



# INFORMATION & SUPPORT PACK FOR SCHOOLS

**It is important for children and young people living with Duchenne muscular dystrophy to have the right support at school, but sometimes it's hard for parents and teachers to know where to begin.**



**Foreword by Victoria Young,  
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Support Officer at Action Duchenne,  
Duchenne Parent, NVQ L4 in  
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People and those who care for them.**

Before my son was diagnosed with Duchenne Muscular Dystrophy and ASD/ADHD back in 2021, I was just a Mum to two healthy children. Life was simple, trauma free and I'd experienced little discrimination. How life has changed since diagnosis, and the amount of tears I have cried out of frustration, trauma and loss due to the lack of understanding I have received at times.

How we wish as 'children of extra need parents' that we didn't have to do so many extra things just to make sure our children are healthy and supported. People say every parent is busy - and that's very true. But I have been just one of those 'every parents' - and life was much much easier for myself and my family when my husband and I were classed as one.

When you are a parent of a child with a life limiting illness like Duchenne you are having to battle and fight for your child and your family to access the same things as everyone else. Sadly this paints a bleak picture on what life will be like for our child as an adult. A non stop 'fight'.

Our Support Team here at Action Duchenne have daily contact with parents and carers struggling with the above. We have created this information and support pack for schools with pupils living with Duchenne, to help provide a good understanding of what pupils with this complex condition, and their families need.

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# WHAT IS DUCHENNE?

Duchenne muscular dystrophy is a rare, muscle wasting condition which occurs mainly in boys and is often diagnosed around the age of 2 to 4. Although there is no cure for Duchenne, improvements in standards of care mean that the prognosis for people living with the condition is better than it has been in the past.

You are likely to hear people mention life-expectancy for people living with Duchenne. You will see numbers ranging from 25 to 50, with 30 probably being the most common. But the truth is that nobody knows the “right” number.

It is important to remember that each person is different and has a unique physical makeup. Your child will experience Duchenne differently to others and giving you a definitive ‘across the board’ life

expectancy for your child is impossible and unfair, particularly as standards of care and therefore life expectancy are improving all the time.

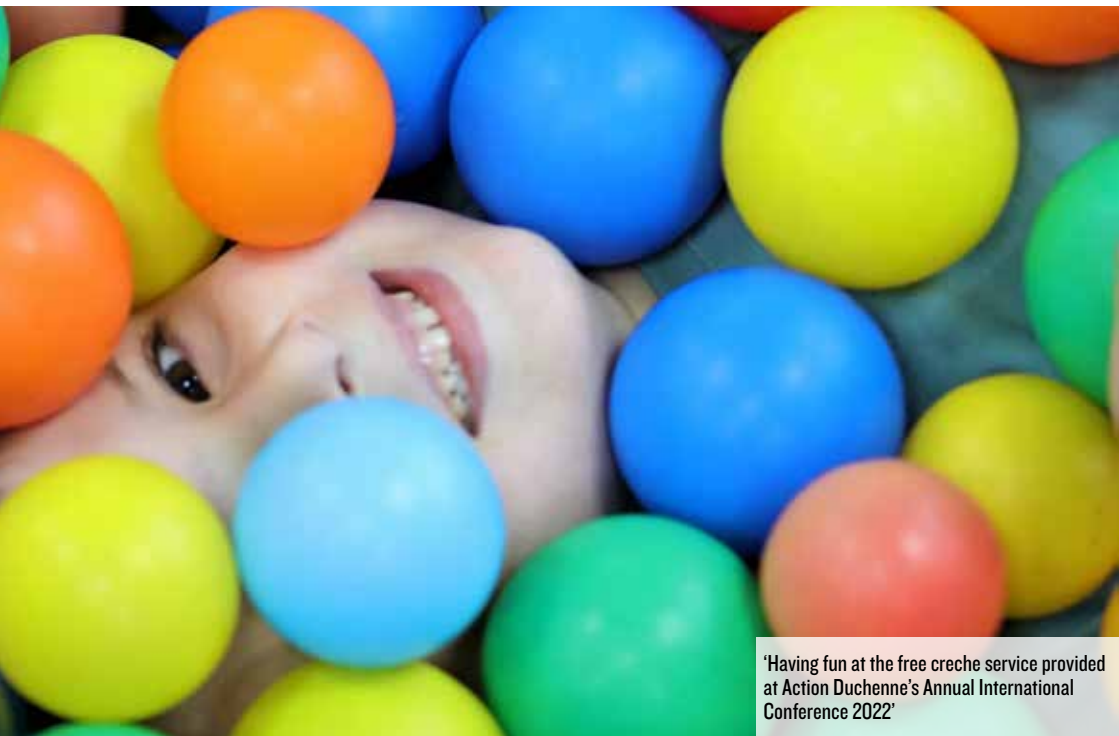
Girls can also have Duchenne, but very rarely. Girls and women can also be [manifesting carriers](#), meaning they have mild symptoms either physically or learning difficulties.

If you want to gain more of an understanding of what it means to be a newly diagnosed family, we highly recommend you watch recordings from our newly diagnosed family information event.

[Adjusting to diagnosis](#)

[Empowering you to make informed decisions and building your team](#)

[Practical tips, research and clinical trials](#)



'Having fun at the free creche service provided at Action Duchenne's Annual International Conference 2022'

# WHAT PARENTS NEED YOU TO KNOW

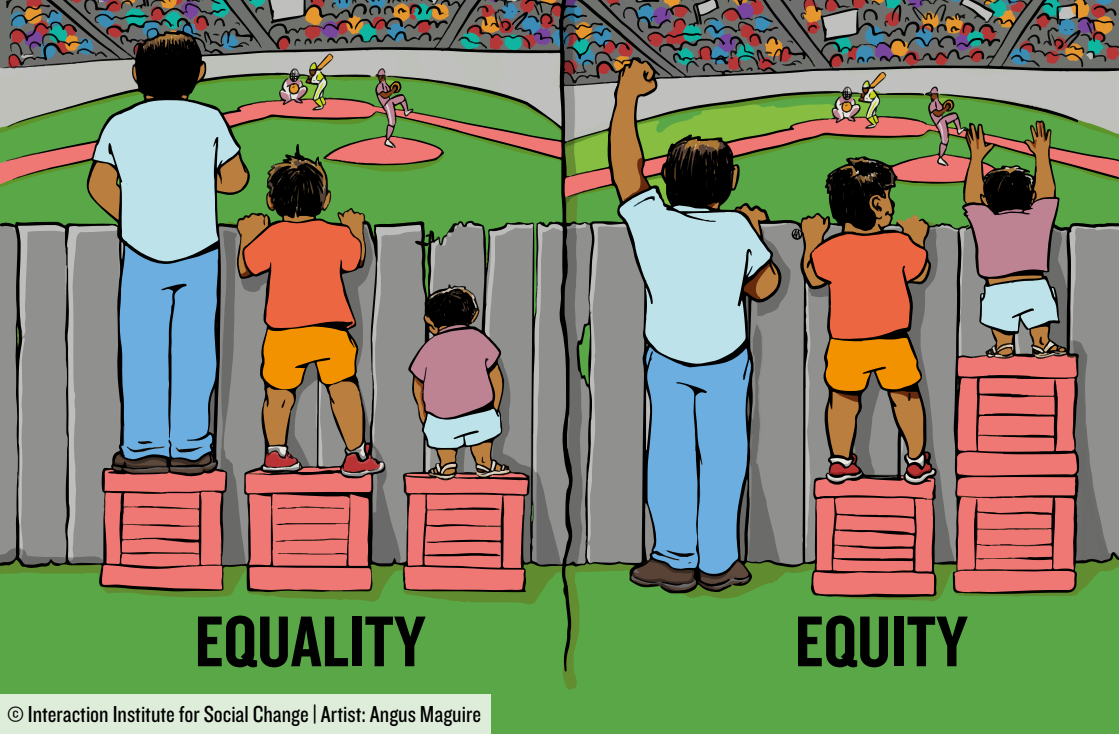
Parents of children with complex additional needs and life limiting illnesses need professionals to understand:

- that they may have experienced trauma from diagnosis
- they experience many secondary traumas from the continued fight for services and support
- their need to provide their children, and family, with a dignified experience of everyday life
- their need to be able to have open conversations about what is working and what is not working for them or their children
- homework is not always on their priority list, after school many parent carers have to take their children to therapies or do stretches with them

## WHAT DOES GOOD SUPPORT LOOK LIKE?

**‘High quality teaching that is differentiated and personalised will meet the individual needs of the majority of children and young people. Some children and young people need educational provision that is additional to or different from this. This is special educational provision under Section 21 of the Children and Families Act 2014. Schools and colleges must use their best endeavours to ensure that such provision is made for those who need it. Special educational provision is underpinned by high quality teaching and is compromised by anything less.’**

**~ SEND Code of Practice 2015**



# EQUALITY

# EQUITY

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Remember that despite their diagnosis, a child living with Duchenne muscular dystrophy is just like any other child. They want to feel:

**SAFE & SECURE**

**LIKED AND LOVED**

**LISTENED TO**

**UNDERSTOOD AND ACKNOWLEDGED**

**RESPECTED AND VALUED**

**ENCOURAGED AND SUPPORTED**

**ABLE TO EXPRESS THEIR NEEDS FOR HELP AND SUPPORT**

**SAFE TO EXPRESS STRONG EMOTIONS & FEELINGS**

**THAT IT IS OKAY TO MAKE MISTAKES, KNOWING THEY WILL BE GUIDED WITH PATIENCE AND TOLERANCE, NOT PUNISHED**

**PROUD OF AND CONNECTED TO THEIR IDENTITY**

It's important that who the child is, what they like and dislike, what they are good at and what matters the most to them is recorded and forms the basis of all support going forward.

# FIRST STEPS

Read and watch the support resources in the [Expert Resources and Training](#) section. Gaining as much knowledge as you can about Duchenne will mean the world to the family and ultimately help you be able to provide the appropriate support. You can also join our [Schools Support Group](#) over on Facebook.

Meet with the family, include siblings that attend your school and let them know that you will do all you can to support them. Children living with Duchenne between 0-25 years old need to have an [Education, Health and Care Plan \(EHC or EHCP\)](#) needs assessment and a plan in place as soon as possible, if they do not have one already.

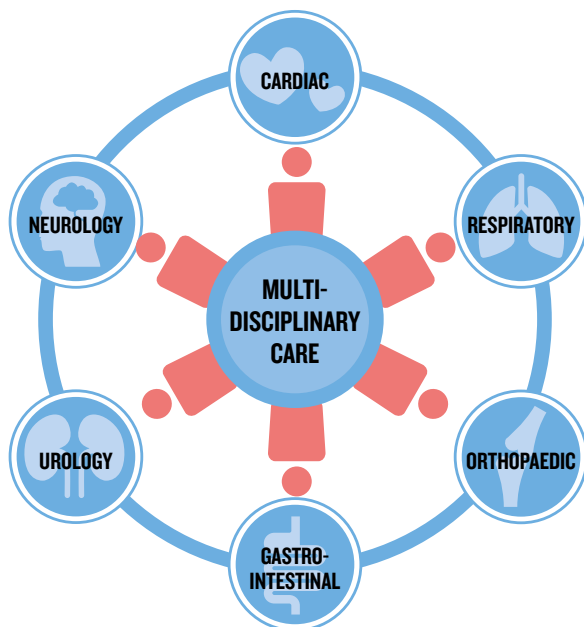
An EHCP ensures children living with Duchenne have access to the specialist support services they need to meet their needs AND plays a vital role in helping them take part and achieve what they aspire to do or be.

It takes a large multi-disciplinary team of clinicians to care for a child with Duchenne muscular dystrophy with a focus on Cardiac, Respiratory, Orthopaedic, Gastrointestinal, Urology, Neurology.

Children with Duchenne will require additional support above the SEND register for many reasons. In particular:

- They have more difficulties with sitting and standing comfortably and safely without appropriate seating or standing support
- Their hand function will be weaker than other children and they will require support to help them with completing and recording their work
- They have more falls and loss of balance. Activities need to be adapted where possible so the child is included fully
- To be included in PE they need additional support and equipment to take part
- Duchenne is associated with increased rates of autism spectrum disorder, attention deficit hyperactivity disorder, obsessive compulsive disorder and anxiety
- 30% of people with Duchenne have cognitive impairment at presentation
- Their concentration and behaviour can be affected due to the complexity of their neuromuscular condition
- They will require additional emotional support for their mental health, well being and self esteem
- Specialist toileting support and facilities will be required as the child gets older
- Staff will need to have manual handling training to support the pupil safely and protect themselves from injury

Children living with Duchenne should have an Occupational Therapist and a Physiotherapist who are often independent from school and employed by local hospital trusts, but this may vary across the country. Occupational Therapists will work with children to help them develop functional skills for everyday life in the areas of self-care, life skills, school work and play. Physiotherapists work alongside school staff, specialist teachers and families to plan delivery and evaluate high quality programmes to promote the physical management of pupils and to ensure that all pupils reach their physical potential, either through assessment, individual therapy, group work or other therapies. They collaborate with all areas in school to improve practice and raise pupil achievement.



## SPECIALIST TEACHERS

They may also have one or several 'Specialist Teachers' who are often independent from school and employed by local hospital trusts but this may vary across the country. If the child has an EHCP, or is in the process of getting one, any specialist teachers needed will be identified within this plan. They are trained in a specific area of SEND and are experts in identifying and addressing the needs within their specialism.

Specialisms include: profound and multiple learning difficulties (PMLD), Specific learning difficulties (SpLD), Physical impairment, multi-sensory impairment, hearing impairment, visual impairment, social, emotional and mental health (SEMH), Speech, language and communication needs (SLT), Attention deficit hyperactivity disorder (ADHD), Autistic spectrum conditions (ASC), English as an additional language (EAL).

The input of these professionals will be vital, so taking the time to understand what support they are putting in place and the methods they are using to help your pupil is key to informing your own knowledge and supporting them.





Children having lots of fun at the free Creche service, provided at Action Duchenne's Annual International Conference 2022

## IN THE CLASSROOM

In Primary School the main considerations for a child living with Duchenne will be around mobility and independence. In Secondary School considerations increase and become focussed around care needs, independence, fatigue, peer support and transition to secondary school.

Children living with Duchenne will:

- have good days and bad days, the condition can be variable
- tire easily and it is important to monitor fatigue and look for any patterns
- fall over more than their peers, if they are still ambulant (walking). All spaces in the school should be clutter free and a risk assessment completed, the same applies if the child is using a wheelchair
- require an [Individual healthcare plan](#)
- need extra time to complete tasks or tests/examinations. Some may also need a scribe
- Have their physical well being affected by tiredness and viruses or minor infections such as colds and coughs

A note on handling a child with Duchenne. Children and young adults will have increasing weakness in the shoulder girdle muscles, they should not be pulled up by the hands or from under the arms. All staff should be trained in moving and handling.





'Lego fun at our Action Duchenne's Annual International Conference'

## WHEELCHAIR USE

The age that children with Duchenne need to use a wheelchair varies, this is mainly because children living with Duchenne have different gene mutations to each other and are in themselves individuals - this means progression of the condition varies greatly.

It is very important to support the child to use their wheelchair in school if they need, or request, to use it in school. For many children living with Duchenne using their wheelchairs while they can still walk is a great way to adjust to using one, socialising and playing in one. It's also great for other children in the school to get used to seeing their peer in a wheelchair.

The child's Occupational Therapist will be able to help you with sorting ramps and extra equipment needed to ensure your school is accessible to them. Making a space accessible is about working together and problem solving, very few schools are built to be wheelchair accessible.

# EFFECTS OF DUCHENNE AND MEDICATION

Duchenne has an impact on a child's emotions and wellbeing, what they eat and drink, their mood and their behaviour. Many children also take a high dose of [corticosteroids](#) which can affect these factors more.



**Appetite** - Ensure that the child has access to healthy snacks, like fruit and vegetables, and also that they drink plenty throughout the day. Children with Duchenne get 'hangry' - and this is not a good place for them to be if they are required to concentrate and complete tasks.



**Mood** - The mental health of children living with Duchenne, and supporting them to cope with this is really important. The social consequences of living with Duchenne have an impact on children's quality of life, for example losing the ability to walk or move like you once used to, can lead to psychological effects and cause social isolation.



**Behaviour** - The child should not be made to feel 'blamed' or 'at fault' for things that they simply cannot control at this time. This does not mean letting them 'get away with it' but working closely with the child and parents to support them through this difficult time. The focus should be on positive reinforcement, rewarding the behaviour you want to see more often and if necessary offering extra privileges or tangible rewards.

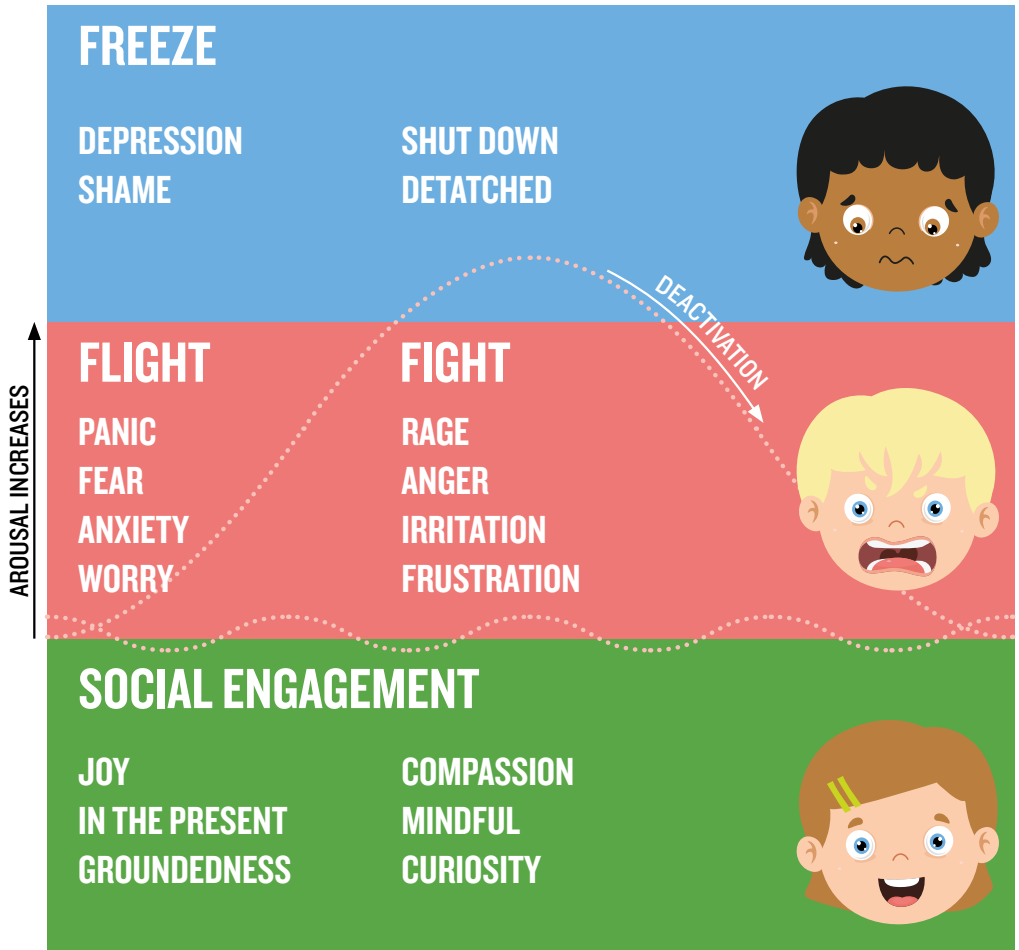
If the child is really struggling with their behaviour it is important to have regular communication with parents. It is very important to ensure you are empathetic and realise that behaviour difficulties are also very stressful for parents and it can be a lot to take to constantly hear negative feedback about their child.

# FRIENDSHIPS AND SOCIAL COMMUNICATION

Children living with Duchenne very quickly become aware that they move differently to their peers. Many will have to sit in specialist seating that is different from their peers. They may have to leave lessons for therapies or 'movement breaks', when their peers don't have to. They will struggle to keep up with their friends running or playing football in the playground. This can result in feeling socially isolated.

A child living with Duchenne may also have a diagnosis of ASD or ADHD, or both. This means they will find social communication tricky.

It is really important to talk to other children about Duchenne and how it affects people. Please [contact our support team](#) for advice.



# PSYCHOSOCIAL ADJUSTMENT

All children living with Duchenne are all very different, and a decline in mobility is very personally experienced by them and their families.

It's completely normal for children living with Duchenne to struggle to come to terms with the changes they experience living with Duchenne. We know that around the ages from 8 to 10 years is when children living with Duchenne begin to realise some of the consequences of the condition.

We have learnt from supporting families that it helps if the children can openly discuss their worries and frustrations with people they trust without the fear of upsetting them. So for teachers and support staff it's important the child knows they can talk to you.

We know it is always really helpful to focus on maintaining self esteem and sense of worth. For example, there are many activities and sports that wheelchair users can do, and there is an opportunity to find new ways of doing things together.

Allowing and supporting children to problem solve during this time is a great way to build their self esteem, and something children with Duchenne often end up being particularly good at.

Many children and young people living with Duchenne can struggle with friendships as they adjust to their new normal, therefore parents and teachers need to encourage social relationships and social support.

## SIBLINGS

You may have siblings of a child living with Duchenne in your school. They will also need your support, as they are trying to process and understand what is happening as well as cope with their own emotions.

Siblings need a space to be themselves, and have time away from witnessing their parents take on a lot of caring duties for their sibling living with Duchenne.

Siblings of children with Duchenne may be more tired than their peers and need more emotional support. Pastoral care should be put in place for Duchenne siblings that is agreed between parents and teachers.



# OUR EXPERT RESOURCES & TRAINING

Below are our most requested resources to help Duchenne families and their teams of professionals to put the right support in place at school. If you have any questions or need further support, please contact us via [info@actionduchenne.org](mailto:info@actionduchenne.org).

[We are Action Duchenne](#)

[Duchenne Explained](#)

[Takin' Charge](#)

[Standards of Care](#)

[Webinar - Talking with children about Duchenne](#)

[Talking to children about Duchenne leaflet](#)

[Webinar - Learning and Behaviour in Duchenne](#)

[Webinar: Understanding the psychology of learning and behaviour in Duchenne muscular dystrophy](#)

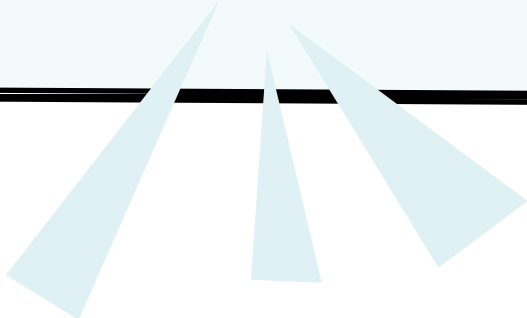
[Physio webinars](#)

[A step by step guide to the EHCP process](#)

[Inclusive PE Lessons](#)

[Transition from Primary to Secondary - Turning Point](#)

[Full list of all our webinars](#)



# OTHER USEFUL RESOURCES

Below are our most requested resources to help Duchenne families and their teams of professionals to put the right support in place at school. If you have any questions or need further support, please contact us via [info@actionduchenne.org](mailto:info@actionduchenne.org).

[Special Education Resource Centre Resources](#)

[Twinkl Inclusion Teaching Resources](#)

[Making friends - supporting your autistic child](#)

[How to play with your disabled child](#)

[Autism, Sport and Physical Activity](#)

[ADHD Fact Sheet](#)

[How to rest your brain with 'green time'](#)

[Learning and Behaviour in Duchenne Muscular Dystrophy Parent Project MD](#)

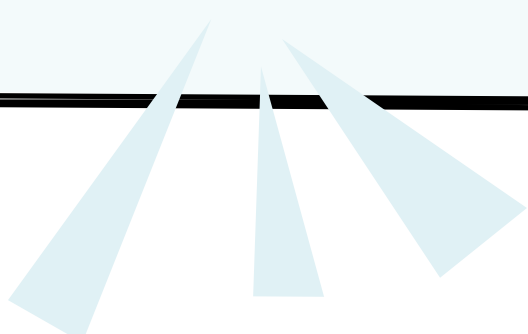
[MDUK Inclusive Education for Children with Muscle Wasting Conditions](#)

[Duchenne and the brain](#)

[Positive Reinforcement](#)

[Wheelchair skills](#)

[SEN Resources - Witherslack Group](#)



# KEY LAWS AND GUIDELINES

[Care Act](#)

[Equality Act](#)

[Children and Families Act](#)

[Education Act](#)

[Special Educational Needs and Disability Regulations](#)

[Special Educational Needs \(Personal Budgets\) Regulations](#)

[Supporting pupils at school with medical conditions](#)

[Disability Rights](#)

[Education Health and Care Plans](#)

[SEND Code of Practice](#)

[School Attendance - Guidance for maintained schools, academies, independent schools and local authorities \(page p19 reduced timetable\)](#)



# CHECKLIST FOR EYFS AND KEY STAGES 1-4

## EYFS TO KEY STAGE 1

- Consider applying for a [Statutory Assessment](#)
- Apply for an [Education, Health and Care Plan](#)
- [Inclusive play time and PE lessons](#)
- Consider using disabled toilet - rails and greater space are often beneficial
- Monitor stamina and fatigue, observe and record patterns
- Introduce keyboard skills

## KEY STAGE 2

- [Education, Health and Care Plan](#) in place and may need reviewing or updating for any decline mobility
- Using wheelchair more in school and introducing [wheelchair skills](#)
- Disability awareness with peers
- Greater input from Physio, OT
- Staff training - 'Moving and Handling' techniques
- Support for recording work - using ICT, scribe etc
- [Inclusive PE lessons](#)
- Greater and more focussed input to support emotional needs and behaviour
- Support with transition to secondary school

## KEY STAGE 3 TO 4

- Check with your local councils about funding available to create a wheelchair friendly space for your pupils
- [Inclusive PE lessons](#) and access to [wheelchair sport](#)
- Access to supportive toileting space to allow for use of hoist, be sensitive to care needs
- Staff training - "Moving and Handling" techniques
- Support for motor skills in practical lessons e.g. DT, art
- Access to ICT - consider access to smaller lightweight Netbooks
- Extra time in examinations / access to scribe
- Giving pupils an effective way of catching up on any missed work
- Support with transition to further education, including careers guidance

# ABOUT ACTION DUCHENNE

**ACTION DUCHENNE HAS  
A VERY CLEAR VISION:  
A WORLD WHERE LIVES ARE  
NO LONGER LIMITED BY DUCHENNE  
MUSCULAR DYSTROPHY**



- Supporting the Duchenne community to bring people together to share experiences and learn from each other
- Working with the NHS to improve care and provide families with the earliest possible access to approved medicines
- Funding innovative and promising therapeutic research opportunities for people living with Duchenne
- Helping to create an inclusive society where everybody is equal and disability is accepted

Action Duchenne is an independent charity led by a volunteer Board of Trustees. Our expertise is driven by the lived experience of our team: half of our staff and Trustees have a direct connection to Duchenne.

We combine that experience with expertise from across business, research and charity sectors to give us an unparalleled ability to deliver complex projects efficiently and successfully. We are truly experts in the Duchenne field.



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