



Guide to DMD for Employers

Contents	Page no.
Advice for employers	03
The implications of DMD for you as an employer, agency or client	04
DMD and its effects on children	05
The causes and treatments for DMD	07
How you can help	09
Employees' rights	011

Advice for employers

You'll be reading this guide because the young child of someone you work with has been diagnosed with Duchenne Muscular Dystrophy (DMD).

You've probably never heard of DMD. It's a rare genetic disease affecting only about 2,500 people in the UK.

That's why we've produced this guide for you. It will tell you about:

- The implications of DMD for you as an employer, agency or client
- DMD and its effects on children
- Ways that you may be able to support the parents at the time of diagnosis

As DMD parents ourselves, we know that supportive colleagues make a real difference to families.

Thank you for reading this guide.

Best wishes

Duchenne UK
and its parent network



The implications of DMD for you as an employer, agency or client

You may well feel a mixture of sympathy for the parents and concern about your own work. As DMD parents, we have found that most employers have both these responses.

We do understand that you've got a business to run or a team to manage. You'll have customers or colleagues who need you to deliver products, services or projects.

So, we'd like to start by answering your concerns.

What's the likely impact on work in the short term?

DMD is a serious illness – but it's not an emergency. It is a progressive illness so children do not experience the more severe effects for many years.

In the first few months after diagnosis, the parents will be experiencing real grief. They have to adjust to a difficult new reality for their child and themselves.

Most newly-diagnosed parents find that they need some time off and experience some distraction at work in the short term.

Also, from the time of diagnosis onwards, the parents will have to take their child to medical appointments. This will be the main impact on their work.

Will the parents be able to keep working?

Many parents of children with DMD work. At Duchenne UK, we know DMD families where:

- both parents work full-time
- both parents work part-time
- one parent works full-time and the other parent works part-time
- one parent works and the other parent stays home
- single parents who work full-time
- single parents who work part-time

If you can give your employee or supplier some time to adjust to the diagnosis, they should be able to continue working.



One in
3,500

boys born worldwide
will have DMD

Only 1 in
50M

girls will
have DMD

DMD and its effects on children

Duchenne Muscular Dystrophy (DMD) is a genetic disease that causes muscle weakness and wasting.

Children born with DMD cannot produce dystrophin, a protein that is vital for muscle strength and movement.

Dystrophin makes muscles stronger and more stable. It acts like a shock absorber and protects muscles from injury as they contract and relax. Without the shock absorber from dystrophin, muscles are weaker and more likely to get torn and damaged.

DMD almost always affects boys because of the way that genes are inherited. Very rarely, DMD can also affect a girl.

Duchenne
Muscular Dystrophy
is a genetic disease

How does DMD affect children?

DMD gradually weakens muscles so the child will become increasingly disabled:

- 2-5 years old – parents and doctors notice the first symptoms of DMD because the child has difficulty walking, running and getting up from the floor
- 5-8 years old – children with DMD are similar to other children their age, although they get tired more quickly
- 8-12 years old – children experience a steady decline in muscle strength and find walking increasingly difficult
- Early teens – many children are full-time wheelchair users
- Late teens – most young people lose the ability to move their arms and experience greater problems with their heart and lungs

Adults with DMD do not have shortened lives. It's unusual for someone with DMD to live beyond their 40s at the most. However, life expectancy and quality of life is increasing all the time because of advances in medical treatments.

More and more young people with DMD are able to lead independent lives and go to university, get jobs and live on their own with the support of a carer. Some men with DMD have also married and had children of their own.



The causes and treatments for DMD

What are the causes of DMD?

Duchenne muscular dystrophy is a genetic disease. It is caused by a mistake in the dystrophin gene that either occurred spontaneously in the child or was inherited from their mother.

Genes are very complicated and sometimes they go wrong. There's nothing that the parents could have done before conception or during pregnancy that would have prevented their child from developing DMD.

Is DMD contagious?

No, DMD is not contagious. It cannot be caught from another person.



Are there treatments or a cure for DMD?

Children with DMD use a range of treatments to protect their muscles and preserve their health. These treatments are improving the quality and length of life for children and adults living with DMD.

Currently, there is no cure for DMD. But there is an army of doctors, medical researchers and fundraisers who are working hard to develop a cure.

What will be done to help the child with DMD?

The child with DMD will be referred to a neuromuscular consultant at a hospital who will manage their treatment.

DMD is a complicated condition so the child will be treated by a team of healthcare specialists. These are likely to include their GP, physiotherapist, occupational therapist, orthotist (who will make splints for their ankles) and a speech therapist.

Most children with DMD take steroids. They are currently the only medicine which has been proven to slow down the progress of DMD. But they have side effects. This means that they have to be managed carefully by the child's doctors and parents.

Beware of advice on the internet and social media

Parents should only use the advice that they receive from the child's neuromuscular consultant, GP and other health care professionals.

It may seem kind to research DMD on the internet and social media for the parents. But there's a lot of mis-information and false hope out there. So, this is likely to stress them rather than help them.

How you can help

When we were newly-diagnosed parents, these were the things that helped us the most at work.

1. Be understanding and supportive

Newly-diagnosed mums and dads need support from the people they work for whether they are employees, zero-hours contract workers or self-employed.

People with good emotional support tend to cope better with difficult life situations, like DMD. If someone is isolated and under pressure, they are more likely to become anxious and depressed.

Some parents may want to talk about the diagnosis and what it means for their child and family. Others may not be ready to talk yet.

So, if you're able to be sensitive to their emotions and listen if they want to talk, you can make a big difference to the parents.

Be understanding and supportive

We know listening to people who are distressed isn't always easy, so we've got a few tips for you:

Do:

- Let the parents lead the conversation about DMD – everyone responds to the diagnosis in their own way.
- Ask them if they feel like talking if you're not sure
- Let them express their anger, grief and fears through talking and crying (crying can make us uncomfortable but it's an important part of processing our emotions)
- Express your own feelings about the news (without burdening the parents)
- Let them know you are there to support them

Try to avoid:

- Brushing aside their concerns by saying things like 'I'm sure everything will work out' – DMD is not that easy
- Telling them that 'everything happens for a reason'
- Accidentally putting pressure on them by saying things like 'You're very strong' or 'Just think positively and you'll manage'
- Tell them about someone else who has a medical condition and how it affected them (especially not 'well, it could be worse; at least your child doesn't have cancer')

2. Give them time and space to come to terms with the diagnosis

Immediately after the diagnosis, the parents will be in shock. They may need a few days off work to process the news.

For the first weeks after they return to work, they may need shorter days or permission to take a break during the day.

3. Give them some flexibility in their working arrangements

As well as coping with the diagnosis, the parents will need to attend appointments with their child's neuromuscular consultant, GP, physiotherapist and other healthcare professionals.

If you can offer them compassionate leave, flexible working hours or unpaid leave, it will be a great help.

4. Give them control over the way the news is communicated to their colleagues

When the parents are ready, ask them how they would like to share the diagnosis with colleagues.

You could offer to tell colleagues that the parents are dealing with a serious family matter, but that they're not ready to talk about it yet. You could explain that they need some time off work and understanding from others.

Do encourage them to talk to colleagues when they are ready. There's no need to keep this a secret.

You could also prepare colleagues by sharing the news for the parents so they don't have to explain DMD to multiple people. You could use the information in this guide to:

- tell them about DMD and its effects on the child
- provide them with listening tips so they can have supportive conversations with the parents
- tell them the parents will be relying on the advice of their neuromuscular consultant and may find it upsetting to be given advice from the internet or social media.

5. Don't ask them to make long-term decisions about their work or career

This is a serious situation, but it's not emergency. The parents do not need to radically reorganise their lives or work at the moment.

Please give them at least six to twelve months before asking them to make significant changes to their work. They'll be able to make better, more informed decisions then.

Employees' rights

If you are thinking through the working arrangements for a DMD parent, you may find it helpful to be aware of their statutory rights.

As DMD parents, we also encourage you to consider the benefits to your organisation of providing more support than just the statutory requirements.

Statutory rights

People's employment rights are protected by law if they are an employee or work on a zero-hours contract.

If they are an employee

The parents will have statutory employment rights as an employee.

They may also have contractual rights from their contract of employment with the business. So, it's worth checking the contract they signed when they joined your organisation.

The parents' statutory rights are:

- the right to take time off in emergencies, including the breakdown in care arrangements
- the right to be protected from discrimination because they are a carer
- the right to request flexible working which can include home working, part-time working and term-time working (if they have worked for your organisation for 26 weeks or more and they haven't already made a flexible working request in the last 12 months)
- the right to 18 weeks' unpaid parental leave (if they have worked for your organisation for at least one year)

You can find out more from Carers UK: <https://www.carersuk.org/help-and-advice/work-and-career>

If they work on a zero-hours contract

If the parents work on a zero-hours contract, they have the same statutory rights as an employed person.

Find out more:

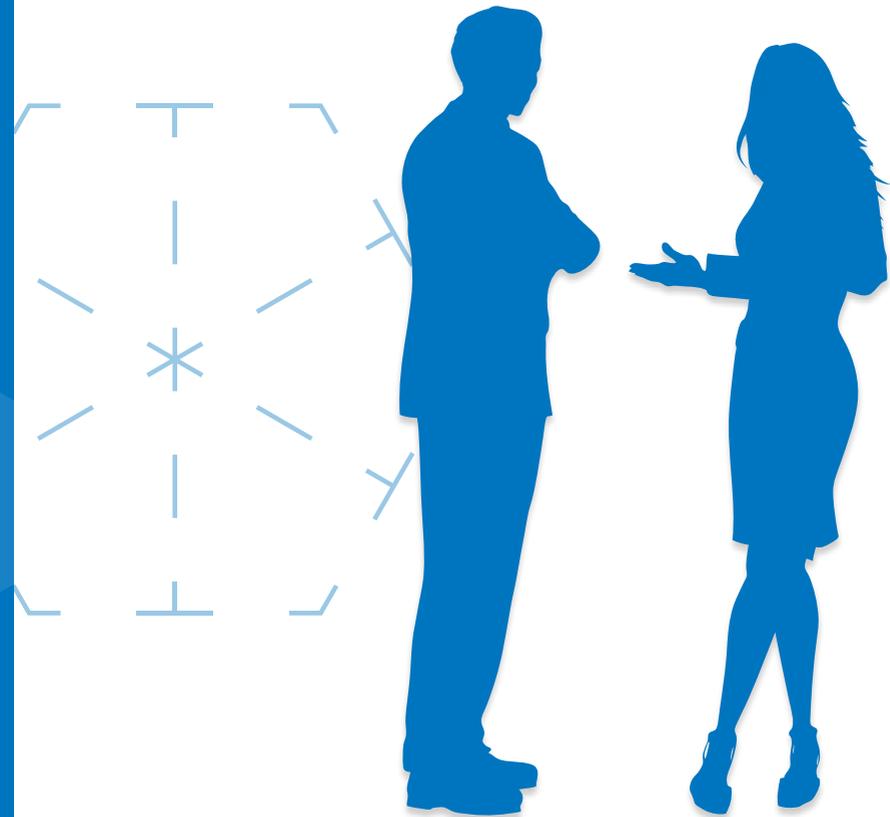
<https://www.gov.uk/government/publications/zero-hours-contracts-guidance-for-employers/zero-hours-contracts-guidance-for-employers>

Benefits of providing more support than their statutory rights

Organisations that treat their employees and agency workers with fairness, respect and support tend to have a more committed and engaged workforce.

Psychologists and organisational behaviour experts have researched into employees' perception of organisational support. The findings across many studies consistently show that greater support has significant benefits for organisations.¹

As DMD parents, we encourage you to be supportive to the newly-diagnosed parent in your workplace. Your support will make a big difference to them and will pay off for you as an employer or manager in the long-term.



¹ L Rhoades and R Eisenberger, 'Perceived Organizational Support: A Review of the Literature', *Journal of Applied Psychology*

