



05

Chapter 05 – Financial and Care Support

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In a nutshell — Financial and care support

1 You're entitled to support from the Government

The Government will pay you a Disability Living Allowance (DLA) because you are looking after a child with a disability. It has two parts – Care DLA and Mobility DLA.

If you are on a low income, you may also receive Carer's Allowance, Universal Credit or other benefits.

When you receive the high rate Mobility DLA, you will also be eligible for a motability car from the Government or be exempt from road tax for your own car.

2 You're entitled to support from your local authority

By law, your local authority must provide health, education and social services to children with disabilities. You'll be entitled to direct payments, short breaks and disabled facilities grants as part of your social care support. You may also be able to get a reduction in your council tax.

You might be able to apply for grants from charities as well – especially if you need equipment for your child.

3 Your child will need assessments for social care and occupational therapy

All children with disabilities are entitled to an assessment of their social care needs by their local authority. This will probably be done by your local Children with Disabilities team.

If you are on a low income, you may receive Carer's Allowance, Universal Credit or other benefits.



You'll be entitled to direct payments from your local authority.



Ask your employer for time to think through what you need.



An occupational therapist (OT) will assess your family home to see if it's suitable for your child for the long-term and help you apply for a Disabled Facilities Grant so that it can be adapted to meet your child's needs.

If your home cannot be adapted, they can give you a medical referral for priority social housing. They will also refer your child to the NHS wheelchair services.

4 You can get help accessing financial and care support

You can get advice about benefits from your local authority and charities which support people with disabilities and those on low incomes.

5 Your work is important too

Your child's diagnosis will have an impact on your work as well as your family life.

Ask your employer (or clients if you are self-employed) for time to think through what you need over the long-term.

Try to avoid making big changes to your work in the next few weeks or months.

Important note

The information in this chapter was correct at the time of writing in 2018. But benefits change frequently. So, we recommend that you look up the most up-to-date information on the internet.

You're entitled to financial and care support

As a parent who is bringing up a child with a disability, you are entitled to support from the Government and your local authority. If you are on a low income, you'll get more support.

This chapter will give you an overview of the support you can get.

We've also produced 'A Guide to Financial and Care Support for DMD Families'. It is a more detailed version of the information in this chapter. You can download it from our website at:

www.duchenneuk.org/resourcesforparents

Financial support from the Government

The Government has a range of benefits which could help you.

You will have to apply for the benefits (except for child benefit). You can find information about eligibility and application processes for each benefit on the internet.

Our 'Guide to Financial and Care Support for DMD Families' has advice about how to apply for these benefits.

Carer's Allowance – www.gov.uk/carers-allowance

You are eligible for Carer's Allowance if your child receives the middle or high level of DLA Care Allowance and you care for them for 35 hours or more per week.

There are no age restrictions on the child who is being cared for.

Disability Living Allowance (DLA)

www.gov.uk/disability-living-allowance-children

Disability Living Allowance (DLA) is given to people who are looking after a child under 16 who has difficulty walking or needs much more looking after than a child of the same age who doesn't have a disability.

You can claim DLA for a child as long as you look after them as if you're their parent. So, you could be their step-parent, guardian, grandparent, foster-parent or older sibling.

There are two types of DLA:

- **Care DLA** – Three rates, depending on how much your child needs looking after
- **Mobility DLA** – Two rates depending on how much help your child needs getting about

The rate of DLA that your child receives depends entirely on their present day-to-day care needs. Their diagnosis and future needs will not be taken into account. Many DMD families do receive DLA payments from diagnosis because their child already has significant needs.



So, people who are caring for babies and toddlers are eligible too.

Each week that you get Carer's Allowance, you'll automatically get National Insurance credits too.

You may also be eligible for additional support from your local authority, reduced Council Tax, Income Support (if you're on a low income), income-based Employment and Support Allowance (if you can't work because of a medical condition or disability) and Pension Credit (if you're over working age).

Universal Credit – www.gov.uk/universal-credit

You are eligible to claim Universal Credit if you are caring for a disabled child or young person.

If you receive Universal Credit, you may also be eligible for free school meals, dental work, prescriptions and hospital fares.

Child Benefit – www.gov.uk/child-benefit

You should already be receiving child benefit because it is paid to everyone who is responsible for a child under 16 in the UK.

Other benefits

You may also be eligible for more benefits from the Government, including:

- **Motability Scheme (www.motability.co.uk)** – Leases cars, scooters and powered wheelchairs to people with disabilities in exchange for their mobility allowance
- **Road Tax Exemption (<https://www.gov.uk/financial-help-disabled/vehicles-and-transport>)** – Available to people who own their own car and receive the high rate of the mobility Disability Living Allowance (DLA)
- **VAT exemptions (www.gov.uk/financial-help-disabled/vat-relief)** – Wheelchairs, adapted beds, hoists, ramps, stair lifts, and adaptations for your car and medical appliances are all exempt from VAT. (The current rate of VAT is 20%)
- **Cold weather payments (www.gov.uk/cold-weather-payment)** – Available to people who receive Universal Credit and paid when the local weather is zero degrees Celsius or below for seven consecutive days
- **Benefits calculator (<https://www.gov.uk/benefits-calculators>)** – You can use a benefits calculator to see if you are eligible for any other support



Support from your local authority

By law, your local authority must provide services and support to your child and you.

The Local Offer in your area –
Google ‘local offer’ + [the name of your local authority]

The local offer is a list of all the services provided by your local authority for children and young people (0 - 25 years old) who have a disability.

Your local authority has a statutory duty to provide a local offer to residents. It must cover health, education and social services. This includes special education provision, short break services, leisure activities and childcare for disabled children.

Direct payments to parents – www.gov.uk/apply-direct-payments

Direct payments are payments that parents receive to buy social care, health or education services themselves, rather than using the local authority’s services.

You can also use direct payments for equipment.

For example, parents might use direct payments to pay for a short break which they arrange themselves rather than using the short break services which their local authority provides.

They are part of your local authority’s care package for your child. They are not a benefit (like the Disability Living Allowance or the Carer’s Allowance).

Your local authority will assess your child’s needs and agree an outcome for your child with you (such as accessing leisure activities or seeing friends and family).

Then, they’ll pay for a service that achieves this outcome (such as paying for swimming lessons or paying for a personal assistant to play sport with your child). But the direct payment cannot be used to pay for something that achieves a different outcome (such as buying a new washing machine).

You can choose to take a mix of direct payments and local authority services. Or you can choose to take only your local authority’s services.



Short breaks

Short break services provide care for children by someone other than their family or school.

Local authorities offer different types of short break services, ranging from a few hours up to a week. They may also include befriending services where charities introduce families with children who have disabilities to each other or volunteers.

Parents can also arrange their own short break services using their direct payments.

Disabled Facilities Grant for making adaptations to your home – www.gov.uk/disabled-facilities-grants

If you need to adapt your home to make it suitable for your child, your local authority may give you a disabled facilities grant to pay for the building work.

For example, you may need to install a lift or a downstairs bathroom in your house. (You can find more information about adaptations in the ‘Your Home’ chapter.)

Your grant must be approved before you begin any building works, and before asking an architect to design the adaptations to your house or applying for planning permission from your local authority. Grants cannot be awarded after you have begun work.

The Social Care Occupational Therapist (OT) at your local authority will assess your home and work out what adaptations you need to make your house accessible for your child.

Social housing

Your child’s OT can also give you a medical referral for priority social housing if your home cannot be adapted to meet their long-term needs.

Council Tax Reduction – www.gov.uk/apply-council-tax-reduction

You may be eligible for reduced council tax if you have a low income, claim benefits or have particular adaptations to your home. Your bill could be reduced by up to 100%. It doesn’t matter if you own your home or rent it privately.

NHS Wheelchair Services

When your child’s needs have changed significantly, ask their OT to refer them to the NHS wheelchair services. Electric wheelchairs are provided by the NHS, not your local authority.

Financial support from charities

You may also be able to get financial support, including grants for family breaks and equipment, from charities such as:

Family Fund

www.familyfund.org.uk

Promise Dreams

www.promisedreams.co.uk

Social care assessments

All children with disabilities are entitled to an assessment of their social care needs by their local authority.

This is because they are considered to be in need. They do not have to be at risk of abuse or neglect.

Your child's assessment will be used to work out which social services they need from the local authority.

What happens during an assessment?

Different local authorities use different assessment processes. Many use the Common Assessment Framework (CAF), the Early Help Assessment (EHA) or social care assessments.

The social worker or other agreed professional will use the assessment to build up a picture of your child's current needs and the family's current ability to meet their needs. They will not predict their future needs.

Your child

is entitled to an assessment

The social worker

will assess their current needs

During the assessment, the social worker will gather information from your child and you and your partner. They will probably want to meet at your family home so they can observe your child's social skills and social environment. They may also wish to see your child at school and talk to their teacher, GP, school nurse and/or neuromuscular consultant. Your child won't have to do any tests.

How do I get an assessment for my child?

Most local authorities have a specialist social worker or team for children with disabilities.

You can request an assessment for your child yourself by telephoning the social care department at your local authority. You can also be referred by your child's GP or their teacher.

Your child will be entitled to new assessments as their needs change. Social care services understand that DMD is a progressive illness.

How soon should I get a referral?

Social care exists to prevent problems for people, as well as solve them. You need to have a defined need to access social services. But you don't need to be in crisis.

So, contact social services when your child's needs are beginning to change and your family is finding it increasingly difficult to meet them. Don't wait until you feel overwhelmed.

Some social services teams are very busy. This can cause delays so it's always better to contact them sooner rather than later.

The social worker may wish to see your child at school and talk to their teacher, GP, school nurse and/or neuromuscular consultant.



Occupational therapy

Occupational therapists (OTs) are the people who will assess your family home to see if it's suitable for your child for the long-term. And they will help you apply for a Disabled Facilities Grant.

If your home cannot be adapted to meet your child's needs, your child's OT can give you a medical referral for priority social housing.

Confusingly, there are two different services which are both called 'occupational therapy':

- **Social care occupational therapy** – For aids, equipment and adaptations in the home (including referrals to wheelchair services)
- **Healthcare occupational therapy** – For bodily functionality (such as help with walking or using pencils)

Some local authorities have combined the two functions into one service. Some haven't.

How do occupational therapists assess your child's needs?

The process is the same for people who live in their own homes, rented homes and social housing.

They will assess your home and recommend the adaptations that you need to make so it's suitable for your child's current and future needs. They can also advise you if you need to move home so that you can choose a new place that it is suitable (or could be adapted so it's suitable).

They will help you:

- **If you own your home** – Apply for a disabled facilities grant for making adaptations
- **If you rent your home:**
 - Apply for a disabled facilities grant for making adaptations if your landlord is willing for the changes to be made
 - Provide a medical referral for priority social housing if you can't stay in rented accommodation

If you live in social housing

Provide a medical referral for a bungalow or other suitable housing; or help you apply for a disabled facilities grant for your current home.

Your child's OT can give you a medical referral for priority social housing

Get a referral sooner rather than later

We encourage you to get a referral to an occupational therapist as soon as you can – even if you think your child won't need adaptations to your home for a few years.

The process for applying for grants and making adaptations or being moved to a suitable council house can take one or two years – or even longer.

You can refer yourself to the occupational therapist team at your local authority. Or you can ask your child's social worker to refer you.

Getting help accessing financial and care support

We recommend that you contact your local authority soon after your child is diagnosed with DMD.

Local authorities vary. Some are more helpful and organised than others.

So, don't wait until you are struggling. Contact them early so you have time to get everything set up properly.

The people in your child's care team – such as their social worker, occupational therapist, physiotherapist or a specialist nurse - can help you access support.

They'll assess your eligibility and arrange direct payments and other types of support. They can also help you to navigate the benefits system.

Look out for people who are helpful and seem to know how the system works. Then, ask them if they will give you advice.

Look out for people who are helpful and know the system

Some authorities are more helpful and organised than others



SENDIASS (Special Educational Needs and Disability Information Advice and Support Service)

Every local authority has a SENDIASS service for the parents and carers of young people (0-25 years old) with special educational needs or disabilities, as well as the young people themselves.

Local authorities must provide this service by law.

Your local SENDIASS offers free, confidential and impartial advice and support. It is run at arms-length from the local authority itself. They will work with you, your child and professional staff to provide the best possible support.

They can provide you with advice and support on:

- Education, Health and Care Plans (EHCPs) and the assessments for them
- Social care and health matters

They can also help you to:

- Understand complicated documents and reports
- Complete paperwork
- Attend meetings with you to ensure your views are heard

You can find your local SENDIASS service through your local authority or on Google.



Charities

These charities have benefits calculators and offer advice about the benefits which you can receive from the Government and your local authority:

Turn to Us
www.turn2us.org.uk

EntitledTo
www.entitledto.co.uk

Policy in Practice
www.policyinpractice.co.uk

Citizens' Advice Bureau
www.citizensadvice.org.uk

You may also be able to get advice about benefits, as well as many other matters, from:

Contact a Family
www.contact.org.uk
- a national charity which supports families who have children with disabilities.

Your local independent living centres (search on Google for your local

Parents' work

Your child's diagnosis is likely to have an impact on your work, as well as your family life.

But you don't need to make any big decisions about your current work or your career at the moment. We encourage you to give yourself at least six to twelve months to come to terms with your child's diagnosis and think about what will be best for your family.

Our 'A Guide to DMD and Parents' Work' can help you think through what to do and how to talk about DMD with your manager and colleagues.

We encourage you to give yourself at least six to twelve months to come to terms with your child's diagnosis and think about what will be best for your family.

Download

You can download 'A Guide to DMD and Parents' Work' from our website at:

www.duchenneuk.org/resourcesforparents



