always apply to statutory providers before approaching charities.

The **Disabled Facilities Grants** factsheet gives examples of statutory sources to approach, so if you haven't already done so, we advise you to refer to this now. We also recommend you seek advice from a specialist disability advice service, such as **Scope Response**, to ensure you have considered and exhausted all possible statutory sources.

### Getting help

If you have approached other sources without success and need the assistance of a charity or grant-giving trust you need to identify which ones you can apply to. Your care manager, social worker, local advice organisation (such as the Citizens Advice Bureau) or disability organisation may be able to provide a list of options.

### Securing funds at the right time

Very few organisations award funds retrospectively so don't approach them for help with debts, or items which you have already bought. If you are already burdened by debt or fear you are about to be it is essential you seek professional advice urgently. Your local Citizens Advice Bureau may be able to help or you could seek advice from The National Debtline.

### Finding details of suitable funders

#### **A Guide to Grants for Individuals in Need**

This is a useful directory which can be found in the reference section of most public libraries. The guide lists numerous options though searching the guide can be quite time-consuming.

#### **Funderfinder**

This online search database features the contact details of voluntary sector organisations (including the Muscular Dystrophy Campaign). To find information you will need to supply details about the circumstances of the person seeking funding. This database then searches the details of hundreds of different grant givers and selects those which are most appropriate.

### Getting started

Once you have your list you can begin the often lengthy and complex business of making applications. If you are applying for a large sum, you're unlikely to get it all from one source. Initially it is best target no more than five or six organisations – concentrate on making a few, very focused applications.

Duplicating the same application to numerous organisations is rarely successful because most grant givers receive more applications than they have funds for, so making your application really specific to their organisation means they are more likely to take notice.

Each grant-giving organisation has its own eligibility criteria so make sure you know what they are. Some will have a standard application form, some will require a letter of application and others will ask for an application form with a personalised covering letter.

Many people waste time and energy making applications that fail because they apply:

- to the wrong organisation (i.e. they do not fit the criteria);
- in the wrong way (e.g. a letter instead of an application form);
- at the wrong time (some grant givers only consider applications once or twice a year and so are not able to consider applications where funds are needed immediately).

## Suggestions for making a successful application

Before you start writing applications set up a 'Fundraising File'. This need not be complicated but it will save you time later and you can start on it while you are waiting for the information from individual grant-giving organisations to arrive. You might find it helpful to take some time to think through the following list of questions and write down your answers:

### 1. What do you need the money for?

Be precise; for example, if it is for an item of equipment, state the manufacturer, model name or number and where you will purchase it. Get a brochure and put it in your file to refer to later.

### 2. How much money do you need?

Obtain the exact price from the supplier. If it is available from more than one source get more than one quote so that you can demonstrate you will be paying a competitive price. Grant givers are impressed by applicants who take the trouble to show they will spend the money wisely.

### 3. What difference will the grant make?

It might be obvious to you how you would benefit from having a particular piece of equipment, or going on a particular holiday, but it might not be obvious to the grant giver as they may not know about your disability or individual circumstances. Would getting the grant also benefit others? Think about the potential benefits to carers or family members and write a brief paragraph to summarise the benefits to all concerned.

### 4. What else might you need money for in the future?

Some grant givers will only make a single payment to an individual; others may limit the number of applications they will consider from an individual in a given period of time (e.g. one application per year). Don't end up disqualifying yourself from applying to a particular grant-giving organisation for an expensive item you really needed just because you previously received a grant for something that wasn't essential or could have been funded from elsewhere. If you know that there are a number of inexpensive things that you are going to need (small pieces of household equipment for example) it might be worth 'bundling' these together into one application.

### 5. What statutory sources have you already tried?

Most funders will not even consider your application if they think funding could be provided by the National Health Service, social services, local education authority or another statutory source. If you have already approached a statutory source and been turned down ask them to put their decision in writing. This is useful evidence that your only remaining option is to approach a charitable grant giver.

## **6. Who can support your application?**

Grant givers like proof that you really need the item you are asking for so gather written evidence from professionals who know you. Suitable people might include your GP, hospital consultant, social worker, physiotherapist, occupational therapist, teacher or a worker from a community or disability organisation who knows you. Some grant givers need a professional to make the application on your behalf. Who might be willing to do this for you? Contact them and ensure they are willing to lend their support. You may find it helpful to ask your regional care advisor for assistance.

## **7. Why can't you fund this yourself?**

Write down your income and outgoings and summarise it to show why you do not have the financial means to be self-sufficient. Many grant givers are impressed by applicants who are willing to contribute something towards the cost themselves, even if it is only a token amount.

## **8. Be honest about your own abilities.**

If making the application yourself will be difficult, is there a friend, family member or professional who has the skills and time necessary to do it for you?

## **9. When making an application focus on one at a time**

Concentrate your energies on one particular grant-giving organisation to avoid confusion, and complete it before moving onto the next.

## **10. Read it carefully**

Always check your application form to make sure you have followed any instructions the organisation has given you. And remember to make the application relevant to them.

## **11. Be clear**

Write succinctly and neatly, avoiding any complex terms or jargon. The people making a decision about your application will probably be considering it alongside many others and if yours is clear and easy to read it may improve your chances of success.

## **12. Keep it concise**

Try not to write any more than two sides of A4 paper and remember to include any supporting documentation.

### **Once you have written the application:**

- Before sending, put it to one side and leave it overnight, then come back to it fresh the next day. Are you still happy with it?
- Consider getting someone not personally involved to check it for you. They may be able to give some interesting insights on how clear the application might be for someone who doesn't know you, and is reading it for the first time.
- Make a copy and keep it safe in your file.
- Not all organisations will acknowledge receipt of your application so if you need to know it has arrived safely, enclose a stamped addressed envelope and request a receipt.
- Make sure you post it in good time to meet any stated deadline.

**Resources:**

A Guide to Grants for Individuals in Need – Directory of Social Change, 2006/07. ISBN 978 1 903991 74 9  
Raising Money for Good Causes – A Starter Guide Jane Sutherland & Mike Eastwood

**Useful organisations:****Funderfinder**

This is a software package sold to not-for-profit organisations to help them identify potential funders.  
The Muscular Dystrophy Campaign can conduct an initial search for you.

0113 243 3008

0113 243 2966 (fax)

info@funderfinder.org.uk

www.funderfinder.org.uk

**National Debtline**

0808 808 4000 (freephone)

0121 410 6230 (tel)

advice@nationaldebtline.co.uk

www.nationaldebtline.co.uk

**The National Association of Citizens Advice Bureaux**

Can provide you with contact details for your local Citizens Advice Bureau. It also provides an online advice guide.

020 7833 2181

020 7833 4371 (fax)

www.nacab.org.uk

www.adviceguide.org.uk

# Guide to transition

## 9. Raising funds for young people

Charitable funds should only be used to pay for things which statutory services are unable to provide – please see our separate factsheet which explains this further.

**The following items should be funded via statutory services:**

**Medical equipment** – provided free of charge by the NHS.

**Medical treatment** – provided free of charge by the NHS (always speak to your consultant prior to travelling abroad to investigate treatment options or for alternative therapies).

**Mobility** – (including manual and powered wheelchairs, walking aids, such as rollators, and vehicles) Wheelchairs and walking aids should be provided by the NHS after an assessment by a relevant therapist or professional. Wheelchair Services are a part of the NHS. Ask for a copy of their criteria. (N.B Vehicles may be obtained via the Motability Scheme by those on the higher rate mobility component of Disability Living Allowance. This is non-statutory provision).

**Home adaptations** – usually funded (for those aged 18 and over) through a means tested Disabled Facilities Grant. Liaise with your local social services occupational therapist. Please note very few charities will fund adaptations.

**Equipment to assist independence at home** – usually provided free of charge by social services following an assessment by an occupational therapist.

**Computers** – funded by the employment authorities for use at work (speak to the Disability Employment Adviser at your Job Centre Plus).

**Care packages** – contact social services. Help may be means tested for ‘personal care’, such as washing, dressing and meal preparation, as opposed to ‘medical care’, which needs to be given by a nurse or doctor. For older people in Scotland personal care is free.

**Holidays** – funding for respite care may be available via the NHS or social services.

### How to obtain help

Professionals (usually occupational therapists, physiotherapists or specialist nurses) should be involved in assessments for specialist equipment you are fundraising for. Remind them to provide a written report confirming the suitability of the equipment.

You may find that a professional is willing to co-ordinate the fundraising effort for you, which can be very helpful but you will also need to be prepared to take on this responsibility yourself.

Only approach those charities or organisations which are appropriate to your needs (those that the applicant meets the basic criteria for).

**This factsheet looks at the most effective ways of raising funds for a specific one-off need via statutory (public, not charitable) services. Find out what your local health and social care trust or education authority can provide you with.**

## Application criteria

Application criteria may be based on one or more of the following:

- Diagnosis.
- What the request is for.
- Where the person needing the help lives.
- The age of the person requiring the help.
- Financial status of the person or family requesting the help.
- Employment background (including periods of military service).
- Support of a relevant professional.
- Amount of finance required.

### Remember the following:

- Never raise funds without the knowledge and agreement of the beneficiary.
- Never raise funds for equipment that the individual has not been professionally assessed for.
- Know how much you need.
- Be very clear with donor charities or individuals that the fundraising is for an individual, not for a registered charity.
- Retain all paperwork and receipts, records of the source of donation and keep clear accounts.
- Return any funds which cannot be used for the agreed purpose.

## Who to ask for further help

Almost all applications require the support of a **qualified care or medical professional**. In most cases those requesting help will be asked to complete an application form which usually involves revealing details of personal circumstances and finances.

**Citizens Advice Bureaux and local solicitors** often hold details of local trusts. People who were in one of the Services (or who are a close relative of someone who is/was) may get help from a service-based charity. Often there are specific trusts for people involved in certain professions/industries (e.g. Teachers Benevolent Fund). Some charities specifically help only older people.

The Muscular Dystrophy Campaign has access to a computer software package called "Funder Finder for People in Need". We are willing to undertake searches for you but cannot make applications on your behalf.

**Local libraries** usually have a copy of the latest edition of *A guide to grants for individuals in need*. This is published by the Directory of Social Change – **0845 077 77 07**.

## UK charities which may be approached by people with muscle disease

### Joseph Patrick Trust

Muscular Dystrophy Campaign

61 Southwark Street

London SE1 0HL

**020 7803 4814**

**0800 652 6352 (freephone)**

**[jpt@muscular-dystrophy.org](mailto:jpt@muscular-dystrophy.org)**

**[www.muscular-dystrophy.org/jpt](http://www.muscular-dystrophy.org/jpt)**

The Joseph Patrick Trust is part of the Muscular Dystrophy Campaign. It provides grants towards the cost of equipment for children and adults with muscle disease. A professional assessment report is required. Applications can be made online.

**Equipment for Independent Living**

6 Quintock House  
Broomfield Road  
Richmond  
Surrey TW9 3HT

**020 8940 2438**

Equipment for Independent Living provides small grants to help fund equipment.

**Family Action**

501-505 Kingsland Road  
London E8 4AU

**020 7254 6251**

**[www.fwa.org.uk](http://www.fwa.org.uk)**

Family Action gives grants for equipment to people of all ages who are on low incomes throughout the UK.

**Independence at Home**

4th Floor Congress House  
14 Lyon Road  
Harrow HA1 2EN

**020 8427 7929**

**020 8424 2937 (fax)**

**[iah@independenceathome.org.uk](mailto:iah@independenceathome.org.uk)**

**[www.independenceathome.org.uk](http://www.independenceathome.org.uk)**

Independence at Home provides small grants to people who live at home and are affected by chronic illness or neurological problems. The grants are only given where the balance left to raise is under £2,000.

**The Jennifer Trust for Spinal Muscular Atrophy**

Elta House  
Birmingham Rd  
Stratford-upon-Avon  
Warwickshire CV37 0AQ

**0800 975 3100**

**[jennifer@jtsma.org.uk](mailto:jennifer@jtsma.org.uk)**

**[www.jtsma.org.uk](http://www.jtsma.org.uk)**

JTSMA helps children and adults with SMA with the cost of wheelchairs and other essential equipment.

**The ACT Foundation**

The Gatehouse, 2 Park Street  
Windsor  
Berkshire SL4 1LU

**01753 753 900**

**[info@theactfoundation.co.uk](mailto:info@theactfoundation.co.uk)**

**[www.theactfoundation.co.uk](http://www.theactfoundation.co.uk)**

The ACT Foundation helps fund equipment for disabled people and modifications to homes, schools, hospices etc.

**The Aidis Trust**

3 Gunthorpe Street  
London E1 7RQ

**020 7426 2130**

**[info@aidis.org](mailto:info@aidis.org)**

**[www.aidis.org](http://www.aidis.org)**

The Aidis Trust advises on the use of, and helps fund, communication aids, including computers.

**The Catharine House Trust**

Ridge Cottage

New Cut

Westfield

East Sussex TN35 4RL

The Catharine House Trust helps to fund equipment.

## **Related publications by the Muscular Dystrophy Campaign**

**Information technology**

This factsheet gives information about what to consider when buying a computer, such as assessments and adaptations.

**Wheelchair Provisions for Children and Adults with Muscular Dystrophy and other Neuromuscular Conditions**

This comprehensive guide is aimed at helping staff plan appropriate wheelchair and seating for children and adults with neuromuscular conditions. Aimed at wheelchair service staff this is also a useful best practice guide for users, parents, carers and other health professionals.

For further information and support contact the Muscular Dystrophy Campaign:

**0800 652 6352 (freephone)**

**info@muscular-dystrophy.org**

**www.muscular-dystrophy.org**

# Guide to transition

**Everyone has basic personal routine activities that need carrying out every day, for example washing, dressing, cleaning their teeth and going to the toilet.**

## 10. Daily living

Muscle disease often causes some very specific difficulties with the way in which a person gets from sitting to standing, or uses their arms due to weakness around the shoulders.

Weakness of muscles in the trunk and around the pelvic girdle result in difficulty in walking distances, climbing stairs, managing uneven surfaces (like cobbles) and rising from sitting to standing. Knees tend to 'give way' causing falls, which can then be followed by extreme difficulty or complete inability in getting up.

Some people may already be using a wheelchair and have little or no ability to get into a standing position unassisted. There may also be weakness in your arms and hands, which can make lifting them above your head difficult and mean that you need a lot of help with carrying out tasks at home.

### Getting help

Many activities which keep your life running smoothly – like washing clothes, cooking, cleaning and shopping – can become increasingly difficult or even impossible over time. The correct advice, support, information and equipment can help maintain your independence.

### Living independently

If you live independently and are experiencing difficulties in managing at home it is useful to think about seeking help. You can get help at home by making a referral to social services. You, a family member, a friend or one of the specialist team you see at clinic can make the referral, but they can take time to process so don't wait until you cannot manage at all before seeking advice.

If you have facioscapulohumeral muscular dystrophy (FSH) you may develop difficulties with your arms and shoulders long before you have difficulties with walking, so seeking advice from an occupational therapist (OT) about your arm function is likely to be helpful.

### Making tasks manageable

If you get tired, try to think about planning activities. You could try spreading tasks throughout the day or week with rest periods in between. If you are more awake in the morning, why not carry out your daily activities then and rest in the afternoon, or vice versa.

### Staying active

It is important to try and remain as active as possible (see our *Exercise factsheet*) but if you live alone or are finding it difficult to manage it might make things easier if you prioritise or change how you do jobs. Some people find shopping on the internet helps for example.

### Getting support

Ask someone else to help you with activities which you are finding particularly difficult. This should make things easier and enable you to save some of your energy for more enjoyable activities. Be aware that due to moving and handling regulations staff employed to support you aren't allowed to lift you or heavy objects but assessment for using the appropriate equipment can be arranged if it is needed.

Depending upon how much help you need and what activities you need help with you may be entitled to state benefits (e.g. Disability Living Allowance) from the Department of Work and Pensions. See our *State benefits factsheet* for more information.

If you are having falls (particularly if you live alone or spend time alone in the family house) it may be wise to consider an alarm system. Most local authorities run a scheme for alarms so contact your social services or social work department for details.

## Accepting change

It can be hard to accept that equipment is needed and there is an argument for maintaining activities like climbing stairs and getting up from a chair for as long as possible. However, many people tend to struggle on when they are finding things extremely hard and don't want to 'give-in' to their condition.

Some specific pieces of equipment can be very helpful. Try to think of these as positive and labour saving – enabling you to get the most out of your life. Rising chairs or lifts can save your energy for more pleasurable activities like socialising with family and friends. Make sure you seek advice about suitability before you buy anything.

Many items of equipment are available through statutory services such as NHS Trusts or social service departments (your occupational therapist, physiotherapist or district nurse can advise).

If you are having difficulties turning electrical items on and off, or opening the door to visitors, environmental controls may be helpful. You can be referred for an assessment by your GP or muscle clinic team.

## Buying equipment

Always try equipment and get advice about its suitability for someone with your condition (including whether it will continue to meet your needs) before buying it. If possible ask someone to be with you during the assessment – professionals involved with you may be prepared to come along, if not, ask a relative or friend.

Be cautious of equipment like electric rising armchairs as many models are not particularly suitable. Chairs which rise vertically rather than gradually tilt are preferable as they are likely to be suitable for a much longer period. Electrically adjustable beds can be very helpful but be aware that some models are better than others for meeting the needs of a person with a neuromuscular condition.

For more information about specific pieces of equipment see the **Further information** section at the end of this factsheet.

**You may find it helpful to view equipment so that you know what is available.**

**Visit an independent equipment advice centre** often known as Disabled Living Centres or Independent Living Centres. You usually need to book an appointment to visit. Some centres offer assessments for equipment with a suitably qualified health professional.

### **Change to Assist UK**

Redbank House

4 St Chad's Street

Manchester M8 8QA

**Tel:0870 770 2866**

**general.info@assist-uk.org**

**www.assist-uk.org**

**Visit an equipment exhibition such as NAIDEX** which organises large equipment exhibitions where entry is free. Venues are fully wheelchair accessible with nearby parking for blue badge holders and you can usually hire wheelchairs and scooters to use at the exhibition.

**020 7728 4262**

**bindi.chakkl@emap.com**

**www.naidex.co.uk**

There are also smaller equipment exhibitions. Details of these are available from the Muscular Dystrophy Campaign:

**0800 652 6352 (freephone)**

**info@muscular-dystrophy.org**

**www.muscular-dystrophy.org**

### **Disability equipment shops**

Most cities now have shops which specialise in equipment for disabled people. Be aware that although staff should be able to provide information on their particular products they aren't likely to have any medical knowledge or training, so probably won't know whether they will be suitable for your particular condition.

### **Equipment catalogues**

It is unusual to find specialised equipment in catalogues but they can be useful for small items like reachers, riser blocks for chairs and cutlery. Small items of equipment like these may also be available free via Occupational Therapy Services.

**Hearing and Mobility** (previously Keep Able)

**0844 8881338**

**customerservices@hearingandmobility.co.uk**

**www.hearingandmobility.co.uk**

### **Care Shop**

**0161 848 4001**

**medical@careshop.co.uk**

**www.careshop.co.uk**

### **Chester Care**

**01244 390749**

**info@chestercare.org**

**www.chestercare.org**

Telecare response Centre operates 24 hours a day, 365 days a year, providing continuous services to clients of Chester and district housing trust and handles emergencies and out of hours service requests.

### **Disabled Care & Mobility**

**01242 524 963**

**info@dcmglos.co.uk**

**www.dcmglos.co.uk**

## **Progressive conditions**

As your condition progresses there may be situations where equipment, re-organisation or extra help cannot solve a difficulty for example, your property might need adapting or you might need to consider moving to a more suitable property. You could be entitled to a Disabled Facilities Grant (DFG) to help cover the costs. The grant is means tested once you are over 19, and you will need to be assessed by an OT before you can qualify for one, so take advice from your local council.

Always make enquiries before you go ahead with any alterations because funding cannot be given for work already carried out. The Muscular Dystrophy Campaign has produced a manual that will be helpful to anyone planning adaptations to their home which also contains sections on useful equipment. You may also find it helpful to refer to the *Disabled Facilities Grants factsheet* in this pack for guidance.

**Professionals who you may come into contact with when dealing with the impact of your condition on daily living are:**

**Consultant in rehabilitation medicine** – a doctor who specialises in helping people with long-term conditions and disabilities to be as independent as possible.

**Occupational therapists (OTs)** – advise on equipment for use in the home, for outside and home adaptations. In most areas you will find OTs are employed within both the Health Service and Social Services and some housing associations also employ OTs. The way in which they work can vary from area to area so it is advisable to contact your local social services or if you live in Scotland, your social work department. Your consultant, one of the muscle team, or your GP should be able to provide information.

**District nurses** – may be able to advise about beds, mattresses and issues related to continence and can be contacted through your GP practice.

**Physiotherapists** – can advise on orthotics, splints, walking frames, wheelchairs etc. You can contact them through your GP or muscle team.

If you need to make contact with any one of the above ask your specialist neuromuscular consultant or one of the muscle clinic team to refer you or provide contact details.

## Further information

The Muscular Dystrophy Campaign produces other relevant factsheets and publications:

- Adaptations manual
- Clothing factsheet
- Mobile Arm Supports factsheet

**Other useful contacts:**

**Disabled Living Foundation**

**0845 130 9177**

**info@dlf.org.uk**

**www.dlf.org.uk**

For general information on equipment and suppliers

**Disability, Pregnancy and Parenthood International**

**0800 018 4730**

**info@dppi.org.uk**

**www.dppi.org.uk**

For information on equipment that may help with parenting

**REMAP**

**tel: 0845 1300 456**

**www.remap.org.uk**

Custom-made equipment

# Guide to transition

## 11. Diet and nutrition

### Professionals and their area of expertise

Several professionals may be involved in diet, nutrition and feeding, including:

**Dieticians** – advise on nutrition, weight control, food consistency, special diets and alternative feeding methods.

**Speech and language therapists** – advise people who are experiencing difficulties with chewing and swallowing on safety, positioning and food/liquid consistency.

These two professionals work closely together to help get the best from an individual's diet and nutrition and can be accessed via a referral from a person's GP, a neuromuscular specialist or a muscle team.

**Occupational therapists** – advise on equipment that can help get food and drink to the mouth, for example specialised cutlery, height adjustable tables or mobile arm supports. They can also provide advice on equipment to assist with toileting and can be accessed with a referral to your local social services.

**District/continence nurses** – advise on continence issues including equipment, such as bottles and portable devices that may be helpful in situations where a person is unable to access their usual toileting facilities. They can be accessed by your GP.

**Physiotherapists** – advise on exercise and activity which combined with a weight reducing diet, may be helpful in assisting weight loss. A referral can be made via the young person's specialist, muscle team or GP.

Professionals are unlikely to be familiar with individuals' particular needs, so we suggest asking them to liaise with your specialist neuromuscular consultant or one of your muscle clinic team.

### General information and advice

Good nutrition is dependent upon the following:

- Adequate intake of the correct food groups – your 'five a day' fruit and vegetables, plus meat or fish.
- Adequate fluid intake – water, juice and hot drinks.
- The ability to go to the toilet and eliminate waste products.

The aim for any young person reaching adulthood is to maintain a stable weight within the normal range for a person of their height and build through a healthy balanced diet. Most people will have less muscle so their ideal weights may be slightly less than in people who don't have muscle disease.

**Many children and adults with muscle disease have concerns about their weight, ability to chew and swallow or ability to get food and drink to the mouth. There may also be practical concerns about being able to use the toilet which tempts people to limit how much they drink. Many difficulties can be overcome with the correct advice and support.**

## Toileting

Adequate fluid intake is also essential for maintaining general health and keeping the body working properly. If your mobility is decreased you might be worried about finding adequate toileting facilities, particularly when away from home. Try to resist the temptation to limit how much you drink to reduce the need to use the toilet as insufficient fluid intake causes dehydration and can cause aches and pains and other more serious problems.

RADAR runs a National key scheme for public toilets which gives access to approximately 3,000 conveniences for people with disabilities – please see details at the end of this factsheet.

## Equipment

If there are physical difficulties with lifting a cup the use of a lightweight, or non-spill cup may be an alternative. Other specialist feeding utensils may also help and are readily available. Straws can also be useful but should be used with caution if you have swallowing problems. Some sports shops stock drinking systems which could be fitted to wheelchairs and may prove helpful.

The medical physics department in many areas can also provide equipment that can make it easier to eat or drink independently (you will need to be referred by a medical professional). There are other options including artificial feeding which may help you manage your condition.

Advice is available from district nurses, continence nurses and/or occupational therapists on products and equipment that may help with toileting. These may be small items such as bottles or portable urinals or larger items such as raised seats or rails to make using the toilet easier.

## Specific dietary advice

Reduced activity due to muscle weakness can lead to a decrease in the strength of bones so it is essential for a diet to include:

- calcium – found in foods such as milk, cheese, yoghurt, sardines, pilchards and figs
- Vitamin D – helps calcium to be absorbed from food – found in foods like oily fish, margarine and eggs.

The body can make vitamin D through the action of sunlight on the skin so getting outside for 20-30 minutes a day will also be beneficial.

Most young adults are aware that being overweight increases the risks of conditions like heart disease and diabetes, and is not good for their general health. Carrying excess weight can also cause added difficulties such as:

- reduced walking ability;
- functional abilities;
- extra strain on respiratory/heart muscles;
- increased risk during surgical procedures.

People with muscle weakness find these difficulties are further increased. If help is needed with moving, the extra weight also makes this harder for carers.

For some neuromuscular conditions, studies have been carried out on the benefits of certain dietary supplements. Ask your muscle consultant for details of whether this would be relevant for your particular condition.

## Weight

For some people with neuromuscular conditions being underweight or experiencing unexplained weight loss can be a problem. If this is the case, the situation should be discussed with a member of the muscle clinic team or a GP. Referral to a dietician may be suggested. Weight loss can be due to a number of reasons, for example:

- Physical problems with feeding – arm supports or feeding systems may help.
- Difficulties swallowing and chewing.
- Nocturnal hypoventilation – night time lack of sleep.
- Repeated illnesses – colds, flu or chest infections.
- Gastro-oesophageal reflux – acid/bile into the throat or heartburn.
- Psychological factors – depression or low self image.

If you are overweight sensible dieting may help to improve your abilities without reducing your muscle bulk or strength.

If your muscles are becoming weaker and walking and other activities are becoming harder, there may be a tendency to put on weight as fewer calories are being used. Modifications to the diet may be necessary.

## Exercise

Trying to maintain some form of regular gentle exercise, for example swimming or cycling as this will help to limit weight increase.

It is advisable to maintain general everyday activities for as long as possible. However, it may be helpful to look at whether equipment can help. You can also plan throughout the day so that rest periods can be incorporated if you become tired or your muscles fatigue quickly. Advice from a physiotherapist or occupational therapist may be helpful at this time.

## Further information

The Muscular Dystrophy Campaign produces a range of factsheets and other publications, which are available through our website or by contacting our Information Service.

Those specifically relevant to this subject are:

- Gastrostomy factsheet
- Alternative therapies factsheet
- Exercise factsheet.

Contact the Information Service or visit our website:

**0800 652 6352 (freephone)**

**info@muscular-dystrophy.org**

**www.muscular-dystrophy.org/publications**

### Further information

**NHS Direct**

**0845 46 47**

**www.nhsdirect.nhs.uk**

Healthy eating advice

**RADAR**

12 City Forum

250 City Road

London EC1V 8AF

**020 7250 3222**

**radar@radar.org.uk**

**www.radar.org.uk**

National Key Scheme run by RADAR

# Guide to transition

## 12. Exercise

### Professionals and their area of expertise

**Physiotherapists** – can advise on specific exercises for your condition but may not recommend 'fitness activity'. Accessing a physiotherapist can be difficult in some areas so ask your GP or consultant for a referral. Adults can find it more difficult to get access to a physiotherapist. Your local muscle team may advise you on the best kind of exercises for you.

**Fitness instructors** – can advise about fitness routines but be wary if you have a long-term condition that affects your muscles. Fitness instructors should seek advice from a medical professional.

### General information and advice

Any activities of daily living are exercise if they require effort (which they usually do!) The weaker you are the more effort it will take to carry out these tasks, so doing things like the washing up, cooking, laundry, ironing, shopping can all be counted as exercise. Doing things which require effort helps to keep you fit and your muscles as strong as they can be.

It is important that you pace yourself and don't wear yourself out doing chores then have no energy left for the fun things in life. Why not get organised and plan your chores in advance, spreading your activities out through the day or week and taking rest breaks as you need them?

Exercise at a moderate level. This means breathing a bit harder and getting a bit warmer but still being able to hold a conversation.

#### Frequency and level

Try to exercise two to three times a week for 30 minutes if possible. However two sessions of 15 minutes or three sessions of 10 minutes are also better than nothing at all.

It is important to start off gently. Don't be too enthusiastic at the beginning as you may overdo it. Gradually increase what you can do over time. Try to exercise regularly rather than in fits and starts.

Choose activities that you can fit into your daily routine fairly easily and that are fun.

If walking and weight-bearing exercises are difficult for you then swimming or exercise in water (hydrotherapy) may be beneficial. If there is a hydrotherapy service in your area your GP should be able to refer you. This is important as it gives you exercise along with therapeutic and social activity benefits.

#### Further information and advice

Primary Care Trusts run *Expert Patient Programmes* to help people with long-term conditions. They may be able to provide you with details of local exercise opportunities.

Your GP may be part of an exercise referral scheme in which case he or she can refer you for exercise advice and support locally.

**Exercise can't change how the disease progresses but it does help to keep the remaining muscles as strong as they can be. Exercise can help with weight control and make you feel better. Any activity that requires effort is exercise.**

Any leisure centre that is Inclusive Fitness Initiative-accredited will have some knowledge of mobility problems, trained staff and some adapted equipment. Visit [www.inclusivefitness.org](http://www.inclusivefitness.org) for your nearest centre.

This factsheet is edited from an original by Jane Freebody MCSP, specialist neuromuscular physiotherapist, John Radcliffe Hospital, Oxford.

The Muscular Dystrophy Campaign is currently (2009) funding two research projects into the impact of exercise on muscle disease. Contact us to find out more.

**020 7803 4812**

**[research@muscular-dystrophy.org](mailto:research@muscular-dystrophy.org)**

**[www.muscular-dystrophy.org/research](http://www.muscular-dystrophy.org/research)**

# Guide to transition

## 13. Holidays

As you move into adulthood you may want to look at holidays that you can go on by yourself and with friends rather than family members. You may wish to go with a carer or personal assistant. This service can be accessed through social services as part of a respite care package or Direct Payments.

**Holidays should be relaxing, fun and free from stress. Advance planning is vital in helping you to achieve this.**

This factsheet only gives details of some of the holidays and services which are available. For further information please contact a specialist organisation such as Tourism for All or your local tourist information centre.

### **When planning your holiday it helps to think through all your requirements.**

- Where are you hoping to go?
- When are you hoping to travel?
- What type of accommodation are you looking for?
- How will you travel; in your car, a hired vehicle, by public transport etc?
- Are you going on holiday alone or with others?
- Do you need help with personal care or mobility, which others with you won't be able to provide?
- Do you have any specific medical needs? For example do you use a ventilator?
- Do you need to take any specialised equipment with you? If so, how will it be transported? Could you hire equipment at your destination?
- What are your specific needs? Remember that using a self-propelled manual wheelchair is very different to using a large, sophisticated powered wheelchair, which is much heavier and needs more space. Ask about steps, gradients, widths of doorways into bedrooms and bathrooms, equipment available on site – especially in the bathroom – and the accessibility of other facilities e.g. dining rooms and bars.
- If you are driving, are there suitable parking facilities?
- Can you obtain your travel insurance at a reasonable cost? Don't rely solely on EHIC cards ([www.ehic.co.uk](http://www.ehic.co.uk)) in Europe and remember that medical costs in the USA are particularly high so you will require a good insurance policy.

## Getting there

The **Disabled Persons Transport Advisory Committee (DPTAC)** is a website that has been set up by the government to help you plan your journeys. [www.dptac.gov.uk/door-to-door](http://www.dptac.gov.uk/door-to-door)

## Luggage

Remember to consider how you will cope with your luggage if travelling alone or with other people who have disabilities.

**Carry my luggage** operates a door to door service in the UK and abroad.

**01472 362 400**

[www.carrymyluggage.com](http://www.carrymyluggage.com)

## Translation of medical information

If you are travelling to a non-English speaking area you might find it helpful to take translated information about your condition with you. Two companies that provide this service are:

### **Doctor Babel**

**support@doctorbabel.com**

**www.doctorbabel.com**

### **Transmedi**

**01162 337 640**

**www.transmedi.com**

## Equipment hire

Basic equipment (manual wheelchairs, raised toilet seats, commodes etc) can often be hired for a short period of time.

### **The Red Cross**

**0844 871 1111**

**www.redcross.org.uk**

## Accessible mainstream holidays in Europe and America

**Enable Holidays** provides detailed, audited information on resorts, travel options and available adaptations.

**0871 222 4939**

**info@enableholidays.com**

**www.enableholidays.com**

## Accessible accommodation in the UK

**Dalraddy Chalet** provides accessible accommodation for six people in three twin-bedded rooms.

Includes Freeview TV.

Capability Scotland

Isla Road, Perth PH2 7HQ,

**01738 632995**

### **Forest Holidays**

Bath Yard, Moira

Derbyshire DE12 6BD

**0845 130 8225** – cabins

**0845 130 8226** – campsites

**fe.holidays@forestry.gsi.gov.uk**

**www.forestholidays.co.uk**

Provides a range of holiday cabins on three sites some of which have been specially adapted for disabled people and wheelchair users. It also has 21 caravan and camping sites across the UK, many of which have disabled facilities. 'Forest Experience' cards are issued free of charge to disabled people (usual cost £12) giving a range of discounts on site and at local attractions.

### **Farm Stay UK Ltd**

National Agricultural Centre

Stoneleigh Park

Warwickshire CV8 2LG

**024 7669 6909**

**admin@farmstayuk.co.uk**

**www.farmstayuk.co.uk**

Holidays on farms using Accessibility Scheme symbols which denote levels of accessibility for disabled people.

**Holidays**

### **Livability Holidays**

PO Box 36  
Cowbridge  
Vale of Glamorgan CF71 7GB

**08456 584478**

**holidays@livability.org.uk**

**www.livability.org.uk**

Provides a range of accessible holiday accommodation (hotels and self-catering) in the UK for disabled people, their families and friends.

## **Holiday accommodation with care**

### **Vitalise**

Head Office, 12 City Forum  
250 City Road  
London EC1V 8AF

**0845 345 1972**

**info@vitalise.org.uk**

**www.vitalise.org.uk**

Holidays for disabled adults and children, offering a range of accessible residential respite breaks and other services designed for disabled people and carers. Provides five purpose-built holiday centres around the UK. Holiday centres are in Southport, Nottingham, Chigwell, Southampton and Cornwall. Accommodation is fully accessible and nursing care is available. Also has self catering accommodation and organises overseas and adventure holidays.

## **Companies providing specialist holidays for disabled people**

### **3 H Fund**

B2 Speldhurst Business Park  
Langton Road  
Speldhurst  
Tonbridge Wells  
Kent TN3 0AQ

**01892 860 207**

**info@3hfund.org.uk**

**www.3hfund.org.uk**

This service provides group holidays in the UK and abroad for disabled people and respite for carers. Care is provided by volunteer helpers, experienced leaders and a nurse or access to local medical facilities. They may also give modest grants in special circumstances.

### **Accessible Travel and Leisure**

Avionics House, Naas Lane  
Kingsway Business Park  
Quedgeley  
Gloucestershire GL2 4SN

**01452 729 739**

**info@accessibletravel.co.uk**

**www.accessibletravel.co.uk**

Offers travel booking service for disabled people and tailor-made trips worldwide. It also offers a range of accessible accommodation in the Mediterranean.

**Access Travel (Lancs) Ltd**

6 The Hillock  
Astley  
Lancs M29 7GW

**01942 888844**

**webenq@accesstravel.co.uk**

**www.access-travel.co.uk**

Offers continental holidays in wheelchair-accessible resorts and holiday homes in France.

**Can Be Done Ltd**

11 Woodcock Hill  
Harrow  
Middlesex HA3 0XP

**020 8907 2400**

**holidays@canbedone.co.uk**

**www.canbedone.co.uk**

Offers a personalised tour planning service for disabled people who want short-break holidays in the UK and overseas.

## Outdoor/activity holidays

Badaguish Outdoor Centre  
Aviemore  
Inverness-shire PH22 1QU

**01479 861285**

**info@badaguish.org**

**www.badaguish.org**

Offers activity holidays with support and accommodation for people with learning, multiple or physical disabilities aged four to 65. Individuals and groups of up to 12 people are catered for.

**Calvert Trust Adventure Centre**

Little Crosthwaite  
Keswick  
Cumbria CA12 4QD

**017687 72255** – phone and minicom

**calvert.keswick@dial.pipex.com**

**www.calvert-trust.org.uk**

An adventure centre near Keswick that provides accommodation, care and facilities for disabled people. Courses include sailing, riding and abseiling. Facilities include a heated indoor swimming pool with sauna and games room.

**Calvert Trust Kielder**

Kielder Water  
Hexham  
Northumberland NE48 1BS

**01434 250232,**

**enquiries@calvert-kielder.com**

**www.calvert-trust.org.uk/kielder**

Close to Kielder Water, the centre accommodates disabled people, their families and friends. Carers can be provided. Ten self-catering chalets are also available. Activities include climbing, walking, archery and swimming.

### **Calvert Trust Exmoor**

Wistlandpound  
Kentisbury  
Barnstaple  
Devon, EX31 4SJ

**01598 763221**

Offers a wide range of activities for people of all abilities and ages, and accessible accommodation.

### **Churchtown**

Lanlivery  
Bodmin  
Cornwall PL30 5BT

**01208 872 148**

**bookings@vitalise.org.uk**

**www.vitalise.org.uk**

Part of Vitalise, Churchtown provides accessible adventure, environmental, leisure and recreation courses. Activities include sailing, canoeing, rock climbing, environmental studies and arts and crafts. The centre has its own nature reserve and swimming pool. Courses can be tailor-made and care staff are available.

### **King Line Cottages**

Ferry Road  
Horning  
Norwich  
Norfolk NR12 8PS

**01692 630 297**

**kingline@norfolk-broads.co.uk**

**www.norfolk-broads.co.uk**

Self-catering holiday lodges in Norfolk. Two day-boats suitable for wheelchair users to hire.

### **Disability Snowsport UK**

Cairngorm Mountain  
Via Aviemore  
Inverness-shire PH22 1RB

**01479 861272**

**www.disabilitysnowsport.org.uk**

Opportunities for disabled people to participate in winter outdoor activities.

## **Travel insurance**

A selection of companies offer travel insurance for disabled people.

### **J & M Insurance Services (UK) plc**

Peregrine House  
Bakers Lane  
Epping  
Essex CM16 5DQ

**0845 338 1638**

**www.jmi.co.uk**

**All Clear Insurance Service Ltd**

All Clear House  
1 Redwing Court  
Ashton Road  
Romford  
Essex RM3 8QQ

**0845 250 5200**

**info@allcleartravel.co.uk**

**www.allcleartravel.co.uk**

**Fogg Travel Insurance Services**

Crow Hill Drive  
Mansfield  
Notts NG19 7AE

**01623 631331**

**sales@fogginsure.co.uk**

**www.fogginsure.co.uk**

## Further information

**Tourism for All** (UK) c/o Vitalise

**0845 124 9971** – information

**0845 124 9973** – bookings

**info@tourismforall.org.uk**

**www.tourismforall.org.uk**

Provides holiday information and advice for disabled people and their carers, including group holidays, activity holidays, holidays for unaccompanied young adults, holidays where care is provided, transport advice and much more.

**RADAR** (Royal Association for Disability and Rehabilitation)

**020 7250 3222**

**radar@radar.org.uk**

**www.radar.org.uk**

Compiles a book entitled Holidays in Britain and Ireland priced £13.50 including postage and package (2008).

**Air Transport Users Council**

**020 7240 6061** (Monday – Thursday, 9:30am-2:30pm only)

**www.auc.org.uk**

Free guide for passengers planning air travel, including information for those with special needs.

**Traveline**

National enquiry service for public transport information.

**0871 200 22 33**

**www.traveline.info**

**Disabled Holiday Directory**

**0134 887 5592** (between 08.30-13.30)

**sian@disabledholidaydirectory.co.uk**

**www.disabledholidaydirectory.co.uk**

Web directory where you can find or add information about accessible holiday accommodation.

# Guide to transition

## 14. Living independently

To identify where you will need help with planning for the future you may want to consider whether you are able to:

- budget all the household costs
- cook for yourself
- do the shopping
- get in and out of your accommodation safely
- pick yourself up from a fall or call for help
- keep the house that you are living in clean
- take care of your personal hygiene
- travel independently and safely.

If your answer to any of the above is no you might want to investigate the following services:

### Employing a carer

If you need assistance with getting around your house you may need to consider employing a carer. This can be arranged via your local social services department. You may refer yourself to social services or get another professional to do it for you. If you are employing your own carers it is important to seek advice around safety and Criminal Records Bureau (CRB) checks.

### Equipment and adaptations

It will be necessary to take guidance from an Occupational Therapist on what adaptations and equipment you need in your home, for example a raised toilet seat, ramps or high/low level sockets in the kitchen to access all electric utensils.

### Emergencies

In case of emergencies such as falls or fires would you be able to pick yourself up or be able to call for help? Alert systems are available that are linked to your local emergency services or to a care agency.

### Transport services

Transport can often present challenges for people with muscle disease. The Muscular Dystrophy Campaign is working hard to campaign for improvements to the public transport system for disabled people. Before travelling, contact your local transport advisory service to help you find out how you can make your destination safely and on time:

**Londoners can get help** with planning their journey by ringing 020 7241 7457, using the online journey planner or your local transport office. Call 020 7241 7457 or email [enquire@tfl.gov.uk](mailto:enquire@tfl.gov.uk) with the subject line 'Travel Assistance Scheme' (London only).

**For general assistance with travel on public transport in the UK** visit [www.direct.gov.uk/en/DisabledPeople/MotoringAndTransport/PublicAndCommunityTransport](http://www.direct.gov.uk/en/DisabledPeople/MotoringAndTransport/PublicAndCommunityTransport)

**There are many factors to consider when assessing what help you need to live independently. Think about how much independence you currently have, how this could be improved with the right support and services in place, as well as how well you might be able to manage a team of carers.**

**The Thistle Travel Card Scheme** was introduced in Scotland in September 2002 to make it easier for people with learning and/or physical disabilities, dementia or epilepsy to use bus, train, or taxi services. Cards are available from transport booking offices, local authority concessionary travel offices, day centres, carers centres and other places.

### **Learning to drive**

If you receive Higher Rate Disability Living Allowance (DLA) you can start learning to drive at the age of 16.

### **Buying a car**

If you want to buy a car you may find it helpful to visit [www.ford.co.uk/mobility](http://www.ford.co.uk/mobility) to find one that suits your physical needs. Even if you aren't sure what your needs are staff at adaptation and assessment centres can match your needs with an adapted car no matter the severity of your disability. You can use the Mobility component of of your DLA to buy a car through the Motability scheme.

### **Organisations that provide help and advice relating to transport**

#### **Queen Elizabeth's Foundation Mobility Centre**

Damson Way  
Fountain Drive  
Queen Mary's Avenue  
Carshalton  
Surrey SM5 4NR

**020 8770 1151**

The centre offers a free information service on all aspects of outdoor mobility. It provides assessment of driving capabilities, advice on appropriate types of vehicles and on conversions and adaptations. A fee is charged for the assessment. The centre can also advise on financial schemes and concessions to help purchase or hire a vehicle.

#### **Blue Badge Helpline**

**020 7944 2914** or **0161 367 0009** (helpline open from 9am – 5pm)

The Blue Badge Helpline can give you more information about using the Blue Badge Scheme.

#### **Concessionary Fare Scheme** (Northern Ireland)

Department for Regional Development  
Ports and Public Transport Division  
Clarence Court  
10-18 Adelaide Street  
Belfast BT2 8GB

**028 905 40650** or **028 905 41128**

**[transport.policy@drdni.gov.uk](mailto:transport.policy@drdni.gov.uk)**

**[www.drdni.gov.uk](http://www.drdni.gov.uk)**

#### **Disability Action** (Northern Ireland)

Portside Business Park  
189 Airport Road West  
Belfast BT3 9ED

**028 9029 7880**

**028 9029 7882** (textphone)

**028 9029 7881** (fax)

**[hq@disabilityaction.org](mailto:hq@disabilityaction.org)**

**[www.disabilityaction.org](http://www.disabilityaction.org)**

Disability Action (NI) provides information on all aspects of disability. It also provides an assessment service, advice on vehicle adaptations and driving lessons in specially adapted cars.

### **Disabled Persons Railcard Office**

Rail Travel Made Easy  
PO BOX 11631  
Laurencekirk AB30 9AA

**0845 605 0525**

**disability@atoc.org**

**www.atoc.org**

### **Mobilise**

Ashwellthorpe  
Norwich NR16 1EX

Tel **01508 489449**

Fax **01508 488173**

**enquiries@mobilise.info**

**www.dda.org.uk**

This charity is the result of a merger between the Disabled Drivers' Association and the Disabled Drivers' Motor Club. It aims to protect the interests of disabled drivers and to encourage and help disabled people to achieve greater mobility.

### **Mobility and Access Committee for Scotland (MACS)**

Scottish Government

Area 2D Dockside

Victoria Quay

Edinburgh EH6 6QQ

**0131 244 0869** or **0131 244 1694**

**macs@scotland.qsi.gov.uk**

MACS is an advisory committee to the Scottish Government and represents the transport needs of disabled people in Scotland. Although it cannot take up individual complaints it can pass on information about problems with public transport experienced by people with disabilities.

### **Motability Car Scheme**

Leases and sells cars, scooters and wheelchairs to disabled people.

Visit **www.motability.co.uk** or call **0845 456 4566**

### **Motability Operations**

City Gate House

22 Southwark Bridge Road

London SE1 9HB

**0845 456 4566**

Textphone **0845 675 0009**

**www.motability.co.uk**

### **Motability Wheelchair and Scooter Scheme**

Route2mobility

Montgomery House

Newbury Road

Enham Alamein

Andover

Hampshire SP11 6JS

Tel **0845 60 762 60**

Fax **01264 384482**

**www.motability.co.uk**

**Passenger Focus**

Passenger Focus is the independent national rail consumer watchdog.

Visit [www.passengerfocus.org.uk](http://www.passengerfocus.org.uk) or contact **0300 123 2350**

**Passenger Transport Executive**

Visit [www.pteg.net/Contactpteg](http://www.pteg.net/Contactpteg) for details of local transport executives or call **0113 251 7204**

**Scottish Driving Assessment Service**

Astley Ainslie Centre

133 Grange Loan

Edinburgh EH9 2HL

**0131 537 9192**

[marlene.mackenzie@nhslothian.scot.nhs.uk](mailto:marlene.mackenzie@nhslothian.scot.nhs.uk)

[www.nhslothian.scot.nhs.uk](http://www.nhslothian.scot.nhs.uk)

The Scottish Driving Assessment Service offers advice to disabled people who wish to drive. It also offers assessment on fitness to drive.

**The Forum of Mobility Centres**

C/O Providence Chapel

Warehorne

Ashford

Kent TN26 2JX

**0800 559 3636**

[mobility@rcht.cornwall.nhs.uk](mailto:mobility@rcht.cornwall.nhs.uk)

[www.mobility-centres.org.uk](http://www.mobility-centres.org.uk)

The Forum of Mobility Centres has 17 UK centres that provide advice and information to older and disabled motorists.

**Transport for London Access and Mobility**

**0843 222 1234**

[info@tfl.gov.uk](mailto:info@tfl.gov.uk)

[www.tfl.gov.uk](http://www.tfl.gov.uk)

# Guide to transition

## 15. Medical follow-up

All the conditions the Muscular Dystrophy Campaign supports are rare so your GP is unlikely to have detailed knowledge about them. Muscle disease is a speciality within neurology so not all neurologists in adult services will be familiar with all the conditions or recent developments in potential treatments and management.

**Many people with muscle disease wonder why they need medical follow up when they have a condition which they have been told there is currently no cure for. However there are a range of important reasons for seeing a neuromuscular specialist – some relate to you and some to any family you may wish to have in the future.**

### Professionals and their areas of expertise

A range of professionals may be involved in your medical follow up and it is important that they communicate not only with you but with one another. Encourage all medical staff you have an appointment with to copy one another in on the letters they write following consultations. Specialists involved may include one or more of the following:

- neurologist
- cardiologist
- respiratory consultant
- nurse practitioner
- orthopaedic surgeon
- physiotherapist
- consultant in rehab medicine
- other specialists in areas such as genetics, speech and language therapy or diet and nutrition.

#### GPs or other professionals

GPs may seek advice from a neuromuscular specialist on whether a health concern you have raised with them is related to your condition, or being made worse by it. For example:

- they may have queries about how medications could affect you and the type of condition you have
- if you need planned or emergency surgery there will be questions about anaesthetic safety (especially important if you have Becker muscular dystrophy, myotonic dystrophy, or some of the myopathic conditions even if you are only mildly affected). If you do not know whether anaesthetic presents a risk then ask your doctor at your next muscle clinic appointment.

#### Other professionals

Other medical professionals you see are likely to need specialist advice (with your permission of course) about your condition and its likely progression. For example:

- occupational therapists will need advice on equipment and adaptations
- employment services, like Access to Work, and driving authorities will need to know more about your condition and how it can affect you
- you may need to contact a social worker or welfare rights officer for advice on applying for disability benefits, or reducing your working hours.

## General information and advice

### Getting an accurate diagnosis

Knowing that your diagnosis is accurate and as precise as possible is of paramount importance. In the last few years much progress has been made in this area. There are many different types of muscular dystrophy and even terms like 'limb girdle muscular dystrophy' are now umbrella headings and can often be further defined into a particular type of limb girdle muscular dystrophy. If your diagnosis is incorrect then the genetic advice you and your family have been given may be completely wrong. This means that assumptions about likely progression or complications could be inaccurate and treatable difficulties could be left untreated. In some cases having an accurate diagnosis could save your life.

If you were diagnosed some time ago, your condition is getting worse, you have not had regular follow ups or been given a clear diagnosis ask your GP to refer you to a consultant at your closest muscle centre for further assessment and advice.

### Genetic advice

Muscular dystrophies and related neuromuscular conditions can affect men and women of all ages and ethnic backgrounds.

Most conditions are genetic which means that the genes causing them can be passed from one generation to another. Patterns of inheritance vary depending upon the condition. A 'new' mutation of a gene may be identified in some instances, one which has not been inherited but can now be passed on to future generations.

Genetic specialists will want to check the certainty of the diagnosis when giving advice. In some cases it is not possible to be one hundred percent sure but it's important to know if there are doubts.

Even if genetic issues are not a concern for you, they may present an issue for members of your extended family who will want to know all the facts so that they can make informed choices when planning their own families. Advances have been made in areas like pre-natal testing and alternative methods of conception, should these be required.

In some areas there will be specialists in the genetics of neuromuscular conditions and your muscle specialist will be able to advise if this is the case.

### Knowing what to expect

Many people living with a long-term condition want to know what to expect so having as accurate a diagnosis as possible is vital. Without it only the most general advice can be given and areas that should be monitored may not be followed up, which could lead to potentially treatable problems being missed.

Knowing which muscles are especially affected and how quickly there may be changes helps with appropriate planning in a number of ways, for example with housing, work and leisure pursuits.

You may also learn that there are other areas of your health that need to be monitored – commonly heart and lung function – and, depending upon your condition, other aspects may need monitoring too. It is important to know about this so that you can ensure that these concerns are not overlooked.

### What can be done to help?

While it is true that there are currently no cures for muscle disease, medical follow up is important as some of the complications that may arise from your condition can be effectively treated or managed – if they are known about.

### Medical follow-up

Specialists in muscle disease will know about medical complications associated with your condition and know which other consultants to refer you to. Often, for example, a particular heart specialist will see the patients of a neurologist and will have built up expertise in this area.

Taking care of yourself is important and other professionals like physiotherapists, dieticians and occupational therapists will have a big role to play here.

### **New developments**

Most people and their families are interested in keeping up to date with research developments and with new ways of managing difficulties that may arise. Specialists can provide this information and explain the reality behind the hype of a newspaper story or the basic facts behind a complex medical paper.

If a recognised expert in muscle disease knows of you, you are much more likely to be invited to participate in research projects or trials. In these situations it is usually essential that your precise diagnosis is known and your suitability to take part is established.

Those living with muscle disease have a huge role to play in improving the level of knowledge about management and treatment of muscle disease. Much is learnt from patients sharing their experiences with clinicians and researchers, and by attending a clinic you are contributing to this process.

### **Further information and advice**

The Muscular Dystrophy Campaign can advise on the location of muscle centres and clinics, Contact **0800 652 6352** (freephone) or email **info@muscular-dystrophy.org**

Occasionally people have difficulties in getting a referral to their preferred consultant and may be told they have to see a locally-based consultant. Your Primary Care Trust (PCT) in England, Local Health Board (LHB) in Wales, or NHS Board in Scotland, may have a say in instructing GPs to do this.

The option to see a specialist with knowledge of your condition should be made available to you and it may be possible to ask your preferred consultant to write to your GP, PCT or board, explaining why a specialist service is needed. Failing this, see the first consultant available and if necessary request a second (or further) opinion about the diagnosis and/or management of your condition.

In some rare conditions funding is in place to ensure that, if they wish, patients from anywhere in the UK can be seen at a particular specialist centre. An example of this is the service in Newcastle for people with a limb girdle muscular dystrophy. The Muscular Dystrophy Campaign can advise on other services for other rare conditions.

### **Getting a second (or further) opinion from a different consultant**

- If you are not happy with the advice you have been given, or with any aspect of a consultant's care you may request a second – usually now referred to as a 'further' – opinion.
- Although you do not have a legal right to a further opinion refusal is rare and any decision to refuse is based on what is believed to be in the patient's best interests, rather than on cost to the NHS. It is therefore in everyone's interests to ensure that you, the patient, are happy with the service you receive.
- If, as may well happen in the case of rare conditions, you have heard that a particular consultant is an expert in your field, explain this to your GP or current consultant. They will generally be supportive of your wish to be seen by people who are familiar with the condition and who may well have access to services that you could also benefit from.
- A relative or carer can request a further opinion on behalf of a patient but the consultant can only arrange this if the patient agrees.
- If your consultant refuses to refer you for a further opinion your GP may still be willing to do so.

**Changing GPs**

If you are unhappy with your GP you can change to any other GP who is willing to take you, provided they cover your geographical area. In the event of difficulty the PCT or health board will allocate you a GP.

**Access to dental care**

It is important to be registered with a local dental practice. If you are on medication always seek the advice of your consultant about the frequency and type of dental care you require, and the risk of any dental procedures.

# Guide to transition

## 16. Hospital admissions

### Professionals and their areas of expertise

Hospital staff are used to dealing with people who are ill, but as many neuromuscular conditions are rare, many ward and department staff will be unfamiliar with the difficulties caused by your condition. You may prefer to have your own carer with you and you should talk to the hospital staff about this preferably before you are admitted as there are sometimes rooms available for carers to stay in close to or on the hospital site.

**Being admitted to hospital presents concerns and difficulties for most people, even if they are usually fit and healthy. If you have a muscle disease these concerns and difficulties may be significantly increased.**

Please remember to take all relevant information with you and ask staff to liaise with your specialist neuromuscular consultant or one of the muscle clinic team.

### General information and advice

#### Planned admissions

Discussing your situation with hospital staff may make the whole experience easier. You may like to consider involving a friend or relative in these discussions, especially if you are feeling anxious or unwell. Things you may want to consider:

- Try to find out as much as you can from your consultant about the tests or procedures you will be having and what is involved before, during and afterwards.
- Write a list of things which you feel might be difficult when you are in hospital.
- If you feel it would be helpful, ask to visit the ward or department before your admission so that you can see the facilities and layout for yourself. This may be possible at your pre-operative assessment if you are under-going surgery.
- Ask to speak with an occupational therapist (OT) as they are likely to be able to help with any equipment you might need. Be aware that you may need a referral.
- If you have movable equipment you use at home that you think would be helpful during your hospital stay, ask if it is possible to take it in with you. Make sure it is clearly labelled with your name.
- If you need to be hoisted it may be helpful to take in your own sling from home. Make sure that it is compatible with the hospital hoist first.
- If you use non-invasive ventilation you will need to take your machine, tubing and mask into hospital with you. Ward staff will need information on what type of assistance you need and how much you need to use it. It may be helpful to bring some written instructions to help with this too.

#### Specific areas of difficulty

If you have difficulty rising from sitting to standing, explain this to staff. Try to ensure you are provided with a high armchair with full-length armrests and a height-adjustable bed.

Moving yourself from lying to sitting and turning over in bed are common difficulties for people with neuromuscular conditions but are not always obvious to staff.

Problems lifting the arms at the shoulder are rarely obvious to other people and hospital staff may not realise that this is a difficulty for you. They may assume, for example that you can reach for items left on a locker, or food left on a table. You will need to make staff aware that this is a specific problem for you and ask them to take this into account.

If you need to sleep in a particular position because of joint contractures or pain, talk to staff about this during the day to allow them time to find extra pillows etc. that you might need. If you have difficulties with pressure ulcers ask if it is possible to speak to a tissue viability nurse who may be able to provide a specialist mattress.

### **Emergency admissions**

These situations are always more of a challenge as clearly no planning is possible. However, the following may help:

- Always carry with you (or wear) information about your neuromuscular condition and contact details for your consultant/s (if applicable) and the Muscular Dystrophy Campaign. Please see the next factsheet for information on how to order special alert cards, bracelets and tags.
- Always carry details of a relative, friend or carer who can provide information about your physical needs and requirements.

### **Further information**

If you are unhappy during your stay or wish to raise any issues following your discharge contact the Patient Advocacy and Liaison Service (PALS) which is available within all health trusts. Details of your local service can be found by:

- contacting your local hospital, GP surgery or health centre
- contacting NHS direct on **0845 46 47** or at [www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)
- searching the Office Directory on the PALS website at [www.pals.nhs.uk](http://www.pals.nhs.uk)

# Guide to transition

**Neuromuscular conditions result in the need for specialist medical interventions that would not normally be considered for the general population.**

## 17. Emergency situations

For anyone **known to have a condition**, however mild the symptoms; **at risk of carrying a condition** or **with a family history of a condition** it is advisable to carry – or wear in the form of a medic alert bracelet or locket – information about the condition at all times in case of an emergency.

It might also be advisable to carry details of a relative, friend or carer who can provide information about your physical needs and requirements should you be admitted to hospital.

### Professionals and their areas of expertise

As neuromuscular conditions are rare professionals who deal with you in the event of an emergency are unlikely to be familiar with the condition and your particular needs so:

- carry written information about the condition with you;
- ask the professional to liaise with your specialist neuromuscular consultant or one of the muscle clinic team;
- suggest they access information from the Muscular Dystrophy Campaign.

### General information and advice

A specific alert card for people with Becker muscular dystrophy is available from the Muscular Dystrophy Campaign.

A specific card for people with myotonic dystrophy is available from:

Myotonic Dystrophy Support Group  
35a Carlton Hill  
Carlton  
Nottingham NG4 1BG  
0115 987 0080  
mdsg@myotonicdystrophysupportgroup.co.uk  
www.myotonicdystrophysupportgroup.org

A general medical card for people with all other neuromuscular conditions is enclosed with this pack.

#### Anaesthetics

Anaesthetics can be an area of particular concern in an emergency situation as people with neuromuscular conditions can be prone to complications arising from the use of anaesthetic agents. Anaesthetics can be a problem for people who have only minimal symptoms and those who are carriers and have no symptoms. It is vital that all medical personnel involved are fully aware of the situation.

#### Heart

Some neuromuscular conditions cause changes to take place within the heart. Depending upon the condition these could include breathlessness, palpitations, chest pain, dizzy spells or blackouts. Monitoring of the heart is likely take place if you regularly attend a specialist muscle clinic, however, many doctors will not be aware of these possible complications. Your specialist should copy any letters about your care to your doctor, but it is advisable to let your doctor know and take copies of any communication, in case they haven't been informed.

## **Breathing**

Weakness of the respiratory muscles can lead to 'under-breathing' (hypoventilation) which causes levels of oxygen in the blood to be too low. Care needs to be taken in this situation as giving oxygen without breathing assistance can be dangerous. Although doctors who regularly deal with this group of conditions will be aware of these complications, others may not. Some patients with neuromuscular conditions need ventilation, often only at night. However when unwell people may need up to 24 hour ventilation. Contact your local ventilation team if you develop a chest infection.

## **Immobility and fractures**

For most people with neuromuscular conditions prolonged bed rest should be avoided as it is likely to make muscle weakness and joint stiffness worse (more than would be usual in a person without one of these conditions). This can result in loss of function which is then difficult or even impossible to regain.

Early mobilisation, getting up and moving, and physiotherapy are recommended. If you have a fracture ensure your muscle team is in contact with the people looking after you.

## **Further information**

The Muscular Dystrophy Campaign produces factsheets and other publications which are relevant to this subject:

- *Anaesthetics factsheet*
- *Heart check factsheet*
- *Making breathing easier factsheet*
- *Becker alert card.*

They are available from:

- our website: [www.muscular-dystrophy.org/publications](http://www.muscular-dystrophy.org/publications)
- our Information Service on **0800 652 6352** (freephone) or [info@muscular-dystrophy.org](mailto:info@muscular-dystrophy.org)
- Regional care advisors at specialist muscle clinics.

Bracelets and lockets are available from a variety of sources, including:

### **Medicalert Foundation**

1 Bridge Wharf  
156 Caledonian Road  
London N1 9UU  
0800 581 420  
[info@medicalert.org.uk](mailto:info@medicalert.org.uk)  
[www.medicalert.org.uk](http://www.medicalert.org.uk)

### **Medical Tags**

106-108 Vyse Street  
Hockley, Birmingham B18 6LP  
0121 233 7455  
[sales@medicaltags.co.uk](mailto:sales@medicaltags.co.uk)  
[www.medicaltags.co.uk](http://www.medicaltags.co.uk)

### **SOS Talisman**

21 Grays Corner  
Ley Street  
Ilford, Essex IG2 7RQ  
020 8554 5579  
[sostalisman@btinternet.com](mailto:sostalisman@btinternet.com)  
[www.sostalisman.com](http://www.sostalisman.com)



# Guide to transition

## 18. Genetic issues and pregnancy

### Professionals and their area of expertise

**Consultant geneticists** – doctors who specialise in conditions caused by genetic faults. They are able to explain the ways in which different conditions are inherited and give advice to family members about whether they could be affected by the condition or be a carrier. They can advise about pre-natal screening and alternative methods of conception and support people through these processes.

**Genetics counsellors** – professionally qualified healthcare staff, often nurses, who specialise in the study of genetic conditions. They work closely with patients and families to provide information and support, and carry out genetic testing and arrange pre-natal screening.

Most staff in genetics departments will have some level of understanding about your condition. However, they may not be familiar with specifics of the condition. If necessary, ask them to liaise with your specialist neuromuscular consultant or one of the muscle clinic team.

### General information and advice

One type of muscular dystrophy will be different from another so an accurate diagnosis is essential to ensure you receive the correct information. Scientists continue to search for the genes that cause all types of muscle disease but there is still a long way to go. A common misconception is that muscular dystrophy only affects males. This is true of certain types, but not all.

#### Referral to a genetics centre

Your consultant or GP can make a referral to a Genetics Centre for you. Staff at these centres are not only able to advise about risks but are also used to dealing with the difficulties of sharing information with others and with particular issues raised due to ethnic background or religious beliefs. They will provide you with information to enable you and your family to make your own decisions. Staff will not try to direct you or be judgemental about your choices.

#### Genetics testing

In most centres genetic testing will not be carried out on children who are not displaying symptoms of a condition. A decision about whether or not they want to be tested can be discussed with them once they are old enough to understand the situation. This is usually during the teenage years at the earliest. It is important to ensure that once they are old enough to understand, your children are aware that you have a genetic condition. This will enable them to make informed decisions about their own futures.

Any other family members who have concerns and wish to discuss their own risks can ask for a referral to their local Genetics Centre. Be aware that having a genetic condition in the family can cause relatives to be upset or worried, and they may not always react in the way you would expect. If a relative is pregnant and has concerns, suggest she requests an urgent referral to her local Genetics Centre via her GP. Consider making your relevant medical records available for the consultation.

If you are considering having children, discussion with your partner and/or other family members is very important. It would also be advisable to talk to staff at a Genetics Centre. They will be able to discuss the risks of your child/ren being affected by the condition.

**Most neuromuscular conditions are genetic, something which naturally causes concerns that children could inherit the condition and that other family members could be affected. Genetic issues are complicated so we strongly recommend you seek advice and support from your local Genetics Centre.**

For some conditions it is possible to carry out pre-natal screening during early pregnancy to see if the foetus is affected. For others this may be possible using screening techniques on blood taken from other affected family members. Genetic screening tests can take many months to process so try to plan in advance if possible. Screening is not likely to be available where the genetic fault has not been identified. Conditions can vary in severity even within families so it may not be possible to say how severely affected any child may be. Procedures such as pre-implantation genetic diagnosis (PIGD) or egg/sperm donation may also be options and these too can be fully discussed.

Conception may be difficult for some couples for a number of reasons. Possible infertility and impotence may affect anyone but there may also be reasons directly related to the type of muscle disease. For example some men with myotonic dystrophy have reduced fertility. For other people there may be a physical difficulty in achieving or maintaining a suitable position for intercourse to take place due to muscle weakness or fatigue. Psychological issues such as poor self-image can sometimes make it difficult to relax and enable sexual activity. Your GP or local family planning clinic may be able to help. Relate employs specialist sexual health advisors who may also be able to assist.

For women it is important to think about and discuss the effect that a pregnancy may have on your own condition with genetics staff or your consultant. Carrying extra weight is likely to make walking more difficult so you may need to temporarily use a wheelchair. Returning to full strength after the pregnancy may not be possible and if your condition also affects your heart or respiratory function you may need extra tests and monitoring during the pregnancy. Consideration will also need to be given to the actual birth itself. For women with some conditions, particularly myotonic dystrophy, there is a risk of complications during the pregnancy.

Although extra planning and monitoring are probably necessary many women with muscle disease successfully have children. Children who do not inherit the condition will be unaffected. Others who do inherit the condition will be affected but will receive ongoing management of their condition. Sadly, some babies who inherit a severe form of muscle disease may not survive or may have a reduced life expectancy.

For both men and women, extra help or equipment may also be needed to help with caring for a new baby. Ongoing parenting issues may also need extra thought and planning.

### **Further information**

The Muscular Dystrophy Campaign produces specific factsheets which are relevant to this subject:

- *Carrier detection tests and prenatal diagnosis factsheet*
- *Inheritance and the muscular dystrophies factsheet*
- *Pregnancy and reproduction factsheet.*

They are available from:

- our website **[www.muscular-dystrophy.org/publications](http://www.muscular-dystrophy.org/publications)**
- our Information Line **0800 652 6352** (freephone) or **[info@muscular-dystrophy.org](mailto:info@muscular-dystrophy.org)**
- Regional care advisors at specialist muscle clinics.

More information on this subject is also available from:

#### **Disabled Parents Network**

08702 410450 [www.disabledparentsnetwork.org.uk](http://www.disabledparentsnetwork.org.uk)

#### **Disability, Pregnancy and Parenthood international**

0300 3300 639 [www.dppi.org.uk](http://www.dppi.org.uk)

#### **Genetic Interest Group**

020 7 704 3141 [www.gig.org.uk](http://www.gig.org.uk)

#### **Government information**

[www.direct.gov.uk](http://www.direct.gov.uk) – there is a section on disabled parents

# Guide to transition

## 19. Overview of services and information

### Advice on NHS Medical Services

Everybody should have a GP. You can register with any GP in your area who will accept you and you can change your GP at any time without giving a reason. If you have difficulties, the Primary Care Trust (PCT) in England, local health boards (LHB) in Wales, NHS Board in Scotland, or Health and Social Care Board (HSCB) in Northern Ireland will allocate you a GP. GPs are responsible for your day-to-day medical needs, will refer on as required and can act as gateways to other services which may be of benefit.

For general information or advice on services in England, Northern Ireland and Wales you can ring NHS Direct on **0845 4647** or visit **www.nhsdirect.nhs.uk**. For information and services in Scotland contact NHS24 on **08454 242 242** or **www.nhs24.com**

In order to see a hospital consultant you will need a GP referral. While you can request to be referred to a particular consultant there may be restrictions on who you can see.

GPs can also refer to other medical services, such as chiropody and physiotherapy. Many disabled people (especially with HMSN) are entitled to free chiropody. Physiotherapy is rarely offered to adults on a regular, indefinite basis, a fact which the Muscular Dystrophy Campaign is campaigning to change. The Neuromuscular Centre in Cheshire offers hydrotherapy, physiotherapy and active exercise programmes for anyone who has muscle disease. Contact 01606 860 911 for more information.

The Royal Association for Disability and Rehabilitation (RADAR) publishes a guide called *If only I'd known that a year ago*, a sentiment expressed by many adults we meet. The guide is aimed at people who have been recently diagnosed and is also helpful for those with progressive conditions.

Contact RADAR to order a copy.  
020 7250 3222  
[www.radar.org.uk](http://www.radar.org.uk)

### Finance

#### Benefits

For advice on benefit entitlements consult a recognised local benefit advice agency. This could be your welfare rights office, usually found in your local council offices, or your local **Citizens Advice Bureau** (CAB). Visit **www.citizensadvice.org.uk**.

A benefits enquiry line is available on **0800 88 22 00** and detailed advice is available on the government website: **www.direct.gov.uk**. You should not be charged for this advice.

#### The personalisation agenda

The personalisation agenda allows you to write your own care plans and decide how your needs will be met (including direct payments and individual budgets).

#### Direct payments

You may be able to get financial support to arrange and pay for any necessary services through the Community Care Direct payments system. Direct payments give you more control over the way your

**One of the best ways to help maximise your independence as you become an adult is to ensure you are knowledgeable about services and your entitlements to them.**

care needs are met. You can use them to pay for a range of services and in any combination according to your individual needs. You can combine services provided directly by social services with others arranged by yourself that you pay for using direct payments.

As of 31 March 2008, 56,000 adults in England and 2,605 people in Scotland received direct payments.

To qualify for Direct Payments in England and Wales, you must be:

- aged 16 or over
- assessed as needing community care services/services as a carer
- willing and able to consent to having and managing direct payments (alone or with assistance).

In Northern Ireland those assessed as needing personal social services are eligible for direct payments, including for their carers. Personalised budgets were also introduced recently in Scotland.

In England, Northern Ireland and Wales, direct payments can't be used to pay for services from your spouse, partner, close relative, their spouse or partner living in your household – other than in exceptional circumstances – but you can use your direct payment to employ a relative who isn't living with you.

Local authorities must provide you with sufficient direct payments to purchase the services you need to meet your needs. Payments must also factor in things like national insurance, employer's liability insurance and sick pay if you employ carers. Your payments must be spent on the services which you have said you need.

If you choose a more expensive way to meet your assessed needs than is 'reasonable', you will have to pay the extra cost yourself. Payments made will not affect your benefits.

You can find out more information about direct payments on the Disability Alliance's website:

[www.disabilityalliance.org/drh34.htm](http://www.disabilityalliance.org/drh34.htm). Information on direct payments is also available on the Department of Health website [www.direct.gov.uk](http://www.direct.gov.uk).

**Disability Information and Advice Lines** (DIAL) operates locally and can give advice. Contact them for details of your nearest centre.

01302 310123

[www.dialuk.org.uk](http://www.dialuk.org.uk)

The *Disability Rights Handbook*, published annually in April, is an easy-to-understand, comprehensive guide on all financial matters.

020 7247 8776

[www.disabilityalliance.org](http://www.disabilityalliance.org)

## Debt

If you are concerned about debt you can get free advice from your local Citizens Advice Bureau. Advice is also available from:

### **The National Debt Line**

0808 808 4000

[www.nationaldebtline.co.uk](http://www.nationaldebtline.co.uk)

### **The Consumer Credit Counselling Service**

0800 138 1111

[www.cccs.co.uk](http://www.cccs.co.uk)

## Employment

Under the Disability Discrimination Act (DDA) it is illegal for an employer to discriminate against a disabled person in a way which cannot be justified. This includes the recruitment process, terms and conditions of employment and redundancy, redeployment and dismissal matters. You can read more about the DDA at [www.direct.gov.uk](http://www.direct.gov.uk)

Employers have a duty to make reasonable adjustments to the work place and/or the work task itself. The Disability Employment Advisor (DEA) at your local Job Centre Plus can offer help finding work after school, college or university. They can advise on schemes such as Access to Work, which help with additional work-related costs, e.g. adaptations or equipment, care support, transport, and advise employers to help you access work.

Disputes with employers can be settled via the Advisory, Conciliation and Arbitration Service (ACAS) or through the industrial tribunal system. Contact your union or the Citizens Advice Bureau for more advice: [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

## Housing adaptations

If, because of your disability, you need to have the property you or your parents own adapted, you may be entitled to help under the Disabled Facilities Grant (DFG) scheme (in England, Wales, Scotland and Northern Ireland).

Once you are 19 these grants are 'means tested' and must be approved in advance. This could mean your parents will be means tested if you are still living at home. For further information speak to your local occupational therapy department, usually based within social services.

If you have significant adaptations made you may be entitled to a reduction in your council tax/rates. Ask your local council for advice.

If you are a council or housing association tenant, or privately renting you need to seek advice from an occupational therapist and liaise with your housing provider.

Be aware that adaptations can take over a year to organise so advance planning is essential.

The Muscular Dystrophy Campaign publishes a guide to adapting your home – the *Adaptations Manual*.

## Equipment

**Wheelchairs** are provided by Wheelchair Services, part of the NHS. There are some restrictions on provision. Your GP or other professional can refer you or, in some areas, you can refer yourself.

**Medical equipment** (e.g. ventilators) is provided by the NHS free of charge after your medical needs have been assessed.

**Nursing aids** (e.g. adjustable beds, commodes etc) are provided via the District Nursing Service.

**Aids to independence** (including bath aids, grab rails, shower chairs, hoists etc) or to assist carers, are provided by social services' occupational therapists.

**Equipment** is usually, but not always, loaned to you free of charge. For short term or holiday use some standard equipment (e.g. manual wheelchairs, commodes etc) can be hired from your local Red Cross medical loans department at a nominal charge.

0844 871 11 11

[www.redcross.org.uk](http://www.redcross.org.uk)

## Care at home

Distinctions are made between medical care and other types of care. All NHS care, such as your GP, district nursing care and out-patient care are free of charge.

For other care needs, such as help with washing, dressing and daily living tasks, an assessment of your needs is undertaken by social services – in conjunction with health service providers if appropriate – and the options for provision discussed with you. Charges may be made for this type of care but your ability to pay should form part of the assessment.

There are numerous private care agencies which you can access at your own expense or via Direct Payments and Independent Living Fund (ILF). This information should be listed in your individual budget, which you are issued once you are over 16. See our *Direct payments factsheet* for more information.

## Respite care

**Residential respite care** may be provided by a community hospital, residential home or a private home through schemes run by social services. Care can be provided in a hospice if a person meets their criteria. No charge is made for care in a hospital or hospice.

**Live-in respite care** can be provided in a person's own home. Social services or social work departments in Scotland may contribute towards the cost of a holiday with care facilities. Daytime respite care may be offered by social services or voluntary agencies (e.g. Crossroads). Your local social services can advise on all these issues. Contact them to refer yourself or the person you care for.

### Carers

If you care for a disabled relative or friend you may be entitled to help or respite and you should ask social services to carry out a carer's assessment.

## Travel

For further advice on travel issues, please see our *Holidays and transport factsheets*. For advice on all travel-related matters for disabled people contact Tourism for All 0845 456 4566 [www.tourismforall.org](http://www.tourismforall.org).

## Toileting

Keys for accessible toilets are available from your local council or from RADAR 020 7250 3222 [www.radar.org.uk](http://www.radar.org.uk)

## Driving

If you are in receipt of the high rate mobility component of Disability Living Allowance you can buy a vehicle through the Motability scheme. This applies even if someone else needs to drive the vehicle. 0845 456 4566 [www.motability.co.uk](http://www.motability.co.uk)

## Further information and advice

If you would like further information please contact the Muscular Dystrophy Campaign. 0800 6526352 (freephone)  
[info@muscular-dystrophy.org](mailto:info@muscular-dystrophy.org)  
[www.muscular-dystrophy.org](http://www.muscular-dystrophy.org)

# Guide to transition

## 20. Record keeping

Some professionals will know more about your condition and circumstances than others. Many will not have experience of working with young people with your condition so will not be familiar with your particular needs. Keeping information and records about yourself and your situation is a good idea, so we suggest that you:

**Having muscle disease means you are likely to have a substantial number of appointments with a variety of professionals and departments regarding different aspects of your condition.**

- keep written information – letters, correspondence and information about your condition – in a folder and take it with you to appointments;
- ask any professionals to liaise with your specialist neuromuscular consultant, care advisor or muscle clinic team member;
- advise them to access information from the Muscular Dystrophy Campaign on 0800 652 6352 or [info@muscular-dystrophy.org](mailto:info@muscular-dystrophy.org)

### Keeping records

- **Appointments** – you are likely to have a number of appointments, so recording them all in one place will help you to remember them.
- **Written information** about your condition is likely to be helpful. A range of factsheets on different types of muscle disease are available from the Muscular Dystrophy Campaign.
- **Keep a list** in your folder of the names and contact details of any professionals involved with you. It is often helpful for professionals to be able to contact each other. Having the information to hand can save time.
- **Most hospital consultants will write to your GP** with details of the issues that were discussed and any other relevant information. Ask them to give you a copy of the letter and, if applicable, ask them to send copies to other relevant professionals. Many will do this automatically but it is useful to check.
- **Your consultant may ask your GP** to monitor some aspect of your condition or arrange a referral regarding making changes to your medication. If so make an appointment with the GP and take your copy of the letter to discuss it with them. If any other professionals write letters or reports about you ask them to send a copy to you and other relevant professionals.
- **Keeping copies of letters and reports** can be helpful in showing how your condition has progressed and may be useful at a later date.

### Telephone calls

Over time you will probably deal with different departments about a variety of issues. Try to keep a written record of:

- the phone number
- the department
- some details of the conversation
- who you spoke to
- when you should expect to hear back from the person or department.

Try to get some idea of when you are likely to get a response (days, weeks or months?) and write a reminder in your diary to ring back if you have not heard anything.

### **Email and text contacts**

Some people prefer to liaise with professionals by email or text. If this suits you check that the professional involved is also happy with this method of communication. Keep all relevant emails so you can refer back to them at a later date, if necessary.

### **Home visits**

Some professionals will visit you at home. If issues are discussed it may be useful to take notes or, if the professional is writing a report or letter following the visit, ask for a copy to be sent to you for your records.

### **Meetings**

If you are involved in meetings with professionals check that minutes are being taken (this should be the case) and ask for a copy to be sent to you. Read through the minutes to check you agree they are correct. If not, contact the relevant person to discuss the issues. You may like to take your own notes at the meeting or have someone present to do this for you.

### **Employment**

As your condition progresses, you may need to talk to your employers about making changes to enable you to continue with your work. It is advisable to keep your own records in case of any difficulties.

### **Equipment you may need**

Equipment, such as a hoist or mobile arm support, is provided by different statutory organisations, or can be bought privately or with charitable funding. It is helpful to keep a record of:

- where each piece of equipment comes from;
- when it was received;
- who to contact in case of repairs or replacement;
- when it needs servicing;
- who is responsible for the cost of repairs or servicing;
- all repairs, cost (if known), how long it took and who paid;
- who to return it to if and when it is no longer needed.

If you have problems with a piece of equipment which is faulty or broken the above records can be invaluable when trying to resolve the situation.

### **Personal support**

Many young people with muscle disease will need some support with activities of daily living. If this support is provided by paid staff they may be individuals you are employing, from an agency or from social services. However they are employed it is advisable to keep:

- a copy of your agreed care plan or the care assessment;
- details of who to contact in an emergency, especially if you live alone;
- contact details for the relevant staff/agency/social services department;
- information on hours or days they are working;
- details of any difficulties or problems;
- details of any cases of staff not arriving as expected.

This information may be helpful if alterations to your support need to be made.

### **Benefits**

Many people with muscle disease will be entitled to benefits at some stage. When completing application forms it is a good idea to seek help from a Welfare Rights agency, Citizens Advice Bureau or a suitably experienced professional. Make sure you keep a copy of completed application forms as they can be useful for reference at a later date. Always keep any letters you receive about decisions on benefits.

### **Record keeping**

# Guide to transition

## 21. Mobility

### Professionals and their areas of expertise

As neuromuscular conditions are rare many professionals will be unfamiliar with your particular needs. We suggest you ask them to liaise with your specialist neuromuscular consultant or one of your muscle clinic team. Some information for professionals is available from the Muscular Dystrophy Campaign. Some of the professionals who may be involved in your care relating to mobility are:

- **Consultant in rehabilitation medicine** – a doctor who specialises in helping people with long-term conditions and disabilities to be as independent as possible.
- **Physiotherapists** – may be able to assist with advice on walking. They may recommend walking aids such as sticks or special splints, known as orthoses.
- **Occupational therapists (OTs)** – provide advice on ways of helping a person to be as independent as possible, often through the use of equipment.
- **Wheelchair Service therapists** – physiotherapists or OTs who specialise in the provision of wheelchairs and seating.

**At some stage most people with muscle disease will experience difficulty with walking. For some it may be problems with negotiating uneven ground or steps and stairs with no handrail. For others the difficulties will be more severe, making walking difficult or even impossible. This section provides further information on where to get help and advice.**

### General information and advice

Although neuromuscular conditions vary considerably and progress at different rates, for many people weakness of muscles in the following areas results in walking difficulties:

**Hips and pelvis** – weakness in this area usually causes difficulty walking distances, climbing steps and rising from sitting to standing. There is also a tendency for the knees to 'give way', resulting in falls. Having fallen there is often extreme difficulty or possibly complete inability to get up.

**Ankles** – weakness here causes difficulty lifting the foot up which can result in the need to lift the knees high if walking to avoid trips and falls caused by 'catching' the toes. Managing uneven ground, slopes and steps can also be problematic. Splints are often helpful in these cases (see our *Orthoses factsheet* for more information).

Any degree of muscle weakness is likely to make walking slower and more tiring due to the extra effort needed. Many people with muscle disease experience considerable fatigue after walking or other physical activities. Muscle pain and cramps can also be a problem.

Initially, walking aids, such as sticks, may be helpful as they can provide some extra support and stability. They also show other people that you have a difficulty, which generally encourages them to hold open doors or give up their seat on buses and trains. Walking aids are usually provided through the physiotherapy service and your consultant or GP should be able to make a referral for you.

When walking becomes more difficult, people often begin to limit their activities, for example, waiting on a bench or in the car while family and friends go for a walk, or sitting outside a shop while others go in. For most this is not an ideal solution. Thinking about alternative methods of mobility, such as wheelchairs or scooters, can mean that you can keep up activities.

Deterioration in mobility can have a significant psychological effect on most young adults who are living or want to live independent lives. Accepting the need for walking or mobility aids and beginning to use them often brings questions from others about why they are needed. You may find it helpful to think about the answers you will give in advance.

Many people find it easier to use these items away from their own local environment initially, for example, when on holiday. This allows the chance to get used to them and realise the benefits that they bring, before needing to deal with questions.

Often, people find that using a wheelchair instead of struggling to walk makes outings much more enjoyable and prevents the problem of needing time to rest and recover afterwards.

If you feel that explaining your change in circumstances to friends, other family members or work colleagues may be difficult or upsetting for you, circulating a letter or email to everyone may save the need for explaining many times.

### **Wheelchairs and scooters**

Throughout most of the UK anyone who has a permanent difficulty with walking is entitled to a manual wheelchair from local NHS Wheelchair Services. Your GP should be able to make a referral. Criteria varies between regions so provision can vary.

For many people with muscle disease standard models are difficult to push independently because of weakness in the arms and shoulders. Alternative models which are easier to push and may be suitable for some people exist but are not always readily available through wheelchair services.

For many people, a powered wheelchair or 'add-on' powerpack may be a better option, but these are not normally provided. Wheelchair services can supply powered wheelchairs for people who need them both indoors and outside but provision is quite limited. As a charity we are campaigning for better service provision across the UK.

Scooters may be an option for some people but these are not provided through statutory services.

The Muscular Dystrophy Campaign has produced guidelines on wheelchair provision for people with neuromuscular conditions which has been circulated to all wheelchair services. The guidelines are also available through your regional care advisor, if applicable, or the Muscular Dystrophy Campaign's Information Service.

0800 652 6352 (freephone)

[info@muscular-dystrophy.org](mailto:info@muscular-dystrophy.org)

### **Shopmobility schemes**

Shopmobility schemes loan wheelchairs and scooters to disabled people for short-term use around the local shopping area. In most areas it is necessary to register with the scheme. There may be a small charge for the service.

For further details contact your local council or the National Federation of Shopmobility.

08456 442 446

[info@shopmobilityuk.org](mailto:info@shopmobilityuk.org)

[www.shopmobilityuk.org](http://www.shopmobilityuk.org)

# Guide to transition

## 22. Further education

### Professionals and their area of expertise

Connexions Advisors can offer advice to people aged 16 to 25. Others can seek advice from their local Careers Advisory Service.

As muscle disease is rare, many professionals will be unfamiliar with your particular needs and college and university staff may request more information about your condition. We suggest you ask them to liaise with your specialist neuromuscular consultant or one of your muscle clinic team. Information for professionals is also available from the Muscular Dystrophy Campaign.

**Being diagnosed with a muscle disease should not prevent you from accessing further education if you want to. Various options are available, both within mainstream and through specialist provision, to help young people access these opportunities.**

### Further education

Further education (referred to as FE) is education for people over the age of 16, which involves study up to A level standard, including GCSEs, BTEC courses and NVQs. Generally colleges offer a wide range of academic and vocational courses which lead to qualifications. Local FE colleges are non-residential establishments and students usually come from the local area. Courses can be full- or part-time.

Funding for such courses is generally supplied, by the Local Education Authority or Education Authority in Scotland, for students up to the age of 19 (and sometimes to the age of 25). Help for older student is often dependent on locally set criteria. Help is more likely to be offered for courses in core skills (English, maths, IT etc) and to those who do not have higher level qualifications. Often people on low incomes are entitled to have fees waived.

Local FE colleges receive money from their funding bodies to pay for additional support that disabled students may need, for example transport. Many people with muscle disease benefit from provision of transport to and from college or funding towards it. Typically this is provided by the LEA for students until they are 21, in some areas 25, but there are other alternatives. In some areas social services provides or pays for transport or the college can apply to the Learning and Skills Council (LSC) for funding. You can also pay for it from an **Access to Learning Fund**. To find out more visit [www.direct.gov.uk/en/EducationAndLearning/UniversityAndHigherEducation/StudentFinance/Extrahelp](http://www.direct.gov.uk/en/EducationAndLearning/UniversityAndHigherEducation/StudentFinance/Extrahelp)

### 16+ education at a special further education college

Those not continuing in school may be interested in attending a special Further Education (FE) college for disabled students. Special colleges offer a range of academic, vocational and life-skills courses which are usually residential. Onsite care and accommodation is provided for disabled students and there are a good range of social and leisure activities available outside of teaching periods.

Funding for specialist colleges is only available when the LEA or EA cannot meet a student's needs locally. In these cases funding might be available via the LSC. It is helpful to have a formal statement from the LEA or EA stating that they cannot meet your needs. If care is a substantial part of the package some funding should be provided by your local social services.

Advisors from the careers service or Connexions can help you with your application and may liaise with LEAs, EAs and the LSC on your behalf. The Association of National Specialist Colleges (NATSPEC) is an organisation which supports specialist independent colleges who provide education and training to disabled students. It can provide details of specialist colleges.

## **University**

If a disabled student wishes to apply to university they should do so in the normal way. Financial arrangements for the course will be the same as for all other students (tuition fees etc are payable) but an annual non means-tested Disabled Students Allowance (DSA) may be available.

DSAs are only available for students in Higher Education. An annual grant worth up to £20,520 is available to full-time undergraduates for non-medical help. Lesser amounts are available to part-time and post-graduate students.

Local social services are responsible for meeting the cost of your personal care needs, regardless of where in the UK you attend university. While a university might provide adapted living accommodation, social services remains responsible for the provision of any equipment you need.

All universities have a staff member responsible for helping disabled students with practical arrangements so they can make their time at university a success. Open University may be an option but can be socially isolating.

We commissioned interviews with 20 young people with muscle disease about their university plans and experiences. They found that the main issues related to social services departments having little knowledge of available care packages. They also reported feeling bewildered due to the huge amount of organisations involved and lack of clear information on which services to access. One student commented: *"When I first contacted social services about going to uni they were very shocked. They didn't really know what to do. They said that it was extremely rare to get a disabled student wanting to move that far away from home. They just need to be a bit more clued up; they seem to think that if you're disabled you're going to spend your time at home."*

In August 2009 the *Trailblazers*, the Muscular Dystrophy Campaign's network of young campaigners, investigated the challenges disabled students face when applying to and studying at university. University representatives were interviewed about how their facilities and services are adapted to ensure equal opportunity for disabled students. University websites were also assessed against five key criteria. The *Trailblazers* then produced *University Challenge*, an indepth review of UK universities and guidelines on how best to enjoy a smooth, productive and enjoyable time in higher education. To order a copy or become a Trailblazer, contact 020 7 803 4807, email [trailblazers@muscular-dystrophy.org](mailto:trailblazers@muscular-dystrophy.org) or visit [www.muscular-dystrophy.org/trailblazers](http://www.muscular-dystrophy.org/trailblazers)

## **Part-time day or evening class learning for leisure purposes**

Access to courses for leisure purposes should be available to all. Course providers are obliged to consider the needs of disabled students and make reasonable adjustments to meet them. It is important that you inform people of your specific needs and share any information that may be relevant. Making sure the class is accessible and free attendance on a course for an assistant are examples of reasonable adjustments.

**Further information**

General advice for disabled students is available from **Skill** – the National Bureau for Students with Disabilities. It runs an information line and publishes many useful guides including some specifically related to Scotland.

0800 328 5050  
[www.skill.org.uk](http://www.skill.org.uk)

The **Connexions Service** supports people until they are 25.

0808 001 3219  
[www.connexions-direct.com](http://www.connexions-direct.com) or [www.connexions.gov.uk](http://www.connexions.gov.uk)

The **Learning and Skills Council** (LSC) is a funding body that operates in England.

0870 900 6800  
[www.lsc.gov.uk](http://www.lsc.gov.uk)

The **Higher Education Funding Council for Wales**

029 2076 1861  
[www.hefcw.ac.uk](http://www.hefcw.ac.uk)

The **Further Education Funding Council** operates in Scotland.

0131 313 6500  
[www.sfc.ac.uk](http://www.sfc.ac.uk)

**Natspec** is a membership association for independent specialist colleges that provides further education or training for students with learning difficulties and/or disabilities.

0117 923 2830  
[chiefexecutive@natspec.org.uk](mailto:chiefexecutive@natspec.org.uk)  
[www.natspec.org.uk](http://www.natspec.org.uk)



# Guide to transition

## 23. Housing

### Moving into adulthood and leaving home

When you move into adulthood your needs are likely to change. You are likely to have a greater desire for independence and privacy, and might be thinking about further education or employment and developing relationships. These things may bring a greater need for independence and a place of your own.

Moving out of your family home demonstrates your ability to be independent and make your own choices, take on board both the freedoms and responsibilities that living in independent housing can bring.

Young people may experience a number of problems finding housing and as a result of this many choose to stay with their parent or guardian. Young people with muscle disease may come up against additional barriers to finding or maintaining suitable housing, which could make it difficult to move into your own house. However, with determination and the right support, it is possible.

Your own circumstances will vary according to your abilities, your care needs and the resources available, so you'll need access to information from a wide range of housing options.

### Key considerations when moving home

Anyone moving out of the family home should consider the following when thinking about where they want to live:

#### Location

It is sensible to consider housing which is near to medical facilities or community resources you use on a regular basis, such as college, shops or libraries.

#### Accessibility

If you need wheelchair access then your new housing might need to be adapted or modified, for example, to include ramps, or hoists tracks. You may require all facilities (living, eating and bathing areas) to be on one level.

#### Design features and fittings

If you do require particular features like ramps, hoists and rails, suitable bathrooms, a certain room size or placement of electrical sockets etc, it is important to get help carrying out alterations. Remember to find out about how to get financial help with making the alterations.

#### Provision for carers

Your new home will need to have space for carers to stay if needed. If a carer or home help is required then you need to know what help is available to pay for this. Information about the Independent Living Fund (ILF), recruiting personal assistants and other assistance through social services may be important. Bear in mind that if you leave your family home either permanently or for a period of time, for example to attend college or work, then your current carer may not want or be able to relocate.

**This factsheet provides guidance on issues to consider relating to housing along with specific information about welfare benefits and other sources of income and assistance.**

The Independent Living Fund is a national resource dedicated to delivering financial support to disabled people and advancing standards of independent living, visit [www.ilf.org.uk](http://www.ilf.org.uk)

## Financial help

There are various support packages available to help you to live in your own home, further details are as follows:

### Guidance on budgeting

Accommodation must be affordable. It sounds basic but, like most young people, you probably won't have direct experience of budgeting for essential costs like rent, mortgage payments, utility bills and insurance costs, or balancing them against available funds for other essential living costs, such as food and clothing. You may find it helpful to seek guidance on household budgeting and Direct Payments before making a decision about living independently.

### Welfare benefits

Knowledge of available benefits, combined with information and support on how to apply for those you are eligible for will be important. Seek professional advice to ensure you don't miss out. Help with applications for housing and council tax benefit, and mortgage interest payments may be sensible. If you are entitled to both Disability Living Allowance and a Carer's Allowance specialist help may be beneficial as they are quite complicated.

Please contact the Welfare Rights Service for full details of your entitlements. Contact 01387 266888 or [info@welfarerights.net](mailto:info@welfarerights.net) or visit [www.welfarerights.net](http://www.welfarerights.net)

### Other sources of financial help

Financial assistance may be available in the following two situations:

1. If a room in a house is changed from an existing use to a bathroom, for example, it is possible to ask for the council tax banding to be reduced.
2. If your income and capital are low enough you may get help with the interest on a loan or mortgage used to move into a new home or/and have improvements carried out to make the accommodation accessible for a family member with a disability.

## Methods of planned relocation and moving home

### Planned re-settlement

In some cases social and other statutory services may work together to provide housing. This is likely to be rented social or communal housing where two or more people may rent a property together.

### Renting

Rented accommodation is a popular option. This is likely to be either through the social or the private housing sectors. Other routes may be available, such as accommodation provided with employment, by educational establishments or various supported housing schemes run by local authorities or charities.

You may be entitled to help with accommodation through your local social services so your first step should be to request an assessment. Your local council will be able to give you contact details for your local social services housing department. Keep the following in mind:

- Disabled students may be able to claim housing benefit.
- High rent is common in the private sector. If you are claiming or plan to claim housing benefit, it is important to check what contribution will be made towards your rent.
- You may find that housing benefit does not cover your full private rental charge as there is a limit to the amount allocated.
- If you are working but on benefits, lower rent could be an option – there is a complex interaction between in- and out-of-work welfare benefits, and working tax credit with housing and council tax benefit.
- If your rent is not covered through housing benefit (or the new local housing allowance) your local authority may provide a discretionary housing payment.
- The new local housing allowance (LHA) is a new way of calculating Housing Benefit (HB) based on the area where you live, number of occupiers in the property and household size. LHA is a much fairer way of calculating HB, as it ensures that tenants in similar circumstances in the same area receive the same amount of financial support for their housing costs.

### **Buying a property**

Unless you have sufficient capital this will involve taking out a mortgage. Income Support or Job Seekers Allowance may be available to help with some of your mortgage interest costs. Help may also be available with loans for adaptations due to disability needs. Careful budgeting and specialist advice are likely to be needed. Local authority, charities and social services may give grants to pay for necessary modifications.

### **Joint ownership of a property**

This is where you club together with friends to share the deposit, joint owner mortgage payments and household bills. Joint ownership can be a great way of getting onto the property ladder and can be done with family or friends.

### **Shared ownership of a property**

This is where you own part of a property with another party (usually a Housing Association) and pay rent to them for the part that they own but allow you to live in. They do not live in shared ownership with you. You may be able to increase your share as time goes by, sometimes to ten percent. This is called 'stair-casing'.

### **Support from social services with re-housing**

For disabled people who have housing needs, social housing may well be provided through social services departments working in partnership with a local authority housing department.

### **Lack of property or unsuitable property**

If you are homeless, will be so within 28 days or if your accommodation is unsuitable, for example you may not be able to climb the stairs, your local authority must provide you with suitable housing – although this initially may be temporary accommodation. Any accommodation provided, including temporary accommodation, must be suitable for you.

### **Local Authority Allocations**

Local authorities run allocation schemes, usually through a system called 'choice lettings'. You apply to join the scheme and are then placed on a waiting list according to the level of priority you have been assessed to have according to your circumstances. These priorities may be based on medical conditions, number of children, how suitable current accommodation is and the length of time someone has been on the waiting list. You are then invited to bid for properties as they become available. Medical priority is assessed by a local authority doctor.

**Choosing to stay at home**

Many young people with muscle disease chose to stay with a parent or existing carer. In this case it is important to consider whether existing accommodation needs adapting to make it accessible, or other alterations made to provide privacy and allow more independence e.g. separate facilities or bedroom. Get advice from your local social services department or care advisor about who to ask for financial help and grants. You will also need an assessment from an occupational therapist. Ask friends in similar circumstances or social services, or visit Independent Living centres to see how other people have adapted housing to suit their needs.

**Other help**

If you move into a new home and are in receipt of income support or Job Seekers Allowance you can apply for a Community Care Grant. This covers the cost of items such as furniture and cookers and fridges. The cost of these items is based on prices in the Argos catalogue.

This factsheet includes some of the points raised by our Great Ormond Street young people's focus group. Our thanks to all those who contributed their thoughts, opinions and time.

# Guide to transition

## 24. Employment

### Professionals and their areas of expertise

As many professionals will be unfamiliar with muscle disease, and the varying symptoms and rates of progression we suggest you take the time to discuss your individual needs with them. If your employer needs specific medical information, your specialist consultant or regional care advisor may be able to write a letter on your behalf. General information for professionals about different types of muscle disease is available from the Muscular Dystrophy Campaign.

**If you have muscle disease you may find practical issues sometimes prevent you from making the most of employment opportunities. To ensure your particular needs are properly assessed and catered for, it is important to equip yourself with information about the support available and your legal rights. This section provides guidance on finding employment and remaining in employment.**

### Finding employment

Contact your local Job Centre Plus and ask them to refer you to the Disability Employment Advisor (known as the DEA). Visit [www.jobcentreplus.gov.uk](http://www.jobcentreplus.gov.uk), contact 0845 6060 234 or textphone 0845 6055 255 for details for your local office.

You can discuss your requirements in more detail with your Disability Employment Advisor, who may offer support through a number of specialist schemes designed to help disabled people to find and/or remain in employment. These schemes currently include:

#### 1. Access to Work

This scheme is available for disabled people who work more than 16 hours per week. Designed to remove some of the practical difficulties you may face, it provides financial support to your employer for, or towards, the cost of specialised equipment or adaptations. This could cover the cost of support workers who help you.

Access to Work can also cover the cost of transport to get you to work if you cannot drive or use public transport. It is the scheme used by most people with muscle disease.

Specialist advice and assessment may be needed to ensure you receive appropriate support – for example, you may require a powered wheelchair for use at work or modifications to a standard computer – in which case assessments with relevant agencies will be arranged.

#### 2. Job Introduction Scheme (JIS)

Designed to give disabled people and employers the chance to trial a work placement, JIS pays a weekly grant towards your wages and training costs for the first six weeks that you are employed. In exceptional cases this can be extended to 13 weeks. Contact your local Jobcentre Plus office or DEA for more information, details are listed at the start of this section.

#### 3. New Deal for Disabled People (NDDP)

This is a voluntary scheme available to people on certain benefits (but not those on Job Seekers Allowance) who would like help finding work. Local job brokers assist with activities like filling in forms, writing CVs and finding suitable vacancies. Contact the NDDP helpline on **0800 137 177** for more information.

#### **4. Residential training**

If disabled people are unable to access training locally they may be offered specialist vocational training at one of 10 centres throughout the UK. These are residential centres where courses can last up to a year. Your DEA can provide further information or you can contact the residential training unit directly on **0191 202 3579**.

#### **There are a number of non-governmental agencies that can also help with employment:**

**Breakthrough UK** aims to help disabled people find jobs and offers a range of support services in the Manchester and Liverpool areas.

0161 273 5412

[www.breakthrough-uk.com](http://www.breakthrough-uk.com)

**Employment Opportunities** offers advice and support to disabled people, including graduates with disabilities.

020 7448 5420

[www.opportunities.org.uk](http://www.opportunities.org.uk)

**Enham** and **Papworth** are two centres that offer training and access to employment opportunities:

Enham, Hampshire

01264 345 800

[www.enham.co.uk](http://www.enham.co.uk)

Papworth Trust

Papworth, Cambridgeshire

01480 357200

[www.papworth.org.uk](http://www.papworth.org.uk)

#### **NeuroMuscular Centre (NMC)**

The Neuromuscular Centre in Winsford, Cheshire offers training in graphic design and IT both at the centre and through distance learning at home. It can offer employment, and help in finding employment, volunteering and work experience opportunities. NMC staff conduct work stations and IT assessments for disabled employees. The centre also provides physiotherapy assessment and provision on a regular or one-off session to people over 18 years of age. The Muscular Dystrophy Campaign is a trustee of the NMC.

01606 860911

[www.nmcentre.com](http://www.nmcentre.com)

**Reemploy** may be able to offer advice on employment opportunities.

0845 155 2700

[www.remploy.co.uk](http://www.remploy.co.uk)

**SCOPE** employment service supports people in gaining and sustaining meaningful employment within large corporations, public sector bodies and local employers. Available to all disabled people, SCOPE works with various government programmes including Workstep and Work preparation. SCOPE can also act as job brokers.

0808 800 3333

[www.scope.org.uk](http://www.scope.org.uk)

**The Disabled Workers Co-Op** is a free database of available jobs.

[www.disabledworkers.org.uk](http://www.disabledworkers.org.uk)

**The Shaw Trust** offers support with employment. It can help with the job seeking costs, job-start grants, benefits advice, work tasters and support in employment. It creates jobs via social enterprise and liaises with government agencies.

01225 716300

[www.shaw-trust.org.uk](http://www.shaw-trust.org.uk)

## Your rights

The Disability Discrimination Act (DDA), passed in 1995, means it is illegal to discriminate against someone on the grounds of their disability. The DDA covers things like application forms, interview arrangements, offers of employment, terms of employment, and benefits and opportunities for training and promotion. The Equality and Human Rights Commission (EHRC) can provide further guidance and advice to disabled people and their employers.

Many young people wonder whether they should disclose the fact that they have a disability to a potential, or current, employer. There is no obligation to do so but you should not lie if you are asked a direct question. If you choose not to share information about your disability you may not be justified in expecting your employer to make reasonable adjustments to meet your needs.

## What to do if you feel you have been discriminated against

### Informal discussion

You might want to have an informal discussion with your employer about your needs and why you feel you are being discriminated against. Remind them of your rights and their responsibilities under the Disability Discrimination Act.

### Internal grievance procedure

If you don't get a satisfactory outcome, you could make a complaint about your treatment through your employer's internal grievance procedure.

### Contacting Acas

If you are still not happy, you might want to contact Acas (Advisory, Conciliation and Arbitration Service). Acas aims to improve organisations and working life through better employment relations and provides up-to-date information, independent advice and high-quality training. It works with employers and employees to solve problems and improve performance.

### The Questions Procedure

Another option is obtain a Disability Discrimination Act questionnaire (DL56) which is available from the Equality and Human Rights Commission and some Citizens Advice Bureaux. You complete the first part of this questionnaire yourself, explaining why you feel you have been discriminated against, and asking your employer to comment on your claim. You then need to ask your employer to reply to the questionnaire. Your employer's answers in the questionnaire should help you decide if you can settle the dispute or need to make a complaint to an Employment Tribunal.

### An Employment Tribunal

You may want to make a complaint to the Employment Tribunal to decide if the law has been broken and may order your employer to change their policy, offer you other employment or pay you compensation. If you want to follow this route you must do so within three months of the date of the act of discrimination.

### The Employment Tribunal Service (ETS)

The ETS can give information about tribunal publications, explain how the tribunal system works and answer general queries about tribunal matters. For copies of free ETS leaflets or further information call the ETS enquiry line between 9.00 am and 5.00 pm, Monday to Friday.

Telephone: 08457 959 775

Textphone: 08457 573 722

As information on this complex subject is subject to change, we suggest you also visit the following for further information:

[www.jobcentreplus.gov.uk](http://www.jobcentreplus.gov.uk)

[www.direct.gov.uk](http://www.direct.gov.uk)

[www.equalityhumanrights.com](http://www.equalityhumanrights.com)

# Guide to transition

## 25. Social care

### Access to services

As seen in the person-centred planning model you should be at the core of the system for your own care. Support must continue as you move from being a child to becoming an adult. Some of you may not wish to have specific social work involvement, but will still need access to someone who can help you and your family through the transition process.

There should be a standard assessment at the start of your transition process, if one has not already been completed by social services, to help plan towards your future needs. This should assess all areas of your life, including your education, health needs and requirements to maintain quality of life and independence and should allow for changes as they occur.

Planning for your future should include regular reviews of your care, attended by a named key worker and consider any additional care needs like hospice, short break residential and paediatric care.

### Moving from children's services to adult services

There will be changes in the way you are assessed and provided for when you move from children's services to adults' services. Key points to be aware of are:

#### Simple things

Like free access to taxis to get to college may not be available once you have moved to adult services. Service varies from area to area – some people find that they have to contribute to fares from their mobility allowances.

#### Physiotherapy

Physiotherapy will be harder to access via adult services. Some physiotherapists will only be available for emergency treatments and others will provide 'maintenance stretches only'. In some areas physiotherapy is available once a week when you are still at school and once a month in a community, not hospital, setting. In some circumstances physiotherapists can show or train carers how to help you follow a tailored programme of stretches.

#### Means testing

All adult services are means tested through Fair Access to Care Services criteria. These criteria, which do not apply to children's services, will be used when you need to access adult services.

#### Benefits

At the age of 16 you can access your own benefits, but it may be decided that control for this remains with your parents until you are 18 or have completed full-time education if your parents are on income support. When you are in further education Students' Support Services can advise you on which benefits you can access or stay on.

**Young people and their families have made recommendations about the social care support which they need elsewhere in this guide. In this section, we have highlighted specific aspects of systems, services and support roles which will improve their long term care.**

## Access to professionals

There are a range of professionals who will be involved in coordinating your social care, education and health needs. You will need them to communicate well and work together to assess, review and deliver services according to your individual needs. It will be important for your GP to be kept informed about your clinical visits and any other therapy interventions. Some of the professionals who you will need access to are:

### **Transition worker/ team**

In some areas a dedicated transition worker/ team may be available to take on the reviews and forward planning which you will need help with in education, employment or day care.

### **Connexions workers**

In many areas Connexions workers act as the transition worker and often as the co-ordinator for reviews which will ensure that you have a named contact throughout transition.

### **Social workers, key workers and local managers**

In other areas there may not be a transition worker or team available to take responsibility for your overall care so you will need additional support from social workers, key agencies and local managers. Speak to your social work team to find out what services are available in your area and ask to be allocated a named key worker/co-coordinator.

### **Your key worker/coordinator**

Will help you to identify your care needs and plan ahead. They will attend reviews, complete the necessary paperwork and talk to you about what to expect when moving into adult services. It will be especially important for you to have access to this kind of support if you don't have a dedicated transition worker.

### **Welfare Rights Officer**

Your social worker or Connexions worker can refer you to a Welfare Rights Officer at your local council office. Your Welfare Rights Officer will conduct an individual family assessment for you and provide advice.

## Help with specific needs

You may need additional help for specific physical or access problems, for example:

### **If your condition is causing you difficulty with swallowing**

You may need access to a Speech and Language therapist. They can help by making recommendations on ways of managing this. Contact [www.helpwithtalking.com](http://www.helpwithtalking.com) for details of local speech and language therapists in your area or visit [www.speechtherapy.co.uk](http://www.speechtherapy.co.uk) for advice on speech therapy.

### **If you are finding it difficult to get around at home**

An occupational therapist (OT) can assist by assessing your home and recommending adaptations, equipment or aids which might help. They will weigh up the cost effectiveness of various options in the long term. A common issue faced in home adaptation is making sure that fire exits are big enough to take a person and their wheelchair outside.

If the adaptations are agreed by the council, an architect will then convert the changes which the OT has recommended into a design plan. Before any work begins, the design plan must be passed to the planning department at the council. The council will seek cost estimates from a building company. There can be lengthy timescales involved and there may be restrictions to how much funding is available for this kind of work.

### **Carers' assessments**

Carers have a right to assessment of their needs if the young person has had an assessment by social services. Contact [www.direct.gov.uk/en/CaringForSomeone](http://www.direct.gov.uk/en/CaringForSomeone) or [www.carersuk.org/Home](http://www.carersuk.org/Home) for more information on carers' assessments and rights.

## **Useful contacts**

### **Council for Disabled Children**

National Children's Bureau  
8 Wakley Street  
London EC1V 7QE  
020 7843 1900  
020 7843 6313 (fax)  
[cdc@ncb.org.uk](mailto:cdc@ncb.org.uk)

### **Contact a Family**

Provides advice, information and support to the parents of all disabled children.  
0808 808 3555  
[www.cafamily.or.uk](http://www.cafamily.or.uk)  
[www.makingcontact.org](http://www.makingcontact.org)

### **Citizens Advice Bureau**

[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

### **Early Support for Children**

[www.earlysupport.org.uk](http://www.earlysupport.org.uk)

### **Family Fund**

4 Alpha Court  
Monks Cross Drive  
York YO32 9WN

0845 130 4542  
01904 621115  
01904 658085 (textphone)  
01904 652625 (fax)  
[info@familyfund.org.uk](mailto:info@familyfund.org.uk)

### **Connexions Direct**

080 800 13 2 19  
07766 4 13 2 19 (textphone)

Connexions and The Family Fund both produce a booklet on transition.





# Guide to transition

## 26. Emotional support

### Feelings

Everybody has a different reaction to finding out about their condition. Some people say that they felt numb or found it difficult to concentrate, others feel overwhelmed or confused about what it means. Many people won't have heard of muscle disease and will want more information. Sometimes people feel angry and upset. All these feelings are, understandably, part of the process of getting used to having a condition that affects your physical abilities. Talking about your feelings can help you deal with this.

**Coming to terms with the progression of your condition can be emotionally difficult, both for you and those close to you. This factsheet covers some of the options available if you want to talk to someone about how you feel about a new diagnosis, changes to your health or anything else you feel upset about.**

### General information and advice

Adjusting to a changing situation takes time. Some people describe it as feeling as though they're on an emotional rollercoaster. Sharing information and talking to people around you should help but not everyone finds it easy to be supportive, and your friends and family might be confused or worried too.

Many people find learning more about their diagnosis helps them to take charge of the situation and plan appropriately. It's a good idea to take time to talk through your options with a range of people to help clarify what information and advice you need, and find out what support is available and who from.

Don't rush major lifestyle decisions like going to college or starting work. In most cases, it's important to do things at your own pace, when you feel the time is right and when you feel that you can handle the changes.

### Talking to someone

Some people want to talk to family and friends, but for others it helps to talk to someone outside their immediate support network, such as a care advisor, GP, health visitor or social worker. Other people may want specialised professional emotional support from an NHS counsellor, child or family psychologist, college or university advisor or similar. You can ask to be referred by your school or social worker for professional support.

### What is counselling and how can it help?

A professionally trained counsellor or a child psychologist can offer you or your family emotional support. Counselling aims to help you find your own solution to issues and helps you make sense of things, resolve specific problems and reach your own decisions. Counsellors are there to listen and enable you to talk about your feelings – speaking out loud about your problems can help put your thoughts in order. Counselling is private and confidential, unless someone's personal safety is at risk.

Counselling sessions are usually held once or twice a week for an agreed period of time, with the same counsellor each time, depending on the need. Sessions usually last 30 minutes to an hour and are provided free by the NHS – private counsellors charge £20-£80 per session. You can ask your GP or school to refer you to a counsellor for emotional support with your condition – bear in mind that there may be a long waiting list for an NHS or school referral.

Some organisations offer counselling by phone or email with a professional person qualified to help you talk through your concerns. Some of these organisations will charge, others may ask for a donation.

If you use a helpline you are only charged for the cost of the call and some helplines have numbers that can be called free or at a low call rate.

### **Genetic counsellors**

These professionals are skilled in helping young people with issues around inheritance and the genetic risks of their condition. You can be referred to a genetic counsellor through your GP or hospital consultant.

### **Peer support services**

Sometimes people find it helpful to talk to other people in similar circumstances - it can help to see that you are not the only person in this situation. Joining a condition specific support group, chat or discussion forum on our website might help. You may be interested in campaigning to make changes to services for young people with muscle disease, in which case joining the *Trailblazers* – the Muscular Dystrophy Campaign's network of young campaigners – could be of interest.

Some people also find attending a Muscular Dystrophy Campaign event helpful.

Contact our Information Service:

0800 652 6352 (freephone)      [info@muscular-dystrophy.org](mailto:info@muscular-dystrophy.org)      [www.muscular-dystrophy.org](http://www.muscular-dystrophy.org)

### **Losing a friend**

Everyone naturally finds the death of someone they are close to very distressing. Some people will find it helpful to talk about how they feel with someone they know at a local clinic or hospice. Services like the Child Bereavement Trust, CRUSE and local bereavement charities may be able to help. Contact your care advisor or the Muscular Dystrophy Campaign's Information Service if you need to talk or want information on where to go for help.

## **Useful contacts**

### **British Association of Counselling and Psychotherapist (BACP)**

The BACP keeps a database of regional counsellors and psychotherapists.

0870 443 5252 (Monday to Friday 9am to 5pm)

[bacp@bacp.co.uk](mailto:bacp@bacp.co.uk)      [www.bacp.co.uk](http://www.bacp.co.uk)

### **Connexions Direct**

Confidential information and advice for young people aged 13 to 19.

080 800 13219      [www.connexions-direct.com/index](http://www.connexions-direct.com/index)

### **Samaritans**

The Samaritans run a 24-hour free helpline which provides confidential and emotional support for people experiencing feelings of distress and despair.

08457 90 90 90      [www.samaritans.org.uk](http://www.samaritans.org.uk)

### **SupportLine**

SupportLine provides confidential emotional support for children and adults. Staff help callers to develop healthy and positive coping strategies and provide details of counsellors, agencies and support groups across the UK.

020 8554 9004      [info@supportline.org.uk](mailto:info@supportline.org.uk)      [www.supportline.org.uk](http://www.supportline.org.uk)

Universities and colleges have a student counselling service. This information is found in each college's handbook.

### **The UK Council for Psychotherapy**

020 7014 9955      [www.psychotherapy.co.uk](http://www.psychotherapy.co.uk)

## **Emotional support**

# Guide to transition

## 27. Peer support programmes

### *Living with MD* programme

The Muscular Dystrophy Campaign runs a series of free one-day events to enable people with muscle disease to meet others in their local area, learn more about accessing local services, and share experiences, advice and tips.

The sessions have been devised with the help of a steering group of adults with muscle disease to ensure that the content is as user-led and relevant as possible.

Topics include:

- life maps and 'your journey with muscle disease';
- managing emotions and dealing with change;
- daily routines and practical tips;
- accessing professional care;
- using your rights to empower you;
- thinking about the future.

After each day we encourage participants to keep in touch through peer-to-peer support networks.

*Living with MD* days run in several areas around the UK.

For further details please contact the Muscular Dystrophy Campaign's Information Service:

0800 652 6352

info@muscular-dystrophy.org

### The NHS Expert Patient programme

Expert Patient programmes are free six-week courses organised by NHS Primary Care Trusts. They aim to teach self-management skills in:

- problem solving
- decision making
- using resources
- developing partnerships
- taking action.

They focus on topics such as dealing with stress, relaxation, healthy eating and effective communication. The course is for people with any chronic condition, so information is quite general, but the aim is to cover common issues that people with any condition may face.

Courses are delivered by volunteers who have a long-term health condition.

Visit [www.expertpatients.nhs.uk](http://www.expertpatients.nhs.uk) or contact your local NHS Primary Care Trust.

**Being diagnosed with a long-term condition can be very daunting. Learning as much as you can about your condition, the services that are available to support you, and techniques for managing difficult times can help you remain positive and stay as well as possible. Meeting others facing similar challenges can also help you to feel less isolated and increase your confidence in managing your condition.**





# Guide to transition

## 28. Sex and relationships

### Professionals and their areas of expertise

Counsellors and health care professionals with organisations like Relate and young people's family planning clinics may not know about your specific condition but they should be familiar with issues around coping with disability.

Taking the time to explain the relevant facts about your disability, its progression and its impact on you both physically and emotionally will enable them to advise you on planning sexual activity or overcoming difficulties. These services are strictly confidential.

Providing them with a factsheet about your condition may be helpful. You can download this information from the Muscular Dystrophy Campaign website – [www.muscular-dystrophy.org](http://www.muscular-dystrophy.org)

### Physical or medical issues

Most types of muscle disease do not affect sexual function or desire. Very rarely, however, some conditions affect fertility. Some women also experience hormonal imbalances and fertility issues. This is certainly not always the case and where it is, help may be available. Ask your doctor if you have any concerns.

Muscle weakness and joint stiffness may make positioning and having sex more challenging but there are many aids that can help. Discussion with a partner and experimenting together is important. Keep in mind that not all sex has to be intercourse, and not all intercourse has to end in orgasm.

Sexual activity should be pleasurable for both partners. Do not feel forced into activities which do not feel right for you. Remember to always practice safe sex for the prevention of sexually transmitted diseases (STDs) and unwanted pregnancies.

Some young people with muscle disease may have heart and/or breathing issues which should be assessed and treated by a doctor, however these are unlikely to prevent you from enjoying a healthy sex life.

Sexual intercourse generally uses about as much energy as walking three miles an hour, and that can be a strain for people with weakened respiratory or cardiac muscles. Some positions require less energy than others so experiment. Many people find a side lying position easier. (source: The American Muscular Dystrophy Association. Visit [www.mda.org](http://www.mda.org) for more information).

Remember that certain medications can cause side effects which might impact on your sex life. Your doctor will be able to advise you so don't suffer in silence! It may be possible to change your medication.

Eating a balanced diet, keeping fit and well rested are important as they will all help you to feel good about yourself.

**Sex is a normal and important part of any relationship. However, sex and sexual relationships will cause anxiety for most people at some point in their lives. For people with disabilities, there may be added physical or psychological issues and this factsheet gives information on possible sources of help. People with muscle disease generally have normal sexual function and desire, factors often not appreciated by others.**

Finally stress and depression can cause sexual and relationship difficulties, so if these are an issue seek medical advice. Depression is an incredibly common problem but is usually treatable so don't try to cope alone.

**The Outsiders Club** publishes a range of explicit leaflets including:

- *Physical Disability and Sexual Intercourse*
- *Practical Sex Tips for Disabled People*
- *Sex with a Heart Condition.*

## Emotional and psychological issues

Seeing yourself as an individual and not as someone defined by your disability is important. Everybody is unique. As The Outsiders Club says: "As long as you're afraid of what other people think it's hard to know your true self and enjoy peace of mind."

The Outsiders club also publishes a range of explicit leaflets including:

- *Disability and Body Image*
- *Personal Relationships and People with Physical Disability*
- *Sex and your Partner with a Disability.*

Its website has a 'Practical Suggestions' section which features a lot of useful, and again, explicit, information. It also runs an online library service for members.

[www.outsiders.org.uk/club](http://www.outsiders.org.uk/club)

## Further information

The following organisations are mentioned in the text above. Please note that the Muscular Dystrophy Campaign is not in a position to recommend organisations and has not evaluated the quality of the advice they give.

### **British Association for Sexual and Relationship Therapy**

Lists locally-based advisers on its website.

020 8543 2707

[www.basrt.org.uk](http://www.basrt.org.uk)

### **Brook**

Provides support for people under 25 and those helping someone under 25.

0808 802 1234

[www.brook.org.uk](http://www.brook.org.uk)

### **Relate**

Relate can offer advice to people experiencing relationship difficulties, including sexual problems. It offers a telephone and email counselling service as well as the traditional face-to-face option. Advice on common difficulties is published on its website and an online book service covering relevant topics is available.

0300 100 1234

[www.relate.org.uk](http://www.relate.org.uk)

### **The Outsiders Club**

0707 499 3527 (Monday – Friday, 11.00 am to 7.00 pm)

[www.outsiders.org.uk](http://www.outsiders.org.uk)