

**Muscular
Dystrophy UK**

Fighting muscle-wasting conditions



**A guide for parents:
children with muscle-
wasting conditions**



About Muscular Dystrophy UK

Muscular Dystrophy UK is the charity bringing individuals, families and professionals together to beat muscle-wasting conditions.

- ▶ We support high-quality research to find effective treatments and cures, and lead the drive for faster access to emerging treatments for UK families.
- ▶ We ensure everyone has the specialist NHS care and support they need, with the right help at the right time, wherever they live.
- ▶ We provide a range of services and opportunities to help individuals and their families live as independently as possible.

About the authors

This booklet has been adapted from the original book, for families with a child recently diagnosed with Duchenne muscular dystrophy, written by Jane Stein, social worker, and Julie Cassell, physiotherapist.

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Other publications

- ▶ *Inclusive education guide for children with muscle-wasting conditions*
- ▶ *Wheelchair Provision for Children and Adults with Muscular Dystrophy and Other Neuromuscular Conditions*
- ▶ Muscular Dystrophy UK's factsheets about living with muscle-wasting conditions, including condition information, medical and health information, as well as psychological and social issues and support

You can order these for free from Muscular Dystrophy UK, or download them from the website.

0800 652 6352 (freephone)

info@muscular dystrophyuk.org

www.muscular dystrophyuk.org

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How Muscular Dystrophy UK supports you

This booklet is designed for you, as parents and/or carers of a child recently diagnosed with a muscle-wasting condition. The aim is to offer support and information to you at this difficult time.

The booklet is in question and answer format and includes the things most parents ask us.

Thank you to all the families who have shared their thoughts and photographs throughout this booklet.

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

- ▶ give you accurate and up-to-date information about muscle-wasting conditions, and keep you updated about progress in research
- ▶ give you tips and advice about day-to-day life, written by people who know exactly what it's like to live with a muscle-wasting condition
- ▶ put you in touch with other families living with muscle-wasting conditions, who can tell you about their experiences
- ▶ tell you about – and help you get – the services, equipment and support you're entitled to.



Abbi Bennett who has Ullrich congenital muscular dystrophy

How do we deal with the diagnosis?

For many families, the diagnosis of a muscle-wasting condition comes as a complete shock. Parents may have suspected something was wrong, however they rarely expect this diagnosis and seldom know anything about any muscle-wasting conditions. For others, there may be a known family history.

There is no right or wrong way to respond.

Muscular Dystrophy UK produces factsheets on most muscle-wasting conditions, and these provide more detailed information.

What happens now?

Depending upon the age of your child at diagnosis, there are a number of things you can do to assist him/her and there is more about this later in the booklet.

It is important to equip yourself with information and identify local sources of support, and have a follow-up plan from the clinic where the diagnosis was made.

What are muscle-wasting conditions?

There are around 70,000 people in the UK living with muscle-wasting conditions. Muscular Dystrophy UK brings together people affected by more than 60 rare and very rare progressive muscle-weakening and wasting conditions.

These conditions cause muscles to weaken and waste over time, leading to increasingly severe disability. They are part of a group of genetic conditions caused by 'mutations' in the genes, sometimes known as 'genetic faults'. In some cases, the mutation is passed from the

parents to their children, while in others the condition is caused by a new mutation. Some conditions affect the heart muscle and vital breathing muscles too.

There is currently no cure or effective treatment for muscle-wasting conditions; however research is progressing.

There have also been many recent and ongoing advances in the management of muscle-wasting conditions.

What shall we say to our child and when?

Coming to terms with the news that your child has a muscle-wasting condition can be extraordinarily difficult for you. If the diagnosis is recent, you may find things can be overwhelming. You may be worried about what the future holds for your child, and how you can help them to live as happy and independent a life as possible.

Many parents wish to hold off from telling their child about the diagnosis for as long as possible. They may feel that they are protecting their child.

Contact the Muscular Dystrophy UK care and support team (**see contact details on p38**), who can support you with helpful information. They can also send you a copy of the booklet: *When your child has a muscle-wasting condition: A guide to talking with your child about their condition.*

“Stanley is the perfect antidote to the concern his condition brings, he is happy, bright and very funny. He continues to teach us what is important in life; family, friends, hope, love and happiness.”

Rob Newman, whose son Stanley has congenital muscular dystrophy

What shall we say to our other children?

Siblings are likely to have questions (and often worries) about their brother or sister too. It can be difficult to judge how much to tell siblings, particularly if there is a large age gap. Generally, it is important to ensure the siblings don't know more about the condition than the child living with it.

It is a big responsibility to expect a child to hold on to this sort of information.



Dan McLellan (second from left), who has Ullrich congenital muscular dystrophy

What shall we say to other adults in the family?

Unless there is good reason not to, tell your relatives the truth. You will need their support and understanding in the years ahead.

As these conditions are usually genetic, other family members may wish to be referred to their local clinical genetics department for advice. Be aware that other people may be frightened or upset by the news and may not react in the way you would expect.

You can talk about these concerns, in confidence, with the team caring for your child and your local clinical genetics department. They are used to dealing with such situations and will not pass on information about you or your child to other family members without your consent.

What if a relative is planning to have children or is pregnant?

If relatives are planning to have children, they can ask their GP to refer them to a genetic counsellor. If a relative is pregnant, she can request an urgent referral. Consider making your child's relevant medical records available for the consultation. This is a common occurrence and genetic counsellors are skilled at, and used to, talking about the issues raised.

How shall we tell our friends?

What you say will very much depend upon how close you are to your friends. If you have a partner, decide together on the people you will share information with and, if you want to keep the information confidential, ensure your friends know that.

Some parents say they needed to give themselves time before sharing the information outside their own close circle. It can often be difficult coping with other people's distress as well as your own.



Stanley Newman, who has congenital muscular dystrophy



Tommy Lloyd, who has limb girdle muscular dystrophy

How do we cope with the information?

How do we cope with the way we are feeling?

There is no right or wrong way to feel. You will probably feel differently at different times. One minute (or day), you may feel able to cope and then the next day you may feel much more fragile. Some parents say they feel as if they are on a giant roller coaster, and then the good days gradually start to outnumber the bad ones.

It is never easy coping with the unfamiliar. Most parents have a vision for their child and it can be very challenging when this vision is changed by something beyond their control.

Some people find that talking to a counsellor or to their care advisor can help. Ask your GP to arrange this, if you would like to do so. Extra support is often just what you need.

How do we cope with each other's feelings?

If you have a partner, you may find that you and your partner cope with the situation differently.

Sometimes one partner wants to talk while the other doesn't. What works for some couples is to negotiate some agreed 'talking time' so that each partner's needs are at least partly met.

If one partner is out at work, the other may take on more of the responsibilities relating to the home and children, including attending clinics. Feeding back information from clinic appointments can be difficult; one partner may not have asked the same questions as the other would have. If you cannot attend appointments together, you may find it helpful to compile a list of questions together, in advance.

Because everyone deals with situations differently, it may be helpful to get support from a trusted friend, or from health professionals.

What about the feelings of others?

It can be very distressing to have a child diagnosed with a muscle-wasting condition, and others will feel for you. They may not be ready for what you have to tell them, so speak to them at a time when you feel strong.

Avoid sharing the information when your children are around. You may think they are busy playing, however they often overhear more than you would expect.

People like to help, so let them know how they can help you. Perhaps they can look after your child(ren) while you have some time to yourselves, or simply just be there for you.

Meeting other families living with muscle-wasting conditions

Many people find it helpful to meet with other families who have a child affected by the same or a similar condition.

You might not feel like it right away. If you do, and when you're ready, speak to Muscular Dystrophy UK, your care advisor or staff at the clinic your child attends. They can put you in touch with a family that has a child of a similar age to yours.

You may wish to contact them by email initially. This allows you to control the amount and timing of the contact, and you don't have to disclose personal details until you've established a relationship.

Most families who have children with muscle-wasting conditions do meet other families at clinics, physiotherapy sessions or events organised by Muscular Dystrophy UK and other support groups.

Other families can be a unique source of information and support. Unlike the health professionals involved, they are experiencing (or have experienced) some of the same emotions and may have faced similar practical challenges.

Muscular Dystrophy UK often brings together families with children who have muscle-wasting conditions. Contact the care and support team at the charity's London office to find out more.

“When Ella was diagnosed with CMT (Charcot-Marie-Tooth disease), it was overwhelming. Our daughter had a condition that we’d never heard of and we didn’t know how we were going to be able to help her. My advice for other parents would be to make sure you have a good support network around you. Let people who want to help, be there for you.”

Lucy Brady



Ella Brady, who has Charcot-Marie-Tooth disease (CMT)

What does the diagnosis mean for our child's development?

What physical changes can we expect to see in our child?

Any physical changes in your child are likely to be subtle rather than sudden or dramatic. In very young children, as they go through normal development, you may initially see positive progress.

However, if your child is walking, it is common for him/her to tire more quickly when walking longer distances, to complain of pain in legs after exercise, to struggle with stairs or to fall frequently. A child may struggle more at the end of the day, particularly if they have been doing physical activities.

Sometimes, weakening of the arms or hands may occur. Writing for long periods, or taking clothing off or putting it on over the head may become more difficult.

If your child is not able to walk at all, changes may take place in their posture or joint position, owing to weakness in some muscle groups.

While it is good to encourage your child to be as active as possible, your child needs to know you understand that some activities are not easy. It is helpful to balance periods of activity with periods of quieter play to avoid exhaustion.

Will our child be in pain as a result of having a muscle-wasting condition?

Most muscle-wasting conditions themselves do not cause pain; however some children may be troubled by muscle

cramps or joint pains. Advice and regular monitoring by a physiotherapist will be beneficial for most children.

Physiotherapists are likely to provide a programme of stretches and exercises to maintain a good range of movement in the joints, which will reduce discomfort. Gentle massage and warmth can help relieve cramps.

Will our child develop eyesight, hearing or speech difficulties?

Most muscle-wasting conditions do not cause difficulties with eyesight or hearing. Weakness of facial muscles, which may affect speech, chewing and the ability to swallow, are not usually a problem in childhood.

Will our child become incontinent?

This is very unlikely. Sensation usually remains normal and children will be aware of when they need to use the toilet.



Dan McLellan, who has Ullrich congenital muscular dystrophy

Of course, accidents can happen if a child delays going to the toilet and is then a little slow to get there. If your child does have difficulties, tell your consultant, care advisor or GP, as they will suggest adjustments if necessary.

Constipation can be a problem in some children, particularly if they are not physically active. It can usually be managed by adjustments to the diet. Again, discuss this with your GP, consultant or specialist nurse.

Will our child have learning difficulties?

Some children with muscle-wasting conditions may also have learning difficulties. If learning difficulties are present, they will not be progressive and with the right input, good educational progress can be made.

Ensure your child is properly assessed by an educational psychologist and discuss whether or not your child needs an Education Health and Care Plan (EHCP) or, in Scotland, a Co-ordinated Support Plan.



Stanley Newman, who has congenital muscular dystrophy

What about schools?

Some children are already at school when they are diagnosed with a muscle-wasting condition, while others may not yet be at nursery school age.

A diagnosis of a muscle-wasting condition does not mean your child cannot attend a mainstream school. This will depend on a variety of factors, including your preference and the inclusiveness of the school. Most children with muscle-wasting conditions are able to attend a local primary school along with their friends.

When selecting a school for your child it is important to explain to the Head Teacher that your child has a muscle-wasting condition. Knowing this will be helpful for the teaching staff, enabling them to plan appropriately for your child. Every school has a Special Educational Needs Co-ordinator (SENCo), who will need to be involved to ensure your child's needs are met in school.

The clinic staff or therapists who work with your child could also talk to school staff about your child's condition and how it will affect them while at school. This may be the case for nursery schools too.

It is important to raise any concerns you have about access. The school you choose needs to be right for your child throughout their time there and as their condition progresses. Local Education Authorities (LEAs), or Education Authorities (EAs) in Scotland, can usually make minor adaptations to buildings. They are not legally required to make every school in the area fully accessible.

Staff at your preferred school should seek expert advice from the LEA/EA if they have any concerns.

Sadie and Abbi Goldthrite, who have facioscapulohumeral muscular dystrophy (FSHD)



The LEA/EA should assess any additional needs your child may have for learning or physical management. They may issue an EHCP or, in Scotland, a Co-ordinated Support Plan.

Most parents of young children don't want their children to be treated any differently from other children, and most schools try to respect these wishes. Allowances will sometimes have to be made, however, to ensure your child's wellbeing. Agree with teachers what these will be and review them on a regular basis.

Other children in the class may ask about your child's additional needs. Discuss with teachers, and your child, what explanation should be given. You may want someone to explain to the class that your child has a medical condition that causes their muscles to weaken and waste, and which makes certain activities difficult or impossible. Let the class know how they can be supportive by, for example, holding doors open. Only do this with your child's consent.

A few children with muscle-wasting conditions may prefer to be in a school for special educational needs, particularly if they have a significant learning difficulty. Classes tend to be smaller, and physiotherapy and other therapy services will probably be available on site. Some parents also find a this school environment more supportive.

Muscular Dystrophy UK publishes a range of factsheets on education, as well as a comprehensive guide for schools, entitled *Inclusive education guide for children with muscle-wasting conditions*.

Will our child get upset or angry? How will he/she cope?

You may be surprised at how well young children cope with their diagnosis. However, as the condition progresses and changes occur, they will have to adapt. Children may express their anger or frustration by displaying challenging behaviour.

Try to keep life as 'normal' as possible, and don't treat your child, who has a muscle-wasting condition, any differently from your other children. Have clear guidelines about what is acceptable behaviour and what is not.

It may be appropriate to give your child more information about their condition to help them make sense of the changes taking place. Try to involve your child in decision-making and give them the space to develop friendships. When you talk to your child, ensure you really listen, otherwise you could assume he/she has the same anxieties you have. They are more likely to be concerned with today, rather than tomorrow (or next year). Avoid being 'over-protective'; as all children do, he/she needs some adult-free time.

Abbi Goldthrite, who has facioscapulohumeral muscular dystrophy (FSHD)



If your child is being teased or bullied at school, seek advice from school staff and work with them. With your child's permission, consider telling classmates about the situation. This is often the best way to gain support and respect.

It can be very helpful to get a health professional to do this, for example the care advisor or the clinical nurse specialist. Some children like to do this themselves, with their teacher supervising.

Some children may benefit from talking to a counsellor. Art or music therapy can also be helpful and fun. Sometimes relatives and friends may treat your child differently – this can create tensions within the family and between siblings, so be clear about your wishes in this area.

What about puberty and sexual issues?

Children with muscle-wasting conditions experience puberty in the same way as others their age do. As they get older, they will require an increasing amount of physical care so think about ways of maintaining privacy and dignity.

Your child will need opportunities to learn about sexual issues and form relationships with others, as any other child their age would. Being physically dependent on others should not prevent your child increasing their independence in thought and actions.



Josh Twine, who has Duchenne muscular dystrophy



Dan McLellan (r), who has Ullrich congenital muscular dystrophy

What do we need to think about when caring for our child?

A multi-disciplinary approach, with the input of specialists such as physiotherapists and occupational therapists, is often the best way to manage a muscle-wasting condition.

Having access to a multi-disciplinary team can ensure someone with a muscle-wasting condition receives a holistic approach to their care. This means that in a single visit to your specialist neuromuscular centre, you can get important input from each health professional involved in your child's care. This includes respiratory, cardiac, physiotherapy and occupational therapy health professionals who, together, can provide your child with better support.

Watch our video about this multi-disciplinary team approach: www.musculardystrophyuk.org/mdt

Do we need to keep attending specialist appointments?

Muscle-wasting conditions are very rare. As most GPs may not see more than one or two patients with these conditions in their entire career, it is helpful to see professionals who have experience of muscle-wasting conditions.

They usually work at specialist clinics and, as experts in this field, they will discuss with you the right issues at the right times, and keep you up-to-date with any new developments, research and clinical trials. Specialist clinics also have established links with other services that may be of help to your child.

The relationship between a family affected by a muscle-wasting condition and the specialist team that supports you, is an important one. A strong relationship, based on good communication, helps to create a supportive environment and if there's ever a difficulty, you and your child will be well-known to the team.

The relationship is also a partnership, so feel free to question why an appointment is necessary, or ask for less frequent appointments if you feel this is appropriate. Different families appreciate different levels of support and the team will be keen to get it right for you. Let them know your preferences.



Unless your specialist centre is very near to you and has a community remit, you will also need support from local paediatricians. They can help you get local services, such as physiotherapy, and can also contribute to a child's EHCP or, in Scotland, Co-ordinated Support Plan.

Local paediatricians will play a role in your child's care should he/she become unwell or be admitted to a local hospital. They work with the specialist team, GP and school health services to champion your child's needs. If you can, space out the visits between the specialist centre and your local centre.

Why has our child been referred to other specialists?

As your child gets older, he/she will need additional support from doctors specialising in the care of joints and the spine (orthopaedic specialists), as well as breathing (respiratory specialists). A cardiologist will be involved in assessing the heart muscle function, and providing treatment if any weakness is found. In some cases, other specialists may also need to be consulted.

How much physical activity and exercise should my child do?

Keep your child as active as possible and try to make the activities fun. There is no need for anything excessive; normal play is fine. Allow your child to join in with PE and games, and they will judge for themselves if an activity is too challenging for them. Your child's local physiotherapist can visit the school to advise on appropriate activities, including PE.

If appropriate, encourage walking. Your child may tire more quickly than their friends, so do make allowances

for this. Activities such as walking up hills, and/or climbing stairs, may be particularly difficult. If your child can manage them, swimming, cycling and horse riding are excellent physical activities.

Have conversations with your child's school about playground safety, and the amount of activity your child can manage, and review this regularly.

What if our child falls over and breaks a leg?

It would be unwise to restrict your child's activity because of fear of a broken bone, however the risks do need to be assessed. If your child does break a bone, ensure that staff at the hospital get in touch with staff at your child's specialist muscle clinic. Contact the relevant professionals yourself too. Where possible, try to avoid having limbs immobilised (particularly in plaster casts) for long periods of time, as once muscle strength is lost, it is not easy to regain.

Alert cards and neuromuscular care plans

Muscular Dystrophy UK has produced a range of different alert cards for people with muscle-wasting conditions. Designed to fit easily into a wallet, the cards outline information about the condition, as well as key recommendations and precautions for consideration during medical emergencies.

Working alongside a range of specialist health professionals, Muscular Dystrophy UK has also developed a care plan that you can complete together with your neuromuscular clinicians. This care plan can then be shown to any health professional to develop a tailored approach to your child's healthcare.

Visit Muscular Dystrophy UK's website to see which alert cards are available. Order your alert card and care plan by emailing info@muscular dystrophyuk.org or call our Freephone helpline on **0800 652 6352**.

Should our child follow a special diet?

There is no evidence to show that a child with a muscle-wasting condition requires a special diet, although some children do experience difficulty with feeding and gaining weight. If this is the case your child is likely to be referred to a speech and language therapist (SALT) and/or a dietician.

If there are no feeding difficulties, it is helpful to establish a healthy eating pattern, which maintains weight within a normal range. Excess weight makes it harder for a child with weak muscles to move. It also makes any moving and handling assistance more risky.

If your child becomes less physically active, they will require a lower calorie intake.

Muscular Dystrophy UK has a factsheet, entitled *Healthy eating for children with neuromuscular conditions, which you may find helpful*.

What are night splints?

As the name suggests, these are splints worn at night. When a joint cannot move through its full range, because of tightened muscles, this is known as a contracture. Night splints help to delay contractures because they hold the joint in a good position during the night. Splints are made from a variety of lightweight materials.

A child should, preferably, wear night splints throughout the night but some children find this uncomfortable. It

Max Gateley, who has Becker muscular dystrophy



may be necessary to find a compromise, for example, wearing the splints on weeknights only, or for just half the night. Some children find it easier to wear just one splint at a time, on alternate nights. If it becomes very difficult, try persuading your child to wear them in the evenings while watching television.

Night splints can be uncomfortable in hot weather and wearing a cotton layer underneath them often helps. Sometimes the orthotist (someone who specialises in assessing for and supplying orthoses, such as supportive footwear or splints) will make air holes in the splint, which can help. It can also be difficult to turn over in bed when wearing splints. If night splints are uncomfortable, or your child grows out of them, contact your physiotherapist or orthotist.

Should our child have physiotherapy?

Most children with muscle-wasting conditions benefit from regular physiotherapy. A programme of exercises and stretching is likely to be suggested. Try to make these fun and part of the daily routine.

The team at your child's muscle clinic will usually make a referral to the local physiotherapy service. If this does not happen, inform the muscle clinic staff or ask your GP for help.

Can alternative therapies help?

There is no scientific evidence of alternative therapies proving helpful. Some non-invasive therapies, such as massage, may be pleasant and relaxing, but do seek guidance from your specialist before undertaking any. Muscular Dystrophy UK has published a factsheet – *Alternative therapies* – that you may find useful to read.

Speak to your GP if you're unsure about any of these therapies for your child.





Alliyah Ashe (l), who has Bethlem myopathy

What should we consider when planning for our family's future?

How can we afford all the things our child will need?

Having a child with a disability can put pressure on a family's finances. It can be helpful to understand clearly what the statutory authorities should provide.

Some essential equipment for using around the house, such as banister rails and bath aids, is provided free of charge by Social Services. Manual and powered wheelchairs are available through Wheelchair Services, which is part of the NHS. The LEA/EA can provide computers for use at school. Find out in good time, as the process of obtaining equipment can be slow.

The Joseph Patrick Trust (part of Muscular Dystrophy UK) and other charities can assist with grants towards the cost of equipment.

Doctors are not experts in benefit issues. Muscular Dystrophy UK's information and advocacy team (**see contact details on p38**) can help you with these applications, if you are having any difficulties. They also have leaflets and factsheets explaining practical and financial support, as well as welfare benefits and what you are entitled to.

Benefits for families on Income Support can be affected by accruing large amounts of Disability Living Allowance (DLA) savings.



Will we need to give up work to care for our child?

There are no rights or wrongs in this situation. Many children with muscle-wasting conditions are in families where their parents work.

However, children with muscle-wasting conditions often require more support from their parents than other children their age. They may need help with practical tasks and have a range of appointments to attend, which may increase in frequency as they get older. As doctor's visits and hospital appointments are generally during the day, you may wish to discuss options with your employer. You are entitled to ask for flexible working to accommodate the support you might need to give your child.

There are lots of different types of flexible working, for example, working from home or working part-time. Read more on the **gov.uk** website.

Get up-to-date advice on benefits and tax credits. Don't assume you're not entitled to help because you are working or have income/savings at a particular level. Not all benefits are income-related. A parent who gives up work to care for a disabled child is generally entitled to financial help.

Will we need to move? Will we need a bungalow?

Many families worry that they will have to move house. With expert advice, you won't need to rush into any decisions. Children with muscle-wasting conditions will eventually need their own bedroom and a suitably-equipped bathroom.

When your child starts to use a wheelchair, you will need to consider how they will get in and out of your house and how they will access communal rooms. As most children are diagnosed many years before these issues become pressing, there is time to plan accordingly. Bear in mind that housing issues can take a long time to sort out.

If you're a council or housing association tenant, it's advisable to let your landlords know at an early stage after your child's diagnosis that major alterations are likely to be needed.

Tenants of private landlords should seek advice from an occupational therapist and the housing department, as it can be difficult to make adaptations to privately-rented properties.

An occupational therapist will help you by assessing your current and future housing needs. You can generally refer yourself to the occupational therapy department, usually based at the local Social Services.

Financial help cannot be given retrospectively, so seek advice on the funding of adaptations. Whether you're an owner/occupier or a tenant, Muscular Dystrophy UK's care and support team can advise you on what financial help you're entitled to. Muscular Dystrophy UK's care and support team can advise you in this regard. The charity's *Adaptations Manual* is a comprehensive guide, which you may find helpful.



Stanley Newman, who has congenital muscular dystrophy

What about research?

Although there are currently no cures or effective treatments for muscle-wasting conditions, we support high-quality research that generates the knowledge essential for understanding the biology of these conditions. This knowledge can then be used in finding effective treatments.

Since Muscular Dystrophy UK was established in 1959, we've invested more than £55m in high-quality research, without which no progress towards a treatment or a cure would be possible. The path to a cure is a long one. However hundreds of scientists around the world are working towards that aim.

Keep up-to-date on research news and progress by visiting our website at www.muscular dystrophyuk.org/research

You can also sign up to receive regular communications from the charity.

Research has also helped improve our understanding of how best to manage muscle-wasting conditions. This has had a positive impact on the clinical care of many children. Your consultant can advise you further.

If you'd like your child to take part in clinical trials, let your GP know. Clinical trials test the benefits of promising treatment approaches, to see if they are safe, have any side-effects, or provide any benefits.

It is also important to join national registries, if they are available for your child's muscle-wasting condition.

Useful resources

Muscular Dystrophy UK

The friendly staff in the **care and support team** at Muscular Dystrophy UK's London office are available to offer free information and emotional support. If they can't help you, they can signpost you to specialist services close to you, or to other people who can help.

61A Great Suffolk Street, London SE1 0BU

0800 652 6352 / info@musculardystrophyuk.org
(Monday to Friday 8.30am to 6pm)

www.musculardystrophyuk.org

Joseph Patrick Trust (JPT)

Muscular Dystrophy UK's welfare fund, the JPT provides grants towards the cost of specialist equipment for children and adults.

61A Great Suffolk Street, London SE1 0BU

020 7803 4814

JPTgrants@musculardystrophyuk.org

www.musculardystrophyuk.org/jpt

Association for Glycogen Storage Disease (UK) Limited

Old Hambledon Racecourse, Sheardley Lane, Droxford,
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Telephone: 0300 123 2790 (Monday to Thursday)

0300 123 2799 (Out of hours)

Association for Glycogen Storage Disease (UK)

Tel: 01332 669670

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Web: www.agsd.org.uk

Becker United

Email: beckersmd@hotmail.com

Web: www.beckerunited.com

CLIMB Children Living with Inherited Metabolic Diseases

CLIMB Building, 176 Nantwich Road, Crewe CW2 6BG

Tel: 0845 241 2173 or Family team on: 0800 652 3181

contact@climb.org.uk

Web: www.climb.org.uk

CMT United Kingdom

3 Groveley Road, Christchurch, BH23 3HB

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Email: secretary@cmt.org.uk / enquiries@cmt.org.uk

Web: www.cmt.org.uk

FSH Support Group

8 Caldecote Gardens Bushey Heath Hertfordshire
WD23 4GP

Tel: 020 8950 7500

Email: fshgroup@hotmail.com

Web: www.fsh-group.org

GAIN

GAIN, Woodholme House, Heckington Business Park,
Station Road, Heckington, Sleaford, Lincolnshire NG34 9JH

Tel: 01529 469910

Helpline: 0800 374803

Email: office@gaincharity.org.uk

Web: www.gbs.org.uk / www.gaincharity.org.uk

SMA Support UK

40 Cygnet Court, Timothy's Bridge Road, Stratford-upon-Avon, Warwickshire, CV37 9NW

Tel: 01789 267 520 (Monday to Friday 9am to 4.30pm)

Email: office@smasupportuk.org.uk

Web: www.smasupportuk.org.uk

Myaware Myasthenia Gravis

Myaware (Myasthenia Gravis Association); The College
Business Centre, Uttoxeter New Road, Derby, DE22 3WZ

Tel: 01332 290219

Web: www.myaware.org

Email: info@myaware.org

Myositis UK

146 Newtown Road Woolston Southampton Hampshire
SO19 9HR

Tel: 023 8044 9708

Email: msg@myositis.org.uk

Web: www.myositis.org.uk

Myotonic Dystrophy Support Group

19-21 Main Road, Gedling, Nottingham, NG4 3HQ

Tel: 0115 987 5869

Helpline: 0115 987 0080

Email: contact@mdsguk.org

Web: www.mdsguk.org

Myotubular Trust

10 Penshurst Close Chalfont St Peter Buckinghamshire
SL9 9HB

Tel: 078 1320 0298

Email: contact@myotubulartrust.com

Web: www.myotubulartrust.com

Nemaline Myopathy

5 Cairnbank Gardens, Penicuik, Midlothian EH26 9EA

Tel: 01968 674998

Web: www.nemaline.org

Carers UK

Carers UK, 20 Great Dover Street, London SE1 4LX

Tel: 020 7378 4999

Helpline: 0808 808 7777

Email: advice@carersuk.org, info@carersuk.org

Web: www.carersuk.org

Carers UK provides information and advice to carers throughout the UK.

Contact A Family

209-211 City Road London EC1V 1JN

Tel: 020 7608 8700

Helpline: 0808 808 3555

Email: info@cafamily.org.uk

Web: www.cafamily.org.uk

Contact A Family is a national charity that provides information and support to families affected by rare disorders. It also puts families in touch with one another.

Disability Rights UK

Ground Floor, CAN Mezzanine, 49-51 East Rd, London, N1 6AH

Tel: 020 7250 8181

Helplines: Disabled Students Helpline – 0800 328 5050, Equality Advisory and Support Service (EASS) – 0808 800 0082, Personal Budgets Help Line – 0300 555 1525, Member Organisations Welfare Rights Advice Service – 020 7250 8184

Email: enquiries@disabilityrightsuk.org

Web: [www.disabilityrightsuk.org/Disability Alliance](http://www.disabilityrightsuk.org/Disability>Alliance) provides advice on benefit matters.

Family Fund

Unit 4, Alpha Court, Monks Cross Drive, Huntingdon, York YO32 9WN

Tel: 01904 621115

Email: info@familyfund.org.uk

Web: www.familyfund.org.uk

The Family Fund provides financial help, through one-off grants, to families on a limited income where a child under 16 is severely disabled.



Muscular Dystrophy UK

– here for everyone with muscle-wasting conditions

We're committed to improving the quality of life of people living with muscle-wasting conditions. We campaign to make sure treatments are available as soon as possible, and that everyone gets the healthcare, benefits and equipment they need and are entitled to.

If you'd like to get involved and make a positive difference, here's what you can do:

- ▶ campaign with us –
in your local area, in parliament, online
- ▶ meet other families at a Muscle Group near you
- ▶ when your child is a little older, he/she may want to join Trailblazers – our growing network of young disabled people who fight social injustices and campaign on issues that are important to them
- ▶ fundraise to support our work (**see p47**)
- ▶ help to raise awareness to ensure the fight to beat Duchenne muscular dystrophy gets the exposure and support it deserves. If you'd like to become a media volunteer, please contact our press team at press@muscular dystrophyuk.org

Research

Visit our website to keep up-to-date with the latest news on research topics relating to a range of muscle-wasting conditions. You can also find out information about patient registries and clinical trials.

Information resources

Muscular Dystrophy UK has lots of helpful resources for you and your child. All of our medical information resources are accredited by the Department of Health's Information Standard, which means they are clear, accurate, impartial, evidence-based and up-to-date:

Condition factsheets: which give detailed overviews of each muscle-wasting condition.

In case of an emergency: alert cards outline the vital and specific issues emergency healthcare professionals need to know.

Specialist care: our GP and physiotherapist training modules are designed for healthcare professionals who provide care to people living with muscle-wasting conditions.

To find out more, contact us at:
0800 652 6352 (Mon-Fri, 8.30am-6pm)
info@muscular dystrophyuk.org





Abbi Bennett, who has Ullrich congenital muscular dystrophy

How can we help beat muscle-wasting conditions?

There are lots of ways to support Muscular Dystrophy UK's work to beat muscle-wasting conditions. If you'd like to fundraise to accelerate the pace of research, or to support our care and information services, please get in touch with us.

You may wish to start your own Family Fund, which is a great way to fundraise for us as a family or group. We look after the admin and paperwork, and you can direct your funds to the areas that most interest you. Please contact our Regional Development team to find out more.

You may have contacts through your work, family or friends that could support our work by, for example, putting Muscular Dystrophy UK forward for a charity of the year partnership.

We hope this booklet has addressed some of your queries and has helped to reassure you. Much more material is available from Muscular Dystrophy UK when you are ready to read it.

Muscular Dystrophy UK is the charity bringing individuals, families and professionals together to beat muscle-wasting conditions. We're providing a range of services and opportunities to help people live as independently as possible.

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

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

0800 652 6352

info@muscular dystrophyuk.org

@MDUK_News

www.muscular dystrophyuk.org

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