

**Muscular  
Dystrophy UK**

Fighting muscle-wasting conditions



# **Inclusive education for children with muscle-wasting conditions: a guide for schools and parents**

Third edition



# Developing this guide

This original publication, sponsored by a grant from the Department for Education, Special Educational Needs Small Programmes Fund, has been further developed by a working party co-ordinated by Muscular Dystrophy UK.

The working party comprised health, education and care professionals, parents, and staff from specialist voluntary organisations. Young people with muscle-wasting conditions were also interviewed and their experiences at school have been incorporated into these guidelines.

Material in this publication can also be found on the Muscular Dystrophy UK website, [www.muscular dystrophyuk.org](http://www.muscular dystrophyuk.org), which is linked to the website of the British Educational Communications and Technology Agency (BECTA), [www.becta.org.uk](http://www.becta.org.uk). Worksheets and other materials are downloadable and available for use, copyright free.

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# Acknowledgements

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The Department for Education funded the original project, and have reviewed this third edition. Muscular Dystrophy UK would like to thank the Department for Education, as well as all the teachers, parents and young people who so willingly gave their time and effort to make this publication possible.

It is hoped that this will empower other schools to improve the lives and educational experiences of pupils with muscle-wasting conditions, enabling them to reach their full potential.

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## About Muscular Dystrophy UK

"I have found this to be an extremely informative and helpful document that I wish I had read two years ago! Having a child with a disability is a huge task for a mainstream primary school, and a huge learning curve.

"Schools can only be truly inclusive for children with a disability when they have the knowledge to start with, as well as the continuing health and social care support and advice as the child's needs change. It is however a partnership with all of us working together, putting the health and wellbeing of the child at the centre, and schools find themselves floundering if that continued support isn't there. That includes the co-operation and support from the family which is key. It is only then that we can truly get on with the task of educating.

"Our local neuromuscular care advisor set us on the right path. Having a named contact person is invaluable for schools as we are not medical people and we worry in case we are doing more harm than good. There is an over-expectation that schools just have to get on with it all under the umbrella of SEND and inclusion, however in reality, the day-to-day implications are the most trying for us.

"I know schools will find this guide really beneficial. All the contacts and links will be a great help too. It's clear and concise, informative and useful, which is what staff want and need. I spend a lot of my time trying to ensure staff are adequately informed to deal with the daily practicalities of having children [in our school] with these conditions, so we can give the children the enriched education they deserve."

**Eileen Hedley, Southfields Primary School**

"This document is full of so much useful information for both parents and schools. It covers a range of topics which we have come across on a regular basis with our students who have MD [muscular dystrophy]. The guide is full of important links to agencies

that are there to help with every aspect of care, without bombarding students and parents with too much information in one go. Students and their families need to know there is so much support that they can easily access; this guide does that.

"Every student's needs are different and just because they may have the same diagnoses, their conditions can vary so much. Also, remembering that they have the same feelings and expectations as their peers.

"The main thing is to keep communications open and make sure that we are all aware of what is happening, how our students are feeling and making all the adjustments to make them feel fully included in all aspects of school life. It is important to respect their individual needs and retain their dignity at all times, whilst keeping a cheerful face and making delicate situations seem normal.

"Since the Statement system has changed to an Education Health and Care Plan (EHCP, in Northern Ireland SEN Statement, and in Scotland, a Co-ordinated Support Plan), we are hoping that this will give students the support they need to carry on to further education at both college and university. It is early days yet, but it should make so much difference to a lot of students and their families. Parents are made aware in these guidelines that these plans are available for their children.

"The checklists/ questions to ask will be very useful for parents viewing schools and colleges. It raises questions that unless you work in education you may not think about. I know that when I was viewing schools for my own children I would have found these useful, and my children didn't have additional needs.

"I have been privileged to have worked with several students with MD over the last few years and feel that this guide would be really useful even with my extensive experience."

**Lesley Fereday, Earls High School**

# Foreword

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We are delighted to present this third edition of our *Inclusive education for children with muscle-wasting conditions: a guide for schools and parents*. It is designed to help meet the need for accessible, up-to-date information about inclusive education for children and young people with muscle-wasting conditions. The guide builds on the impact of the two earlier editions, which were very well received by families and the teaching community, with more than 10,000 copies having been distributed.

The guide draws on the wide expertise represented by the members of the working party who generously gave their time and their insights to develop this third edition. We give them our warm thanks. We also wish to thank and recognise the valuable support of the Department for Education.

Along with practical advice and information for schools and families with children of all ages, this guide also looks at transition issues. It recognises the importance of ensuring inclusion in all aspects and enabling children to enjoy and make the most of their time and opportunities in school. A strong partnership between the school and the family is essential; this guide helps to provide the basis for shared understanding and suggests effective strategies to apply in the classroom.

The guide reflects the changes made to the Statement system and the new arrangements in place. It offers advice about health issues, emphasising the variability of muscle-wasting conditions, and highlights the need for social, emotional and psychological support. We do hope parents and schools find this revised edition informative and helpful.

Robert Meadowcroft, Chief Executive  
Muscular Dystrophy UK

"Our youngest son Harry has SMA type 3. We had many difficulties with secondary transfer relating to funding for necessary adaptations. This had a huge effect on our family. The school has academy status, which made the scenario considerably worse. Muscular Dystrophy UK was amazing throughout our fight. They offered support, advice and were always there throughout the process. We were lucky to have a positive outcome and Harry starts year 7 next week.

"We're so grateful Muscular Dystrophy UK has developed these comprehensive education guidelines to help families like ours. I don't know how we would have overcome all the hurdles we faced without this support. We have the utmost gratitude to the charity for all their help."

Joanne Worrell, Hertfordshire

# Introduction

*Inclusive education for children with muscle-wasting conditions: a guide for schools and parents* is written for schools, special educational needs advisors, teachers and educational support assistants who have children in their schools with muscle-wasting conditions. The guidance is also helpful for parents working in partnership with their child's school to provide the best possible educational experience for their son or daughter. (Throughout this guidance we will be using the term 'parent', which will also mean 'carer')

This guidance has been written within the context of current legislation and in line with the Department for Education's Special educational needs and disability (SEND) code of practice guidelines, which are applicable in England and Wales. While legislation differs in Scotland and Northern Ireland, we hope that the information and advice contained in this guidance will be helpful to schools throughout the UK.

Chapter 2 is written for teachers within the context of the National Curriculum Key Stages.

Materials can be photocopied or downloaded from the Muscular Dystrophy UK website. Folders, for pupils, can also be ordered (free of charge) from Muscular Dystrophy UK.



# First steps

There are approximately 2,500 children with muscle-wasting conditions attending schools in the UK. These rare and very rare genetic conditions can be inherited or acquired out of the blue, and can present in childhood or adult life. Many schools, therefore, will have no experience of children with these conditions, or any knowledge of how to include him or her fully in the life of the school.

Unlike many other children with physical disabilities, children with muscle-wasting conditions will have changing needs during their school careers, as their muscle strength deteriorates. Schools need to be prepared and ready to deal with these changing needs. A child may be fully mobile when he or she enters the school, for example, and by the time he or she leaves, could be in a powered wheelchair, needing help with eating, and personal care, such as going to the toilet.

Most children with muscle-wasting conditions can be fully included into a mainstream school. Some, however, may start their education at a mainstream school and then transfer to a school for special educational needs because, as their condition progresses, they may need additional support. It is essential for schools to plan for:

- ▶ a fully accessible school environment
- ▶ a supportive curriculum
- ▶ appropriate educational and care support staff training
- ▶ collaborative working with parents and other professionals
- ▶ positive messages about disability for the child, other pupils and adults within the school environment.

The following sections detail the key areas that need to be considered in putting together any plan.

## Put the child's needs first

In addition to enabling a child to fulfil his or her academic potential, schools should also help children make friendships and develop a self-identity outside the family. Schools can play a vital role in assisting, allowing and encouraging a child to live and think independently. The role of education is ultimately to ensure that children mature in their understanding of themselves and their future.

It is important to ensure there is clear inclusion in a school and that teachers and pupils have good awareness of disability.

## Working together

Clear communication between home and school is vital for children with muscle-wasting conditions. This may go beyond the normal requirements of home/school liaison. School staff, particularly those who work closely with the pupil, will need to work with the parents throughout the time their child is in school to be clear about the messages they want communicated to pupils. It is important to establish what parents have told their child about his or her condition as well as what, and how, they wish school staff to communicate about this.

Good awareness training for staff can produce positive outcomes and experiences for pupil, parents and staff alike. Important communication skills are vital, such as listening, being flexible and responding quickly and appropriately to the pupil's changing needs.

Think through your school's strategy and policy on discussing the condition with the child, other pupils, and adults. Remember that school children have access to the internet and will look up words such as 'muscular dystrophy' or 'Duchenne muscular dystrophy' to gain information. Neither you nor the family will be able to prevent the child or other pupils from doing this, so it is important to plan for this possibility: have a means of providing support as well as giving truthful and positive answers if questions are asked.

Many of these principles also apply to the needs of pupils who have siblings with muscle-wasting conditions. As well as special educational needs co-ordinators (SENCOs) and other educational professionals, there are more people who can advise and support you, including social workers, health professionals, physiotherapists, occupational therapists, specialist nurses, psychologists and your local neuromuscular care advisors.

### **Planning ahead**

Careful planning is needed to anticipate the needs of the child. Adaptations to the school and even to the curriculum often take more time than you think. You need to have healthcare, moving and handling, risk assessment, evacuation, crisis management and training plans in place from the start.

### **Phase transfer and transition planning**

It is never too early to begin planning ahead for the next transition, whether it's pre-school to primary, primary to secondary school, secondary school to further or higher education, and on to work or other day provision.

# Chapter 1

# General information

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## 1.1 Diagnosis

Some children will have a diagnosis of their muscle-wasting condition when they begin their school life. Others will still be having investigations and tests, and some will only begin to show signs and symptoms of the condition when they are already at school.

It may be that school staff will be the first to recognise a problem, perhaps during PE or a games lesson. Should this happen, the specific concerns need to be discussed sensitively with parents and the school medical officer, who may suggest referring the child to a paediatric consultant. Do remember, however, that many children have co-ordination and movement difficulties. This does not necessarily relate to a muscle-wasting condition.

Obviously the time around diagnosis will be extremely stressful for all family members. Chapter 4 deals with this in more detail. Once a child has been diagnosed with a muscle-wasting condition, it is vital to:

- ▶ find out accurate information about the specific condition and how it is likely to progress (you can visit Muscular Dystrophy UK's website, or call the helpline on 0800 652 6352 to find out more)
- ▶ discuss the child's condition and related needs with his or her family, while being aware that they may find it difficult to share information, especially about how the condition may progress
- ▶ gain practical information and advice from specialist advisory teachers, health professionals and your local neuromuscular care advisor.

## 1.2 Neuromuscular conditions

More than 70,000 children and adults in the UK have a muscle-wasting condition (please note that we use the umbrella term 'muscle-wasting conditions' to refer to muscular dystrophy and related neuromuscular conditions). A further 350,000 people are affected indirectly as family, friends or carers.

Muscle-wasting conditions cause muscles to weaken and waste over time, leading to increasing disability. These rare and very rare genetic conditions may affect not only the muscles in the limbs, but also those of the heart and lungs, sometimes significantly shortening life-expectancy.

Genetic conditions result from alterations in the genetic make-up of an individual. They may be caused by defects in single genes or whole chromosomes, parts of which may be lost, duplicated, misplaced or replaced. Genetic disorders can be caused by defects in one or more genes. (Contact Muscular Dystrophy UK to find out more.)

In these conditions, a gene may fail to produce one of the proteins needed for normal muscle function. While the conditions are generally inherited, in some cases, they occur 'out of the blue' with no family history of the condition.

Muscular Dystrophy UK also supports families living with conditions that affect nerves, including spinal muscular atrophy (SMA) and the hereditary sensory neuropathies, which cause muscle weakness. The junction between the nerve and muscle (neuromuscular junction) is affected in the myasthenias.

Below is a brief summary of some of the more frequently encountered conditions. For more in-depth information on a specific condition please read the Muscular Dystrophy UK factsheets available to download from [www.muscardystrophyuk.org](http://www.muscardystrophyuk.org) or call 0800 652 6352.

### Duchenne muscular dystrophy

Duchenne muscular dystrophy, one of the more common conditions, is a life-shortening muscle-wasting condition, caused by the lack of a vital muscle protein called dystrophin. The condition causes muscles to weaken and waste over time, leading to increasing and severe disability.

Duchenne muscular dystrophy currently affects around 2,500 people in the UK and around 100 babies are born in the UK with the condition each year. It is caused by genetic mutations on the 'X' chromosome, meaning almost all of those affected are male. These mutations prevent the body from producing the vital protein, dystrophin, which is needed to build and repair muscle.

Most children with Duchenne muscular dystrophy are diagnosed by the age of five. Most will use a wheelchair by the age of 12, and will face life-threatening health problems by their late teens as the muscles of the heart and lungs weaken. Few of those born with the condition currently live to see their 30th birthday; with medical advances, however, life-expectancy is improving.

The right specialist healthcare and equipment, including access to heart and respiratory experts and regular physiotherapy, can make a significant difference to both quality and length of the life for people with Duchenne muscular dystrophy.

While the condition is severely disabling, many of those living with Duchenne muscular dystrophy lead full and active lives. There are authors, designers, campaigners

and Paralympians with Duchenne muscular dystrophy.

### Learning abilities in Duchenne muscular dystrophy

Some children with Duchenne muscular dystrophy may also have learning difficulties or find some aspects of learning more difficult. These are rarely severe and are not progressive. The main difficulties are usually language and communication skills.

The protein dystrophin is absent from muscle tissue and it is now known that part of the protein is also missing from the brain. The contribution made by dystrophin to the brain is not fully understood, although it is thought to be involved with selective cognitive processes.

Most children with Duchenne muscular dystrophy do not have any difficulties with their ability to learn, however, it is thought that all do have some cognitive involvement. It is generally believed that a little over two-thirds of those who are diagnosed with Duchenne muscular dystrophy have an IQ score one point lower than their peer group, which means that they score within the average range. However, about 19 percent will have a more significant difference with a score in the 70s, and some will fall into the high average group.

It is important to stress that there is much variability in skill, so accurate assessment is required to inform appropriate management.

Studies indicate that the main difficulties experienced by these children are verbal skills and reading skills, limited verbal memory, reduced attention and poor social and interpersonal behaviour skills. These are the 'hidden problems' of Duchenne muscular dystrophy and can sometimes be overlooked when the primary concerns seem to focus on physical skills and access.

It has been suggested that about half of all children with Duchenne muscular dystrophy are thought to have a form of developmental dyslexia. This could be, in particular, a difficulty with phonological processing, which can mean a reading age two years behind their class group. These children can struggle to learn when presented with too many verbal instructions or non-contextual aural information, which is not accompanied by kinaesthetic or visual re-enforcement. They may, therefore, find it difficult to repeat back verbal information presented only once.

There can be a reduction in digit span, which is a measure of short-term memory. It involves testing the number of digits a person can remember and recall in a correct sequence after hearing or seeing them. A child needs to recall approximately six digits in order to utilise phonics. If this is not possible, the strategies employed in the classroom need to focus on memory development. Phonological skills underpin reading.

The social interaction difficulties can manifest as the child's being less compliant or not noticing social subtleties.

These difficulties are thought to be a direct result of compromised verbal skills and can be a great source of stress to caregivers. These children and young people can be skilled in other areas, for example rote memory, which does not require mental manipulation. Long-term memory is effective and intact so these skills need to be nurtured in educational and clinical settings. Some children with Duchenne muscular dystrophy can appear to have difficulties processing sensory information from the environment around them. In these cases, the children would require support from an occupational therapist.

All involved in education and care must be mindful that the difficulties experienced by children with Duchenne muscular dystrophy

can be far-reaching and go beyond physical difficulties. Consequently, it is essential to have accurate assessment for the most effective and accessible teaching techniques to be employed to deliver the national curriculum. Any assessment needs to cover the child's development, academic skills, verbal abilities, working memory and attention span.

### **Suggested strategies for use in the classroom include:**

- ▶ assessment – developmental level, academic milestones, sensory and aural processing (this information may need to come from different people who know and support the child, for example parent/carer, OT, SENCO and neuromuscular care advisor)
- ▶ simplifying instructions
- ▶ breaking aural information and instructions into chunks appropriate to the results of the aural processing assessment
- ▶ introducing a sensory programme, if this is deemed to be a barrier to learning
- ▶ frequently checking the child's understanding of information
- ▶ using mixed media presentations, with emphasis on visual and kinaesthetic learning
- ▶ introducing games and activities that help the child to practise memory improving strategies
- ▶ using phonological awareness as with the dyslexic population
- ▶ using time-limited activities to promote success, followed by an activity of choice.

Each strategy should be employed in a way that does not alienate the child who is already aware that he is different from his peers. In addition, parents need to be supported through the process of assessment so they can carry through the suggested management techniques at home.

### **Communication needs**

Some boys with Duchenne muscular

dystrophy may have delayed acquisition of language skills, and therefore delayed expressive language. This can have a significant impact on their social life, affecting their ability to build and maintain friendships.

Pupils may have difficulties with processing and retaining complex information delivered verbally by an adult. This can mean that they are unable to carry out a full set of instructions and can look like they are distracted or just being difficult. For example, when a parent asks a young child to get ready to go to the park by going to the toilet, washing their hands and getting their coat and shoes, they may only follow one instruction. This is because the volume of information is likely to be too much for the child. To those who do not understand the hidden problems of Duchenne muscular dystrophy, this can be frustrating.

Some parents report that their child is 'very clever' because they have a keen knowledge of certain topics of interest. On closer assessment, it is often the case that the child has an extensive vocabulary related to this, but it may mask the difficulties listed previously. In such cases, the agenda is set by the child and it is harder to engage him in other learning tasks such as asking questions or engaging with activities not closely related to the topic of interest. The child's knowledge of topic-specific vocabulary can affect how the teacher assesses the child's ability to function in class and may therefore affect expectations.

### Becker muscular dystrophy

Becker muscular dystrophy is a genetic muscle-wasting condition, which causes muscles to weaken and waste over time leading to increasing disability. It is caused when the body's ability to produce a fully-functioning version of a vital muscle protein called dystrophin is compromised.

Over 2,400 people in the UK are thought to have Becker muscular dystrophy. Most people

with the condition are diagnosed by the time they reach their 20s and indeed, some are severely affected from childhood. However, others do not know they are affected until well into adult life.

Becker muscular dystrophy almost always affects boys and men. It is not uncommon for several members of a family across generations to be affected. The severity of the condition varies. People with Becker muscular dystrophy may struggle with sport as children, with muscle weakness becoming more pronounced in their teens or 20s, causing difficulty in walking quickly, running and climbing stairs. In most cases they will continue to be able to walk until their 40s or 50s, but for some the decline in mobility will be much faster.

### Spinal muscular atrophy

Spinal muscular atrophy (SMA) is a rare inherited neuromuscular condition, of which there are several distinct types. The condition may affect crawling and walking ability, arm, hand, head and neck movement, breathing and swallowing. SMA does not affect a child's intellectual development.

There are four main types of SMA, and they vary in severity:

#### SMA Type 1

The symptoms of SMA Type 1 appear within the first few months of life, sometimes before birth. It is the most severe form of SMA. Children are never able to sit unaided and rarely survive their second birthday. However survival rates are increasing and with full ventilator support there are a small number of children with SMA Type 1 attending school.

#### SMA Type 2

The symptoms of SMA Type 2 usually appear between the ages of seven and 18 months. The condition is severely physically disabling, with children never able to stand unaided. Though this is a serious inherited

neuromuscular condition that may shorten life-expectancy, improvements in care standards mean that the majority of people can live long, fulfilling and productive lives.

### **SMA Type 3**

The symptoms of SMA Type 3 appear after 18 months of age. Children are able to stand and walk, though will experience reduced walking ability over time. It is a less disabling condition. Life-expectancy for children diagnosed with SMA Type 3 is normal and most people can live long productive lives.

### **SMA Type 4**

The symptoms of SMA Type 4 appear in adulthood. It is also known as Adult Onset SMA and is not life-threatening.

## **Myotonic and congenital myotonic dystrophy**

Myotonic dystrophy is a genetic condition, which causes muscles to weaken, stiffen and waste over time, leading to increasing disability.

Myotonic dystrophy affects approximately 9,500 people in the UK. The age at which symptoms appear can vary from birth to old age. The condition is progressive and the earlier symptoms appear, the more severe they will become.

Muscle stiffness or 'myotonia' is a characteristic symptom, especially in the hands. People may also experience muscle weakness in the face, jaw and neck, often resulting in speech and swallowing difficulties. Heart problems, digestive problems, and cataracts may also be caused by myotonic dystrophy.

High-risk complications for people with myotonic dystrophy include an irregular heart rhythm and chest infections caused by weakened chest muscles.

## **Congenital (from birth) myotonic dystrophy**

Children with congenital myotonic dystrophy tend to reach physical and learning milestones later than their peers.

Often children with congenital myotonic dystrophy have facial weakness and a lack of facial expression. This does not mean that the child is unresponsive; it is simply that he or she may be unable to make the usual range of facial movements.

The severity of the condition varies considerably from child to child. A few affected children need to use a wheelchair. Significant features, particularly in congenital myotonic dystrophy, are learning difficulties (which can be severe), tiredness, lethargy and cataracts at an unusually early age.

## **Congenital muscular dystrophy**

Congenital (from birth) muscular dystrophy refers to a number of genetic muscle-wasting conditions which take effect from infancy, causing muscles to weaken and waste over time and leading to increasing disability.

It is thought that around 500 people in the UK have congenital muscular dystrophy, the main forms being Ullrich congenital muscular dystrophy and merosin-deficient congenital muscular dystrophy.

Congenital muscular dystrophy is caused by mutations in genes affecting the production and repair of muscle. Mutations causing the condition have been discovered across at least 19 genes and there are likely to be many more. Owing to the complexity of the condition and the number of genes affected, some people will never know which type they have.

The types fit into two groups: the first cause weakness in all the muscles in the body, but do not affect the intellect; the second cause muscle weakness, along with learning difficulties, and sometimes seizures.

The severity of congenital muscular dystrophy varies greatly between types and individuals. Some children affected will walk, but sometimes this can be delayed until five years of age or older. Some children who have achieved independent walking may lose this ability later on because, as they grow heavier, the muscles are unable to cope with a greater strain. Other children may never be able to walk.

### Facioscapulohumeral muscular dystrophy

Facioscapulohumeral muscular dystrophy (FSHD) is a genetic muscle-wasting condition that particularly affects the muscles of the limbs, shoulders and face. It is thought to be the third most common form of muscular dystrophy, affecting over 1,300 people in the UK and at least 140,000 worldwide.

FSHD is caused by a genetic mutation that causes the production of a toxic protein in the muscle, which kills the muscle cells. Often several generations of a family may be affected by FSHD, which can be diagnosed at any age and varies widely between individuals, even within the same family. The earlier muscle weakness appears, the more severe it is likely to become.

Approximately 10 to 20 percent of people with the condition eventually require a wheelchair. The muscles of the eyes and mouth can also be involved, affecting facial expression, and the ability to smile.

### Limb girdle muscular dystrophy

Limb girdle muscular dystrophy is a large group of conditions that cause weakness of the large muscles at the top of arms and legs, attached to the shoulder and pelvic 'girdles'. In some people, the muscles of the heart and lungs are also affected, leading to life-threatening health problems. Around 1,400 people in the UK have one of the many types of limb girdle muscular dystrophy.

A very wide range of genetic mutations, all affecting the production and repair of muscles, cause limb girdle muscular dystrophy. Owing to this complexity, approximately 25 percent of all people with limb girdle muscular dystrophy do not receive a precise genetic diagnosis.

Some people with milder forms will never become seriously affected, while others may struggle to lift their arms above their heads, or lose the ability to walk. The muscles of the legs may deteriorate faster than those of the upper body, resulting in frequent falls, difficulty in running and climbing stairs, and rising from the floor. Usually, the earlier the symptoms become apparent, the more severe the condition will be.

### Congenital myopathies

This is a group of inherited muscle conditions that are present from birth.

Congenital myopathies include central core disease, congenital myopathy with fibre-type disproportion, multi (mini) core disease, myotubular (centronuclear) myopathy and nemaline myopathy.

Congenital myopathies are conditions where changes in the muscle cells make them less able to contract. All these forms of congenital muscular dystrophy lead to muscle weakness and a decrease of muscle tone in early childhood. Later in life they are sometimes associated with delayed motor development and speech and learning difficulties.

About 1,000 people in the UK have a form of congenital myopathy.

### Charcot-Marie-Tooth disease

Charcot-Marie-Tooth disease (CMT) is a progressive, inherited condition which affects nerves controlling movement of the hands and lower legs. It affects around 23,000 people in the UK, an equal spread of male and female.



Also commonly referred to as hereditary motor and sensory neuropathy (HMSN), CMT can involve loss of feeling in the hands and feet (the 'sensory' component). The term 'neuropathy' refers to the peripheral nerves, which connect the spinal cord to the muscles, joints and skin, carrying messages in both directions, and which do not function normally.

The first symptoms of CMT include difficulties picking up the feet and very high foot arches. These are usually apparent from childhood. Those affected may have problems with balance and walking longer distances, bone abnormalities, loss of reflexes and weakness of the hands. It is unusual for people to lose the ability to walk, however some will need to use walking aids as they grow older.

Owing to loss of sensation in the hands and feet, people with CMT need to be very careful to prevent and detect injuries to these areas. This is particularly important when planning PE activities, as the foot or ankle can be damaged without the pupil's being aware. Fine motor skills may also be affected as the pupil may not receive sensory feedback from the equipment. This could result in difficulties with handwriting, manipulating science or technology equipment, distinguishing temperature, sharpness or pain.

### Myasthenia gravis

Myasthenia gravis is an autoimmune condition. It is caused when the body's immune system attacks the junctions responsible for transferring messages from the nerves to the muscles. It causes weakness and fatigue in the muscles of the limbs, face, eyes and throat, and also in the respiratory muscles vital for breathing.

Myasthenia gravis is thought to affect between 5,000 and 10,000 people in the UK – about 15 in every 100,000 individuals. It can develop at any age from childhood to extreme old age. Most of those affected are

female, although men are more likely than women to develop it in later life.

The impact of the condition is very unpredictable and can vary dramatically day-to-day and between individuals. Frequently, the muscles of the eyes and face are affected, causing double vision, drooping of the eyelids (the child looks as if he or she is sleepy) and making it difficult for the child to smile. The arms and legs may be weak and, in severe cases, there can be problems with breathing muscles.

Myasthenia gravis can also cause speech disturbances, such as slurred speech, which can cause difficulty in a classroom setting and when socialising with peers. Swallowing difficulties are also common in myasthenia gravis. Swallowing is a complex process involving around 50 pairs of muscles. These muscles can become fatigued, particularly towards the end of a meal or when food has required a lot of chewing. It is important that a child with swallowing difficulties has an assessment with a speech and language therapist, so that recommendations can be put in place to help manage the symptoms.

Please note that even after successful treatment of juvenile myasthenia gravis, pupils can be left with significant neuromuscular fatigue. This may make it difficult when returning to school once treatment is finished and symptoms have improved. The fatigue is unpredictable; it can present a day or two after a period of physical exercise or emotional stress and can be very debilitating.

### Congenital myasthenic syndrome

This condition, which is very rare, can be difficult to distinguish from myasthenia gravis. It is a genetic condition in which one of the proteins at the neuromuscular junction functions abnormally. The symptoms and signs are similar to myasthenia gravis. The first evidence of the condition is at birth or shortly afterwards. In some cases the

child experiences potentially fatal episodes of breathing failure. Drugs can help the weakness and it may improve spontaneously as the child gets older. Again, speech and swallowing difficulties can be common.

### Mitochondrial myopathy

Mitochondrial myopathies are a group of conditions that particularly affect muscle, but may also affect every other part of the body, including the brain and the eye.

Mitochondrial myopathy is caused by genetic faults, which affect the function of mitochondria (the parts of muscle cells that generate the energy required for a muscle to contract). The causes and results of mitochondrial myopathy vary but most lead to some form of muscle weakness, and some affect specific parts of the body.

About 3,500 people in the UK have mitochondrial myopathy. The impact of mitochondrial myopathy varies dramatically from person to person. Many of those diagnosed are unaware that there is a family history of the condition.

The most common symptom is a combination of mild weakness of the arms and legs, droopy eyelids and difficulty moving the eyes. Some people only have the weakness in their arms and legs and find this gets worse if they exert themselves. In others it is more severe. For example, some babies with the condition may have difficulties with swallowing and feeding, which can affect their life-expectancy.

### Metabolic myopathies

Also known as metabolic muscle conditions, these are conditions that interfere with the way muscles provide energy.

Metabolic myopathies, which include McArdle's disease and Pompe disease (also known as acid maltase deficiency, or glycogen storage disease type II) are caused

by mutations in the genes involved the production of energy in skeletal muscles. The mutations generally block the chemical reactions that take place during energy production, so the muscle cells cannot work properly. In some cases, this can lead to episodes of muscle damage, causing acute kidney failure. In others there is progressive muscle weakness.

Metabolic myopathies that affect young children tend to be the most severe and can, in some cases, be fatal. Those with a later onset tend to have less severe symptoms, and in very mild cases changes in diet and lifestyle can ease symptoms. About 700 people in the UK have a form of metabolic myopathy.

### Neuromuscular conditions (non-specified)

Despite medical and technological advantages, a number of people will not have a definitive diagnosis of their muscle-wasting condition.

Not having a diagnosis can be difficult for these children and their families. However, they should keep in close contact with their care advisor or specialist nurse to find out what research is taking place or if there are any clinical trials. It is important for school to understand that the pupil will have specific difficulties which need to be managed to optimise safety and to enable the pupil to achieve their academic potential.

### Information resources

Muscular Dystrophy UK has alert cards and Information Standard-accredited factsheets on a number of muscle-wasting conditions – including those without a specific diagnosis. The alert cards include information on the vital and specific issues that affect children with these conditions. They also outline key recommendations and precautions that non-specialist clinicians would need to know in times of worsening health.

## 1.3 Key issues for the conditions

- ▶ Mobility and physical activity
- ▶ Falling/losing balance
- ▶ Fatigue
- ▶ Upper limb function
- ▶ Personal care and comfort
- ▶ Moving and handling
- ▶ Seating, standing, comfort and positioning
- ▶ Temperature control
- ▶ Eating and swallowing
- ▶ Going to the toilet
- ▶ Self-image and emotional wellbeing
- ▶ Communication needs

The above issues are discussed in Chapter 5: Health Issues.



# Chapter 2

## Access to schools and the curriculum

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This chapter provides guidance on how to include all pupils fully within a mainstream school.

Education at its best should provide opportunities, not stumbling blocks, for adult life, regardless of the prognosis of a medical condition. In order to achieve this and enable a pupil to maximise his or her physical independence, three key areas need to be addressed:

- ▶ establishing a positive and inclusive ethos
- ▶ taking into account any increasing difficulty the pupil may experience in moving his or her body, and
- ▶ addressing physical limitations in the environment that restrict the pupil's independence.

This chapter provides information on the support needed throughout the school day – within and beyond the curriculum. When an inclusive school ethos is successfully managed, together with an accessible curriculum and environment, then you have created a fully inclusive school. It is not possible, however, to manage a successful inclusive educational experience without the following:

- ▶ an understanding of the condition and how it will affect the child and family **Chapter 1**
- ▶ teamwork and the identification of a key worker **Chapter 3**
- ▶ an accessible physical environment with appropriate equipment **Chapter 6**
- ▶ a clear understanding of the health, personal care and changing needs of pupils with a muscle-wasting condition **Chapter 5**
- ▶ emotional support for the child, family, staff and other pupils **Chapter 4**

- ▶ adequate school/educational policies firmly in place **Chapter 7**
- ▶ moving and handling policies and procedures **Chapter 8**.

This chapter also concentrates on the needs and changes within and beyond the curriculum at the various key stages.

The pupil's needs will change during their time at school as muscle strength changes. This can happen very rapidly, and schools need to be prepared.

Schools can play a vital role in assisting and encouraging a child to live and think independently. Along with the role of the parents, education can play a part in helping children to mature in their understanding of themselves and their future.

### 2.1 Early years setting (day nurseries, pre-schools, playgroups and childminders)

The Early Years Foundation Stage (EYFS) sets the standards for learning, development and care for children from birth to five years old. All OFSTED-registered early years providers must follow the EYFS, which states that providers must have arrangements in place to support children with special education needs SEN or disabilities.

When a child enters early years setting, staff may notice that they may have some physical developmental delays. Activities, such as toilet training and feeding, may require more support. Additional difficulties that may be apparent have been listed in the Key Stage 1 section, which follows.

All early years settings know that play is vital for all children. It is the way children explore and make sense of the world around them. Play offers opportunities to relax, express feelings, and develop social and cognitive skills necessary for school and later life. All children need the fun of play and learning opportunities.

If staff members have concerns that a child is struggling to achieve the core learning and development requirements of the EYFS, they must discuss this with the child's parents and/or carers and agree how to support the child. Staff must consider whether a child may have a special educational need or level of disability that requires specialist support. They should link with, and help families to access, relevant services from other agencies as appropriate. Further guidance on this can be found in Key Stage 1 and Key Stage 2, as well as 'Assessing the Pupil' below.

## 2.2 Key Stage 1

Key Stage 1 covers the period from Upper Foundation, through Year 1 and Year 2 (from five to seven years old).

While some children with muscle-wasting conditions may enter school in a wheelchair, (those with SMA or congenital muscular dystrophy, for example) those with Duchenne muscular dystrophy or neuropathies (for example, CMT), are likely to be walking. All children should be encouraged to join in activities as far as they are able.

Before starting school, it is important to have planning meetings to ensure the child, family and school are supported to meet these needs. Advice from an occupational therapist (OT) and/or a physiotherapist can be invaluable in deciding what type of equipment will help maintain the child's independence. Some children may not yet be diagnosed with a muscle-wasting condition. A teacher

might notice the child having difficulties, such as:

- ▶ struggling to get up from the carpet
- ▶ frequently falling in the playground
- ▶ poor balance
- ▶ slow when climbing stairs
- ▶ difficulty using apparatus in PE lessons
- ▶ tiredness during the afternoon session
- ▶ a noticeable change in stamina over the week
- ▶ poor handwriting because of weak pencil grasp
- ▶ slowness in eating food
- ▶ weak cough
- ▶ frequently off school with chest infections
- ▶ difficulties with learning.

Teachers often notice how different one child's mobility is from another's, and this can help with diagnosis. If you have concerns about a child's physical development, you need to discuss this first with the parents and then discuss making the appropriate health referral. It is important to remember, however, that while many children have co-ordination and movement difficulties, these are not necessarily related to a muscle-wasting condition.

## 2.3 Key Stage 2

Moving through Key Stage 2, Year 3 to Year 6 (from seven to 11 years old), children with muscle-wasting conditions, who have impaired walking, fine motor difficulties, or are wheelchair users, are likely to become more aware of the differences between themselves and other children. This awareness has implications for their self-image.

A child with a muscle-wasting condition, while usually still ambulant, will become weaker. Walking will become limited and gross motor skills and the muscles in the upper body will start to be affected. Provision of specialist equipment should be introduced at this stage.

It may be necessary to use specialist equipment, such as standing frames. If writing becomes affected, the pupil could require a computer or scribe. It is best to introduce alternatives to paper/pencil recording, i.e using ICT, before the child's upper body strength becomes significantly weaker. As the physical difficulties increase, some pupils may present challenging behaviour as they begin to realise the implications of their diagnosis.

Some children with Duchenne muscular dystrophy may have specific learning difficulties; however these do not get worse as the condition progresses.

## Assessing the pupil

Issue	Strategy	Resources
<ul style="list-style-type: none"> <li>▶ Recognition of the problem.</li> <li>▶ Child has a recognised muscle-wasting condition.</li> <li>▶ No formal diagnosis but assessed as having a muscle-wasting condition.</li> <li>▶ Delayed development?</li> <li>▶ Are there medical needs?</li> <li>▶ Delayed learning?</li> <li>▶ Delayed speech?</li> </ul> <p><b>Is statutory assessment appropriate or not?</b></p> <ul style="list-style-type: none"> <li>▶ There is an expectation for schools to make some provision for children with SEN needs from their own budget.</li> <li>▶ If the child's needs are not met with the SEN support then an application for EHCP/CSP needs assessment should be considered.</li> <li>▶ LAs delegate budgets to schools; this can eliminate the need for an EHCP (in Northern Ireland SEN Statement, and in Scotland a Co-ordinated Support Plan), but SENs should be undertaken.</li> <li>▶ Statutory assessment or delegated funds?</li> </ul>	<ul style="list-style-type: none"> <li>▶ Gather information about the child from those who know him – including parents, early years setting, advisory teachers and health professionals.</li> <li>▶ Arrange a planning meeting to bring professionals, parents and nursery staff together.</li> <li>▶ If child has a specific condition, get information from reliable sources such as the Muscle Centre the pupil attends for medical appointments, or Muscular Dystrophy UK.</li> <li>▶ Ensure effective communication – talk to the family and professionals involved and agree channels of communication. Get consent for sharing information with parents.</li> <li>▶ Assess mobility needs and access to the school, as well as movement around the building.</li> <li>▶ Assess learning – for example, specific learning difficulties, autism, ADHD.</li> <li>▶ Consider EHCP (in Northern Ireland SEN Statement, and in Scotland a Co-ordinated Support Plan).</li> <li>▶ Monitor, record and review the situation.</li> <li>▶ Involve Special Education Needs Co-ordinator (SENCO).</li> </ul>	<ul style="list-style-type: none"> <li>▶ Family knowledge.</li> <li>▶ SENCO.</li> <li>▶ Professionals involved with the child – including Muscle Centre team, PT, OT, SALT.</li> <li>▶ Information in these guidelines.</li> <li>▶ CAF Directory <a href="http://www.cafamily.org.uk">www.cafamily.org.uk</a></li> <li>▶ Professionals' reports.</li> <li>▶ Muscular Dystrophy UK <a href="http://www.muscular dystrophyuk.org">www.muscular dystrophyuk.org</a></li> <li>▶ Condition-specific charities.</li> <li>▶ See Chapter 7: Educational and School policies.</li> <li>▶ IPSEA – Independent Parental Special Education Advice <a href="http://www.ipsea.org">www.ipsea.org</a></li> <li>▶ Nasen – provides information for those who work with or care for children and young people with special and additional educational needs and disabilities. <a href="http://www.nasen.org.uk">www.nasen.org.uk</a></li> <li>▶ SEND Code of Practice 2014 0-25 <a href="http://www.gov.uk">www.gov.uk</a></li> <li>▶ SEND summary document in the Early Year Settings and Key Stage 1 <a href="http://www.councilfordisabledchildren.org.uk">www.councilfordisabledchildren.org.uk</a></li> <li>▶ Children and Families Act 2014.</li> <li>▶ Equality Act 2010.</li> </ul>

## Assessing the pupil (continued)

Issue	Strategy	Resources
	<ul style="list-style-type: none"> <li>▶ Hold regular review(s) during each school year to include planning for next academic year.</li> <li>▶ Call multi-agency meetings as and when necessary.</li> <li>▶ Be flexible and ready to respond if a child's physical abilities deteriorate.</li> <li>▶ Attend relevant in-service training (INSET) sessions.</li> <li>▶ Identify a Key Worker.</li> <li>▶ Identify staff training and allocate time.</li> </ul>	

## The school environment

Issue	Strategy	Resources
<p><b>Creating an accessible environment – including a wheelchair user</b></p> <ul style="list-style-type: none"> <li>▶ Classrooms – seating, tables, doors.</li> <li>▶ Playground – safe areas to sit and play.</li> <li>▶ Toilet – support rails, raised seat.</li> <li>▶ Dining room – assess balance, when walking and carrying.</li> <li>▶ Cloakroom – bag hooks at appropriate levels.</li> <li>▶ Hall – suitable seating.</li> <li>▶ Accessing building.</li> <li>▶ Accessing practical subjects (art, technology, science).</li> </ul>	<ul style="list-style-type: none"> <li>▶ Undertake an access audit of the school site and discuss with LA.</li> <li>▶ Review access plan annually and plan for future needs including toilet/bathroom adaptations.</li> <li>▶ Install grab rails, handrails, ramps, lifts, etc.</li> <li>▶ Ensure adequate space in classroom, suitable seating and tables, door openings.</li> <li>▶ Provide safe areas to play and sit in the playground.</li> <li>▶ Lower cloakroom pegs.</li> <li>▶ Identify safe routes around the school.</li> <li>▶ Ensure there are seated areas in playground.</li> </ul>	<ul style="list-style-type: none"> <li>▶ See Chapter 6: Environmental considerations.</li> <li>▶ Specialist advice from advisory teachers, Paediatric Therapy Services, LAs planning department.</li> <li>▶ Health professionals, including Muscle Centre team.</li> <li>▶ See Chapter 12: Managing playtime/ break time.</li> </ul>



## The school environment (continued)

Issue	Strategy	Resources
<p><b>Therapy and use of specialist equipment, including storage and maintenance of equipment.</b></p> <ul style="list-style-type: none"> <li>▶ Splints.</li> <li>▶ Assisted stretches/physio.</li> <li>▶ Medical room and table.</li> <li>▶ Hoisting and slings.</li> <li>▶ Wheelchair.</li> <li>▶ Specialist seating.</li> <li>▶ Standing frame.</li> <li>▶ Feeding.</li> <li>▶ Breathing/clearing secretions.</li> <li>▶ Important to balance therapy and curriculum needs.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Ensure effective communication with parents and child.</li> <li>▶ Hold regular meetings with parents and professionals to share information, review current plan, assess and plan ahead.</li> <li>▶ Review if EHCP (in Northern Ireland SEN Statement, and in Scotland a Co-ordinated Care Plan) is needed.</li> <li>▶ Identify key worker(s), who will provide care.</li> <li>▶ Ensure therapist and health professionals advise school on what equipment is required.</li> <li>▶ Risk-assess the impact on school environment, staff training and other pupils.</li> <li>▶ Identify what training is required for staff to use equipment, who will provide this, and how often training needs to be updated.</li> <li>▶ Ensure there is a balance between education and therapy.</li> <li>▶ Work with child, parents, professionals and school timetable to identify the most appropriate time to use equipment.</li> <li>▶ Keep a record of who has provided equipment.</li> <li>▶ Establish who is responsible for equipment maintenance and service costs.</li> <li>▶ Consider availability of support staff when equipment is being used.</li> <li>▶ Consider proximity of classroom to specialist toilet/support facilities, with regard to movement to and from the classroom.</li> </ul>	<ul style="list-style-type: none"> <li>▶ See Chapter 6: Environmental considerations.</li> <li>▶ The pupil and their parents.</li> <li>▶ Community Children's Nurse.</li> <li>▶ Advisory teacher.</li> <li>▶ OT and physiotherapist.</li> <li>▶ Neuromuscular care-advisor (NCA).</li> <li>▶ SENCO.</li> <li>▶ OT and physiotherapy reports.</li> <li>▶ Manufacturer's/supplier's guidelines.</li> <li>▶ Use 'Pupil Support Timetable' to monitor balance of therapy and education.</li> </ul>

## The school environment (continued)

Issue	Strategy	Resources
<p><b>Transport</b></p> <ul style="list-style-type: none"> <li>▶ Children with mobility difficulties may struggle to walk short distances, and may tire easily.</li> <li>▶ LAs have clear policies relating to transport for children with SEN. This information should be made available to parents.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Discuss with parents – does the child have a Blue Badge?</li> <li>▶ Check whether or not a safe place is required to drop off and collect the child.</li> <li>▶ Consider school activities away from the school, and whether transport is required and is accessible.</li> <li>▶ Make reasonable adjustments, as the school is required to do, to enable child to be included.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Advisory teacher.</li> <li>▶ SENCO.</li> <li>▶ LA transport team.</li> <li>▶ Equality Act 2010.</li> </ul>

## Policies and managing risks

Issue	Strategy	Resources
<p><b>Key worker</b></p>	<ul style="list-style-type: none"> <li>▶ Identify key worker(s).</li> <li>▶ Identify training needs and how key worker will be supported/supervised.</li> <li>▶ Provide time for training, attending meetings.</li> <li>▶ Prepare for any changes, liaising with key worker, child and parents.</li> </ul>	<ul style="list-style-type: none"> <li>▶ See Chapter 3: Working together – roles and responsibilities.</li> <li>▶ SENCO.</li> <li>▶ Advisory teachers.</li> <li>▶ Local colleges.</li> </ul>
<p><b>Moving and handling</b></p> <ul style="list-style-type: none"> <li>▶ Children with deteriorating muscle strength/function may require help with moving around the school and transfers within building, including hoisting, and transfers between chairs.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Risk assessment.</li> <li>▶ Risk-assess child's ability to move, and provide written instructions for staff, in consultation with the child's physiotherapist.</li> <li>▶ Ensure staff members receive training that is deemed competent by a suitably qualified person.</li> <li>▶ Identify equipment required, for example handling belt, hoist, grab rails and ensure appropriate training is given.</li> <li>▶ Consider identifying a core group of staff to provide care, to ensure they remain competent and familiar with child's needs.</li> </ul>	<ul style="list-style-type: none"> <li>▶ SENCO.</li> <li>▶ See Chapter 8: Safe moving and handling.</li> <li>▶ Examples from other schools.</li> <li>▶ PT.</li> <li>▶ OT.</li> </ul>

<b>Policies and managing risks (continued)</b>		
<b>Issue</b>	<b>Strategy</b>	<b>Resources</b>
	<ul style="list-style-type: none"> <li>▶ Effective communication with staff, family and child to ensure consistency in care.</li> <li>▶ Assess whether child requires assistance at mealtimes (to help collect, carry and cut up their food).</li> <li>▶ Devise policy if one is not already in place.</li> <li>▶ Ensure staff members get appropriate training.</li> <li>▶ Check equipment and keep records of all servicing and maintenance.</li> </ul>	
<p><b>Safe evacuation</b></p> <ul style="list-style-type: none"> <li>▶ In case of emergency, consider whether child is a wheelchair user or they can walk downstairs independently; are they able to walk quickly?</li> </ul>	<ul style="list-style-type: none"> <li>▶ Review emergency procedures.</li> <li>▶ Complete Personal Egress and Evacuation Plan with pupil, parents and all staff that support the pupil in school.</li> <li>▶ Identify any equipment or staff training required.</li> </ul>	<ul style="list-style-type: none"> <li>▶ See Chapter 6: Environmental considerations.</li> </ul>
<p><b>School uniform</b></p>	<ul style="list-style-type: none"> <li>▶ Suggest shoes with Velcro, modified uniform, alternative garments, elasticated, loose clothes, for example, Polo shirts, tracksuit bottoms.</li> </ul>	<ul style="list-style-type: none"> <li>▶ See Chapter 7: Educational and school policies.</li> </ul>
<p><b>Staff training and support</b></p> <ul style="list-style-type: none"> <li>▶ Raise awareness.</li> <li>▶ Build confidence.</li> <li>▶ Provide information for all staff.</li> <li>▶ Consider additional support/ supervision for staff closely involved with children who have complex/ palliative care needs.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Agree with parent what information can be shared with staff/child and pupils.</li> <li>▶ Build up a bank of written information.</li> <li>▶ Visit other schools attended by children with muscle-wasting conditions.</li> <li>▶ Identify key worker – for children with complex needs. It is helpful to share responsibility but not to have too many people involved, if consistency in approach and knowledge is to be maintained.</li> <li>▶ Allocate time for staff training and attendance at meetings, for children with more complex needs. Invite specialist neuromuscular staff to address staff on INSET days.</li> <li>▶ Contact relevant charities for written information on conditions.</li> </ul>	<ul style="list-style-type: none"> <li>▶ NCA specialist nurse.</li> <li>▶ Community children's nurse.</li> <li>▶ Local training.</li> <li>▶ Advisory teacher</li> <li>▶ Educational Psychology Services (EPS).</li> <li>▶ Chapter 3: Working together – roles and responsibilities.</li> <li>▶ Chapter 5: Health issues.</li> <li>▶ Condition-specific charities.</li> <li>▶ Muscular Dystrophy UK.</li> </ul>

Curriculum		
Issue	Strategy	Resources
<b>Access to curriculum</b> <ul style="list-style-type: none"> <li>▶ National Curriculum.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Introduce keyboard skills.</li> <li>▶ Consider whether an EHCP (in Northern Ireland a SEN Statement and in Scotland, a Co-ordinated Care Plan) is required, if increasing needs.</li> <li>▶ Carry out regular reviews.</li> <li>▶ Include child in all aspects of learning, through forward planning and awareness of disability.</li> <li>▶ Consider how child can access after-school curriculum and lunchtime clubs, to promote friendship groups and sense of belonging.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Advisory teachers.</li> <li>▶ <a href="http://Communicationmatters.org.uk">Communicationmatters.org.uk</a> – experts in alternative communication.</li> <li>▶ Educational Psychology Services (EPS).</li> <li>▶ SENCO.</li> <li>▶ Equality Act 2010.</li> <li>▶ Disability Sports Scotland.</li> <li>▶ Paralympic sports, including Boccia, curling.</li> </ul>
PE		<ul style="list-style-type: none"> <li>▶ Chapter 11: Physical Education (PE).</li> </ul>
Swimming/hydrotherapy		<ul style="list-style-type: none"> <li>▶ Chapter 11: Physical Education (PE).</li> </ul>
<b>School trips</b> <ul style="list-style-type: none"> <li>▶ Accessibility of venues for wheelchair users.</li> <li>▶ Children, who usually walk, may need to use a wheelchair on school trips.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Assess venues for suitability and accessibility.</li> <li>▶ Hire adapted vehicles where necessary.</li> <li>▶ Ensure suitable toilets are available.</li> <li>▶ Complete risk assessment to include any moving and handling issues.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Chapter 13: Preparation for a school residential visit.</li> <li>▶ Equality Act 2010.</li> <li>▶ Contact venue or look at facilities online.</li> <li>▶ SENCO.</li> </ul>
<b>Child suffers from fatigue</b> <ul style="list-style-type: none"> <li>▶ Appears tired in the afternoon sessions.</li> <li>▶ Noticeable change in stamina as the week progresses.</li> <li>▶ Need to pace activity.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Monitor changes in stamina during the day and as the week progresses, and if child complains of muscle pain/aches or misses school regularly after day of physical activity at school.</li> <li>▶ Where possible, Introduce new concepts in the mornings.</li> <li>▶ Allow extra time to complete tasks in the afternoons.</li> <li>▶ Allow rest periods, and provide suitable location.</li> <li>▶ Review if additional support is required in the classroom.</li> </ul>	<ul style="list-style-type: none"> <li>▶ See Chapters 3 and 5: Working together – roles and responsibilities, Health issues.</li> <li>▶ Use 'Pupil Support Timetable' to identify when increased level of adult support may be required.</li> <li>▶ Parents.</li> </ul>

Curriculum (continued)		
Issue	Strategy	Resources
<p><b>Communication</b></p> <ul style="list-style-type: none"> <li>▶ Some children may have a very quiet voice and/or be slow to speak.</li> <li>▶ Facial muscles may be weak and it can be difficult for child to show expressions, for example, smile or show interest. Eyelids can drop and make children appear sleepy. It is difficult for people to assess child's mood/interest in lessons.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Talk to parents to seek their advice on how to assess their child's mood/interest in activities.</li> <li>▶ Talk to the child; don't assume they lack interest or understanding.</li> <li>▶ Consider where child sits in the classroom, and how they communicate with other children and teacher. Consider other options, and give the child time to respond. Ensure the class respects the need to wait.</li> <li>▶ Consider IT options.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Speech and Language Therapy (SALT) Services.</li> <li>▶ SENCO.</li> <li>▶ Advisory teacher.</li> <li>▶ Condition-specific information.</li> </ul>
<p><b>Emotional support</b></p>	<ul style="list-style-type: none"> <li>▶ Consider lunchtime clubs/after-school activities the child can participate in with their peers.</li> <li>▶ Consider how to promote self-confidence and problem-solving skills with the child and their peers.</li> <li>▶ Discuss with parents and child about sharing information with peers.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Muscular Dystrophy UK leaflet: <i>Same but different</i></li> </ul>

Physical limitations		
Issue	Strategy	Resources
<p><b>Pupil has difficulty with mobility and exercise:</b></p> <ul style="list-style-type: none"> <li>▶ struggles to get up from the floor</li> <li>▶ falls frequently in the playground</li> <li>▶ has poor balance – unsteady when walking, falls easily or falls easily when bumped</li> <li>▶ tires easily when walking</li> <li>▶ has difficulty climbing stairs</li> <li>▶ has difficulty using PE apparatus</li> <li>▶ is unable to join in with peers playing at break time</li> </ul>	<ul style="list-style-type: none"> <li>▶ Seek guidance from physiotherapist on how to help.</li> <li>▶ Movement. This may include strategies such as assisted walking and/or aids.</li> <li>▶ Risk-assess stairs and provide support as identified.</li> <li>▶ Monitor any falls.</li> <li>▶ Consult therapists regarding posture/seating concerns.</li> <li>▶ Consider the approach to the PE curriculum/swimming. Ensure inclusive approach is established.</li> </ul>	<ul style="list-style-type: none"> <li>▶ See Introduction, Chapters 1, 5 and 6: General information, Health issues, Environmental considerations.</li> <li>▶ Wheelchair training from appropriate professionals.</li> <li>▶ Whizz Kids.</li> <li>▶ 2010 Equality Act.</li> </ul>

<b>Physical limitations (continued)</b>		
<b>Issue</b>	<b>Strategy</b>	<b>Resources</b>
<ul style="list-style-type: none"> <li>▶ Cannot keep pace with peers when walking, and needs frequent rest.</li> <li>▶ Children who usually walk may need to use a wheelchair for school trips.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Provide extra supervision at playtime and provide seating areas in playground, school corridors.</li> <li>▶ Encourage 'buddy' system during unstructured playtimes.</li> <li>▶ Identify and forward plan for when the use of a wheelchair may be necessary.</li> <li>▶ Plan for possible progression from manual chair to an electrically powered indoor or outdoor chair (EPIOC).</li> </ul>	
<p><b>Pupil has poor hand movement/grip/sensation</b></p> <ul style="list-style-type: none"> <li>▶ Poor handwriting and weak pencil/pen grip.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Contact OT for assessment, advice/resources to address difficulties with recording work.</li> <li>▶ Use simple, modified tools such as sloping board, handhugger pencils, fingertip ruler.</li> <li>▶ Consider alternative recording to writing, by using information and communication technology (ICT).</li> <li>▶ Introduce keyboard skills at an early stage.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Chapter 14: Information and communication technology.</li> <li>▶ OT.</li> <li>▶ SENCO.</li> <li>▶ Advisory teachers.</li> <li>▶ IT software programmes.</li> <li>▶ Voice-recognition programmes.</li> </ul>
<p><b>School trips</b></p> <ul style="list-style-type: none"> <li>▶ Accessibility of venues for wheelchair users.</li> <li>▶ Children who usually walk may need to use a wheelchair on school trips.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Assess venues for suitability and accessibility.</li> <li>▶ Hire adapted vehicles where necessary.</li> <li>▶ Ensure suitable toilets are available.</li> <li>▶ Complete risk assessment to include any moving and handling issues.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Chapter 13: Preparation for a school residential visit.</li> <li>▶ Disability Act 2010.</li> <li>▶ Contact venues or look at facilities online.</li> <li>▶ SENCO.</li> </ul>

## Medical and Therapeutic issues

Issue	Strategy	Resources
<ul style="list-style-type: none"> <li>▶ Personal hygiene/going to the toilet.</li> <li>▶ The need for support with personal care can change rapidly and a child able to manage personal care at one time may not be able to do so later.</li> <li>▶ For a wheelchair user, and those with a significant degree of muscle weakness, help will be needed with personal care and going to the toilet.</li> <li>▶ Constipation and/or diarrhoea may be associated with the child's condition.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Discuss with family the best ways of meeting the child's personal care needs.</li> <li>▶ Complete an assessment of needs, identifying training and equipment required to transfer child safely. Involve child and family in the assessment and complete a Moving/Handling Plan for staff to follow.</li> <li>▶ Ensure all staff involved with personal hygiene are aware of the plan and have considered safeguarding and infection prevention policies.</li> <li>▶ Ensure necessary adaptations have been completed and equipment is available.</li> <li>▶ Identify a key worker for the family to liaise with.</li> <li>▶ Follow best practice and have a small core group of people involved with the child's personal care needs to ensure privacy and consistency of approach.</li> <li>▶ Identify a suitable toilet; plan for the provision of a disabled toilet if one is not available.</li> <li>▶ Identify and request equipment that may be needed, for example, hoist, sling, urinal bottle, Closomat toilet, grab rails, etc. Ensure provision of infection prevention materials, such as gloves, hard surface wipes, etc.</li> <li>▶ Ensure there are hygienic disposal facilities in the toilets.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Local authority Moving and Handling Advisor/OT.</li> <li>▶ Muscular Dystrophy UK <i>Adaptations Manual</i>.</li> <li>▶ NCA/specialist nurse.</li> <li>▶ Appropriate toilet.</li> <li>▶ Suitable hoist.</li> <li>▶ Continence advisor.</li> <li>▶ ERIC.</li> <li>▶ Refer to local policy.</li> </ul>
<p><b>Outpatient appointments/hospital admissions</b></p> <ul style="list-style-type: none"> <li>▶ Child may require planned surgery.</li> <li>▶ Children with muscle-wasting conditions may see many different therapists and doctors and need to attend frequent outpatient appointments, including consultants, therapists, Wheelchair and Orthotic Services.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Liaise with family and ensure school staff members are kept informed.</li> <li>▶ With planned hospital admissions, liaise with family about keeping their child up-to-date with school work.</li> <li>▶ Assist in maintaining school friendships.</li> <li>▶ Ensure child gets additional support in school post-surgery, a shortened day or different equipment, if required.</li> <li>▶ If necessary, liaise with relevant hospital or home tuition service</li> </ul>	<ul style="list-style-type: none"> <li>▶ Chapter 5: Health issues.</li> </ul>

Medical and Therapeutic issues (continued)		
Issue	Strategy	Resources
<b>Outpatient appointments/hospital admissions (ctd)</b> <ul style="list-style-type: none"> <li>▶ Child may require planned surgery.</li> <li>▶ Children with muscle-wasting conditions may see many different therapists and doctors and need to attend frequent outpatient appointments, including consultants, therapists, Wheelchair and Orthotic Services.</li> </ul>	<ul style="list-style-type: none"> <li>▶ With planned hospital admissions, liaise with family about keeping their child up-to-date with school work.</li> <li>▶ Assist in maintaining school friendships.</li> <li>▶ Ensure child gets additional support in school post-surgery, a shortened day or different equipment, if required.</li> <li>▶ If necessary, liaise with relevant hospital or home tuition service.</li> </ul>	
<b>Emergency care</b> <ul style="list-style-type: none"> <li>▶ Child may have to be admitted to hospital unexpectedly from home or school.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Liaise with family re warning signs and prevention strategies.</li> <li>▶ With emergency admissions, liaise with family re current situation and when their child will be well enough to return to learning.</li> </ul>	<ul style="list-style-type: none"> <li>▶ School nurse.</li> <li>▶ Muscular Dystrophy UK: alert cards, individual healthcare plan (free).</li> <li>▶ Specialist nurse/NCA.</li> <li>▶ Chapter 5: Health issues.</li> <li>▶ Medical alert.</li> </ul>
<b>Eating and drinking</b>		<ul style="list-style-type: none"> <li>▶ Chapter 5: Health issues.</li> </ul>
<b>Breathing</b>		<ul style="list-style-type: none"> <li>▶ Chapter 5: Health issues.</li> </ul>
<b>Medication</b>		<ul style="list-style-type: none"> <li>▶ Chapters 5 and 7: Health issues, Educational and school policies.</li> </ul>

For a child with a muscle-wasting condition, there are likely to be a several external professionals seeing the child and guiding staff. It is helpful for ongoing review and assessment if the school keeps a record of the name, contact details, involvement and contribution of every professional involved with the child. A communication book, used by school and parents, provides a useful two-way communication channel for school and external professionals to keep in touch with parents.

While at school, a child may have many different needs to accommodate within the curriculum. It might be useful to use an individualised timetable to record when care is needed.

An example of a 'weekly overview' is given on page 31, with completed tasks highlighted. A blank copy, which can be photocopied or downloaded, is included in Appendix 1.

Things to be recorded on the form include:

- ▶ mobility and postural needs (changes in seating from wheelchair to class chair)
- ▶ therapy input from an OT or physiotherapist
- ▶ use of standing frame
- ▶ wheelchair training
- ▶ specific activities for children with learning difficulties.

It is important to keep a record of actual achievements against the plan. Information should be recorded about the child's physical abilities and the assistance required for each activity. Keep parents informed when any activity has not been implemented.













## A pupil support timetable

(For blank form see Appendix 1)

Pupil \_\_\_\_\_

Support staff \_\_\_\_\_

Monday	PE 	Numeracy 	Break	Literacy 	Break	History	RE
Tuesday	Literacy	Numeracy		Science 		Geography	Music
Wednesday	DT 	Literacy		Numeracy		Science 	History
Thursday	Numeracy	Literacy		Geography		Science 	ICT
Friday	Literacy 	Numeracy 		PE		Art 	Music

-  Powered chair
-  Standing frame
-  Walking with rollator
-  Specialist chair
-  Physical management routine

### Comments

Monday \_\_\_\_\_

Tuesday \_\_\_\_\_

Wednesday \_\_\_\_\_

Thursday \_\_\_\_\_

Friday \_\_\_\_\_

## 2.4 Secondary school

### Introduction

Moving on to secondary school can be exciting, challenging and worrying for all pupils, whether they have a medical condition or not. As a teacher, you are aware of this and are experienced in helping new pupils integrate successfully and establish their place within the school. For those pupils with a physical and/or learning disability, as for those with some muscle-wasting conditions, it is important to plan ahead to achieve the same goals. There are people and organisations to help you. Your school will most likely have a SENCO/ASN Scotland, who is responsible for organising planning meetings and in-service training about the pupil's needs.

### Other sources of information and support include:

- ▶ parents
- ▶ NCAs
- ▶ OTs
- ▶ physiotherapists
- ▶ other health professionals
- ▶ Muscular Dystrophy UK
- ▶ Trailblazers' reports and top tips for young people, written by young people.
- ▶ Disability, Information, Advice, Support Service (England) – [iassnetwork.org.uk](http://iassnetwork.org.uk) (should be in every Local Authority)
- ▶ Independent Parental Special Education Advice (IPSEA) – [ipse.org.uk](http://ipse.org.uk)
- ▶ Special Educational Needs and Disability (SEND) Code of Practice 20154 0-25 [www.gov.uk](http://www.gov.uk)
- ▶ Department for Education and Department of Health, England – applies to 0-25 years in education or training
- ▶ Children and Families Act 2014
- ▶ Enquire (the Scottish Advice Service) for additional support for learning [www.enquire.org.uk](http://www.enquire.org.uk)
- ▶ Children in Scotland National Agency for voluntary, statutory and professional organisations working with children and their families in Scotland [www.childreninscotland.org.uk](http://www.childreninscotland.org.uk)

## 2.5 Key Stages 3 and 4

Not every pupil with a muscle-wasting condition will require additional support. For those who do, the scale will vary considerably. For example, it may vary from requiring extra time to get from class to class, to one-to-one support for all educational needs and personal and domestic activities.

Schools should identify and support pupils with SEN. Pupils may be supported from within the school's own resources under SEN support, or an Education Health Care Plan (EHCP) (a Co-ordinated Care plan in Scotland, or an SEN Statement in Northern Ireland) provided by the Local Authority (LA).

During this time of transition to adulthood, it is worth remembering that pupils with a muscle-wasting condition will experience the same feelings as their peers. In addition, they may be dealing with feelings of uncertainty about how their condition will affect their future hopes and aspirations.

For those with a life-limiting, progressive condition, parents and all adults involved need to liaise closely to agree how much, by whom and when the pupil is to be told about their condition. Schools may wish to consider establishing a support network for these pupils and for staff and peers who work closely with them. (This may be the case for siblings of children with muscle-wasting conditions too.)

<b>School issues</b>		
<b>Issue</b>	<b>Strategy</b>	<b>Resources</b>
<p><b>Identifying challenges</b></p> <ul style="list-style-type: none"> <li>▶ Knowledge of the pupil and their muscle-wasting condition.</li> <li>▶ How schools ensure that staff are aware of adjustments that may be required for the pupil to access the full curriculum.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Ensure the SENCO or equivalent, takes responsibility for: organising familiarising school visits for pupil and parents pre-start date; providing specific information about pupil to relevant teaching and support staff (could be through SEN support).</li> <li>▶ Provide general information about the condition to departments through whole school INSET; review INSET needs regularly to ensure new staff are fully briefed.</li> <li>▶ Do forward planning for potentially sensitive areas of the curriculum, for example, biology, relationships.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Pupil.</li> <li>▶ Parents.</li> <li>▶ NCA.</li> <li>▶ OT.</li> <li>▶ PT.</li> <li>▶ Neurology Consultant (NC).</li> <li>▶ General Practitioner (GP).</li> <li>▶ Children and Families Act 2014.</li> <li>▶ Local IASS.</li> <li>▶ IPSEA.</li> <li>▶ Equality Act 2010.</li> <li>▶ SEN or EHCP (equivalents in Northern Ireland and Scotland).</li> </ul>
<p><b>Assessing the pupil:</b></p> <ul style="list-style-type: none"> <li>▶ Consider whether SEN support or an EHCP/CSP assessment is required.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Assess whether the child's physical/cognitive condition is affecting his/her mobility and ability to learn.</li> <li>▶ Monitor record and review the situation.</li> <li>▶ Call multi-agency meetings and, when necessary, establish whether SEN support (funded through the school's own resources) or an EHCP (Scotland and NI equivalents) needs assessment is required.</li> <li>▶ Where the school cannot meet the pupil's needs, notify the Local Authority who must agree to carry out an EHCP/CSP needs assessment.</li> <li>▶ Assess the pupil's moving and handling needs.</li> </ul>	<ul style="list-style-type: none"> <li>▶ As above.</li> <li>▶ Local Authority Moving and Handling Standards, Policies and Procedures.</li> </ul>

<b>School issues (continued)</b>		
<b>Issue</b>	<b>Strategy</b>	<b>Resources</b>
<p><b>Physical access</b></p> <ul style="list-style-type: none"> <li>▶ Pupils with mobility needs may move slowly, making them vulnerable in congested corridors.</li> <li>▶ Wheelchair users can add to the congestion in corridors.</li> <li>▶ Careful planning can minimise these hazards.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Draw up an individual access plan (referring to moving and handling assessment) to ensure inclusion in all school activities.</li> <li>▶ Seek advice from health, local authority and health and safety personnel.</li> </ul>	<ul style="list-style-type: none"> <li>▶ As above.</li> </ul>
<p><b>General subject and departmental issues</b></p> <ul style="list-style-type: none"> <li>▶ Access to all subjects.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Carry out risk assessments where required, to enable pupils to carry out tasks. Staff should acknowledge the difference between 'unconventional' and 'unsafe' ways of doing things, for example, leaving class early to avoid congestion/busy passages.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Health and Safety Executive guidance on moving and handling in health and social care.</li> <li>▶ Local policy</li> <li>▶ NCA.</li> <li>▶ OT.</li> <li>▶ PT.</li> </ul>
<p><b>Emotional issues</b></p> <ul style="list-style-type: none"> <li>▶ The pupil with a progressive condition may experience emotional feelings of loss, owing to ongoing loss of mobility, which may be reflected in behaviour, attitude and school work. Parents may also experience emotional feelings displayed in their behaviour. Staff working closely with pupils may also experience similar emotional feelings.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Ensure staff members receive training in disability awareness and have access to counselling. This will ensure staff members are able to anticipate and respond appropriately to the pupil's needs; staff members are able to recognise their own limitations and when to seek help; staff are aware of when parents need support and are able to seek advice on managing more complex issues. Ensure there is a support network available in school for pupils to express their feelings, with onward referral, as required.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Parents.</li> <li>▶ Pupil.</li> <li>▶ Peers.</li> <li>▶ Staff.</li> <li>▶ NCA.</li> <li>▶ OT.</li> <li>▶ PT.</li> <li>▶ Muscular Dystrophy UK publications.</li> <li>▶ Bereavement counselling publications.</li> <li>▶ Psychologist.</li> </ul>
<p><b>Puberty, sexual health and relationship issues</b></p> <ul style="list-style-type: none"> <li>▶ Pupils with muscle-wasting conditions will generally experience the same issues as their peers. In addition, those on steroid treatment (such as those who have Duchenne muscular dystrophy) may experience delayed puberty, which can affect behaviour.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Where there are sensitive issues, offer pupils one-to-one discussions. Encourage staff to seek advice from relevant professionals and organisations.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Pupil's medical team, NCA; OT; PT.</li> <li>▶ Muscular Dystrophy UK (including Trailblazers relationship report: <i>It's complicated</i>).</li> <li>▶ Counselling.</li> <li>▶ Talking about sex, sexuality and relationships – guidance and standards <a href="http://www.open.ac.uk/health-and-social-care/research/sexuality-alliance">www.open.ac.uk/health-and-social-care/research/sexuality-alliance</a></li> </ul>

<b>School issues (continued)</b>		
<b>Issue</b>	<b>Strategy</b>	<b>Resources</b>
<p><b>Puberty, sexual health and relationship issues (continued)</b></p> <ul style="list-style-type: none"> <li>▶ At an age when pupils are highly self-conscious, they may rebel against wearing orthotics, special footwear or using a mobility aid.</li> </ul>		
<p><b>Medical and therapeutic issues</b></p> <ul style="list-style-type: none"> <li>▶ A pupil may have routine medical and/or therapeutic requirements, which need to be planned for. It is also important to bear in mind unexpected hospital admissions.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Include medical and/or therapeutic sessions in the pupil's SEN support plan or the EHCP/CSP. Do note: a particular therapy can be included in a SEN or EHCP/CSP even if it is not available from the local health service. It should be treated as special educational provision, not health or social care provision. For unexpected or prolonged hospital admissions, consider hospital or home tuition.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Children and Families Act 2014.</li> <li>▶ Hospital tuition service.</li> <li>▶ Home tuition service.</li> <li>▶ IT.</li> <li>▶ NCA.</li> <li>▶ OT.</li> <li>▶ PT</li> <li>▶ NC.</li> </ul>
<p><b>Policies and managing risks</b></p> <ul style="list-style-type: none"> <li>▶ Safeguarding; Safer Moving and Handling; Personal Egress and Evacuation Plans (PEEP), Emergency Evacuation Procedures.</li> <li>▶ School uniform policy: pupils who are wheelchair users, wear splints or have poor hand function, for example, may have difficulty adhering to the policy.</li> <li>▶ Examination arrangements: pupils may need adjustments in order to complete exams.</li> </ul>	<ul style="list-style-type: none"> <li>▶ The school should come to an agreement with parents and pupil about what clothing is acceptable. Make reasonable adjustments to the uniform policy. The pupil and parents should be aware of the agreed extra help (called access arrangements) in public examinations. A scribe; ICT support and/or extra time may be provided in line with the Examination Board procedures. Pupils should be allowed to practise agreed adjustments before the exams.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Guidance from the Examination Board.</li> <li>▶ NCA.</li> <li>▶ OT.</li> <li>▶ PT.</li> <li>▶ NC.</li> </ul>

<b>School issues (continued)</b>		
<b>Issue</b>	<b>Strategy</b>	<b>Resources</b>
<p><b>Transport</b></p> <ul style="list-style-type: none"> <li>▶ Some pupils with muscle-wasting conditions may need a car or an adapted vehicle to get to and from school, and on planned trips. Arrival and exit from school need to be considered.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Document the pupil's transport needs in their SEN support plan or EHCP/CSP. It should state the type of vehicle required, how often it will be needed; escorts required; who will provide and who will fund. Arrangements for school arrival and exit need to be made. Identify suitable set-down and pick-up points. Ensure support staff and/or peers are available. This could also include plans for independent travel to and from school, as well as disabled parking spaces.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Local Authority (LA) policy on home-school transport; Children and Families Act 2014; LA-recommended transport contacts; parents; peers; staff.</li> </ul>
<p><b>Transition</b></p> <ul style="list-style-type: none"> <li>▶ As well as transitioning through the education system into further or higher education/careers/apprenticeships, young people with muscle-wasting conditions will also transition from children's' health and social services to adult services. For some, this will be minor; for others, it will be more challenging as it will involve changing healthcare professionals, for example, medical team, therapy services, adult wheelchair services, adult social care.</li> </ul>	<ul style="list-style-type: none"> <li>▶ For children aged 13 or 14, find out if a neuromuscular care advisor is involved. Invite them to SEN and EHCP/CSP reviews along with relevant health and/or social service staff. Ensure organisations work together, with the parents' consent, by sharing relevant information that will assist the pupil to prepare for transition. There may also be work being carried out by the neuromuscular team to support, plan and inform ahead of the move. This needs to dovetail with work undertaken in school.</li> <li>▶ Transitional review.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Local careers advice. If the pupil can't name an NCA you will be able to find one for the area on the Muscular Dystrophy UK website.</li> <li>▶ NCA.</li> <li>▶ OT.</li> <li>▶ PT.</li> <li>▶ NC.</li> </ul>

## 2.6 Parents' checklist

### Deciding on a school for your child

All parents need to consider their children's specific needs when deciding which school is best for them. You should be able to choose from the widest range of mainstream and SEN schools, private and public, in your area. Senior specialist staff in these schools should advise parents about:

- ▶ existing facilities, support services, policies and procedures for pupils with disabilities
- ▶ specific changes to the building structure, timetables, etc., that would be planned and implemented for your child
- ▶ access to the school's curriculum
- ▶ school ethos, including partnership with parents (respecting your wishes, for example, about what your child and other children are told about the muscle-wasting condition), bullying, complaints management.

This checklist is designed to be as comprehensive as possible. Many schools may not have dealt with some of these issues before and will have to put facilities and support in place for your child.

### Looking at written information (prospectus) about the school

- ▶ Does the prospectus indicate what, if any, facilities are available for pupils with disabilities?
- ▶ Does the prospectus welcome pupils with disabilities, and is there space on the application form to detail your child's individual needs?

### Looking at the school buildings

- ▶ You should tour the building with a senior specialist advisor at the school and the NCA or other healthcare professional.
- ▶ Are all areas of the building accessible? (Look at school layout, furniture, equipment, noise levels, and lighting.)

- ▶ Is it easy to find your way around the building? Will help be given? Are notices at the correct height for wheelchair users?
- ▶ Are doorways wide enough for wheelchairs? Do they open safely? These considerations also need to apply to any temporary buildings your child might use.
- ▶ If there are access difficulties, will alternative rooms be used?
- ▶ Is there access to the science, art and music rooms?
- ▶ Is suitable seating available, along with a range of table heights or adjustable-height furniture?
- ▶ Is there a lift? How much of the building can be accessed via the lift? Will your child have independent access to the lift (for example, a fob to use the lift independently)? Are call buttons accessible?
- ▶ Is there privacy for the toilets? Are the toilets adapted to meet your child's needs? Is a Cloimat toilet available?
- ▶ Is there a quiet rest area or somewhere to 'chill out' with a friend?
- ▶ How accessible is the dining area? Can a wheelchair user move around the dining hall easily? Are there adjustable tables? Are the counter and cash desks at the right heights? Can the dining staff have eye contact and also hear what wheelchair users are saying?
- ▶ Are there lockers for pupils? If not, can pupils leave personal possessions, such as laptops, in a secure place? Is it near the school entrance?
- ▶ Is an accessibility plan in operation at the school?
- ▶ What are the emergency procedures for evacuating pupils with impaired mobility, or wheelchair users? Can more than one pupil be evacuated at the same time? If not, what is the time delay between individual evacuations? What arrangements are in place if no safe evacuation is available? Is there a safe holding area? Is the fire service aware

that the school has pupils with impaired mobility, or who are wheelchair users?

- ▶ What building work is likely to be taking place in the future?

### Accommodating your child's needs

- ▶ How will your child's care and learning needs be assessed and monitored? How will you be involved in planning the provision to meet your child's needs?
- ▶ Will the school respect your views and take them into consideration?
- ▶ What channels of communication are in place for home/school liaison (for example, diaries, planners or drop-in sessions)?
- ▶ What general provision is made for practical issues, such as carrying bags, help with dressing, help at lunch and break times, printing class work and homework, etc.?
- ▶ Is there a manual handling policy? Was this recommended by the LA or by therapists?
- ▶ Can lessons be re-timetabled to take into account your child's needs?
- ▶ Are children with disabilities segregated because of support needs? Do teaching staff rely on educational support assistants (ESAs) to partner them?

### Access to support needs and support staff

- ▶ How will the school assess the level of support staff (educational support assistants) for your child?
- ▶ How often is this provision reviewed?
- ▶ What academic needs will the ESAs address?
- ▶ What care and support needs will the ESAs address? Will there be support provided at lunch and breaks? What help is available to those who may need feeding, and how is this implemented? Do they respect the child's instructions? Is sufficient time allocated to helping children eat?
- ▶ What lunchtime arrangements are in place to help pupils collect their meals?

- ▶ Do dining room and canteen staff understand why children need furniture at a specific height?
- ▶ What care and support is provided for personal care needs, such as going to the toilet?
- ▶ Do trained staff members understand the need for discretion to maintain the child's dignity (respecting confidentiality, for example, or leaving the pupil alone and returning when summoned)?
- ▶ What happens if the child needs change? (Some children wear pads and can soil themselves without realising it. Other children may have an accident.) Is the right equipment available?
- ▶ When the ESAs are absent, is somebody else trained to step in?
- ▶ What records will be kept for informing staff of how to deal with your child's needs?
- ▶ What special training will be available for staff?
- ▶ Can your child receive the physiotherapy and occupational therapy he or she needs, during or after school?
- ▶ Will your child be able to use a standing frame or an upright wheelchair during school time?
- ▶ Are meaningful, academic activities available, when pupils are in standing frames?

### Access to the curriculum

- ▶ How will the school make the full curriculum accessible for your child?

### General issues

- ▶ How will the school alert you to any problems with your child's learning?
- ▶ Will you be told if homework is late or not being done?
- ▶ Is there a homework timetable, or pupil planner?
- ▶ Does an ESA check that homework is recorded properly?
- ▶ Are staff members careful not to give out homework at the end of the day when



your child may be rushing for a bus or taxi?

- ▶ Can your child leave lessons earlier/later/at the front of the queue?
- ▶ Will homework be provided if your child is unable to attend for a long period?
- ▶ Will notes of missed lessons be available from pupils or support staff? (LAs provide cover, which can be used for this purpose.)

### Sports and PE

- ▶ How will your child's PE abilities and potential be assessed?
- ▶ Will your child have full access to PE, including swimming?
- ▶ Is there an inclusive PE policy?
- ▶ Is specialist equipment available?
- ▶ Will your child have the opportunity to participate in all team sports?
- ▶ What is the swimming provision at the school?
- ▶ Is there access to an indoor heated swimming pool with hoists, wheelchair access changing area and showers?
- ▶ Is swimming timetabled to allow enough time to get changed?

### Information and communication technology (ICT), design technology, equipment and science labs

- ▶ Will your child have full access to ICT, design technology and science labs?
- ▶ What additional equipment is available (for example, computer-aided design equipment)?
- ▶ Can an ESA set up ICT equipment at the beginning of the lesson?
- ▶ Is there a system for safely transporting and storing laptops?

### Extra-curricula activities and trips

- ▶ How will your child be included in clubs and after-school activities?
- ▶ Is transport available for after-school clubs and are they accessible?
- ▶ What training do staff members at after-school activities receive about pupils with disabilities?

- ▶ What transport arrangements are available for pupils with disabilities?
- ▶ What support is available for residential trips? Are parents expected to attend, or are they discouraged from attending?

### Work experience

- ▶ Are there resources/funds available to facilitate work placements for pupils with disabilities?
- ▶ Does the school positively promote work placements for pupils with disabilities?
- ▶ Is a member of staff responsible for access audits/risk assessments of placement providers?
- ▶ Are the staff members who are involved in placement development, fully-trained in disability awareness?

### Homework

- ▶ Will your child's level of abilities be considered before homework is given?
- ▶ Is there a supervised homework club?

### Pastoral care

- ▶ What is the school's anti-bullying policy?
- ▶ Will pupils be made aware of your child's needs – to understand why some children use wheelchairs and standing frames, for example?
- ▶ Are pupils made aware of the safety issues of some disability equipment?
- ▶ Who is responsible for mentoring pupils who are facing emotional difficulties?
- ▶ Does the school refer to external sources, such as Muscular Dystrophy UK, or an NCA, for support when appropriate?
- ▶ Do pupils get a chance to mingle without adult supervision?
- ▶ How are complaints handled? Who is the appropriate person? Will your child have easy access to a SENCO?

### Getting to school

- ▶ How long will your child be on transport in the morning?
- ▶ Can he or she attend later?
- ▶ Are there alternative methods of

registration to avoid signing a late book (for example, letting the ESA sign the register)?

- ▶ Does the school telephone parents when transport arrangements change, owing to emergencies, fire drills or bad weather?

### School governance and parental choice

- ▶ What criteria are in place for offering places and how will support be funded?
- ▶ Is disability training available to school governors?
- ▶ Is there a governor who takes an interest in SEN?
- ▶ What is the appeal process, if you don't get a place for your child at this school?

# Chapter 3

# Working together – roles and responsibilities

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## 3.1 Education guidelines

### Education staff

Team work is the only way to provide an effective school response to meeting the changing needs and abilities of pupils with muscle-wasting conditions. Liaison between school staff and external agencies is vital, and the identification of a key worker within school essential.

Any member of school staff can be the key worker, but it should be someone who can build a relationship with the pupil. The key worker helps staff plan and manage the pupil's development on a daily basis, setting clear objectives to maximise independent mobility, and encouraging the use of gross and fine motor skills. The school ethos should aim to ensure the continuing development of social skills and self-esteem throughout school life.

Learning targets should be discussed individually with parent/child.

### Head teacher

The head teacher is responsible for the organisation, management and control of the school, and takes guidance from quality improvement officers and head of service from the local council. The head teacher has overall line management responsibility for staff, although the scale of this task can vary, depending on the size of the school. In a large secondary school, for example, there will be several tiers of management. A small primary school, however, may have relatively few staff and the head teacher could also have direct teaching commitments or additional co-ordinator responsibilities.

### Support staff

Every school has a designated member of staff who is responsible for co-ordinating special educational needs provision within the school. This person is called the Special Education Needs Co-ordinator (SENCO), Additional Support Needs (ASN), or an Inclusion Manager.

For further information on additional support for learning in Scotland, please contact [enquire.org.uk](http://enquire.org.uk)

Working with the head teacher, senior managers and colleagues, the SENCO/ASN should be closely involved in the strategic development of SEN/ASN policy and provision. He or she will also have responsibility for the day-to-day operation of the school's SEN/ASN policy, co-ordinating provision for pupils with SEN/ASN.

The SENCO/ASN often has line-management responsibility for ESAs who enable individuals who have SEN to participate in every aspect of school life. The SENCO/ASN will also organise training opportunities for colleagues as appropriate.

### Class teacher/form tutor

A class teacher works in a primary school and often has additional responsibility for an area of the curriculum. Primary school classes are usually comprised of pupils of the same age. Secondary schools allocate pupils to a form tutor who, as well as having pastoral oversight of those children, also works within a particular faculty in the school. A class teacher or form tutor with responsibility for a pupil with a muscle-wasting condition should understand how the condition will affect the pupil's learning. They will supervise

the support staff to work alongside the pupil in their lessons, and liaise with parents, the SENCO/ASN and a range of outside agencies.

### **Educational support staff (ESS)/Pupil Support Assistant (PSA) Scotland**

An ESS/PSA will work closely with the class teacher. They also spend considerable time working directly with the child to help him or her be as independent as possible, while managing a progressive medical condition. An ESS/PSA will support different curriculum areas which have been identified by the school and the Local Authority (LA). The number of hours an ESS/PSA works will reflect the changing needs and physical abilities of the pupil.

### **Lunchtime staff**

Schools appoint their own lunchtime supervisors and assistants. Sometimes, a school will employ an additional lunchtime assistant to cater for the needs of a pupil with a muscle-wasting condition. The assistant works alongside other supervisors but may have a specific duty to oversee the safety and welfare of a particular child who could need help, for example, with feeding, or going to the toilet. Supervision should be discreet, so the pupil's dignity and privacy are respected, and they are able to interact with their peers without a constant adult presence. It is important to include lunchtime staff in training sessions held to inform school staff about the diagnosis.

### **Advisory teachers (England only)**

An advisory teacher has specific responsibility for co-ordinating the LA's response to pupils who have physical and medical difficulties. Advisory teachers work alongside teachers and LA officers. They often have a wealth of experience of working with children who have a wide variety of needs. They have knowledge, which is transferable, and often access to advice about equipment that can assist learning activities. They may also have contact with planning departments and other specialist services.

Advisory teachers work with OTs, PTs and voluntary agencies, and maintain close contact with parents. Their concern is the overall wellbeing of the pupil, as well as his or her educational progress. They will often be involved with statutory assessment procedures, the annual review process, and any tribunal hearings brought under the Special Educational Needs and Disability Act 2014.

### **Educational psychologist (EPs)**

EPs are highly skilled and trained in meeting the needs of young people with complex needs.

EPs work in collaboration with pupils, parents, schools, education departments and other agencies. They use their expertise in psychology to help understand and meet the needs of children and young people who may be experiencing learning, behavioural, developmental, social or emotional difficulties.

EPs use a variety of approaches: whole-school development work, staff training, collaborating with relevant groups of people (parents and pupils, for example), one-to-one work with the pupil, or a combination of these strategies. EPs also help schools promote the mental health and wellbeing of pupils. They do this by, for example, offering advice and support on developing self-esteem, as well as guidance on issues such as bereavement and bullying.

### **School nurse**

The role of the school nurse varies between different authorities and schools. Some secondary schools may have a nurse on site, who will be involved in developing, implementing and monitoring a pupil's Health Care Plan. The school nurse should be aware of all children in the school who have muscle-wasting conditions so he or she can liaise, when necessary, with other healthcare professionals.

### Neuromuscular care advisor (NCA)

The local NCA is a valuable resource to co-ordinate and disseminate healthcare information within primary and secondary schools. They often attend school meetings to discuss the appropriate care plans of SEN/ASN. Sharing specific information about their condition has a positive impact on the learning experience of a pupil with a muscle-wasting condition.

### Community paediatricians

Community paediatricians specialise in the care of pupils and young people (from birth to 19 years of age), who have additional medical needs. They review a pupil's progress throughout his or her school life. Following the diagnosis of a muscle-wasting condition, the community paediatrician may advise the education authority and possibly request an EHCP/CSP assessment. They may refer the pupil to the Paediatric Therapy Service and may also take part in the review process if an EHCP (equivalents in Scotland and Northern Ireland) is in place. Ideally, when a pupil is nearing the end of his or her school career, the community paediatrician should liaise with the careers advisor, health teams, education department and social services.

### Education Welfare Officers (England)

Education Welfare Officers work closely with schools and families to resolve attendance issues and promote effective working relationships between home and school. They help parents meet their responsibilities to secure education for children and young people, and promote regular school attendance. Each school maintained by the LA has an Education Welfare Officer who is responsible for the attendance of all pupils in the school. The Education Welfare Service works within a statutory framework. In many schools, a Pastoral Care Officer will adopt this role.

### Quality Improvement Officers (Scotland)

In Scotland, there are no Education Welfare Officers however, there are Quality Improvement Officers. They have responsibility for ASN, Getting It Right for Every Child (GIRFEC), and social work, and in addition they advise schools. Most schools have a school social worker, but their remit is very large and they are often shared across local authorities for a huge number of schools. In these instances, some schools deal directly with their local Social Work department.

### Learning mentors

Learning mentors provide a complementary service to teachers and other staff. They address the needs of learners who require help in overcoming barriers to learning in order to achieve their full potential.

### Outreach service – Scotland

In Scotland, there are no learning mentors, however there is an Outreach Service. Here, specialist trained teachers work one-to-one with pupils from a number of schools, on a priority basis. There are strict criteria for getting this additional support and, as these vary, they should be discussed with your NCA.

### Specialist educational needs and disability information advice and support services (SENDIASS, formerly known as Parent Partnership Services), and Mediation Services (Scotland)

The SENDIASS (England) and Mediation Services (Scotland) provide impartial information and guidance for parents and pupils with SEN/ASN on how SEN/ASN procedures are implemented by schools and LAs. These services aim to support and empower parents to play an active role in their child's education. They can also mediate if parents find themselves in disagreement with a school or LA.

## 3.2 Working with parents and the child

Parents have a critical role in their child's education. They have unique strengths, knowledge, information and experience, which are vital to develop an overall view of their child's needs and to develop plans to support him or her.

Strong and clear communication between home and school is essential for an effective working relationship to develop. This may mean regular, planned meetings and a 'home/school meeting book'. Many parents may feel overwhelmed by the range of statutory assessment procedures, as well as the number of professionals they have to meet. Parents are asked to attend many meetings and appointments, which can be, extremely stressful and emotionally and physically demanding.

As muscle-wasting conditions are genetic, parents may also be affected. If they too have a disability, it may be helpful to know how it affects them and, therefore, how it is likely to progress.

Take into account cultural and religious differences when managing a pupil's personal care and intimate hygiene procedures. You may need to make use of culturally-specific services for passing information on to school staff and promoting good communication between school and home.

Religious and cultural groups deal with medical conditions and disability in a variety of ways. Most muscle-wasting conditions are genetic, and this can be a sensitive issue for some families. At the time of diagnosis, all parents should be offered counselling through their local health services. However, some families may react differently to this information and may or may not wish to share it with school staff. Parents may choose not to inform the child of the pattern or

potential outcome of his or her condition, particularly when the condition is life-limiting.

At times, schools may need to take the initiative with parents to find out what they have told the pupil. In the case of a younger child, schools should work closely with parents and respect their views to ensure that the pupil receives the same information at home and school. Any difficult questions posed by the pupil should be considered in advance, if possible, and discussed with the parents.

When a child reaches secondary school, there needs to be close liaison between parents and school. Parents and teachers need to be aware that a pupil in secondary school may use the internet to find out about his or her condition and its progression. Information learnt this way could come as a shock to the pupil and put the school in a difficult position.

It is crucial however, for the wellbeing of the pupil, that both parents and school discuss the issues around knowledge and treatment, to develop a united approach. Work with the child and listen to his or her needs.

Children can also become wary of the number of professionals they encounter, each appearing to make decisions about their life. It is particularly important, as they become older and more aware of their physical differences, that children are encouraged to participate in and contribute to discussions about their education.

# Chapter 4

# Social, emotional and psychological support

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Schools work in partnership with the multi-disciplinary team to support children with muscle-wasting conditions, along with their families. For this to be effective, schools must fully understand both the diagnosis and prognosis of the condition, and the physical changes that are likely to take place in the child during his or her time at school. SEN advisors and physical difficulties teaching advisors are employed by the LA, and can offer advice and information. The NCA and healthcare professionals will visit schools to give specific advice.

They can also provide information towards the formulating of an EHCP (SEN Statement in Northern Ireland, Co-ordinated Care Plan in Scotland).

## 4.1 Dealing with diagnosis

Everyone handles news of a diagnosis with a muscle-wasting condition in their own way. Where the prognosis of the condition is life-limiting, there is likely to be a wide range of reactions. What all parents must face, however, is the reality of living with their child's progressive condition. Coming to terms with a diagnosis can often mean a period of fluctuating emotions for the entire family, and this could continue for a long time. Some feelings may re-surface as the condition progresses and the child begins to lose specific skills.

Most families will have been given an accurate diagnosis and prognosis, but may be unable to emotionally process and deal with the information they have received. Some families choose to tell their child everything about the condition, some say nothing, and others give their son or daughter limited

information. There is no right or wrong way. Each family finds their own way of managing this with the support of professionals, as and when needed, for direction and support.

Some parents find being active on social media offers them a form of support and another way of being in contact with other parents for peer support and guidance.

Families are likely to have strong views on what their children should and should not know about their condition. It is vital that schools sensitively raise the issue with the family about what the child has been told, and find out whether the information he or she has been given is age-appropriate. Staff members need to understand what the parents' views are about sharing information, and the importance of working together with professionals to develop a plan to support their child and the wider family.

Difficulties can arise, for example, if an older child searches on the internet for information about his or her condition and begins to ask questions that require honest answers. Similarly, schools also need to be aware of how much the affected child's siblings understand.

Agree with the parents on appropriate and consistent responses to be given to questions asked by the child. These responses should be included in the whole school plan, so other staff members are aware of what to say. A few parents want to protect their children from the reality of the situation and, in these cases, it may be necessary to seek specialist advice to ensure that the needs of the child are being met.

## 4.2 General support for the child, family, staff and pupils

Muscular Dystrophy UK has developed helpful guides for parents and/or carers of children recently diagnosed with a muscle-wasting condition. The aim is to offer support and information to families at this difficult time, and to answer the questions most parents/carers ask. (See Resource list.)

The family should have access to support from a specialist medical team via their local paediatrician, and health and social care professionals. In some areas, there may be support groups that enable families to meet other families in similar situations. In addition, they may be offered psychological support, via their GP, from a clinical psychologist or EP. Many families with children with life-limiting conditions access support from their local children's hospice, where they may go for respite care and to meet other children with the same condition. Hospices offer a wide range of services to support the whole family, including siblings groups, counselling, training and professionals that can offer support through different stages of the child's life especially around the difficult times such as end-of-life, or when the condition deteriorates.

### Support for siblings

It is important to remember that the siblings of children with muscle-wasting conditions will have needs of their own. Some older siblings may well be aware of the diagnosis and prognosis, while others may be worried and not feel able to ask the questions they may have. Even younger children will be aware there is 'something different' about their sibling.

Many siblings can feel left out of what is going on, and may have feelings of loss, jealousy, guilt and anxiety. These are quite normal, as their lives have changed too. If you are concerned about the sibling of a child with a muscle-wasting condition, it is

important to raise the subject, in a gentle manner, with the family and agree on an appropriate support plan. Siblings may benefit from having someone to talk to who is outside the family, and it could be helpful for them to know that there is an identified adult in school who can provide them with emotional support. A learning mentor could undertake this role.

A book for siblings of children with muscle-wasting conditions is available free of charge from Muscular Dystrophy UK.

### Staff support

Having a child in the classroom with a life-limiting and progressive condition will have a practical, emotional and psychological impact on staff. They will need information about the condition and the expected effect on the child, including how to manage this in a classroom setting. A whole-school approach should be developed to ensure the changing needs of the child are fully understood by all staff, including support staff, such as lunchtime supervisors and visiting teaching staff. Staff and ESAs develop a close relationship with the child and can be asked searching questions by the child. Having the knowledge and confidence to manage these situations encourages an open and honest approach that, in turn, supports the child and family.

Thought needs to be given to support staff working closely with the child, as well as those who have experienced a recent bereavement or have children of a similar age. These support staff may be particularly affected by the reality of working with a child with a progressive condition. Senior management needs to be aware of the possible impact on staff and provide appropriate support.

### Supporting other pupils

The whole-school approach should consider the emotional and psychological needs of all the children. Other pupils might not know the diagnosis, but keeping disability



on the timetable and regularly re-visiting it as a school can highlight and encourage an awareness of the general issues about disability and changing needs. For example, if one pupil needs to use a wheelchair sometimes, but walks at others times, this encouraging of awareness of children's changing physical needs as a school combines an individual and a wider school approach. Special attention may also need to be paid to the child's close friends.

Get in touch with Muscular Dystrophy UK for the latest publications about disability, which are available for children.

### 4.3 The child's needs

Support for the child's mental health and wellbeing is essential. Professionals can provide this, but children will often seek support from those people they feel comfortable with at school. It may be that they will ask an ESA or a lunchtime carer searching questions about their condition.

Often valuable support for a pupil with a muscle-wasting condition comes from another pupil with a similar condition. Liaison with a NCA/specialist nurse or local paediatrician can provide opportunities for this connection, or events and support groups organised by MDUK.

Understanding a child's condition is important in creating realistic expectations for him or her. It is essential to concentrate on what children can do rather than what they can no longer do. Let them make their own decisions, even when they are physically unable to perform certain tasks. Allow them, for example, to make their own choices at lunchtime, rather than having decisions imposed on them by an adult.

Working towards social inclusion can be difficult and it is important to give children the opportunity to integrate with their peers,

without adult supervision. A 'buddy' or peer support system can be particularly helpful during break and lunchtimes to promote positive social interaction. Schools should also promote positive role models of disabled people throughout the curriculum.

#### Behavioural challenges

All pupils need the same structure and discipline in class. The usual positive classroom management strategies should be employed in line with school pastoral policy. It is important to acknowledge and understand that a pupil with a muscle-wasting condition may have limited ways of expressing his or her feelings and could behave in an angry, frustrated, stubborn or withdrawn manner. Help the pupil deal with these feelings at the right time and in an appropriate way. The Educational Psychology Service may be able to offer help and advice. Some schools have access to a counsellor who comes into the school, or the NCA/specialist nurse may be able to offer support sessions.

#### Self-esteem and body image

Some children with a muscle-wasting condition may have experienced social exclusion as a result of their condition. They might have been unable to participate fully in many everyday activities and watched their peers and siblings develop, using skills they will never have. Their body will look different from their peers. Their self-esteem, therefore, may be low and they may have a poor body image.

It is important staff members are aware, and find opportunities to enhance self-esteem by, for example, promoting opportunities to succeed and using positive disabled role models in teaching. The personal, social, health and citizenship education (PSHCE) curriculum may provide opportunities to develop self-esteem through related activities.

### Depression and anxiety

All children can experience depression and anxiety. They may show this in a number of ways – lethargy, withdrawal, irritability, and changes in appetite and sleep patterns, lack of interest and loss of school performance. Staff should be aware of this possibility and closely monitor any impact on the child and manage the situation appropriately. These feelings are normal reactions to a progressive condition. If they are sustained over a long period of time, discuss with parents the possibility of seeking professional advice.

### Sexuality and relationships

All young people have teenage anxieties and experiences, including hormonal swings, and general anxieties around friendships and relationships. They will also wish to explore their sexuality – physically and through discussion with their peers – and should be encouraged to do this appropriately, within normal social boundaries.

A pupil with a muscle-wasting condition may have additional questions relating to his or her own physical needs and abilities, such as, ‘Will I ever have a girlfriend/boyfriend? Will anyone fancy me with my disability? Will I be able to have sex? Will I be able to get married and have a family?’ Such questions need to be answered, at school and home, in a sensitive and factual manner. There is, for example, no reason why a pupil with a muscle-wasting condition should not have sex or experience fulfilling relationships.

A pupil’s view of his or her sexual attractiveness is linked to how he/she perceives his/her body. Young people with progressive conditions will constantly be re-adjusting to a changing body image.

### Personal care

Menstruation will bring new challenges for both the young woman and the staff involved in her personal care. The subject needs to be sensitively discussed between the pupil and,

in most cases, her mother. Ideally this should happen before the start of her periods, so that consideration can be given to adding to the current personal care plan as changes occur. This avoids sudden changes and helps to smooth the process as much as possible.

During the personal care of young men, it is not uncommon for them to experience involuntary erections. Support staff need to be aware of this and may need additional training and support to deal with this sensitively. If support staff feel uncomfortable or have any concerns that a pupil’s behaviour is inappropriate, they should discuss this with their line manager.

### Loss and bereavement

There are no rigid rules in dealing with loss and bereavement. Everyone is different and every situation is different. Schools will, nevertheless, need to prepare a whole-school plan on how to deal with the death of any pupil. The plan should cover: contact with the family; informing staff, children, and other parents; providing support for staff and pupils; identifying a key person to co-ordinate; marking the death with a memorial or thanksgiving service. Many children with life-limiting conditions will have received support from their local children’s hospice, and this will continue for the family and siblings after a child has died.

The feelings of the child’s siblings and close friends at school need to be sensitively addressed. Emotions such as loss and grief can continue for a long time and it is not uncommon to be dealing with them years later.

### Key strategies in dealing with a death

- ▶ Acknowledge the death, don’t ignore it. Do something to mark the fact that someone has died. Some schools release balloons; others may have a special assembly or pastoral service.
- ▶ Tell small groups before telling the

whole school. Be aware of any 'best friends' and do something different for them, if needed.

- ▶ This is a loss for the class as well as the school. Work out with the class what to do and be led by them and their reactions.
- ▶ Don't change the layout of the classroom immediately, but do acknowledge that the young person isn't there any more.
- ▶ Let teachers and other staff show their emotions and allow them to acknowledge that they are finding it hard. Offer additional support.

#### Further support:

- ▶ Cruse Bereavement Care  
[www.cruse.org.uk](http://www.cruse.org.uk)
- ▶ Child Bereavement UK  
[www.childbereavementuk.org](http://www.childbereavementuk.org)
- ▶ Childhood Bereavement Network  
[www.childhoodbereavementnetwork.org.uk](http://www.childhoodbereavementnetwork.org.uk)
- ▶ Child Death Helpline  
[www.childdeathhelpline.org.uk](http://www.childdeathhelpline.org.uk)
- ▶ The Compassionate Friends  
[www.tcf.org.uk](http://www.tcf.org.uk)
- ▶ Mind  
[www.mind.org.uk](http://www.mind.org.uk)
- ▶ Samaritans  
[www.samaritans.org](http://www.samaritans.org)
- ▶ Winston's Wish  
[www.winstonswish.org.uk](http://www.winstonswish.org.uk)



# Chapter 5

## Health issues

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To establish all the appropriate requirements for health needs, all involved need to have some understanding of the medical condition and the impact it will have on the pupil. Planning ahead, taking into account the views and wishes of pupil and family, seeking advice from health professionals and advisory teachers, all lead to best possible outcomes.

### 5.1 Individual healthcare plan (IHCP)

It is good practice to draw up an IHCP for every child with a medical condition, irrespective of what level of support they need. This should summarise the pupil's condition, identify emergency situations and detail the procedures to follow. Schools should agree with parents how frequently the IHCP will be jointly reviewed. (The recommendation is at least once a year.)

#### Additional health information

##### Emergency care plans

Some pupils with more complex medical needs will have an individual emergency care plan for use in all settings, not just at school. These may contain detailed information on medications and medical equipment, such as non-invasive ventilation and cough assist machines. All involved need to know if a plan is in place and what to do in an emergency.

Local health teams or those from the specialist neuromuscular team will provide specific advice.

##### Alert cards

Muscular Dystrophy UK and several other charities produce alert cards for specific muscle-wasting conditions. These give a brief overview and clear advice on condition

management, when to seek help and what to do in emergency situations. Older pupils should be encouraged to carry these in their purse/wallet or phone case. Schools can also hold copies of these cards for use in emergency.

Some pupils may wear alert necklaces or bracelets.

### 5.2 Education, Health and Care Plans (EHCP)

See Chapter 7: Educational and school policies.

### 5.3 Medical emergency

If an emergency situation were to arise, it should be handled in the same way as for any pupil. Parents should be notified if the pupil is unwell. For more serious medical emergencies, an ambulance should be called. Following the guidance within IHCP/ emergency care plan or alert cards, it should be made clear to any health professionals attending that the child has a muscle-wasting condition. All supporting information should be handed to them.

### 5.4 Functional ability

#### Moving and handling

Moving and handling policies are covered in Chapter 8, and sample forms are included in Appendix 1.

#### Walking and standing

Some pupils with muscle-wasting conditions will be walking, some will use mobility equipment and others will be wheelchair users. A child's condition can fluctuate with fatigue, growth and general health. For some,

there is a noticeable and predictable change during their time in education.

Pupils who are able to walk may find it tiring to carry a heavy rucksack and bag. They may change their posture in order to cope, and this could have an adverse effect on their balance and stability. Encourage pupils in secondary schools to use lockers rather than carry heavy bags between classrooms. Support staff can help by carrying bags and equipment.

Pupils who are walking might need to use mobility equipment, take rest breaks or use a wheelchair for part of the day. As their condition changes, the young person may need to use a wheelchair full-time. This transition can occur quickly. Arm weakness can mean that children are unable to self-propel a manual wheelchair and then need to use a powered wheelchair.

Foot splints maybe worn to help walking and help prevent joint contractures. A child can feel awkward using a standing frame or Knee, Ankle, Foot Orthoses (KAFOs), particularly in a classroom during lesson time. This all needs to be sensitively handled and planned, and the pupil's PT will guide the school on when and how to do this. They may also need to be talked about, matter of factly, with the class, and the benefits of their use explained to pupils

Pupils who don't walk may benefit from therapeutic standing for part of the school day. A standing frame is used, which helps to stretch muscles and maintain range of movement in hips, knees and ankles. Standing gives a change of posture from sitting. The back, hips and legs are held in an extended position, which may help to prevent shortening of the muscles, curvature of the spine and helps maintain good function of internal organs. Some pupils may use wheelchairs that have a standing function. Not all children will stand, and for those who do, it may not continue

throughout their time at school. The child's PT will advise on what is most appropriate.

### Upper limb and hand function

Many muscle-wasting conditions cause weakness in the upper limbs. This may not be apparent on first meeting or seeing a child, particularly if he or she is using a powered wheelchair. It is easy to assume that a youngster can use his or her arms and hands normally. It is very important to determine the child's level of upper limb weakness.

In some cases, for example, a child may not be able to put his or her hand up in response, or to call for the teacher's attention. In this situation, another method of communicating with the teacher will need to be devised. The simplest tasks, such as opening a pencil case, handling books and writing for long periods of time, may not be possible.

The pattern of weakness varies, depending on the condition. Some pupils may have hand weakness while shoulder muscles are relatively strong; for others the opposite is true. Careful assessment by an OT will determine the most appropriate and timely interventions to maximise hand function.

The height of tables and the position of seating are important if the child is to reach his or her full potential. A table and tray that are too low, for example, will cause the child difficulties.

A child with weakness in the upper limbs may also need help with self-care when getting changed for PE, games or swimming, for example, or putting on a coat. A pupil might be unable to raise their arms enough to feed themselves/scratch their nose/push up their glasses or reach for objects in the classroom.

Writing may be difficult but simple equipment such as writing slopes and extra pen-grips can assist the pupil with hand function. ICT or powered or mobile arm

supports may also help optimise a pupil's abilities. Some pupils will need to use alternative methods of writing and recording; timely specialist assessment by OT and IT access team will identify the most suitable equipment and training needed for pupil and support staff. See Chapter 14: Information and Communication Technology (ICT).

Needs will change over time, so regular review is important. A variety of methods, from writing with modified pens, using a scribe, using standard and specialist software programmes, through to integrated communication aids can be used depending on the complexity of the pupil's condition. Providing the right equipment at the right time can make a significant impact on the pupil's function, confidence and educational achievement.

The young person's OT and PT will be able to carry out an assessment of upper limb use. They should work with the young person and the support worker on ideas to enable them to manage or adapt techniques.

### Feeding/swallowing

Some children with muscle-wasting conditions have specific problems with swallowing. Food or drink may go down the wrong way, so that instead of going to the stomach, it goes into the airway; this is called aspiration. Early indications of this could include coughing and choking, either while feeding or shortly afterwards. If this happens regularly, the child could be more prone to chest infections and could also find it hard to put on weight.

Other children with muscle-wasting conditions may eat very slowly because of the shape of their mouths or weakness in their chewing and swallowing muscles. Weakness in arms and upper limbs can also affect their ability to feed themselves. Eating a meal can, therefore, take a long time and feel like a chore.

It is important to discuss with the pupil and parents how to manage the situation. Seek advice from a speech and language therapist (SALT) and/or OT on appropriate management.

Some pupils may have a naso-gastric (ng) tube. This is a thin piece of tubing that goes via the nose into the stomach, and through which specially prepared feed is given to the child. The tube is visible on the child's face as it enters the nose, and a child using this type of device is likely to feel self-conscious.

Some pupils will have a gastrostomy tube (peg-tube), which sends food straight into the stomach. This can reduce problems and ensure the pupil is always well-fed without taking too much time and effort. Some children will require feeding through these tubes at school, and this will need to be discussed with healthcare professionals and the school SENCO. Feeding needs should be included in the pupil's healthcare plan.

### Speech and communication

Speech is generally not a problem, although shortness of breath and weak muscles can make the voice very faint. Children might, therefore, be nervous about speaking in groups or in a crowded and noisy environment. If you have specific concerns, request a referral to a SALT.

### Continence

Most children with muscle-wasting conditions will not have a problem with continence. However, problems with going to the toilet are often a major source of anxiety for pupils, families and school staff.

It is important to encourage children to drink plenty of fluids to prevent dehydration and prevent urinary infections. It will also help to prevent constipation and abdominal discomfort. Some children with muscle-wasting conditions will avoid going to the toilet regularly because they are self-conscious

about asking for assistance, and it takes time out of their break times/lunchtimes when they socialise. This can become more of an issue as children develop into self-aware adolescents. They may restrict their fluid intake to reduce the need for assistance with transfer to and from the toilet. This is often out of embarrassment and/or to minimise the time and effort involved if hoisting equipment is required for a safe transfer.

Staff members need to deal with this sensitively, while trying to establish if this is causing difficulties. You can seek help and guidance from the child's healthcare team for continence problems. In some cases, it may be necessary to consult a specialist continence advisor.

It can be helpful to work with the young person and their family to find out what drinks the young person has during a normal day, look at their preferences and suggest ways to add drinks into the school day. It is not uncommon for a young person to come to school without having had a drink because of the time pressure and parents not being aware of its value.

Children with muscle-wasting conditions may need to empty their bladders regularly, and therefore need to go to the toilet more frequently. Another common problem is constipation, which can cause pain, discomfort and urinary problems, and could result in soiling. If constipation is a problem, ensure that the child has enough fluids during the day and alert the parents who can discuss the issue with their medical team. In many cases, medication is available to alleviate any difficulties.

## 5.5 Staying healthy

### Diet/exercise

Any excessive weight gain will put an additional burden on already weakened muscles. It can be difficult for pupils with

muscle-wasting conditions to maintain their weight within normal limits, when he or she has limited mobility and suffers from fatigue. Steroid medication can also contribute to weight gain. As you would do with all pupils, encourage a healthy balanced diet. It is important for those who are overweight to get specific advice, as dieting and sudden weight-loss can be harmful.

As a general principle, encourage pupils to exercise within their own capabilities. Swimming is an excellent form of exercise and most children should be encouraged to swim. Seek specific advice from the child's PT.

While some children with muscle-wasting conditions can be prone to putting on excessive weight, others may be underweight. They may not take in enough calories because of difficulties with chewing and swallowing and/or because they feel embarrassed in front of their friends about being helped to eat.

If school staff members notice that a pupil is putting on, losing, or not gaining sufficient weight, they should alert the parents and healthcare professionals involved with the child. Dieticians and SALTs can support the child with this issue.

### Sleep

Children with muscle-wasting conditions can often have disturbed sleep patterns. Some children may need additional support with their breathing at night. They may also need turning and repositioning in bed many times during the night. As a result, they can be exhausted during the day, and this can affect their concentration and ability to work effectively. Schools need to be aware that a pupil can become tired more easily and may need to have a place for him/her to rest or 'chill out' for a while.

### Fatigue

Many muscle-wasting conditions affect respiratory function. It is important,



therefore, to alert health professionals if a child complains of frequent headaches (especially in the morning), increased tiredness, or appear to have a changing level of concentration.

Walking around school or college may take a great deal more energy for children than it takes at home. This can have an impact on concentration and mood. Make parents and health teams aware, if this becomes a problem. Careful timetabling to minimise walking distances may help, and sometimes a child will need to use a wheelchair in school long before using one regularly at home.

In some rare conditions, children and young people may still be able to walk but have significant respiratory and cardiac issues. These disabilities are somewhat hidden, so health teams can provide specific advice about how much is reasonable for them to do.

### Physiotherapy

Physiotherapy is an essential part of managing any muscle-wasting condition.

Following diagnosis, the parents will receive advice on an appropriate physical management plan. This may involve stretches, exercise, and the use of splints during the day and/or at night, standing frames, hydrotherapy, as well as advice on respiratory care. Aspects of this plan can be incorporated into the school day. Specialist equipment, such as a standing frame, may be used in the most appropriate lessons. The pupil's PT will advise and demonstrate the best way to do this. Orthoses (splints) will be prescribed by the pupil's PT or medical team and supplied through the NHS. These may need repositioning during the course of a school day, or after PE and swimming.

All school staff involved with using equipment, applying splints, doing stretches or exercises with the pupil should have specific training from the PT. They should

report any changes or difficulties to the PT as soon as possible.

### Hydrotherapy/swimming

Children with muscle-wasting conditions may benefit from hydrotherapy sessions, if these are available. Swimming is also an excellent form of exercise, and most pupils should be encouraged to swim, whenever possible. Swimming provides a supported medium for movement (helping to maintain a range of movement in the joints). Swimming is beneficial but can cause fatigue immediately afterwards; rest and something to drink should resolve this.

#### Certain factors should be considered when arranging a swimming session:

- ▶ how accessible the pool is
- ▶ if lifts and hoists are available, if needed, to transfer the pupil safely
- ▶ if there is extra space available, if help is required, for dressing and undressing
- ▶ if a pupil, who wears splints, can walk safely from changing-room to poolside without them
- ▶ a child requiring full assistance will take longer to get changed before and after a swimming session
- ▶ who will support the child, and if there will be a person in the water, as well as one who stays dry who can assist with personal care tasks.

The temperature outside and in the pool is also important. Pupils with muscle-wasting conditions do not generate the same level of body heat as others, and can be more sensitive to cooler temperatures. Wearing a thin wetsuit or UV suit can help the pupil to keep warm in the water. Consider the temperature of the changing area and whether any alterations need to be made. A cold child will not enjoy a swimming session.

A child may also be aware of the shape of his or her body. This may cause embarrassment, particularly if the condition has caused noticeable changes. Handle the situation

carefully and sensitively to avoid any potential psychological difficulties. See Chapter 11: PE.

## 5.6 Medical interventions

### Steroid medication

Steroids can have an effect on muscle strength in boys with Duchenne muscular dystrophy. They will not cure the condition but, when used by boys who are still walking, they can stabilise or even improve muscle strength for a while, allowing boys to walk for longer. Not all boys respond to steroids and it is still unclear as to how they work. Their use also needs to be balanced against possible side-effects. Some parents may decide, after discussion with the child's consultant, not to use steroids. Refer to Muscular Dystrophy UK's factsheet: *Steroids and Duchenne muscular dystrophy*.

Steroids are usually administered at home by parents, with their usage closely monitored by the healthcare team. However, steroid use and dosage should be clearly documented on IHCP, emergency plans and on alert cards, along with planned action should the young person become unwell at school.

### Other medication

Any other medications should be administered as agreed with parents, pupils and healthcare team, and should be clearly documented on IHCP.

In some conditions, it is very important for medications to be administered at specific times.

### Surgery

There are circumstances where a muscle-wasting condition causes changes in body shape or joint range. This may further limit function, or cause serious medical complications. At this point, surgery may be considered. For some, this may be surgery on the ankles and tendons around the feet.

More complex surgery could be required to correct any curvature of the spine. This type of surgery is a major undertaking; there will be a very detailed assessment process and investigations before making a decision. All possible risks and benefits are explained to the child and parents, and they may be anxious before the operation.

Visits to the hospital, and time recovering from an operation can disrupt the pupil's school attendance. Every child's experience of surgery and time away from school will be different.

When a child returns home after surgery, it may help to do some schoolwork. Home tuition may be necessary for a short while, followed by a phased return to school.

After surgery, the pupil will need a re-assessment to identify any changes in their mobility, ability to transfer, moving and handling, upper limb use and ability to self-care.

Existing equipment will need re-adjusting after spinal surgery, as the child's position and shape will change:

- ▶ it may be necessary to use hoisting equipment for the first time
- ▶ existing tables and desks will need to be adjusted to accommodate changes in height
- ▶ toilet support needs to be reconsidered and may need changing.
- ▶ a padded toilet seat can aid comfort following surgery
- ▶ slings, used for transferring with a hoist, will need to have suitable head support.

Transport authorities should be alerted, as most children will grow in height following spinal surgery. Check to ensure there is adequate headroom in any vehicle used by the child.

Discuss with healthcare professionals before surgery what action is required, so appropriate plans can be put into place. The local OT and/or NCA will co-ordinate a meeting with the family and the team who support the young person. This will ensure everyone has information about the procedure, changes to care, time lines and so on. They will also support the school in planning a phased return, pacing, and any changes to care, handling or exercise programmes.

### Respiratory/ventilation

This is a key area of healthcare for pupils with muscle-wasting conditions. Some children have very weak respiratory muscles and are carefully monitored by specialist professionals. Early treatment of coughs, colds and respiratory infections is necessary, as pupils can become ill quite quickly. All staff members need to be extra vigilant and parents should be alerted if the pupil becomes unwell.

Some children may also need chest physiotherapy to help clear any secretions. This can involve the use of suction and/or a cough assist machine, if the child's cough is not strong enough. For most children, this will be done at home but some more vulnerable pupils may need to bring specialist equipment in to school. Careful planning will be required for pupils needing this level of care for any residential trips. All staff members need individual training to use this equipment.

Respiratory complications may mean a pupil has to spend time away from school, which could affect his or her education. Depending on the circumstances, the pupil may be able to continue with schoolwork at home, while he or she is recovering.

Some children may develop symptoms of nocturnal hypoventilation. This happens when a child cannot breathe effectively at

night because of weak respiratory muscles, and carbon dioxide builds up in the body. As a result, the child can feel lethargic, may suffer from headaches, and may find it difficult to get going in the morning. Concentration and wellbeing will be affected. If any change is noticed, alert parents. Ventilation equipment supports effective breathing and the medical team may decide that night-time ventilation support is required. This can relieve symptoms and make the child feel much better.

Although this type of equipment is generally used at night while sleeping, some pupils may need extra assistance during the day. A portable ventilator can be attached to a wheelchair and the child can use it via a nasal mask or mouth-piece. If a child needs this level of support at school, then careful planning and training of all involved staff is essential. Children can use this equipment effectively in a mainstream setting, following discussions with school and healthcare professionals on all aspects of management. Further information is available in the *Making Breathing Easier* factsheet available from Muscular Dystrophy UK.

### References

- ▶ *The Department for Education Supporting Pupils at School with Medical Conditions* February 2014 (DFE-0024-2014)
- ▶ *Special Education Needs and Disability; A Guide for Parents and Carers DoE* August 2014 [www.gov.uk](http://www.gov.uk)
- ▶ *0 to 25 SEND code of practice: A guide for Health Professionals DoE and DoH* September 2015



### Template: Individual Healthcare Plan (IHCP)

Name of school/setting \_\_\_\_\_

Child's name \_\_\_\_\_

Group/class/form \_\_\_\_\_

Date of birth \_\_\_\_\_

Child's address \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Medical diagnosis or condition \_\_\_\_\_

\_\_\_\_\_

Date \_\_\_\_\_

Review date \_\_\_\_\_

### Family contact information

Name \_\_\_\_\_

Relationship to child \_\_\_\_\_

Phone no (work) \_\_\_\_\_

(home) \_\_\_\_\_

(mobile) \_\_\_\_\_

Name \_\_\_\_\_

Relationship to child \_\_\_\_\_

Phone no (work) \_\_\_\_\_

(home) \_\_\_\_\_

(mobile) \_\_\_\_\_

### Clinic/hospital contact

Name \_\_\_\_\_

Phone no \_\_\_\_\_

### GP

Name \_\_\_\_\_

Phone no \_\_\_\_\_

Who is responsible for providing support in school: \_\_\_\_\_

\_\_\_\_\_

### Template: IHCP (continued)

Describe medical needs and give details of child's symptoms, triggers, signs, treatments, facilities, equipment or devices, environmental issues, etc.:

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Name of medication, dosage, method of administration, when to be taken, side-effects, contra-indications, administered by/self-administered with/without supervision.

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Daily care requirements:

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Specific support for the pupil's educational, social and emotional needs:

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Arrangements for school visits/trips etc.:

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Other information:

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Describe what constitutes an emergency, and the action to take if this occurs:

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Who is responsible in an emergency (state if different for off-site activities):

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Plan developed with:

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Staff training needed/undertaken – who, what, when:

---

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Form copied to:

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# Chapter 6

# Environmental considerations

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Adaptations to the school should be guided by the young person's current and predicted needs, through SEN and EHCP/CSP planning assessment and review process.

It is vital to take a longer-term view and plan more than an academic year ahead. An overview for the time the pupil is in education should be given to ensure needs are met in a timely and appropriate way.

Failure to have the right access and equipment in place at the right time is hugely distressing. Pupils and families don't always have a clear understanding or acceptance of future needs, so this is a very sensitive topic. It is important to know what the pupil's own understanding of their condition is and, where possible, involve them in the planning. Be mindful that discussions about funding can be upsetting for families; they may feel they are a burden on the system or may become angry if funding streams are not clear. Preparation ahead of meetings can greatly reduce anxiety for all involved.

The key questions are:

- ▶ what do we need?
- ▶ when do we need it?
- ▶ how do we get it?
- ▶ who provides funding for this?
- ▶ where do we go for advice?
- ▶ what will be needed in the next setting?

The answers to these questions vary between types of school and LAs. Close working with access/buildings officers, health team and the family is essential, with sources of help and information included in reference section.

*Designing for disabled children and children with special educational needs. Guidance for*

*mainstream and SEN schools – BUILDING BULLETIN 102* has some detailed guidance for large, new-build projects, which may be useful when considering adaptations.

## 6.1 Access and evacuation

Careful consideration should be given to the school environment for a pupil with a muscle-wasting condition. What a child needs will vary depending on his or her level of mobility, and will change over time. A child who is able to walk at the beginning of his or her school life, for example, may be a full-time wheelchair user later. Forward planning is essential, together with an accessibility plan developed and adopted by the school.

Areas to consider:

- ▶ access to school entrance and classrooms, dining hall, sports facilities, toilets and the playground
- ▶ accessible and inclusive playground equipment
- ▶ circulation space in classrooms and corridor
- ▶ ramped access to emergency exits
- ▶ a Personal Emergency Evacuation Plan for wheelchair users and those with limited or slow mobility
- ▶ accessible toilets and changing areas
- ▶ transport to and from school.

### Access to the school

Organise a site inspection/Access Assessment Visit of the school to ensure that it is fully accessible and to complete an Individual Access Plan for the pupil. It is vital to have someone who understands how the condition will change over the child's time in school at this meeting. An OT, PT and NCA can

help, as the parents and pupil may not have the insight or experience to do this. Meeting the needs of a pupil with a muscle-wasting condition may mean altering and adapting the school site beyond accessibility guidelines, especially in toilet and changing areas.

Ramps provide wheelchair access, and step lifts (which can be used internally and externally) could also be an option. An ambulant child may need handrails on steps and stairs, both inside and outside the building. Check that there are no obstacles blocking access to stairs.

Uneven ground, rough surfaces and mat wells could be trip hazards.

Gravel and cobbles can cause problems for wheelchair users. Look for alternative routes or consider track ways.

Turning space is very important and a whole school policy needs to be agreed. Pupils with mobility difficulties may move slowly, making them vulnerable in congested corridors. Wheelchair users can add to this congestion. Try to keep corridors and shared space clear, to allow wheelchair access.

Allow pupils with mobility difficulties, or wheelchair users, to leave class early if they wish to, thereby avoiding congestion in corridors. Lunchtimes can also be busy and it may ease any access difficulties if pupils with mobility difficulties can be first in the lunch hall.

### Playgrounds

The playground needs to be assessed for accessibility and possible adaptations. Benches should be made available for ambulant children, to limit fatigue by providing them with a chance to rest, and allowing pupils with balance and co-ordination difficulties to sit safely with their friends. Benches also encourage social interaction for wheelchair users, enabling other pupils to communicate at the same eye level.

Having a playground 'buddy' system can help reduce isolation and expand social circles for pupils who find this difficult.

Consider the playground's location, as exposed north-facing sites can be windy and cold. This may cause difficulties for pupils with muscle-wasting conditions (see Chapter 5: Health issues). Have alternative arrangements in place, such as indoor play with friends, for when the weather is cold.

### Storage

Think about safe and secure storage space for equipment, such as standing frames, mobile arm supports and hoists. Powered wheelchairs, which remain at school, will need to be charged overnight. Children with muscle weakness may also find it tiring to carry bags full of schoolbooks around with them, and would benefit from a secure locker or storage room. Such an area would be most convenient if located near the school entrance.

### Access to the classroom

Ensure that there is a height adjustable table, which can ensure a pupil's comfort by supporting his or her arms, and clear access to all classrooms. This may mean re-arranging classroom furniture in every area the pupil uses to access the curriculum.

A pupil who is ambulant, but tires easily, is best positioned near the classroom entrance. Powered wheelchairs provide a pupil with freedom of movement and independence. They can be quite large, particularly the adult sizes, but they are very easy to manoeuvre and pupils quickly become proficient at handling them. Some have a riser facility, which can mean that the young person can independently adjust the height to enable them to sit at the right height for activity.

Upper limb weakness is associated with many muscle-wasting conditions. It is essential that table and tray heights are correct, allowing



the pupil to rest his or her elbows on a supportive surface. This stabilises the upper limb girdle, maximising function.

When muscle weakness is severe, a pupil may need help from a member of staff to position his or her arms and hands appropriately. Some pupils may use special equipment, such as mobile arm supports, to assist upper limb function. The OT or advisory teacher can help by assessing a pupil's level of functioning.

### Access to the dining hall

Some pupils with muscle-wasting conditions can be self-conscious at lunchtime if they cannot eat independently because of their upper limb weakness. Many children are too embarrassed to ask for assistance or do not want help eating in front of their friends.

Some of these difficulties can be avoided if there is good access within the dining hall.

#### Key areas include:

- ▶ height of the serving counter
- ▶ if a canteen style system is used, ensure the serving counter is not too high. Can the pupil see the food on offer and make a choice?
- ▶ can the pupil safely carry the tray?
- ▶ a height-adjustable table, or table set to the correct height, may be needed for the pupil's comfort and to allow them to feed themselves
- ▶ specially adapted cutlery and crockery can also help pupils to be independent, although they may be reluctant to use them in front of others
- ▶ some pupils, who need to use equipment or have a helper to feed them, may prefer to eat in a quiet or private area. Discuss this with pupils, and be aware that it is important to sit and interact socially with friends during the lunchtime break.

## 6.2 Equipment

### Wheelchairs

Some pupils may use a self-propelled wheelchair for some of the time, even though they can still walk for short distances. This helps them conserve energy and allows them to travel further and faster. If a child is using a manual wheelchair (one that can be pushed), staff need basic training in how to push and collapse the chair, and use it safely.

Cushions and supports may be used within a wheelchair to maintain a good seating posture. It is important that staff involved with the care of a pupil know how to use and position this equipment. The pupil's PT or OT will give advice on how to position the young person in the seat and will ensure staff members are given an understanding of postural care needs.

Other pupils may use a powered wheelchair. A risk assessment should be completed in school, to capture the needs of the young person, as well as staff and other young people.

There are various wheelchair proficiency training programmes, which promote the safe use of powered wheelchairs and could be incorporated into a PE or games lesson. Other schemes may also be available locally, through Wheelchair Services or OT and PT departments.

Some powered wheelchairs have many different modes and functions, which can alter the angle and height of the seat. The pupils themselves are usually expert in using their own wheelchairs, however it is helpful for staff to have some understanding of its operation.

What happens when there's a fault with the wheelchair? Where it is owned by the school, repair and maintenance of the wheelchair is the school's responsibility. With privately-owned equipment, such as powered wheelchairs that have been funded by the

family or a charity, the school should alert parents if there is a fault with it. Repair and maintenance of such equipment is the sole responsibility of the family.

Lap belts should always be worn and adjusted correctly in powered and manual chairs. Some pupils may have an additional harness for travelling, which can be removed once in school. OTs will advise.

### Evacuation issues

A full risk assessment, and health and safety review, is essential to develop emergency evacuation procedures for pupils with disabilities. All staff must be aware of the Personal Emergency Evacuation Plan (PEEP) for pupils with SEN. The relevant PEEP paperwork should be completed in line with the local authority guidance.

All emergency exits should be checked for accessibility.

The fire policy for the building must be strictly adhered to. This may mean not using lifts, making use of safe zones, or using an evacuation chair.

Use of evacuation chairs needs very careful consideration and assessment. They are not always suitable for pupils with muscle-wasting conditions. The pupil may not have sufficient postural control to remain stable within the chair even with appropriate straps in place.

Careful timetabling can help avoid some problem areas of the building if necessary, but any changes to the timetable need to be requested well in advance.

- ▶ *Fire Safety Law The Evacuation of Disabled People from Buildings 2011*  
[www.dhsspsni.gov.uk](http://www.dhsspsni.gov.uk)
- ▶ [www.nifrs.org/firesafe/downloads/evacuation.pdf](http://www.nifrs.org/firesafe/downloads/evacuation.pdf)
- ▶ [www.gov.scot/Resource/0040/00402451.pdf](http://www.gov.scot/Resource/0040/00402451.pdf)

### Standing frames

A standing frame is a piece of equipment used to maintain an upright supported standing position, while stretching the hip and knee, and ankle joints (see Chapter 5: Health issues). Standing frames are prescribed by the pupil's PT, as part of the child's physical management plan. If a standing frame is used in school, staff will need guidance from the PT on its use, as well as how to get the young person in and out of it safely.

How and when to introduce a standing frame into the timetable need to be sensitively planned and managed. Ideally, the pupil should be included in the lesson while standing; many standing frames have trays or can be placed next to a height-adjustable table to allow for this. Consideration needs to be given as to where and how the transfer into the standing frame takes place.

### Special seating

Weakness of the trunk muscles in pupils with muscle-wasting conditions can cause problems with the spine (see Chapter 5: Health issues). Special consideration should be given to the seating position.

Some pupils will need a different school chair to give stability and to maximise the use of their upper limbs and hands. A child who is mobile may need a chair that offers support and allows him or her to move independently to and from a standing position. Some chairs have hydraulic or powered height-adjustment.

Staff should be aware of the correct seating position for the pupil, especially if they are involved with transferring and handling. Specialist teaching and therapy staff can offer advice and help staff to feel more confident with the equipment and what to use and when.

Specialist chairs may need to be moved between classrooms, and this should be identified on the individual timetables.

An OT or PT, in conjunction with an advisory teacher, can assess a child's needs and make recommendations on what seating support is required. Regular reviews will be needed, along with frequent adaptations and modifications, as the pupil grows or their muscle strength changes.

### Height-adjustable table

A work surface at correct height is important for the pupil's arm and hand function. The pupil should have access to a table at an appropriate height, which provides good support for the elbows and forearms.

Children using wheelchairs will need a table that accommodates the height of their wheelchair. If pupils choose to work on their wheelchair tray, ensure it is big enough for workbooks, keyboards, and recording equipment.

Many wheelchairs have powered seat-risers, which offer more flexibility and control for the child so they can select the optimal height for the specific task.

### Hoists/slings

Special equipment is needed to safely transfer a pupil. An appropriately trained professional should carry out a full moving and handling assessment. There may be a charge for this.

A method of hoisting the pupil is most likely to be recommended, once weight-bearing transfer is no longer safe or a sideways transfer becomes too slow and requires too much effort.

#### There are two main types of hoist:

**1. mobile hoists**, which can be moved from one location to another. They can be electrically or manually operated, and will require their own storage space and need to be charged regularly

**2. tracking hoists**, which are electrically operated, and use a ceiling- or wall-fixed tracking system. They are especially recommended for use in toilets, and for personal hygiene activities.

As a minimum, a school will require an electrically-operated mobile hoist to transfer a pupil from the ground to a wheelchair and changing plinth.

Hoists are used in conjunction with slings, and an assessment will identify the correct type and size of sling needed. The sling supports the base of the spine to either the shoulder, or crown of the head – if head and neck support is required – and includes support and padding for posture and comfort.

An 'all day' sling, which can remain in situ between transfers to reduce handling, may be prescribed as pupils grow and it becomes more difficult to apply the sling. OTs will advise if this is appropriate.

### Equipment safety and maintenance

If the school provides specialist pieces of equipment, such as standing frames, hoists and slings, then consideration should be given to their maintenance and safe use. All moving and handling equipment must comply with LOLER (Lifting Operations and Lifting Equipment Regulations 1998) and be inspected before use and serviced every six months.

Staff should have training and be deemed competent in the use of equipment, and this should be an essential component of the induction process or ongoing Professional Development. (See Chapter 2: Access to school and the curriculum.)

## 6.3 Adaptations to the school lifts

Lifts may need to be installed to make the school site accessible. If there are already lifts in place, check they are suitable for a child and wheelchair. If the lift is to be used unaccompanied, the controls must be at a wheelchair-accessible height. Pupils with severe upper limb weakness will probably require assistance to operate the lift controls. Step-lifts could be considered as an alternative for small flights of stairs.

Advice is also available from the LA Access Officer and specialist advisory teachers.

### Toilet and personal hygiene requirements

A toilet should have at least enough space for a portable hoist and any other transfer equipment that may be required, such as an overhead tracking hoist. Pupils and carers need privacy during transfers, as well as a spacious, safe and warm environment.

#### Boys

Some boys find using a urine bottle quicker and more convenient than transferring to the toilet. They will still need help with moving forward to the front of the seat cushion on their wheelchair. Some wheelchairs are not conducive to using a bottle, so some boys may find it easier to be transferred to plinth and use a bottle there.

Some will consider the use of sheath and leg bag rather than having to transfer. Refer to OTs or continence service for advice.

#### Girls

Female urinals (Uri-bags) are available on prescription. They are small and compact, and can be very helpful, particularly on school trips. However, many girls find this very difficult and therefore it may be necessary to take a portable mobile hoist on trips to allow for full transfer on to the toilet.

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

### Specification for an accessible toilet for pupils with a muscle-wasting condition

Part M of the building regulations states that an accessible toilet should be a minimum of 1,500mm x 2,000mm. While these measurements are adequate for adult public toilets, schools will need more space and perhaps a changing and physiotherapy area. It is often accepted that the physio area should be separate from the toilet area where possible. If this is not possible, it may be possible to separate the areas with screens.

#### 1. Suitable for people with a wide range of physical disabilities and needs

All adaptations should enable as much independence as possible, and have a flexible design, particularly with regard to the positioning and height of fittings. It is essential to plan for the needs of three disability groups:

- ▶ children who are disabled, but able to walk
- ▶ wheelchair users who can transfer out of their wheelchairs independently or with minimal help
- ▶ wheelchair users who have arm weakness, who cannot transfer out of their wheelchairs and need to be hoisted.

#### 2. Suitable for the needs of carers

European Community rules have recognised the importance of Safer Moving and Handling and the prevention of musculo-skeletal disorders. A well-designed toilet area will make the process easier for the pupil and staff.

#### 3. Able to withstand regular and heavy use (for multi-use facilities)

The facilities must be robust, durable and suitable for those with complex needs.

#### 4. Attractive

The equipment should be aesthetically acceptable and easy to clean, with storage for personal toiletries or continence products.

## 5. Good value for money

The cheapest equipment is not always the best buy. Consideration needs to be given to looking at a range of options and then making decisions based on appropriateness, and the young person's ongoing needs. An OT should be involved in developing design and layout.

While the initial impetus for the work may be the needs of a particular child, it is important, where possible, to design a room suitable for all disabled children. This can prove to be cost-effective in the long term. Pressalit Care Ltd offers a free design service and video, which illustrates its products and features.

Consider not only the size and layout of the toilet, but also how it is accessed from an outside corridor and its overall location in the school building.

The following specification is detailed and differs from what may be considered standard. Please share it with all involved in the process, especially building/estates team at the earliest opportunity.

### Specification for accessible toilet with changing bench/shower

#### General principles

Standard accessible toilets may not meet the needs of all pupils with muscle-wasting conditions. Needs vary according to the specific condition, but often by the time the pupil reaches late Key Stage 2 and into Key Stage 3, they require assistance to manage personal care tasks such as going to the toilet. This is likely to be with support from one or two carers to use the toilet, and may involve them being changed on an adjustable-height changing bench. A hoist system may also be needed (mobile or fixed) to safely transfer the pupil from their wheelchair.

This specification allows all these needs to be taken into consideration, and provides a safe place for both pupil and carer/s to use.

#### Room dimension and choice of hoist

Minimum dimensions of the room will vary depending on whether a mobile or fixed hoist is used. For ceiling track hoist, the minimum recommended dimensions are 3m x 3.4m. The choice of ceiling hoist will be critical for the installation of hoists, generally 2.6m x 2.8m is preferred and 2.4m is a minimum. Check with individual manufacturers for their requirements.

If the ceiling is particularly low, it may be possible to use a hoist which has tapes from the hoist unit rather than a spreader bar. It is also important to consider the structure of the ceiling as this may preclude the mounting of a hoist from the ceiling, but wall mountings may be possible.

There are two main types of ceiling tracking – a gantry hoist, which enables the user to hoist anywhere in a room space or a single fixed track, which is more limiting and may enable transfers between two fixed places only.

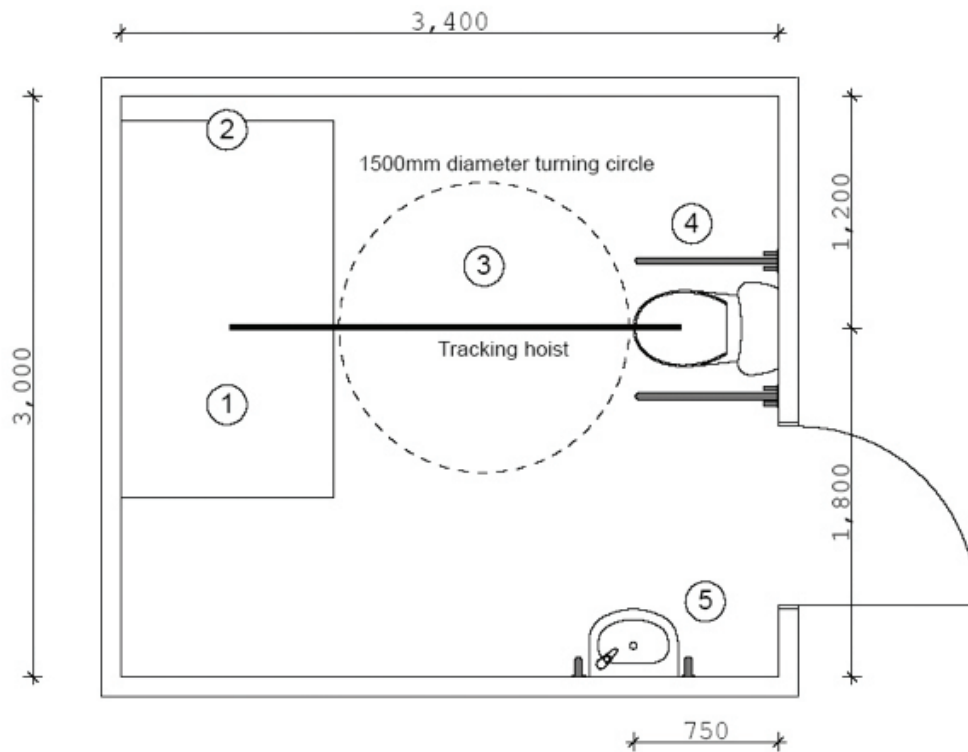
The benefits of a gantry hoist over a mobile hoist include:

- ▶ no need for storage and it does not get in the way
- ▶ always available when it is needed (though care needs to be taken that it is always returned to the charging point after each use)
- ▶ a safer option when moving and handling a person
- ▶ more dignified and the user will feel better supported by being physically closer to the handler
- ▶ greater raising and lowering range.

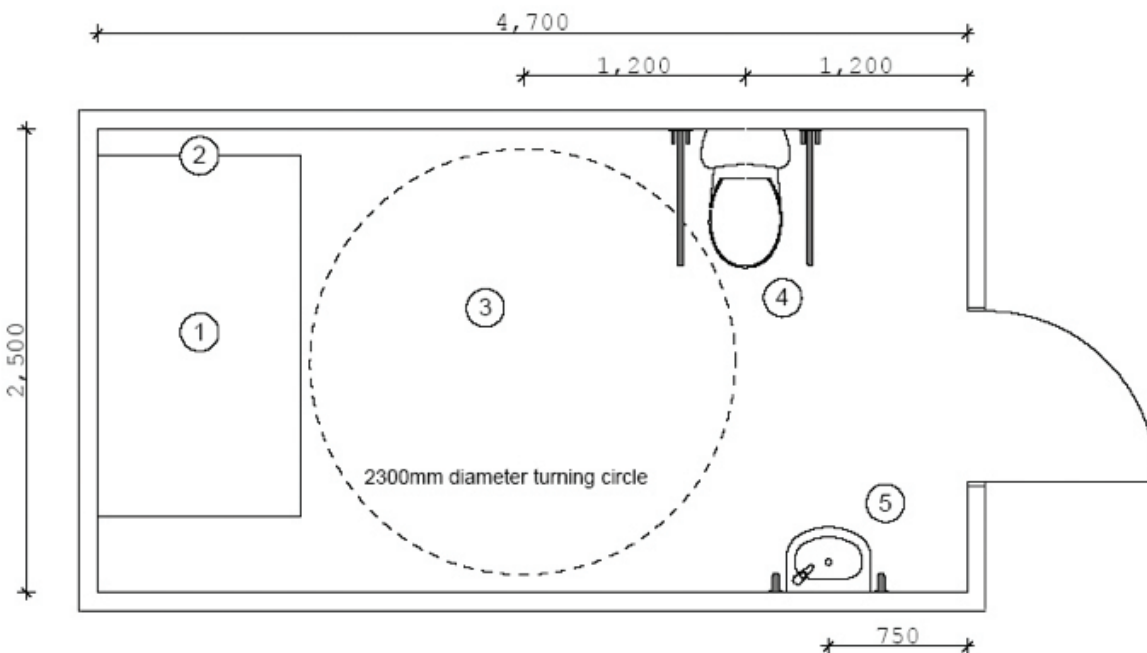
Space needed for a portable hoist is significantly greater (2,300mm turning circle) than that of a ceiling-mounted hoist, so the room should be at least 2.5m x 4.7m.

## Room layout:

### Example layout with fixed track hoist



### Example layout with mobile hoist



## Key

- ▶ Height-adjustable changing bench
- ▶ Wide tear-off paper rolls to cover the bench
- ▶ Fixed tracking or mobile hoist
- ▶ Centrally-placed toilet with room on either side for the carers
- ▶ Hand basin
- ▶ All measurements in mm

## Room features

### Decoration

Gloss surfaces should be avoided so that any glare is eliminated.

Two bands of coloured tiles around the room will highlight the difference between floor and walls. One band should be placed at floor level and one at 750mm.

The colour of the walls and the colour of the sanitary fittings should contrast, as should the floor.

### Lighting

Should be a minimum of 150lux.

Diffused fluorescent, to ensure no glare and an even distribution.

### Toilet doors

Should be outward-opening. If this is not possible, an inward-opening door can be used but there must be more usable floor space than the minimum standards to accommodate the swing of the door into the cubicle. The door must also be able to open outwards in an emergency (in case the user has fallen behind it).

Have a clear width opening of at least 850mm, 900mm preferred.

Be light and easy to open and fitted with rising butt hinges or, where door closers are absolutely necessary, a very lightweight closer, set to the minimum closing force and slowest closing speed.

Be colour/tonally contrasted to its surroundings.

### Door handles

Should be 'L' shaped push/pull handles on both sides of the door.

Colour/tonally contrasted to the door.

### Locking mechanisms

The indicator bolt/lock should be one that operates from a lever handle with a diameter of 20-35mm.

There must be an indicator bolt and an emergency release facility for opening the door from the outside.

### Alarm cords and switches

Should be red, to indicate their purpose.

Must be connected to visual and audible alarms, both inside and outside the toilet.

Switches (if used as an alternative to cords) must be large, rocker type or re-settable push pads, with one set at 950mm and one at 250mm above finished floor level.

Two acorn cups should be attached to the cord at heights of 950mm and 250mm above floor level, to ensure assistance can be called for from either a seated position or from the finished floor level if someone has fallen.

## Toilet area

### Cistern and WC

To be positioned so that the centre line of both is at least 1,200mm from the wall.

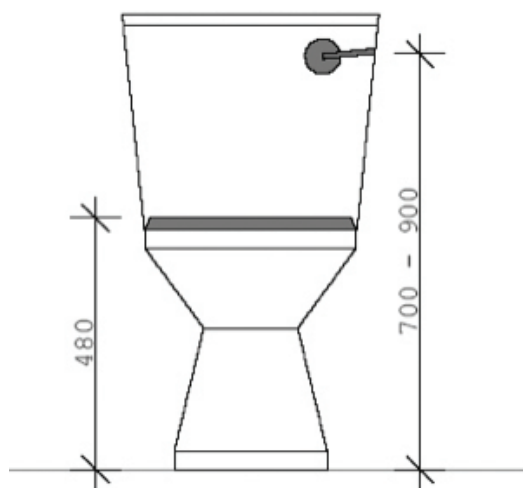
The front edge of the WC should be 750mm from the rear wall (whether the cistern is concealed or front mounted). This ensures wheelchair users can reverse sufficiently backwards to transfer. Consider the soil pipe in this measurement, as this can frequently prevent a toilet support being pushed far enough over the toilet bowl.

The height of the WC must be 480mm to the top of the toilet seat above the finished floor level.

However, this may be too low for some people, so a portable/removable raised toilet seat should be made available.

The seat must be un-contoured and continuous, and also be a dark colour in contrast to the light colour of the WC pan. For some pupils, additional support may be required to enable them to sit comfortably and in a supported way on the toilet. This support could come from a simple free-standing toilet surround, a fixed surround such as the MD toilet surround (see References p70), which has the added benefit of support at the front of the user so they can be supported propping forward on to it, or from a shower chair such as the Freeway T40 (see References p70).

- ▶ Occasionally, schools will consider the use of a bidet toilet, which washes and dries at the touch of a switch. Consideration needs to be given to frequency of use versus value for money. These products are commissioned and adjusted for single users and would need to be maintained. The pupil's needs should be assessed by the company's representative meeting the pupil on site to ensure the bidet toilet is compatible with the pupil's needs. This type of toilet can be used as a standard lavatory, with extra features being used.
- ▶ The toilet roll needs to be in reach and this may be a bar on a drop-down rail to the side of the user.



### Flush handles

Must be spatula-shaped, which allows people with limited use of their hands to flush the toilet. This also means it can be pushed down by a fist or elbow, if someone is unable to use their hands.

Positioned 700-900mm above finished floor level and fitted on the transfer side of the cistern.

An acceptable alternative is an infrared device, activated by hand movement.

### Drop-down/hinged support rails

To be fitted 350mm from the centre line of the WC on the lateral transfer side at a height of 700mm to top of the rail.

Should incorporate a counterbalancing spring, which means the rail can be lowered and raised with minimum effort.

Should be coated in a non-slip material and colour/tonally contrasted to the background.

### Wash basin area

#### Hand basin and tap

Basin fitted at a height of 750mm to the top of the rim.

- ▶ The basin should be wall-mounted with no pedestal, support or vanity unit underneath to allow access for wheelchairs. If it has a shallow bowl, there is more knee space beneath the unit. Consideration may be given to a height-adjustable basin.
- ▶ The tap should be a single lever action mixer tap, with the water temperature controlled to 40 degrees centigrade.
- ▶ An acceptable alternative to a lever is an infrared device that controls the water flow automatically when a hand is positioned under the tap.

### Paper towel dispensers

Fixed, so that the dispensing point of the holder is 950mm above finished floor level.



### Soap dispensers

Lever type dispenser or fitted with an infrared sensor, which activates when hands are positioned underneath.

Lever control, to be at a height of 950mm above finished floor level.

### Electric hand-dryers

Must be automatic.

Positioned next to the soap dispenser over the basin.

Should be fixed at a height where the sensor is activated when hands are raised to a height of 1,000mm above floor level.

### Grab rails

Must not project more than 85mm from the wall surface and must be 35mm in diameter.

Should be coated in a non-slip material and colour/tonally contrasted to the background.

Grab rails must be fixed very securely; extra fixing points should be considered.

### Changing bench area

#### Changing bench

The changing bench should be wall-mounted.

It should be height-adjustable, ideally with electric motor, moving from wheelchair level to a safe caring height.

It should include a side safety rail with gaps of no more than 6cm.

A shower can be incorporated into the changing bench. Models are available with integrated water collection tray or with a drop-down splash protection curtain to prevent the carers from getting wet.

It should be possible to fold the bench up against the wall when not in use to maximise space.

### Paper roll dispenser

Wide tear-off paperroll to cover the bench, to help keep the changing bench clean and hygienic.

### Bin

A large sanitary/disposable pad bin should be provided in addition to bins for paper towels and general rubbish.

- ▶ Storage should be planned for disposable items, such as hard surface wipes, gloves, aprons, wipes, and also spare clothing if necessary.

### Links

- ▶ [www.armitage-shanks.co.uk/professional/docm.html](http://www.armitage-shanks.co.uk/professional/docm.html) for fixtures and fittings
- ▶ [www.changing-places.org/index.asp](http://www.changing-places.org/index.asp) Changing places website
- ▶ [pressaliticare.com](http://pressaliticare.com) for changing bench (nursing bench Model No:R8518)
- ▶ *Department for Children, Schools and Families, Building Bulletin: Designing for Disabled Children and Children with Special Needs pdf*

### Bibliography:

- ▶ *Part M: Access to and use of buildings – Building Regulations 2000 2004 Ed.*
- ▶ *Designing to Enable Gateshead Access Panel 1997*
- ▶ Changing Places  
[www.changing-places.org](http://www.changing-places.org)

### Shower/changing bench or mobile plinth Wash/dry toilets



## Transport

Pupils with muscle-wasting conditions, who receive transport to and from school, may need an adapted vehicle. If the pupil is walking or can safely transfer from their wheelchair and be seated safely for duration of the journey, they should travel on a standard vehicle seat.

When a pupil has to be transported in their wheelchair, then a tie-down and occupant restraint system (WTORS) allows a wheelchair to be secured to the vehicle floor, and the passenger in the wheelchair to benefit from a properly fitted seatbelt system. This must be done in line with the wheelchair manufactures, WTORS instructions and the LA's own transport policy. All staff should have specific training for this procedure.

### For further information:

- ▶ MHRA ([www.mhra.gov.uk](http://www.mhra.gov.uk))
- ▶ Community Transport Association UK ([www.ctauk.org](http://www.ctauk.org))
- ▶ Department of Transport ([www.dft.gov.uk](http://www.dft.gov.uk))
- ▶ Wheelchair manufacturers (leaflets/instructions).

Also remember, although a pupil is able to walk around school, he or she may find it difficult or even impossible to negotiate high steps on and off school buses.

Transport arrangements will need to be altered as a pupil's muscle weakness progresses.

All the above points need to be considered when planning school trips, as well as transport to and from school.

Pupils with muscle-wasting conditions may also become fatigued more easily, and lengthy periods of time on school transport can be exhausting, especially if there are many stops and drop-off points en route. A pupil with weakened muscles has to work

extremely hard to maintain postural stability in a moving vehicle. Long journeys may well have an adverse effect on a pupil's ability to focus and concentrate when he or she is at school, and could prevent a child reaching his or her full academic potential. Fatigue, after a tiring journey home, can affect a pupil's ability to complete homework.

Pupils with muscle-wasting conditions will need accessible transport to participate in, and benefit from, after-school clubs, activities, and trips and holidays. It can be quite difficult to meet the needs of all pupils on these outings, for example, a wheelchair accessible coach will have a reduced number of seats for other pupils, and availability of this type of transport can be limited so needs to be booked well ahead.

### References

- ▶ [www.rospa.com/rospaweb/docs/advice-services/road-safety/practioners/minibus-code-of-practice.pdf](http://www.rospa.com/rospaweb/docs/advice-services/road-safety/practioners/minibus-code-of-practice.pdf)
- ▶ Department of Transport [www.dft.gov.uk](http://www.dft.gov.uk)
- ▶ [www.dailycare.co.uk/2012/muscular-dystrophy-toilet-support-frame](http://www.dailycare.co.uk/2012/muscular-dystrophy-toilet-support-frame)
- ▶ [www.easycare systems.co.uk/shop/index.php/shower-bathing/shower-chairs/freeway-shower-chair-range/freeway-t40-attendant-propelled.html](http://www.easycare systems.co.uk/shop/index.php/shower-bathing/shower-chairs/freeway-shower-chair-range/freeway-t40-attendant-propelled.html)

# Chapter 7

# Education and school policies

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## 7.1 Schools response to pupils with special educational needs

*The Special Educational Needs and Disability Code of Practice 0-25 years (The code)* provides statutory guidelines, policies and procedures relating to Part 3 of the Children and Families Act 2014. This relates to children and young people, with SEN and Disabilities, under the age of 25, to help them 'achieve the best possible educational and other outcomes' – section 19 (d). GIRFEC (Scotland).

A child is anyone from birth up to the end of compulsory school age (currently 16 years old), and a young person is anyone over compulsory school age (over 16 years old) and below 25.

There are many different types of early years' settings, schools or colleges which a child or young person can attend. These are covered by the Code of Practice, and also include apprenticeships, traineeships and supported internships for young people with SEN and disabilities.

### Information, advice and support for parents and young people

Chapter 2 of the *SEND Code of Practice 0-25* covers 'Impartial Information, Advice and Support'.

The code says that LAs must arrange for children and young people – for whom they are responsible and who have SEN or disabilities – as well as their parents, to be provided with information and advice about matters relating to their SEN or disabilities.

Each LA must take steps to make these services known to children, their parents

and young people in their area. They must ensure that their Local Offer\* includes details of how information, advice and support can be accessed. Most LAs have established SEN and Disability Information, Advice and Support Services (SENDIASS) (formerly Parent Partnership Services), and these services may also provide information, advice and support for young people, although LAs may commission this service separately.

However the service is provided, it must be impartial and provided at arm's length from LAs and Clinical Commissioning Groups.

\*The Local Offer brings together information about the help and support available for children and young people with special educational needs and/or disabilities (SEND) and their families.

## 7.2 Identifying SEN

If staff members are concerned that a pupil may have SEN, they should talk to the parents and discuss what action the school is considering.

For children who have been identified as having SEN or a disability, they may be supported under SEN Support or they may have an EHCP/CSP/SEN/ASN (Scotland) Support.

The Code recommends a graduated approach to supporting children and young people with SEN and Disability, which has four stages of action:

- ▶ assess
- ▶ plan
- ▶ do
- ▶ review.

The special educational 'provision' given to children throughout this approach is referred to as SEN Support.

#### The Code identifies four broad areas of need:

- ▶ communication and interaction
  - ▶ cognition and learning
  - ▶ social, emotional and mental health
  - ▶ sensory and/or physical needs.
- 
- ▶ **Assess** – it is the teacher, and the SENCO who are responsible for carrying out a clear analysis of a pupil's needs. They should draw upon teacher assessments, experience of the child or young person's previous attainment, the views or concerns of the parents, the pupil's own views and, if relevant, advice from external support services.
  - ▶ **Plan** – in consultation with the parents and pupil, the teacher and the SENCO should agree the adjustments, interventions and support that are to be provided through SEN Support. The pupil's parents, and everyone who works with the pupil, should be made aware of their difficulties, the outcomes sought and the strategies required to enable the child or young person to achieve the identified outcomes.
  - ▶ **Do** – the teacher retains the responsibility for working with the child or young person on a daily basis. Even if the pupil receives one-to-one or small group support from a teaching assistant, it is the teacher who is responsible for the pupil. Everyone involved should work closely to plan and assess the impact of the support and interventions and how they can be linked to classroom teaching. The SENCO will continually support the teacher, advising on the effective implementation of support.
  - ▶ **Review** – the effectiveness of any support or intervention must be

reviewed and the impact upon the pupil's progress towards identified outcomes should be evaluated.

This evaluation should then inform feedback into the analysis of the child's needs. The teacher, working with the SENCO, should revise the support in light of any progress the pupil has made, deciding upon any changes needed to support the outcomes.

#### SEN/ASN (Scotland) Support Plan

In the SEN/ASN Support Plan, schools should record what SEN they have identified a child as having, what outcomes they expect the child to achieve with SEN provision, and what provision is being put in place to reach those outcomes. After each assess, plan, do, review cycle, the plan/record should reflect any changes that are needed to support the outcomes. Parents should have clear information about the impact of the support provided, so that they can be involved in planning the next steps.

### 7.3 Funding For SEN

The new school funding system and SEN Funding is agreed locally and is given to schools under three main headings:

#### Element 1:

is an amount of money given for each pupil in the school and is often referred to as AWPU (Age Weighted Pupil Unit). Schools get most of their funding based on the total number of pupils they have in the school, with each pupil attracting a certain amount of money. The amount varies from one authority to another and, for example, there is usually more funding for each pupil in a secondary school than in a primary school. There is an acceptance that this amount can be around £4,000, although some schools may receive less than this amount. This is the core budget for each school and it is used to make general provision for all pupils in the school, including pupils with SEN.

**Element 2:**

is the school's notional SEN budget. This means that as every school receives an additional amount of money to help make provision to meet children's SEN, this is called the 'notional SEN budget'. The amount in this budget is based on a formula, which is agreed between schools and the local authority. The formula usually gives more money to schools that have more children on free school meals and more children who are not doing as well as others in English and maths. This provides a good guide as to how many children with SEN a school is likely to have. The government has recommended that schools should use this notional SEN budget to pay for up to £6,000 worth of special educational provision to meet a child's SEN. It is perceived that most children's SEN provision can be for less than £6,000.

**Element 3:**

is 'top-up' or 'high needs' funding. If the school can show that a pupil with SEN needs more than £6,000 worth of special educational provision, it can ask the LA to provide 'top-up' or 'high needs' funding to meet the cost of that provision. Where the LA agrees, the cost is provided from funding held by the LA in their 'high needs' block. Element 3 is provided by the LA for an individual pupil who has a high level of needs and schools are expected to use this funding to make provision for that individual pupil to meet identified outcomes.

**EHCP needs assessment**

Some children and young people may not make the progress expected of them, even with help at SEN Support. When this happens, the LA may carry out an EHCP needs assessment (CSP in Scotland).

You, or your child's school, can ask the LA to carry out an EHCP/CSP needs assessment. A young person can make the request if they understand sufficiently well themselves, otherwise the parent can make the request on the young person's behalf. The school should trigger an EHCP/CSP needs

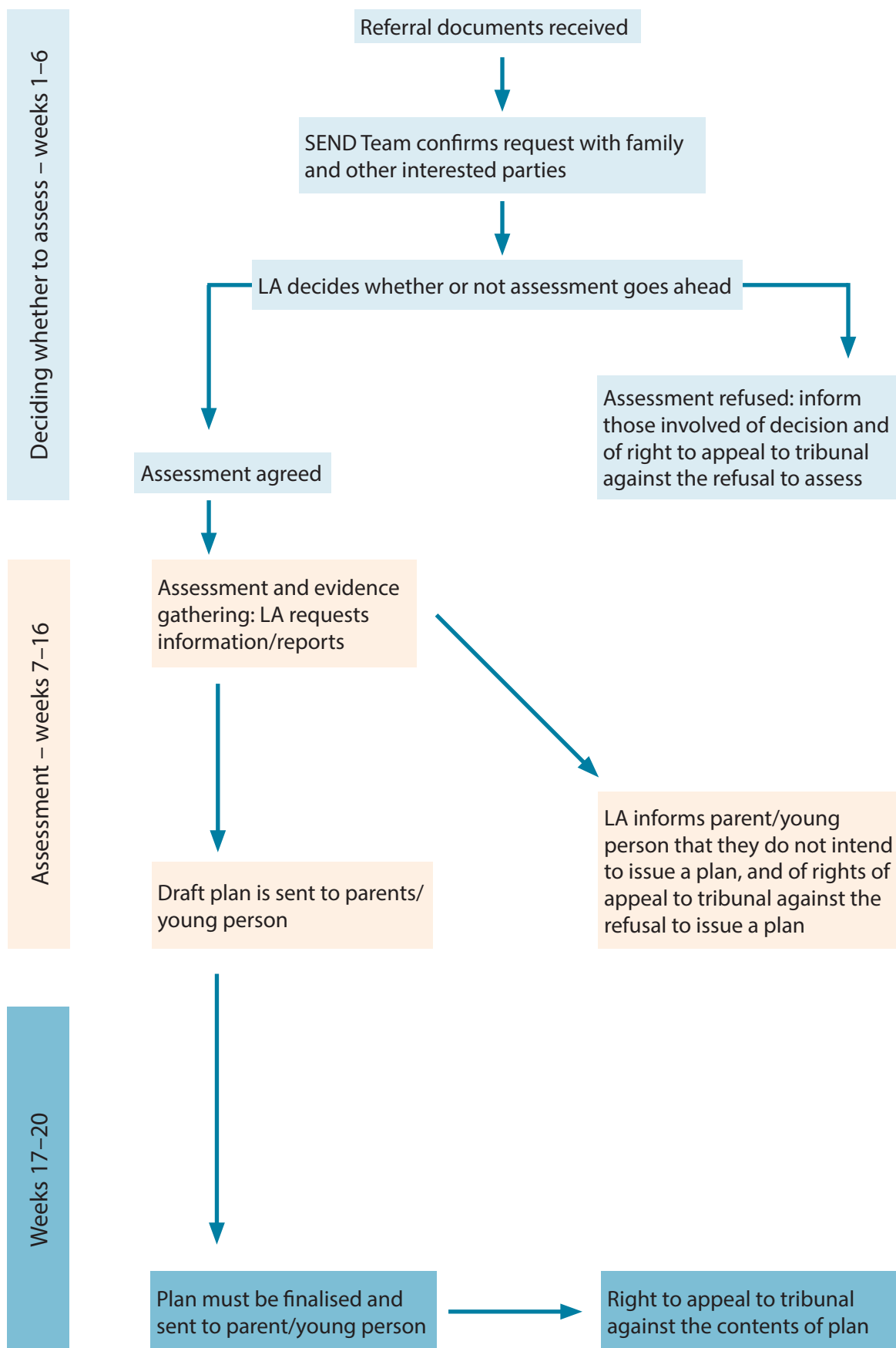
assessment where they cannot meet a child's needs. This could be, for example, if they don't have the expertise or funding to identify either those needs or the provision/support the child requires. They should also do so when they know what the child's needs are and what provision should be put in place, but they cannot make that provision. However, the LA will expect to see evidence of the action taken by the school as part of SEN Support.

**The Code states:**

In considering whether an EHCP (CSP in Scotland) needs assessment is necessary, the LA should consider whether there is evidence that despite the early year's provider, school or post-16 institution having taken relevant and purposeful action to identify, assess and meet the special educational needs of the child or young person, the child or young person has not made expected progress. (9.14)

### Timeline for assessment

The whole process – from the initial request for an assessment to the final issuing of the EHCP (CSP in Scotland) – is to be completed within 20 weeks.



## 7.4 Contents of the EHCP/CSP plan

EHCP/CSP plan must contain specific information that relates to a child's or young person's SEND. It must also be specific about the additional support or interventions that are needed to meet those needs.

EHCP/CSP plans are broken down into 11 sections. The SEND Code of Practice 0-25 is specific about the information that should be detailed in each section of an EHCP/CSP.

**Section A** – the views, interests and aspirations of the child or young person and family

**Section B** – what the SEND is

**Section C** – any health needs relating to their SEND

**Section D** – any social care needs relating to their SEND

**Section E** – the outcomes sought for that individual child or young person

**Section F** – what support is needed for the child or young person's SEND

**Section G** – any health provision reasonably required by the learning difficulties or disabilities which result in the child/young person having SEND

**Section H** – any social care provision, which must be made for a child/young person under 18 resulting from s.2 of the Chronically Sick and Disabled Persons Act (CSDPA) (1970)

**Section H2** – any other social care provision reasonably required by the learning difficulties or disabilities, which result in the child/young person having SEND/ASN

**Section I** – the name and type of school or other placement

**Section J** – personal budgets (including arrangements for direct payments)

**Section K** – advice and information gathered during the assessment.

There are four key principles underpinning an EHCP/CSP assessment and the contents of an EHCP/CSP plan. These require the LA to consider:

1) the views, wishes and feelings of the child and his/her parent, or the young person

2) the importance of the child and his/her parent, or the young person, participating as fully as possible in decisions relating to the exercise of the function concerned

3) the importance of the child and his/her parent, or the young person, being provided with the information, advice and support necessary to enable participation in those decisions

4) the need to support the child and his/her parent, or the young person, in order to facilitate the development of the child or young person (Children and Families Act, section 19).

### Reviewing the EHCP/CSP plan

If a child or young person has an EHCP/CSP plan, it must be reviewed annually by the LA and the first review of the EHCP/CSP plan must be held within 12 months of the plan being finalised. All subsequent annual reviews must be held within 12 months of the previous review.

The Code of Practice has detailed information about the processes that must be followed when reviewing an EHCP/CSP plan. The most important process that must be followed is for the LA to consult with the parent of the child or young person (and with the school or institution being attended if there is one) about the EHCP/CSP plan.

Information must be gathered from parents and young people, and from professionals about the EHCP/CSP plan and then circulated two weeks before the annual review meeting. After the meeting, a report of what happened must be prepared and circulated to everyone who attended or submitted information to be discussed.

After the meeting, the LA reviews the EHCP/CSP plan and must notify the parent of the child or the young person of any decision made, within four weeks of the meeting.

#### Decisions could include:

- ▶ to maintain the EHCP/CSP plan unchanged
- ▶ to amend the EHCP/CSP plan
- ▶ to cease to maintain the EHCP/CSP plan, if they think it is no longer necessary for it to be in place.

In each case, even if the LA decides to do nothing, there is a right of appeal triggered to the Tribunal about the education contents of the plan.

#### SEN and Disability Tribunal

You can appeal to the First-tier Tribunal (Special Educational Needs and Disability) if you disagree with your LA's decisions about your child's special educational needs. This is the case, for example, if they refuse to:

- ▶ assess your child's EHCP/CSP needs
- ▶ re-assess their SEN
- ▶ create an EHCP/CSP
- ▶ change the EHCP/CSP. You can appeal if they reject or stop the EHCP/CSP, or if a school or LA has discriminated against your child or someone else because of your child's disability.

#### Mediation

One of features brought in by the Children and Families Act 2014 is compulsory consideration of mediation before most types of cases can be brought to the SEND Tribunal.

All LAs have some form of dispute resolution services, which try to resolve disputes between parents and LAs. Such 'informal' dispute resolution will undoubtedly continue to take place, either with the support of the Information, Advice and Support Service or the LA's complaints service.

However, dispute resolution of this nature is voluntary and it does not always take the form of mediation.

The new requirement is compulsory consideration of 'formal' mediation. This now applies in most cases where a parent or young person wishes to appeal to SEND Tribunal against certain decisions of the LA, and about the contents of the education sections of an EHCP/CSP. This means that for most types of appeal, where a parent or young person does not want mediation, they will need to obtain a mediation certificate to prove that they have at least 'considered' it. This certificate comes from a mediation advisor and shows that the parent/young person has been informed about the mediation service but has decided against it.

If the parent/young person does attend mediation and if it is successful, then this may prevent the need for a Tribunal hearing. If it is not successful, the parent/young person will instead need a certificate to show that they have participated in mediation before proceeding with an appeal. An appeal cannot be registered without this certificate.

#### The Local Offer (not in Scotland)

The LA must publish a Local Offer that contains information about all of the services it expects to be available for children and young people with SEND, for whom they are responsible. This must include any schools, colleges or services that the LA uses for children or young people outside the LA's area.

The Local Offer should not be just a directory of services or series of links. It must state



clearly what the LA expects to be available in terms of:

- ▶ what schools/colleges and other settings will provide from the funding they receive for SEND
- ▶ what schools/ colleges and other settings in its area will provide from the funding they receive to support those with a disability
- ▶ EHCP provision
- ▶ training provision
- ▶ transport arrangements between home and school/college/early years' settings
- ▶ support for preparing for adulthood and independent living.

For further information, or to view the *SEN and Disability Code of Practice 2015.4 0-25* years, visit [www.gov.uk](http://www.gov.uk)

### The Equality Act 2010

The Equality Act came into force on 1 October 2010. It combines over 100 pieces of legislation into one single Act. The Act provides a legal framework to protect the rights of individuals and to advance equality of opportunity for all. The Act provides Britain with discrimination law to protect people from unfair treatment, and promotes a more equal society.

Follow the links below for free, downloadable information and guidance on:

- ▶ The Equality Act 2010
- ▶ *Schools Guidance*
- ▶ *Guidance for Education providers – Further and Higher Education*
- ▶ Auxiliary Aids and Services
- ▶ Reasonable Adjustments for Disabled pupils
- ▶ [www.equalityhumanrights.com](http://www.equalityhumanrights.com)



# Chapter 8

## Safer moving and handling

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'Moving and handling' includes a wide range of activities that staff in school may need to undertake in order to support a young person's direct or indirect needs. It includes tasks involved with looking after the young person directly and in moving inanimate objects. This includes lifting and putting down, carrying, pulling, pushing, throwing and catching. Not all actions are directly linked to helping a young person to move. It is also important for those working with a young person to recognise that, frequent

repetition of an activity, stabilising activities, holding positions for any length of time and poor or awkward posture can have a detrimental effect. So, it is important that all staff members are supported to learn the best way to carry out activities.

### Legislation

There is no such thing as 'safe moving and handling', though there are safer techniques.

**There is legislation to support this including:**

<p>Health and Safety at Work etc Act (1974)  <a href="http://www.hse.gov.uk/legislation/hswa.htm">www.hse.gov.uk/legislation/hswa.htm</a></p>	<p>This is the employers' and employees' duty to ensure that there are reasonable and practicable solutions to problems, the workplace is safe, and the appropriate equipment and training are provided. Staff also need to be provided with suitable equipment for all tasks and be competent and supported in using the equipment.</p>
<p>Management of Health and Safety at Work Regulations (1999)  <a href="http://www.legislation.gov.uk/uksi/1999/3242/regulation/3/made">www.legislation.gov.uk/uksi/1999/3242/regulation/3/made</a></p>	<p>This involves risk assessment to ensure staff members, who have needs such as being young workers, pregnant and so on, are assessed and advised.</p>
<p>Workplace (Health and Safety Welfare) Regulations(1992)  <a href="http://www.legislation.gov.uk/uksi/1992/3004/contents/made">www.legislation.gov.uk/uksi/1992/3004/contents/made</a></p>	<p>This supports the workplace being well maintained, with temperature and humidity control, clean, light and ventilation.</p>
<p>Manual Handling Operations and Regulations (1992)  <a href="http://www.legislation.gov.uk/uksi/1992/2793/made">www.legislation.gov.uk/uksi/1992/2793/made</a></p>	<p>This lists the moves that are included in moving and handling, and goes on to say that, when possible, lifting should be avoided and risks minimised.</p>
<p>RIDDOR (1998) (Updated 2013)  <a href="http://www.hse.gov.uk/riddor/">www.hse.gov.uk/riddor/</a></p>	<p>This is the system for reporting if things go wrong, and how to learn from mistakes.</p>

Lifting Operations and Lifting Equipment Regulations LOLER(1998) and (2014)	This states that equipment for lifting should be inspected every 12 months, and equipment used for people, every six months. It also says that this equipment should be used by competent people.
Provision and Use of Work Equipment Regulations PUWER (1998) <a href="http://www.hse.gov.uk/work-equipment-machinery/puwer.htm">www.hse.gov.uk/work-equipment-machinery/puwer.htm</a>	This refers to periodic, risk-based inspection and maintenance.
Human Rights Act (1998) <a href="http://www.legislation.gov.uk/ukpga/1998/42/contents">www.legislation.gov.uk/ukpga/1998/42/contents</a>	This states that everyone has the right to be treated without degrading treatment, pain and anguish of body and mind.
Equality Act (2010)	This Act ensures that everyone is treated without direct or indirect discrimination, and insists on the fair and equal provision of services.

Musculoskeletal disorders are injuries that can occur when a muscle, joint or group of muscles are pushed harder, faster, longer, differently or without rest. This can lead to short- or long-term discomfort, weakness, pain, changed sensation and changed range of movement. This usually has an impact on how a person carries out their normal day-to-day activity. It is important not only to try to minimise risk to workers, but NHS Back Care Advisors now recognise the need to encourage healthy lifestyle choices for those with a caring role. These choices can include maintaining a healthy weight, and exercising for strength and flexibility.

Many young people with muscle-wasting conditions will require assistance to move as their condition progresses. This could include support for walking, assistance with transfers between chairs, or even using a hoist. It could also include helping young people to access equipment such as standing frames, or helping with care tasks such as going to the toilet, or adjusting their position.

### Training

It is the school's or college's responsibility to ensure staff members are trained and that

they maintain their competencies. Anyone who works in school with a young person with a muscle-wasting condition should have generic moving and handling training to introduce them to the principles. This is often available through the Local Education Safer Moving and Handling team, but it is important also to check locally. Usually, once this training has taken place, the therapists who know the young person will work with staff on specific tasks.

### Assessment and planning

It is important to recognise that for all moving and handling, a risk assessment should take place. This may form the basis for a moving and handling plan, although there are many variables, such as how the young person feels, if the handler has any health problems, changes to the environment, and so on. Staff must therefore apply the principles of dynamic risk assessment to capture and respond to these variables.

Schools must have a robust safer moving and handling plan, based on assessment, which looks at the whole situation, the young person (or load) and the environment. This is often carried out with the therapists or the

Local Education Moving and Handling Team and a plan written that captures the child's needs. The plan needs to be specific and to list each move, the technique required, the equipment needed and the competent staff required. It should cover the daily school routine, although it will also be necessary to write separate plans for trips, Personal Egress and Evacuation Plans, and out-of-

school activities. It should be remembered that the right equipment and techniques can enhance independence. Plans should be reviewed annually, or when there is a significant change in function.

The acronym TILEEO (task, individual, load, equipment, environment, other) is often used to support the planning:

### TILEEO table

<b>Task</b>	<p>What is the aim/purpose of the task?</p> <p>What moves are required?</p> <p>Does this involve staying in a supporting position for periods of time?</p>
<b>Individual</b>	<p>Is the handler competent to handle?</p> <p>Is the handler fit to handle on that day and time?</p> <p>Have risk assessments been undertaken if they are pregnant, injured, a young worker, etc.?</p> <p>If there are two handlers, are they used to working together? Have they discussed how best to carry out the move?</p>
<b>Load</b> (this relates to either the person or an object)	<p>Does the person know what is going to happen?</p> <p>Is the person calm and consented to be handled?</p> <p>Could the person potentially move in an unpredictable way?</p> <p>Does the person have behavioural problems, which could have an impact on handling?</p> <p>What are the young person's preferences, and can these be incorporated safely?</p> <p>If it is an object, is it stable, unbalanced, symmetrical?</p>
<b>Equipment</b>	<p>Is the equipment safe to use?</p> <p>Has it been checked and is there a log of maintenance?</p> <p>Is the equipment clean?</p> <p>Is the equipment fit for purpose?</p> <p>Is the equipment for the sole use of the young person?</p>
<b>Environment</b>	<p>Is there space for care tasks?</p> <p>Where is the move to? Is it clear and ready?</p> <p>Is the floor clear? Are there any slip, trip or fall hazards? Are there any ramps or slopes to negotiate?</p> <p>Is there enough light?</p> <p>Is the temperature suitable to work in and to provide the care required?</p>
<b>Other</b>	<p>This captures team work, satisfaction, management obligation, changes to report to SENCO, and so on.</p>

The TILEEO review needs to take place regularly, as circumstances can change. This is particularly important when there is a change in personnel, or the young person experiences any changes in their condition or mobility.

As part of the plan, there must be discussion about whether one or two handlers are required. This needs to be guided by local policy, including that which relates to safeguarding. It is needs-led, although often – when the handler is competent and confident, has enough time and the correct equipment – it can be safe for one person to handle.

### Equipment

The health professionals that know the young person should advise when equipment is required to support moving and handling. It is the responsibility of the school to ensure it is correctly maintained in line with health and safety legislation. This may include liaising directly with companies who have installed the equipment or with the provider, if it has been financed by the LA.

Those working with the young person on a daily basis will notice changes as the young person grows and equipment needs altering or re-provision. This needs to be fed back to the SENCO, who can then arrange the appropriate reviews.

### Risk assessment forms

Contact your LA for risk assessment forms. Examples of joint health/education risk assessment, and moving and handling forms are provided in Appendix 11. These can be adapted for use by your school, in conjunction with your local health trust. *The Five Steps to Risk Assessment* document published by the Health and Safety Executive is a useful resource to support the process. It can be found at [www.hse.gov.uk/risk/controlling-risks.htm](http://www.hse.gov.uk/risk/controlling-risks.htm)

# Chapter 9

# Extended schools provision

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## 9.1 Partnership working

The LA's specialist teaching service offers a variety of support to children in mainstream schools, who have muscle-wasting conditions. How this support is organised can vary between authorities.

Some LAs have a specialist team, often known as the Physical Difficulties Support Service, while others co-ordinate outreach work between SEN and mainstream schools. The form of this outreach partnership is likely to be unique to the LA, and can take a variety of approaches. It may, for example, encourage staff from mainstream schools to look at systems in SEN schools or staff from SEN schools to visit mainstream schools and advise directly. Sometimes, for example, if a child is in a hospital school, staff may work together to facilitate a joint placement.

The LA's SEN department should be the first point of contact for any school that has pupils with muscle-wasting conditions and wishes to access local provision and assistance.

## 9.2 Hospital schooling

In November 2001, the government published statutory guidance on the education of young people with medical conditions<sup>1</sup>. This was in response to concerns that children with medical needs were in danger of being excluded from the school system.

It has been possible, for many years, for young people to be educated in hospital, although the value of this has not always been fully recognised. The 2001 guidance states that children in hospital have a right to as much education as their condition allows,

and identifies good practice guidelines.

One of the most important roles of the hospital teacher is to provide continuity of education for the pupil. Establishing links between home, school and the hospital can help to ensure a smooth transition from one situation to another. It will also minimise disruption to education if a young person is regularly admitted to hospital. Parents can help by informing schools of admittance to, and discharge from, hospital, and convey work from school to the child.

Young people at home, unable to attend school for more than four weeks because of their condition, have a right to five hours of home tuition a week.

## 9.3 Respite/hospice care

### Respite care

If a family meets the LA's eligibility criteria (usually linked to the severity of the child's disability), they may be able to access support from the Social Services department. This support can be provided through respite care, family link, night-sitters, personal care and/or direct payments.

A local authority may provide respite care directly, or pay a local voluntary organisation for the service. Children who qualify for respite care usually stay in a residential establishment for two or more nights a month, either at weekends or during the week. The child attends school as usual, although arrangements with transport providers may need to be changed.

1. Access to Education for Children and Young People with Medical Needs, DfES, 2001

### Family link

This form of respite care is provided by a family (who will have undergone assessment similar to that of foster carers) in their own home. Although some severely disabled children may use the service during the week, it is normally provided at weekends and may include an overnight stay. The child attends school as usual, although arrangements with transport providers may need to be changed.

### Night-sitters

This service is available for families with children who need a lot of attention during the night. The sitter stays with the child overnight, on a regular basis, so that the parents can have an uninterrupted night's sleep.

### Personal care

Families with a child who finds it difficult to wash and dress him or herself may be entitled to help in the mornings and evenings. This is particularly if parents need to look after other children or work shifts.

### Direct payments

A family entitled to help with personal care may choose to employ their own carers, rather than use those provided by the local authority. In this case, they will receive payments directly from their LA to fund the care.

### Hospice care

Caring on a daily basis for a child or young person with a life-limiting condition can place a physical and emotional strain on all members of a family.

There is a range of opportunities that may be available to families to support parents in their role as carers. Children's and young person's hospices offer care and support to children and young people with a shortened life-expectancy, as well as their families. For children who meet their criteria (these criteria are available to read on each children's

hospice website), hospices can provide short breaks, day care, emergency care, symptom control and terminal care. In some areas, there is a 'home from home' service, catering sensitively to the family's individual needs.

Many hospices have young persons' units, which can offer support for young people until they reach adulthood. They can also support young people with guidance on transition to adult services, and some have transition and youth workers. These units will often offer opportunities for young adults to meet with their peer groups and participate in various activities.

The hospice can also help with transition to adult palliative care services. Your NCA may also be able to offer support with this.

While provision varies, many hospices provide support 24 hours a day, and care may also be provided in the home.

When a child or young person dies, bereavement support is available to parents, siblings and grandparents for as long as they need it.

Professionals working with families may also contact the hospice for help and advice.

Further information is available at [www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)

### Short breaks

Short breaks offer disabled children and young people the opportunity to have enjoyable experiences which help them become more independent and form friendships outside their family. They also give parents and carers time to do normal things which other families take for granted, like doing the shopping or going for a run. Short breaks can be day, evening, overnight or weekend activities and may take place in the child's home, in the home of an approved carer, or in a residential, specialist or mainstream community setting.



Since April 2011, LAs have been under a duty to provide a range of short breaks services. Since October 2011 they have also been required to publish a local Short Breaks Duty Statement showing what services are available, how they are responding to the needs of local carers and how they can be accessed, including any eligibility criteria. LAs must consider the needs of local parents and carers when preparing their statements and must review them on a regular basis.



# Chapter 10

# Transition

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## 10.1 Transition planning

For teenagers, preparation for adult life is an important part of their planning and support. Transition should start early and ideally well before Year 9 (age 13-14). Discussions about their future should focus on the child or young person's strengths and capabilities, the outcomes they want to achieve, and the best way to support them for the future.

Considering post-16 education is part of this planning, but should also include transition to adult health and social care services, leaving education and training and progressing into employment. Young people's aspirations and needs will not only vary according to individual circumstances but they may also change over time as they get older and approach adult life.

From Year 9, the EHCP/CSP reviews should include a focus on preparing for adulthood. These plans will include supporting the young person up to the age of 25. Even if you do not have an EHCP/CSP, it is important that transition planning begins at this stage and it should be part of your review. Each review thereafter must include a focus on preparing for adulthood.

Preparing for adulthood should include:

- ▶ looking at options for further/higher education, training and /or employment
- ▶ exploring options for independent living
- ▶ being able to participate in society and contribute to the community
- ▶ being as healthy as possible in adult life.

## Checklist

Transition planning should:

- ▶ ascertain the young person's views and aspirations, and how these can be met
- ▶ be person-centred and support young people to participate as fully as possible in the planning and decision-making process, with the use of an advocate if appropriate
- ▶ listen to the views of parents and help them to support their children through the process
- ▶ look at the options available for further/higher education, training and/or employment, this may include options such as supported internships, apprenticeships and traineeships
- ▶ ensure the curriculum meets the child's physical/health/educational and, ultimately, work aspirations
- ▶ determine whether work experience is appropriate and help facilitate a placement
- ▶ ensure the pupil has appropriate life skills, including how to access social and community activities and opportunities for developing friendships, and a network of support
- ▶ be flexible enough to accommodate exam arrangements and early college placement
- ▶ look into options for supported or independent living, or who they may wish to live with in the future.
- ▶ give advice around the transition process from specialist paediatric services to adult health care.

Schools should invite to the Year 9 annual review meeting:

- ▶ pupil
- ▶ parents or carers

- ▶ SENCO
- ▶ relevant members of teaching and support staff
- ▶ social services
- ▶ LA officers, educational psychologists and advisory teachers, as appropriate
- ▶ local college staff, if necessary
- ▶ paediatric/adult medical services
- ▶ transition services
- ▶ agencies who can assist with career planning and work placements
- ▶ NCA/specialist nurse.

## 10.2 Making choices

Although they have the right to free education up until the age of 25, young people will need to decide whether or not to continue with their education.

In making this decision, young people with muscle-wasting conditions should have the same educational choices as other pupils:

- ▶ to stay at the school they currently attend
- ▶ to move to another school or sixth form
- ▶ to go to a further education or residential college
- ▶ to aim for higher education/university, or
- ▶ to undertake open learning.

To make an informed choice, the young person may also need help and advice about work options. These could include accessing colleges that offer courses designed to provide pathways to employment, while considering independent care support, personal budgets or direct payments.

Schools should work in partnership with the various agencies mentioned above to ensure a cohesive, timely transition into adulthood. They should identify current needs for care and support, and consider whether the young person is likely to have needs for care and support after they turn 18 and, if they do how those needs might be met.

Further details can be found here:

- ▶ [www.gov.uk/government/publications/send-code-of-practice-0-to-25](http://www.gov.uk/government/publications/send-code-of-practice-0-to-25)

Muscular Dystrophy UK has guidance for young people about healthcare transition. For more info call **020 7803 4800** or email [info@muscular dystrophyuk.org](mailto:info@muscular dystrophyuk.org)

# Chapter 11

# Physical education (PE)

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The National Curriculum states:  
'The aim of high-quality physical education curriculum inspires all pupils to succeed and excel in competitive sport and other physically demanding activities. It should provide opportunities for pupils to become physically confident in a way which supports their health and fitness. Opportunities to compete in sport and other activities build character and help to embed values such as fairness and respect.'

Department for Education, 2013

Schools have a responsibility to make 'reasonable adjustments' to their policies and practice for PE, aim for accessibility and promote equality. Teachers need to think creatively to set suitable learning outcomes that respond to the diverse needs of the class and overcome barriers. Some educationalists refer to the 3Ps – Presence, Participation and Performance – when thinking about PE. This can focus the teacher on thinking about how to ensure the young person accesses PE, what modifications can be made and what they want to achieve. Inclusion is a process and it involves everyone in planning, delivering, evaluating and modifying lessons.

## The evidence for exercise in muscle-wasting conditions

For people living with muscle-wasting conditions, exercise may have benefits for maintaining or improving muscle strength, maximising function and minimising contractures. A lack of exercise can contribute to de-conditioning, and the development of a vicious cycle whereby the person gains weight thus making exercise more difficult. People who live with muscle-wasting conditions need to exercise with care and take advice relevant to their condition from

the healthcare professionals who see them regularly.

Anziska and Sternberg, 2013

## Benefits

The benefits of joining in with PE are far-ranging and include not only the benefits of physical activity, but also the knowledge and awareness of the principles of a healthy lifestyle, teamwork, leadership skills and the 'feel-good' factor associated with activity. Exercise and physical activity may help a person to maintain their ability to perform daily living tasks, help maintain bone density, and help maintain a healthy weight, release the 'feel-good' hormones and help with sleep.

## Pacing

It is not uncommon for young people with muscle-wasting conditions to find that they are enthusiastic to participate in PE, but to then feel over-fatigued afterwards. This is tricky to explain to a young person who loves joining in but then does not understand the after-effects.

It is often useful to use stories such as the 'Hare and the Tortoise' to explain to younger children that they don't have to be the fastest to be successful, and that working too hard can mean you don't achieve your goal. This can be used in conjunction with diaries where they mark their activities on to a blank diary and colour-code them according to how tired they are. This helps when explaining trends, and cause and effect. It also helps to explain the 'boom and bust cycle' where a 'boom' of activity caused you to 'bust'!

Pacing activity in PE helps to enable participation and should aim to let the

young person enjoy the lesson but not to the detriment of activities later in the day. It can be useful to use a simple equation to try to establish how much activity is reasonable. It depends on the teacher's knowing how much activity will cause fatigue, and is an estimate to be used as a guide only:

$$\text{Time} \times 80 = \text{number of minutes of activity}$$

The Borg Scale (Borg RPE scale. Copyright Gunnar Borg, 1970, 1985, 1994, 1998) offers another effective way to monitor the intensity of exercise and the physiotherapist can advise the levels to aim for:

0	nothing at all
1	very light
2	fairly light
3	moderate
4	somewhat hard
5	hard
6	
7	very hard
8	
9	
10	very, very hard

Some young people may also wear a pedometer, or an electronic measuring device, to track exercise. This can help the young person understand how their activity levels impact on their fatigue, and help them to plan how physical activity fits in with all their other activities.

The key to success is in the preparation and it can be useful to divide this into:

- ▶ present moment awareness – how is the young person today?
- ▶ prioritising – what does the young person need to learn?
- ▶ planning – what, how, why, when, who and where?
- ▶ pacing – what causes the fatigue and how can reasonable adjustments be made?

### Ideas to try

1. Look at the class as a whole, so that all young people are integrated into an activity as much as possible.
2. Save energy by using a wheelchair to get to and from the activity.
3. Aim to do part of the activity well, rather than the whole activity.
4. Keep it fun.
5. Break activities into manageable chunks.
6. Add in rest periods.
7. Plan activities in a realistic time-frame by thinking about what the young person can do before they get tired, in other parts of their school day.
8. Think about how to do a task differently, for example, sitting instead of standing, using different equipment, or making changes to the environment.
9. Be prepared to vary the activity if the young person is having a difficult day.
10. Celebrate success!

### The barriers to joining in with PE

- ▶ **Pre-conceived ideas.** Young people with muscle-wasting conditions, as well as their families, can have pre-conceived ideas about the possibilities of joining in with PE. These can range from wanting the child to join in with all aspects without any differentiation, through to not wanting the child to participate at all. It is important to reassure the young person as well as their parents that schools are skilled at looking at individual

differences and adapting the curriculum to meet the needs of a range of children. It is valuable to spend time with parents to reassure them that the staff will work with the young person's physiotherapist to ensure activities are safe and no movements are contraindicated.

- ▶ **Teachers' fears.** Teachers can sometimes feel overwhelmed about having a child with physical needs in their class. Their fears may include not having sufficient space or equipment, health and safety risks, not having staff to support the lesson, or worries about how long it will take the young person to get ready at either end of the lesson. Managing PE to ensure the curriculum is delivered to all the children, while not excluding anyone, can heighten this anxiety. So, it is important not to under-estimate the importance of getting information about the condition and the young person's abilities, assessment and planning. With the right information, most teachers are really creative in adapting games and activities. This planning may include ways to reward effort, rather than focusing on National Curriculum or P-score achievement.
- ▶ **Equipment and costs.** The concerns that a range of specialist equipment will be required can be a worry. However, borrowing from other parts of the school can be helpful. Often, young children will have access to lighter and smaller equipment, which can help in grading skills. It is also useful to look at schemes, such as the supermarket sports voucher schemes or asking the Parent Teacher Association to fundraise for equipment.
- ▶ **Sensory profile.** Some young people can struggle with PE lessons because they find it hard to process information from the environment. This can include noise, movement and sound. The OT should be

able to work with the child, parents and school to assess and formulate a plan.

- ▶ **Progressive conditions.** Most muscle-wasting conditions are progressive and many will also change with time. The young person may realise that the gap in physical skills is growing, and this can lead to reluctance to participate. This can show in a number of ways, and may include changes in their behaviour and their mood. Those working with the child need to be mindful of this, and support the young person. If this leads the young person to question their knowledge about their condition, parents should be made aware and advice sought from the NCA and therapists. It is important to plan activities that are fun and enable the young person to succeed.
- ▶ **Pain.** Young people with muscle-wasting conditions may report pain and this may stop them from wanting to join in with physical activities. Prolonged periods of sitting in a wheelchair, or joint weakness and contractures, can be a cause. These young people can also report muscle fatigue, which they see stopping them joining in. Reasoning with the young person about the benefits of inclusion in PE can support them to understand how to participate and pace themselves and should not be underestimated as part of a healthy lifestyle message.

### Planning

It is helpful to break down all aspects of the PE lesson, so that planning goes into all stages right from changing into PE kit.

### The practicalities of PE

1. Where are the changing rooms? Are they accessible? Do they meet the needs of the young person?
2. Can the young person get there?
3. Where will the lesson take place?
4. If the young person is not moving around

as much as others, will they get cold? What can we do to prevent this?

5. Who is available to support the young person? What are their training needs?
6. If the activity means moving between different surfaces, how will the young person do this?
7. Does the school have a range of PE equipment, which will help when differentiating activities?
8. What lesson follows PE and how will increased activity levels affect this?

Safer Moving and Handling may differ slightly in PE from other activities in the school day. Looking at the changing rooms, the location for the lessons and the type of activities should enable the staff to think about how best to keep the young person and themselves safe. This could potentially mean adapting techniques, sourcing equipment and training, or addressing structural access issues in the gym or sports hall. The local therapy team and the LA's Officer can advise.

It could also mean looking at who supports the young person in this lesson, and applying an assessment framework to ensure they are trained, competent and fit to move and handle.

The school can ask the local therapy team to become involved in assessing the child in PE. This will mean that staff will have a baseline for activity and whether there are any contra-indicated moves. It also enables the staff to work alongside the therapists to look at activities which meet therapy goals, and fit the National Curriculum. It is often useful to look at pacing and grading of activity in PE, as this can often be meaningful to the young person.

Often the language used when asking children to carry out a task can foster an ethos of inclusion. For example, asking the class to 'practise chest passes with a netball' could be exclusive, whereas asking them to 'choose a ball to pass' could allow the child to roll or

kick and still achieve a pass. The objective is defined so that everyone can achieve it at their level in this case. Using the creative ideas of the young people can extend the repertoire of accessible skills, and should be fostered where possible.

Many PE activities can be modified to provide a 'more level playing field'. This could be as simple as everyone playing volleyball while sitting on the floor, 'bum shuffling' football, or everyone using the same equipment as the young person. It might also mean looking at specialist sports and incorporating them into the Learning Outcomes through activity, playing the game, or inviting the local specialist team in to coach a session.

Sometimes parts of the PE curriculum can be difficult to modify to provide sufficient challenge and inclusion for everyone in the class. In these cases, parallel activities may need to be considered. It is often useful to choose an activity that a small group can participate in and perhaps rotate the groups regularly so everyone gets an opportunity to play the game with the young person. This is seen as positive, as the activity chosen will be one that everyone is able to achieve and can sometimes lead to a new interest or activity some young people may wish to pursue in their leisure time.

Following on from the success of the Paralympic Games and Invictus sporting events, there is an increased awareness of the range of sports available for disabled people. It may be possible to look at some of these as a whole class activity. It is worth looking at local clubs to see what is available locally.

Using technology to support activity through games such as the Wii / Kinect can have health benefits and can be used in a PE session with a small group of participants. Games need to be selected, which mirror the learning outcomes of the lesson but are an additional resource to explore.



The school can access support from Youth Sports Trust, as they employ Inclusion Support Workers nationally.

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

### Adapting lessons

It is helpful to look at levels of inclusion when modifying lessons. This is known as the Inclusion Spectrum (Training and Development Agency, 2009).

1. **Open activity** – everyone does the same with minimal adaptation or modification.
2. **Modified activity** – all young people work to their ability level and changes are made to support this. The lesson should aim to stretch everyone. The Space, Task, Equipment, People (STEP) template (see on p91) can be applied to support changes.
3. **Parallel activity** – participants are grouped according to ability level and each group takes part in a graded/differentiated version of the same activity.
4. **Alternate/disability sport** – everyone takes part in a sport, which is accessible to disabled people. It may be valuable to look at what organisations run locally and may be happy to visit or provide information. Adapted activity – the lesson is based on an accessible sport in which the young person with a muscle-wasting condition can participate. They could teach a sport or skill or as a group, young people could carry out a project to learn rules, improvise equipment, and organise a tournament. It could also include looking at the accessible activities in the area, which could open opportunities for activities not available in school. This may include dance, mountain trike sessions, adapted outdoor adventure sports, and so on.

### The Space, Task, Equipment, People (STEP) template offers way to make an activity harder or easier:

S	Space	<p>Where is the activity happening?</p> <ul style="list-style-type: none"> <li>▶ shorter distances if mobility is a challenge</li> <li>▶ smaller areas for games</li> <li>▶ zones and visual markers to define areas to work in</li> <li>▶ enlarging the space to improve reaction time</li> <li>▶ staggering start times for different groups of abilities</li> <li>▶ the child's ability to perform in the chosen space may also be considered if they struggle with sensory processing, as sports halls can be noisy, cold and have harsh lighting.</li> <li>▶ can the location be changed if the surface is unsuitable for moving around on foot or in a wheelchair?</li> </ul>
T	Task	<p>What is happening?</p> <ul style="list-style-type: none"> <li>▶ simplify the task</li> <li>▶ how is the teaching delivered?</li> <li>▶ re-write the rules</li> <li>▶ vary the speed that everyone participates at</li> <li>▶ change the format, for example, everyone kneels or sits/throws underarm/uses left hand</li> <li>▶ plan the activity around the strengths of the young person.</li> </ul>
E	Equipment	<p>What is being used?</p> <ul style="list-style-type: none"> <li>▶ provide a range of equipment</li> <li>▶ lighter equipment</li> <li>▶ vary target sizes and placement</li> <li>▶ be creative, think beyond PE – borrow from younger classes where equipment may be lighter or smaller. All equipment can be graded, for example</li> <li>▶ if a wheelchair is being used, does it have anti-tip bars fitted?</li> </ul>
P	People	<p>Who is involved?</p> <ul style="list-style-type: none"> <li>▶ working with 'buddies' who have similar abilities</li> <li>▶ team work, with differentiated roles</li> <li>▶ assistance from another pupil</li> <li>▶ coaching as an activity, etc.</li> </ul>

### If the activity requires bats and balls you could differentiate using a similar format to the following:

Bat	Ball
Wheelchair Any part of the body Glove bat Short badminton or tennis racket Normal racket Kwick cricket bat Flat rounders bat Normal rounders bat	Balloon Slightly deflated beach ball 'Floater' air-filled balls Foam ball Soft tennis ball Tennis ball Rounders ball

By identifying the barrier to inclusion, it may be possible to use creative options to support skill development. Sometimes equipment will need to be purchased but it may be worth looking at voucher schemes or Parent Teacher Association funding to help with this.

### Ideas to try:

- ▶ a board or gutter for a seated person to use to roll balls down to access a target
- ▶ a floor-based tee so that a young person can kick or strike a static ball when they are balanced
- ▶ tethering a ball by attaching a line, so that a young person can pull the ball back in to themselves
- ▶ rebound boards, for example, on the side of a table tennis table, so the ball is more likely to 'stay in play'
- ▶ glove bats or modified bats that have straps to help the young person grip the handle.

### Participation

This should include giving young people a voice, listening to them and involving them in school-life decisions. Listening to their ideas encourages empowerment.

Participation may mean different things to different young people, and it is important to let them know the options available. These might include participating in the activity, scoring, refereeing, coaching or being the captain of a team. These options could be dovetailed with the physio programme, the warm-up and cool-down or some participation with the actual activity. Value comes from setting achievable goals.

Parents also need to be consulted about their children's participation. They will often need reassurance and information about the overall benefits of the subject, how the PE curriculum will be delivered, and the support their child will receive. Parents need to understand the benefits of the lesson and to be reassured that their child is not

being put in vulnerable situations or feeling undermined. In particular, consideration needs to be given to teenagers as they may have increased awareness of the variance in skills between them and their peers. They can be reluctant to be seen as being different so the planning needs to be treated with a great deal of sensitivity. Perhaps these teenagers might prefer to learn a new skill, for example, coaching/refereeing.

### Indicators of an inclusive lesson might include:

- ▶ clear learning objectives
- ▶ all young people take an active role in the lesson
- ▶ as much physical activity as possible
- ▶ no eliminations
- ▶ sufficient challenge for all participants
- ▶ progression
- ▶ everyone is involved in decision-making and feedback
- ▶ respect for each other, the rules and the equipment
- ▶ some team work
- ▶ participants enjoy the activity.

### Contra-indications (a movement that is not recommended because it is potentially dangerous)

With each condition, there may be some contra-indicated activities or physical moves, so it is important to work alongside the therapy team supporting the child.

It can be important for a child to move in a particular way, wear supportive footwear, and be advised not to jump from equipment, and so on. The physiotherapist will be able to advise on specifics related to a particular condition.

It is also important to think about the potential for injury, how best to manage this and whether or not a health professional needs to be notified.

It is also important to be aware that some neurological conditions, such as Charcot-Marie-Tooth disease (CMT), make it very difficult for young people to participate in PE. They may already have issues with their body image as a result of foot abnormalities, poor balance, being unable to walk as quickly as their peers and suffering from, in some cases, overwhelming fatigue. There may also be difficulties with dressing and undressing for PE. Although the benefits of inclusion are important, the young person should always have a choice, and their decision should be recognised and supported.

### Getting changed and ready

Getting changed and ready for a PE lesson can mean one of two things to young people with muscle-wasting conditions. It can either offer opportunity to practise personal care skills, or it can cause the young person to become fatigued and not be able to join in with the lesson effectively. Look at what is important to the individual, and make a plan accordingly.

In either situation, look at the environment, assess, plan for reasonable adjustments, and ensure any equipment is available.

Some schools will think creatively and plan alternative strategies to avoid changing either taking more time or causing fatigue. In some schools, a young person will come to school in jogging bottoms and only need to change their top, while in other schools, the whole class will come to school wearing PE kit.

The supporting adult will need to know the techniques for assisting the young person and be sensitive and flexible in their approach.

### Swimming

Swimming is part of the National Curriculum for young people in KS2 and it needs to be planned with thought to every part of the activity. Consider the following:

### Transport

- ▶ How does the school get children to and from the pool?
- ▶ Will the usual travel arrangements work for the young person?
- ▶ Will they need a different type of transport?
- ▶ What are the additional costs and who will fund these?
- ▶ Will the young person be more fatigued after swimming?
- ▶ Will different arrangements need to be made to get them back to school?

### Access

- ▶ Can the young person get into the pool building and access all parts that they need to?
- ▶ What are floor surfaces like, and can the young person manage these safely?
- ▶ Is there space for the young person to change in the changing rooms?
- ▶ Is there a personal care suite with hoist and plinth?
- ▶ If the young person is hoisted in the personal care suite, are the sling and the hoist compatible?
- ▶ How will the young person get into the water?
- ▶ How will the young person get out of the water?

### Support

- ▶ Which staff members will support this activity?
- ▶ Will a member of staff be required to go into the water?
- ▶ Is there a member of staff who will not go into the water, and be able to assist with personal care once the young person is out of the water?

### Time

- ▶ It may take longer for the young person to get ready. How will this work if there are strict times for the transport?

## Temperature

- ▶ How warm is the water?
- ▶ Will cooler temperatures affect the young person?
- ▶ How can this be managed?

## Fatigue

- ▶ Will this activity significantly tire the young person?
- ▶ Will they be able to carry out all other tasks that day after swimming, or will they be too tired?
- ▶ Can swimming be arranged for the end of the day so the young person can go home straight afterwards?
- ▶ Can the time in the water be shortened to conserve the young person's energy, and also allow time for personal care before getting back on transport?

## What activities or movements can be carried out in the water?

- ▶ Seek advice from the physiotherapist.

## Sport beyond school

There are a growing number of sporting opportunities for people living with disabilities, particularly following high-profile coverage of the Paralympics and Invictus Games. The BBC has a dedicated Disability Sports page at [www.bbc.co.uk/sport/disability-sport](http://www.bbc.co.uk/sport/disability-sport).

## Ideas for adapted sports

Below is a list of sports that could potentially be incorporated into the school sports programme, or be discussed with the young person as an out-of-school opportunity. Please note, the list is not exhaustive.

- ▶ Wheelchair basketball – fast-paced, requires upper limb strength sufficient to propel the chair. [www.gbwba.org.uk/gbwba/welcome.htm](http://www.gbwba.org.uk/gbwba/welcome.htm)
- ▶ Inclusive zone basketball – this is a game with two teams of players, and can be played with a combination of wheelchair and standing players.

[www.gbwba.org.uk/gbwba/index.cfm/get-involved/inclusive-zone-basketball/](http://www.gbwba.org.uk/gbwba/index.cfm/get-involved/inclusive-zone-basketball/)

- ▶ Pollybat – a table-top game that has evolved from table tennis. It is an accessible form of table tennis. [www.ntu.ac.uk/adapted\\_sports/games\\_development/games/polybat/index.html](http://www.ntu.ac.uk/adapted_sports/games_development/games/polybat/index.html)
- ▶ Pollybat squash – played like Pollybat, but with a table up against a wall with the table legs elevated on blocks. Sides are created for the table out of cardboard or plywood, for example. The ball is played up the ramp, it bounces off the wall and is returned by the opponent.
- ▶ Table cricket – table-top cricket game. [www.lordstaverners.org/table-cricket](http://www.lordstaverners.org/table-cricket)
- ▶ Target cricket – adapted from table cricket, it is useful for a young person who has a learning disability. [www.ntu.ac.uk/adapted\\_sports/adapted\\_games/target\\_cricket/index.html](http://www.ntu.ac.uk/adapted_sports/adapted_games/target_cricket/index.html)
- ▶ Table hockey – table-top hockey game.
- ▶ Floor lacrosse – adapted lacrosse, which can be played indoors or outdoors. [www.ntu.ac.uk/adapted\\_sports/adapted\\_games/floor\\_lacrosse/index.html](http://www.ntu.ac.uk/adapted_sports/adapted_games/floor_lacrosse/index.html)
- ▶ Tee ball – rounders/baseball skills, breaking throwing/catching into manageable skills. [www.littleleague.org/learn/about/divisions/TeeBallDivision.htm](http://www.littleleague.org/learn/about/divisions/TeeBallDivision.htm) [www.baseballpositive.com/tee-ball](http://www.baseballpositive.com/tee-ball)
- ▶ Pyramid shuttle – the player travels to collect an item at three progressively further points, returning each time to score on the try line.
- ▶ Zone hockey – integrates ambulant and mobility-impaired players. [www.ntu.ac.uk/adapted\\_sports/adapted\\_games/zone\\_hockey/index.html](http://www.ntu.ac.uk/adapted_sports/adapted_games/zone_hockey/index.html)
- ▶ New Age Kurling. [www.gbKurling.co.uk](http://www.gbKurling.co.uk)
- ▶ Short mat bowls.
- ▶ Powerchair football. [www.thewfa.org.uk](http://www.thewfa.org.uk)
- ▶ Boccia. [gb-boccia.org](http://gb-boccia.org)
- ▶ Table tennis. [etta.co.uk/our-sport-modules/table-tennis-for-people-with-disabilities](http://etta.co.uk/our-sport-modules/table-tennis-for-people-with-disabilities)

## Sports resources

- ▶ Athletics.  
[academy.uka.org.uk/parallel-success](http://academy.uka.org.uk/parallel-success)
- ▶ Boccia England  
[www.bocciaengland.org.uk](http://www.bocciaengland.org.uk)
- ▶ Sport England. [www.sportengland.org/our-work/disability](http://www.sportengland.org/our-work/disability)
- ▶ English Federation of Disability Sport.  
[www.efds.co.uk](http://www.efds.co.uk)
- ▶ Finding a Sport. [parasport.org.uk](http://parasport.org.uk)
- ▶ Northern Ireland. [www.dsni.co.uk](http://www.dsni.co.uk)
- ▶ RADAR (general resource about sport – not specifically for children).  
[www.disability.co.uk/doing-sport-differently-0](http://www.disability.co.uk/doing-sport-differently-0)
- ▶ Scotland.  
[www.scottishdisabilitysport.com/sds](http://www.scottishdisabilitysport.com/sds)
- ▶ Sports Opportunities. [www.wheelpower.org.uk/WPower/index.cfm/who-we-are](http://www.wheelpower.org.uk/WPower/index.cfm/who-we-are)
- ▶ Support for Adapted Sports.  
[www.sportanddev.org/en/learnmore/sport\\_and\\_disability2/actors\\_involved\\_in\\_sport\\_\\_\\_disability/international\\_organisations/international\\_federation\\_of\\_adapted\\_physical\\_activity](http://www.sportanddev.org/en/learnmore/sport_and_disability2/actors_involved_in_sport___disability/international_organisations/international_federation_of_adapted_physical_activity)
- ▶ TOP Sportsability On-Line Learning Resource. [topsportsability.co.uk](http://topsportsability.co.uk)
- ▶ Training. [www.disability.co.uk/doing-sport-differently](http://www.disability.co.uk/doing-sport-differently) / [inclusivepe-eng.co.uk](http://inclusivepe-eng.co.uk)
- ▶ Wales. [www.disabilitysportwales.com](http://www.disabilitysportwales.com)
- ▶ Wheelchair Dance.  
[wdsauk.co.uk/about-us](http://wdsauk.co.uk/about-us)
- ▶ Wheelchair Football Association.  
[www.thewfa.org.uk](http://www.thewfa.org.uk)
- ▶ Wheelpower. [www.wheelpower.org.uk](http://www.wheelpower.org.uk)
- ▶ Youth Sports Trust.  
[www.youthsporttrust.org](http://www.youthsporttrust.org)
- ▶ Young Coaching Opportunities.  
[www.efds.co.uk/resources/past\\_programmes/582\\_young\\_officials](http://www.efds.co.uk/resources/past_programmes/582_young_officials)

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*7 Ways to Include a Student with Special Needs in Physical Education.* Friendship Circle. [www.friendshipcircle.org/blog/2013/11/12/7-ways-to-include-a-student-with-special-needs-in-physical-education](http://www.friendshipcircle.org/blog/2013/11/12/7-ways-to-include-a-student-with-special-needs-in-physical-education)  
*Education.* Participation Works Partnership.

## [www.participationworks.org.uk/topics/education](http://www.participationworks.org.uk/topics/education)

*National curriculum in England: physical education programmes of study* Published 11/09/13. [www.gov.uk/government/publications/national-curriculum-in-england-physical-education-programmes-of-study/national-curriculum-in-england-physical-education-programmes-of-study](http://www.gov.uk/government/publications/national-curriculum-in-england-physical-education-programmes-of-study/national-curriculum-in-england-physical-education-programmes-of-study)  
*Pacing Activity.* Australian Pain Management Association. [www.painmanagement.org.au/2014-09-11-13-35-53/2014-09-11-13-36-47/166-pacing.html](http://www.painmanagement.org.au/2014-09-11-13-35-53/2014-09-11-13-36-47/166-pacing.html)

*Boom and Bust. Moving Into Balance.*

[www.movingintobalance.co.uk/pacing](http://www.movingintobalance.co.uk/pacing)

Pete Moore, Jessica Bird & Dr. Frances Cole.

(2012). *The Pain Toolkit.* [www.paintoolkit.org/downloads/ptk-for-teenagers2012.pdf](http://www.paintoolkit.org/downloads/ptk-for-teenagers2012.pdf)

Training and Development Agency.

(2009) *Including Pupils with SEN and / or Disabilities in Primary Physical Education.*

Manchester. [www.dera.ioe.ac.uk/13804/1/physicaleducationpe.pdf](http://www.dera.ioe.ac.uk/13804/1/physicaleducationpe.pdf)

*Sainsbury's. Active Kids 2013 – Inclusive Resource.*

Rankin (2012). *Qualitative Research Report: Exploring Why Disabled People and Deaf People Do not Participate in Sport.* English Federation of Disability Sport. England.

Anziska & Sternberg (2013). *Exercise in Neuromuscular Disease. Muscle and Nerve.* New York.

## Planning For PE

Name:	DOB:
Year group:	Teacher:
Support adult:	

## Generic planning

Considerations	Comments / plans
List the young person's strengths	
List the young person's needs: <ul style="list-style-type: none"> <li>▶ physical / movement</li> <li>▶ sensory</li> <li>▶ learning</li> <li>▶ behaviour</li> <li>▶ medical</li> <li>▶ other</li> </ul>	
What are the young person's interests?	
Are there any contra-indications to joining in with activity?	
Does the young person require help to move around in the environment: <ul style="list-style-type: none"> <li>▶ independently?</li> <li>▶ with supervision?</li> <li>▶ with physical assistance?</li> <li>▶ with equipment?</li> </ul>	
Can the young person get on and off equipment: <ul style="list-style-type: none"> <li>▶ independently?</li> <li>▶ with supervision?</li> <li>▶ with minimal physical help, for example, holding a hand?</li> </ul> Can they get down on to the floor independently? Can they get up from the floor independently?	
What preparation needs to happen before PE and does the young person know: <ul style="list-style-type: none"> <li>▶ what to expect?</li> <li>▶ how they are going to be joining in with the activity?</li> <li>▶ who will be supporting them?</li> <li>▶ how they will be supported?</li> </ul> Do they need information presented in a particular way, for example, kinaesthetically, visually, simple instructions, etc.?	

## Lesson-specific planning

What is the learning outcome for the lesson?	
What are the activities planned?	
How will outcomes be measured?	
Does the risk assessment relate to the young person and the activity planned?	
Have the young person's views been taken into account?	
If the activity is modified for the young person, how can other children in the class be included?	
Will the young person be undertaking a parallel activity for part of the session, for example, physio stretches?	



# Managing playtime/break time

Playtimes and break times can be anxiety-provoking times of the school day for pupils with muscle-wasting conditions. There are many reasons for this, but they often relate to concerns about a young person's safety and inclusion. However, with planning, playtime and breaks can add value to the young person's day.

### Benefits

The benefits of being outdoors and in a less structured environment can include:

- ▶ a rest from formal learning
- ▶ an opportunity for informal learning through fun, friendships and laughter
- ▶ a time of refreshment – mentally and/or nutritionally
- ▶ time with friends
- ▶ free movement in the space
- ▶ sunshine, particularly Vitamin D levels.

### Reasonable adjustments

Breaks are part of the school day and should therefore receive as much planning as other more formal learning.

### Things to consider:

#### Staffing

- ▶ Who will be available to supervise or support the young person?
- ▶ Do the staff members on playground duty know about the muscle-wasting condition?
- ▶ Do they recognise that they can't stop a young person falling, though they can take the right action to try to minimise risks?

#### Getting ready to go outside

- ▶ Changing into outdoor shoes and putting on a coat, hat and gloves takes time.

- ▶ This time can mean the child is last to go outdoors and may not be included in games.
- ▶ Discreet support could facilitate better inclusion. Or is it an opportunity for the young person to practise their self-help skills?

### Games and activities

- ▶ Young people can feel safer if they are close to an adult in the playground, particularly if they have balance or stability problems, or they fall frequently.
- ▶ Games with an adult and a small group of friends can be considered.
- ▶ Can playtime buddies be helpful, to join in with more accessible games? They may also notice if a young person is not being included by their peers.

### Pacing

Many young people struggle to pace their activity through the day and can become fatigued as a result. It is difficult for young children to self-regulate this however, as they get older, many realise they can save energy for the important aspects of school. In practical terms, this might mean:

- ▶ accepting a little help to get ready to go outdoors
- ▶ using the wheelchair to travel to the playground and then getting out to play
- ▶ choosing less energetic games
- ▶ using some of the time to relax in a quieter area.

### Quieter areas of the playground

- ▶ Is it possible to identify a quieter and less exposed area of the playground to use for less boisterous games?
- ▶ Can this area have some seating?

- ▶ Can this area have a selection of lighter weight toys and games, such as:
  - ▶ target games, such as quoits or skittles
  - ▶ lightweight balls and bats
  - ▶ Velcro bats and balls
  - ▶ circus skill games – diablo, juggling balls, gym ribbons
  - ▶ giant outdoor games – Jenga, Connect 4, chess
  - ▶ lawn croquet
  - ▶ robust musical toys – ‘boom wackers’, wind chimes, wall of sound
  - ▶ chalk boards/graffiti wall (chalks only).

As is the case during other times of the day, every child has different needs. It is important to review regularly and make changes.

# Chapter 13

## Preparation for a school residential visit

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(This section is designed to help parents of children with muscle-wasting conditions.)

### Planning ahead of the trip

Going on a residential trip is often one of the highlights in a young person's school career. It offers opportunities to bond with the peer group, while providing team-building activities that develop roles and trust. It is important to try to plan and make reasonable adjustments for a young person with disabilities so they are able to engage equally in experience. The parents or carers and the school will need to work closely together, and should call upon the expertise of relevant professionals to assess and facilitate a safe and enjoyable experience. The following information aims to guide you.

### Access visit

Schools often have a favoured residential centre that they use each year and the booking is often made 12 months in advance of each class group's trip. This gives you time to discuss the suitability of the chosen location well in advance, and you can visit it a few months before you go. Often, it is worth visiting the site at a similar time of year to the actual trip so that you see the paths and activities in similar weather conditions.

You may want to consider the pros and cons of taking your child on an access visit. Every family and young person is different. Some parents feel that if they take their child, it can raise expectations while others want the child to help make decisions about what is right for them.

You will find more information and ideas about what to look for on a residential trip later in these guidelines.

### Travel to the residential centre

Often the travel to the centre is the start of the adventure for the whole class. Discuss the practicalities of the transport arrangements with school as some schools will travel on public transport while others take a coach. Your child's ability to walk and manage steps will determine whether or not the chosen mode of transport will work.

If the class travels by train, you will need to look at the access at both stations and think about the return journey too. It may be worth doing a quick visit to the station at the same time as the access visit.

If the class travels by coach, consider whether your child will sit in their wheelchair or a normal seat on the coach, and what type of access the vehicle has. If they travel in a normal seat, will they be able to manage the steps up on to the vehicle? If not, can the school request a vehicle with the ability to drop the floor to kerb level?

If the transport issue cannot be resolved, you may need to transport your child in your own vehicle. This obviously is less inclusive, but offers a safe option. In some cases, parents have made arrangements to take another child as a companion. The school will advise you on this.

### Access around the centre indoors and outdoors

It is important to know your child's abilities in moving round on rough, stony or muddy ground, as many centres will have paths that can be a challenge. If your child uses a wheelchair, think about whether or not the wheels will cope with the conditions, gradients, etc. The weather conditions may

affect paths, and in some locations the paths are gravel, which will be difficult for both a manual and a powered wheelchair.

Some centres have access to rugged outdoors wheelchairs with larger tyres. However, if your child needs to have some support around their head or trunk, these wheelchairs may not be a suitable option. Discuss your child's needs with the centre staff members, who may be able to suggest options and adjustments that could be made. They may have had experience of other children with limited mobility, and can think creatively about the problem.

If your child walks but has an above average risk of falling, think about how they would get up from the floor without injury to themselves or staff who might be assisting. Often it is more likely for children to fall, or for their legs to give way, when they are fatigued. Consider reducing the risk by using a wheelchair between activities.

### Staying warm and dry

Another factor to consider is how your child will stay warm and dry while they are outdoors at the centre. Often, planned activities will take place in all but the most extreme weather conditions. Your child will almost certainly need to have warm clothes and a waterproof coat and trousers, however extra layers may be needed and a contingency plan put in place so that they can get back indoors if they need to.

### Range of activities

Often the programme is set a few weeks before travel. While you may not want to 'spoil the surprise' of the activities planned for your child, it may be worth discussing the plans with him or her. This gives them the chance to discuss their preferences with you and leaves time to plan how to make the activity accessible. For example, your child may use a wheelchair, and for a particular activity they made need to travel across grass or gravel,

so there may be matting available to use. Or perhaps your child particularly wants to go on a zipwire. Once you've checked with your local therapists about the safety of this, you may want to discuss the practicalities of getting your child to the start of activity, for example, the top of the tower.

Centre staff may have appropriate moving and handling equipment or have links to resources such as local Fell Rescue services that may be able to help. You sometimes need think creatively to problem solve send make an opportunity happen!

### Sleeping accommodation

The evenings are often a time for group activities, followed by the social bonding of chatting to friends. So it is important to make sure there are opportunities for integration; these are important to the overall experience of the child or young person.

From a practical perspective, the room, space, type of bed, storage and proximity to adult assistance need to be assessed and reasonable adjustments made. Each young person's needs must be considered when an environmental visit is undertaken before the trip.

It is wise – if it is possible – to choose a bedroom with an en-suite bathroom. This is more important if the child is hoisted, although it is obviously not always an available option. Alternatively, a facility with a fully accessible bathroom with a changing bed, hoist, rails around the toilet and enough space for carers to perform hygiene tasks, may be an option.

Some centres have separate accommodation that is more accessible and offers flexible bedroom configurations and adapted bathrooms, as well as rooms for the carers.

Many centres have bunk beds, which can be tricky if the child requires assisted transfers. Even if the child is usually independent at

night, with the combination of physical activity, fresh air and maybe less sleep, the child may need more assistance than usual. Plan for this by arranging for a single bed (often the bunks can be separated into two single beds), practising assisted transfers, and providing suitable moving and handling equipment. You may need to raise the height of the bed; this may require liaison between the child's OT and the local Community Equipment Store.

Consider how the child will alert adults if he/she needs help during the night. This will differ according to the child's needs, parents' requests, available resources and the practicalities. It could be as simple as having a 'buddy' system, or using available technology such as a mobile phone, radio or remote control doorbell.

### Bathroom

Consider the preferences and needs of the child when assessing the suitability of the bathroom space. At minimum, the child will require the use of a toilet and wash basin, but a shower should also be considered.

### Toilet

Where possible, the routines and techniques used at home should be replicated. It may be necessary to take a free-standing toilet surround, or raise the height of the toilet to enable independent transfers. If this is the case, the toilet and space around it will need to be measured to check that equipment will be safe, appropriate and fit for use. It is important to consult the child's OT to check local arrangements for fitting equipment.

If the child is hoisted, you are likely to struggle to use a mobile hoist as the legs are unlikely to get far enough to towards the rear of the toilet. This leaves the person stranded in front of the toilet bowl. You may need to consider taking a commode, although this will reduce carer space in the room. Ideally, a ceiling-mounted hoist would be the preferred option.

Consider how the child will receive personal or intimate care, and who will provide it. If the child is hoisted, it will be necessary to have a changing plinth/shower stretcher in the bathroom. Note that toileting slings are not an option with children who have muscle-wasting conditions, owing to the risk of shoulder injury.

You could consider using one bedroom, (ideally single occupancy) for toileting, if a mobile hoist is required. The bed, with a suitable cover on it, would then be used for changing and intimate hygiene. This is really not ideal, but it could be the difference between the child's attending and not. Of course, the child would still need access to a wash basin, although a hand-washing bowl brought to the child may suffice for a day or two.

### Help for personal care tasks

Staff, who will be taking on personal care tasks, will need to liaise closely with the child's parents or carers before the trip. In this way, they can ensure they have detailed knowledge of routines, habits and techniques. It should not be assumed that the way things are done in school will work first thing in the morning, or when they are fatigued.

It is important that the child is happy with the person selected to carry out their care tasks. Often this will be the same ESA that supports them in school, but at least two people should be identified to provide cover in a 24-hour period.

Staff will need to be assessed as competent in meeting the care needs of the child and will require time for training. These competencies could include:

- ▶ assisting with toilet routines
- ▶ applying splints
- ▶ using overnight ventilation equipment
- ▶ using overnight gastrostomy feeds
- ▶ physio exercises to maintain respiratory health.

In addition, staff will need time to meet with parents and the child so they are aware of how the child may respond to differing environments, fatigue, disturbance to normal bed times, etc.

### Red flags and care plans

Children with muscle-wasting conditions can fall ill, and many residential centres are located a reasonable distance from a hospital with expertise and knowledge to deal with the problem. To ensure the child receives the appropriate care, staff will also need access to Emergency Care Plans and to know how the child may present when unwell. Ask the child's parents if they have 'red flags' (signs/symptoms), which they use to indicate when medical advice should be sought.

Muscular Dystrophy UK has produced alert cards for a range of muscle-wasting conditions. These cards outline possible symptoms and situations, as well as key recommendations and precautions that non-specialist clinicians would need to know during a time of worsening health. It is helpful for the school to have one of these at hand.

### Dining area

When reviewing facilities during the access visit, consider factors such as access to the dining room, height of counter-top service, getting to the table, assistance with cutting food and help with eating.

### Activity planning, fatigue, pacing and grading

When planning the activity programme, parents, school staff and residential centre staff need to be mindful of the activities that a child would like to participate in. It is important to balance this against what is practical and available without undue risk. If possible, the child should be part of this process so he/she can make informed choices. This may mean some activities can be adapted or the child can take on a different role within the group, for example

problem-solving, being the group co-ordinator.

Think creatively about how to make activities safe and effective for a child. For example, use different types of archery bow or a whole body harness for a zipwire. However, thought needs to be given to the whole activity – from the time the young person starts their journey to the activity:

- ▶ what is the flooring like for their wheelchair?
- ▶ are there steps to access the activity?
- ▶ how will the child transfer on to the equipment?
- ▶ do they need to wear personal protective equipment, and if so, how do they get it on?
- ▶ are there any parts of the centre where wheelchairs cannot be used for health and safety reasons, for example crate stacking where the child may not be able to move out of the way quickly enough?

In addition, it is important to look at the knowledge, skills and competencies of those who are assisting the child. There may be staff members who are not fully aware of any contra-indications, or the child's preferences.

Most children want to be accepted alongside their peers on residential trips. Although they are fatigued and may feel even more tired after the trip, they still want to join in. However, they need to have the opportunity to rest, and this may take some careful negotiation from the staff supporting the child. It often works to have discussed this with the child before going on the trip to ensure an activity accessible to everyone is available. Some children will want to take time to rest on their bed and play a computer game, while others may want to repeat one of the less strenuous activities. Either way, if a child is using their wheelchair all day, it is valuable to encourage them to take some time out of the chair for a stretch.

### Risk assessment

Staff members responsible for caring for the child may have to increase their skill base to include tasks that the parent/carer usually undertakes at home. This may include overnight feeds, morning chest physio, use of overnight ventilation, administration of medication and so on. Seek the advice of both parent/carer and the most relevant healthcare professional, and ensure training and competency checking are undertaken.

### Safer moving and handling

All tasks need to be thought through before the activity, and the appropriate controls and measures put in place to minimise risk.

By applying TILEEO (see p80 in Chapter 8: Safer moving and handling), the team around the child can minimise risk to both child and handler. It is important to be mindful of the variability caused by fatigue, environmental fluctuations, or even the motivation of the young person. It is also reasonable to assume that some of the handling techniques may be carried out by handlers who are less familiar with the child's preferences, or the contraindications of holding a child in a particular way. For this reason, it is essential to have clear team planning and communication, before and during each move. It is also important to review the move after its conclusion, so that any change can be implemented.





## Residential visit – action plan

Name:	DOB:	NHS:
Date of visit:	Location:	
Present:		

### Background

When is the residential visit to take place?

Probable needs of young person at time of visit:

- ▶ physical
- ▶ medical
- ▶ learning/emotional.

Concerns about environmental restrictions:

Child's views:

Parents' views:

Considerations	Action plan, time frame and accountability
<p><b>Travel</b></p> <p>How will the class get to the centre? Coach/public transport/own transport? Will the young person be able to travel with their peers? What are the barriers? What adjustments will need to be considered? If they can't travel with their peers, what are the alternatives? Will the same arrangements be made for the return journey?</p>	
<p><b>Access around the centre</b></p> <p><b>Outdoors</b></p> <p>What are the path surfaces made from? Are there steps or gradients? Are these accessible by a wheelchair? Are there alternative routes around the site? Are these more accessible?</p>	

Considerations	Action plan, time frame and accountability
<p><b>Access around the centre (continued)</b></p> <p>Are the paths affected by inclement weather and would this affect moving around the site?</p> <p>Are there any paths that would be unsuitable for the young person?</p> <p>Does the centre have a rugged outdoors wheelchair? Would this offer enough support for the young person, for example, head/trunk support?</p> <p><b>Indoors</b></p> <p>Is there level access into the centre?</p> <p>Once inside, are there downstairs facilities? For example, bedroom, bathroom?</p> <p>Are there any steps into rooms, such as the dining room or lounge?</p>	
<p><b>Access to activities off-site</b></p> <p>Are all activities on the site?</p> <p>If not, what activities will need to be accessed off-site?</p> <p>How will the young person travel to these locations?</p> <p>Consider the paths, steps, stairs, gradients, floor surfaces at the off-site venue; will these represent any obstacles?</p>	
<p><b>Participation</b></p> <p>What activities are offered? List them.</p> <p>Does the young person want to take part in a particular activity?</p> <p>Are there any activities perceived as too risky/contra-indicated?</p> <p>Can reasonable adjustments be made to any activities to make them safe and accessible?</p> <p>Are there any external organisations that could provide support to make an activity achievable?</p>	
<p><b>Daily living</b></p> <p><b>Sleeping</b></p> <p>What bedroom facilities are available? Bunk beds, single beds, shared occupancy rooms?</p> <p>Is there sufficient space in the bedroom for the young person, especially if they have care needs?</p> <p>What height is the bed (measured from top of the mattress to floor when a person is seated on the edge of the bed)?</p> <p>Is this a suitable height for independent transfers?</p> <p>What adjustments/modifications can be made?</p> <p>Will reasonable adjustments need to be made to make the space more accessible? What needs to be done?</p> <p>Can the young person stay in the same room as his/her friends?</p>	

Considerations	Action plan, time frame and accountability
<p><b>Daily living (continued)</b></p> <p>Where will support staff stay, in relation to the young person? How will the young person get help if required?</p> <p><b>Bathroom and toilet</b></p> <p>How close is the bathroom to the bedroom? How will the young person get to the bathroom? Is the bathroom adapted? In what way? (It may be useful to draw a floor plan which includes measurements to help with planning.) Are the adaptations suitable for the young person's needs? Can the young person get on and off the toilet independently? Will they require help/equipment? If the toilet is inaccessible, are alternatives such as a commode in the bedroom an option? (This would mean others would need to leave the room. It should only be used as an option if careful planning takes place.) Are there other toilets the young person can use? (Apply the above questions to these too). Is the shower accessible? Is there a seat/rails? Can the young person shower themselves or do they need help? Would a wash-down be adequate if the shower is inaccessible? Consider all risks, if water sports are on the activity list.</p> <p><b>Staying warm and dry</b></p> <p>What clothing will be required, and can this be put on and taken off easily? Does the centre have any personal protective equipment that could be used, if needed? Are there any significant risks if the young person gets wet/cold?</p>	
<p><b>Safer moving and handling</b></p> <p><b>Risk assessment</b></p> <p>How does the young person move currently?</p> <ul style="list-style-type: none"> <li>▶ Independently</li> <li>▶ With supervision and/or support</li> <li>▶ With assistance</li> <li>▶ With equipment</li> </ul> <p>It is likely that the same methods will still be effective in the residential setting?</p> <p>What alternatives could be considered to make sure the plans are future-proofed? Are there alternative ways to transfer on/off beds, chairs toilets?</p>	

<b>Considerations</b>	<b>Action plan, time frame and accountability</b>
<p><b>Health and care needs</b></p> <p>Are there specific health needs?</p> <ul style="list-style-type: none"> <li>▶ Physio exercises/stretchers</li> <li>▶ Splints</li> <li>▶ Feeding, for example, assistance, gastrostomy</li> <li>▶ Chest physio</li> <li>▶ Ventilation support</li> <li>▶ Emergency Care Plan</li> </ul>	
<p><b>Assistance</b></p> <p>Who will assist the young person?</p> <p>Are there enough support staff to cover the 24-hour period so they each get rest breaks?</p> <p>Do they support the young person in school already?</p> <p>Will they need additional training/competency checking? List what is needed.</p> <p>Who will provide the additional training?</p>	
<p><b>Managing fatigue</b></p> <p>What plans can be made to support the young person when they become fatigued?</p>	

# Chapter 14

# Information and communication technology( ICT)

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ICT is integral to everyday living and should be available to children and young people living with muscle-wasting conditions in their full range of environments. This means looking at options that give the young person access to technology, which travels with them between home and school and into other settings. There are many perceived benefits to using accessible technology in the educational setting. It can motivate the user, while also assisting the person in pursuit of their academic goals, and enabling social inclusion. It can be used in parallel with writing and drawing or as a replacement, or a combination of both. The young person's needs and wishes should be assessed regularly and plans made to find the most appropriate resources for them.

Often it is the parent, carer, teacher or OT that initiates a conversation with SENCO about difficulties recording work, fatigue, or an approaching transition. This should be a trigger to plan an assessment, which includes the young person, their family/carers, and the professional healthcare team who know the young person.

## Assessment

Assessment needs to look at the skills and abilities of the young person. It should also consider what already works well for him/her in non-educational settings, while capturing what is important to them and identifying their goals.

It should initially look at how the person currently records work, their posture, position, seating, table height, upper limb function and hand function. It also needs to be at the relevant developmental level of the young person and the academic expectations of

teachers. It also needs to take into account the variability in a young person's ability as they become more fatigued during the school week.

Once the assessment is complete, and you have identified what works well and what the problems are, solutions need to be planned. It is likely that some solutions will be readily available in school, and can be set up with minimal modification. This could include use of laptop computers, netbooks or tablets, and may be complemented by advice on posture, positioning, wrist supports and pacing of activities. This advice should be available from the young person's OT. Monitor the effectiveness of the solutions and make changes to advice accordingly.

When a young person's needs are more complex, further assessment needs to take place and, if necessary, advice sought from specialists. In some LAs, there may be a technology consultant or a specialist teacher with knowledge of the application of ICT. There may also be an IT technician or teacher who has expertise to share; sometimes a regular idea can be adapted or modified.

The local Disabled Living Centre could be approached for advice about equipment, switch controls, interfaces and so on. However, any assessment needs to include the therapy staff members who know the young person, their muscle-wasting condition, contra-indications and implications for function.

Once solutions to problems are in place, there is a need for consistency when equipment is set up, especially if it will need to be transferred between people and settings. Additionally, postural change needs to be

considered so staff members get it right every time; subtle changes in posture can affect hand use.

Some young people may have needs which cannot be resolved using local expertise and which require further assessment and planning. In some parts of the country, there are commissioned assessment and advisory services provided by ACE centres. These centres provide complex assessment of Augmentative and Alternative Communication Technology and run free information days every month, although a full assessment incurs a cost.

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

AbilityNet is a national charity that offers advice and information about adapting technology, including advice on personalising a standard computer. (See 'My Computer My Way' on their website.)

[www.abilitynet.org.uk/homepage](http://www.abilitynet.org.uk/homepage)

In Scotland, Communication and Assistive Technology for People with Disabilities can be accessed online, offering factsheets, as well as webinar advice and support.

[www.callscotland.org.uk/home](http://www.callscotland.org.uk/home)

Organisations such as Pretorian [www.pretorianuk.com](http://www.pretorianuk.com) and Oneswitch [www.oneswitch.org.uk/index.htm](http://www.oneswitch.org.uk/index.htm) are useful for young people who want to look for switch options. This is not an exhaustive list, so it is worth searching further.

It may be also valuable to contact the local Disabled Living Centre, as they may have advice on the use of technology and ideas to try.

### Red flag and triggers

There are key times in a young person's education when the question of access to technology should be asked, so it needs to be on the agenda at all meetings. Dependent on the muscle-wasting condition, the triggers

may vary. These key times arise with transition planning between any of the educational key stages, in the lead-up to the start of GCSE work, and when there are changes that affect function significantly, such as spinal surgery.

1. The Early Years – some children will present with reduced control or power to produce accurate fine motor skills from an early age. It is important to consider introducing age-appropriate technology to support Early Years learning. This may be using switch technology to operate cause and effect toys, or early use of touch screens. It may be possible to access advice through a specialist service available at the local Disabled Living Centre.

As the child starts to mark-make and to write letters, a hand function assessment by an OT may advise use of simple supports, such as a neoprene wrist splint. This on its own, or combined with a 'hand over hand' technique, may be sufficient to enable the child to explore the concept of shape through messy play. This could be drawing in sand or cornflour, making shapes with materials such as dough, finger painting, etc. By exploring through sensory learning, the child should develop an understanding of early letter formation. This can then either be replicated on the page or be used with writing Apps on a tablet.

Using technology parallel with hand function may enable the child to experience the success of producing quality work.

2. Increased recording of work – as young people progress into Key Stage 2, the need to record increased amounts of work may mean that hand fatigue is a barrier to creativity. Getting a large numbers of ideas on to the page in a timely way can become difficult, and this may lead to frustration or a level of unwillingness to try. It is important to explore techniques to enable the young person to record ideas quickly.

This may include mapping ideas in a simple format, such as colourful mind mapping, or, voice recording using Accessibility options in Word or a specialist App for a tablet.

As work increases, it is useful to look at ways of reducing the amount of copying the young person does. This may be as simple as providing paper work sheets or PowerPoint slides before the lesson, or making them available electronically so that they can then be filled in. The camera built into iPad and Android tablets is also useful for capturing content from whiteboards or smartboards and other written materials. This feature of the creative use of tablets is often overlooked.

3. When preparing for examinations – whether SATs tests or GCSEs – planning in advance is important. Early planning and communication are essential to success. Share information between the relevant people at the right time and seek advice from the examination boards. All the detail around making special access arrangements for national examinations can be found at: [ncatools.education.gov.uk/Access-Arrangements/Home.aspx](http://ncatools.education.gov.uk/Access-Arrangements/Home.aspx)
4. Change of function influences change of access to both writing and use of technology. There is often a delay between assessment and provision, so it is important to plan ahead. This should be seen as an opportunity, rather than a backward move for both the pupil and the school. The assessment process needs to be re-visited as before.
5. Planning for university is one of the main transitions that a young person makes. It encompasses all aspects of daily living and a huge amount of change and, if technology options that work are retained, the young person will feel that they are in control of their decisions. At the earliest planning meetings, technology needs to be on the

agenda so that the university can continue or develop the right options. It is important to understand that LA funding for a student with an EHCP/CSP will cease when they go on to higher education. If, however, they are progressing on to a further education course, the funding will continue.

Other funding for higher education is available, i.e. Disabled Students Allowance (DSA). [www.gov.uk/disabled-students-allowances-dsas](http://www.gov.uk/disabled-students-allowances-dsas)

### Barriers

The introduction of technology needs to be treated sensitively, so that it is seen by the young person as being a positive way to enable them to be included and to achieve their optimum. It should, where possible, be accessible to others in the class too so it is recognised as being usable by all.

Most young people have a strong desire to feel part of their group and not be different, so occasionally some students may resist technology. The careful integration of the right help at the right time can make a difference, however personal choice must be respected. Often careful negotiation of what, why and when needs to take place. Making technology exciting and fun, and introducing it early is often easier than introducing it when the young person may be identifying that they are different from their peers. If the young person sees equipment such as tablets with appropriate Apps, smaller and easier-to-use mice, laptop computers and simple supports, they are more likely to embrace it as enabling. Young people must see success!

Even when some young people have significant difficulty mark-making and writing, some parents, teachers and professionals can be insistent that recording with pencil and paper is preferable to using technology. Some seem to view it as 'giving in' or a step backwards. Every young person is different; however reasoning through the need to

record and be successful academically should be made. This may require negotiation and many young people will use technology in parallel with writing.

Insurance can sometimes be listed as a barrier, particularly when equipment leaves school premises. This needs to be discussed at a local level and sensible plans made.

There is a move towards young people bringing their own devices into school across mainstream school as well as with young people who have additional needs, and this comes with the issues of security. This is commonly referred to as BYOD (Bring Your Own Device) and increasingly both mainstream and SEN schools will have policies to deal with this approach to accessing technology. Young people love to personalise devices, however this has an impact on safe use, so devices need to be compatible with school security policies. There is no 'norm' here, with some schools operating a blanket ban on BYOD, and others openly encouraging parents to provide their children with tablets and laptops, which move freely between home and school. It helps if the SENCO can work with the Network Manager or IT Technician to resolve these issues.

Increasingly, third-party ICT and facilities management companies manage ICT infrastructures in schools, especially high schools. They, rather than the school's Leadership Team, will develop the policies that will determine the use of BYOD.

Some young people may need to use advanced technology options, which can mean that they are ahead of their peers technologically. Coupled with this, the educational setting may not have the experience or knowledge of the device and its software, and struggle to support this as a sustainable option. Early identification of this and access to support are essential to ongoing success.

## Funding

As touchscreen technology and voice-activated programmes develop, it is becoming more possible to find answers from mainstream solutions.

Once a problem is identified, a range of creative solutions can be explored. Often there is a wide range of resources in school and collaborative working between staff working with the young person, the SENCO, the OT and the IT technician can identify options. Many are free or low-cost, and free advice can be sought from organisations such as the Disabled Living Centre, AbilityNet and other supporting organisations. Also, don't underestimate the value of consulting the supplier of the equipment, as many users will find a sympathetic and knowledgeable contact in their local supplier. As devices such as mobile phones and tablets advance it may be possible to look at the range of options the product offers.

Sometimes talking to a product expert can deliver options the care team or school may not have thought of. On occasion, a young person may need more specialised equipment that could incur a cost. This may mean looking for funding through charitable organisations. Often charitable support will provide partial funding, so sometimes you'll need to approach more than one charity.

The Joseph Patrick Trust, Muscular Dystrophy UK's welfare arm, provides grants towards the cost of specialist equipment for children and adults with muscle-wasting conditions. The equipment could include assistive technology, powered wheelchairs, adapted computers, and electric beds.

[www.muscular dystrophyuk.org/jpt](http://www.muscular dystrophyuk.org/jpt)

There are other local and national charities that are keen to support technology, and the local Disabled Living Centre will be able to give you an updated list. Some families fundraise for specialist equipment, which is not available through statutory provision.



Some charities or organisations hire out or lend equipment for certain activities, such as gaming. It is worth looking around to see what is available.

VAT is payable on all equipment not 'designed solely for use by disabled people'. This includes standard computers, however, equipment such as specialist keyboards or software that is 'designed solely' for use by disabled people qualifies to be zero-rated. There are two concessions for eligible customers only:

- ▶ if the computer is a tool to help overcome communication problems, or
- ▶ if the computer is for the personal or domestic use of a disabled person.

### Practical solutions to everyday problems

Once a problem is identified, solutions need to be negotiated which are practical, and which can be used within school policy on internet safety and safeguarding.

It is helpful not to overcomplicate solutions to problems. Start off by looking at what works for the young person in other settings, as well as mainstream solutions. Technology is constantly developing. Products such as laptops, netbooks, tablets and smartphones offer a wide range of accessible solutions for young people with muscle-wasting conditions.

### Some common problems

**Fatigue.** This can often prevent a young person from recording sufficient amounts of work, and the effort of writing can reduce creativity and quality. In turn this can have a negative impact on motivation and sometimes behaviour.

### Suggested solutions

- ▶ Using planning tools such as mind maps, or, templates available through Word, enables the young person to record work by using key words, which they can later go back to and expand upon. This can also include worksheets that teachers

prepare for the class, which the young person can complete electronically.

- ▶ Using voice-recording apps, or a Dictaphone, enables the young person to voice record their ideas to write/type up later.
- ▶ Through Key Stage 3, workload and examinations increase so this often means looking again at how to record work. It may be helpful to look at the accessibility options on the young person's computer; to do this access the settings where there may be an option to enable recommendations for solutions: these could include keyboard changes, options for mouse control, visual adaptations, voice activation, etc. Further adaptations can be made, for example, adding a glide pad or mouse with smaller, lighter controls. For these adaptations, consult an IT technician for advice or technical assistance.
- ▶ Using e-readers, such as Kindles, or e-reader apps, can help to reduce fatigue. Most school literary texts are available free for out of copyright publications. Chunks of text can then be copied and pasted into a Word document, which saves typing lengthy pieces of text or quotes.
- ▶ Using lighter-weight tablets. They are easier to move and handle and their smaller keyboard require less hand and wrist movement.
- ▶ Exploring alternative, creative methods of recording and presenting work, such as delivering a piece of work as a news report or a radio broadcast.

**Reach.** In some muscle-wasting conditions, upper limb weakness makes reaching for objects difficult, while fine motor skills are intact. Practical solutions to this need to be sought, trying simple solutions first.

### Suggested solutions

- ▶ Using a tray on a powered wheelchair, or setting a height-adjustable table correctly to support a young person's arms. Some

young people will also choose to have a lightweight keyboard resting on their lap, which is ideal if they are able to touch-type. With Bluetooth technology, keyboards that are only a few grams in weight can be used with a screen set at an optimum position for the user. Sometimes, a small beanbag-type tray or cushion can be used to support the keyboard optimally, or a piece of Dycem mat under the keyboard can stop it slipping.

- ▶ Using a soft beanbag-type support cushion for a tablet. This can be helpful, although the cushion needs to be placed securely to provide sufficient stability.
- ▶ For young people who have upper limb movement when gravity is removed, using a powered mobile arm support can be helpful. This allows for a sufficient range of arm movement to use their desk space without help. The provision of these needs to be timely, and cost/funding implications need to be considered. The young person, family and school need to work together with their OT to make the most of this solution, and interim measures should be put in place where possible.

**Dexterity.** It can be very frustrating for young people who have difficulty mark-making, writing, and drawing, or who struggle to produce tidy written work. The use of technology to support their recording of work can be really positive. There is a wide range of options available.

### Suggested solutions

- ▶ Using a smaller keyboard or a netbook, maybe with a wrist support. This could also be combined with using an alternative keyboard layout to the standard QWERTY design.
- ▶ Using an on-screen keyboard can reduce the amount of pressure required to strike keys.
- ▶ Installing an app – for example, Write Pad – enables the young person to write on the screen with their finger/stylus, with

the words appearing on screen as font. This could be combined with the use of software/apps with predictive text.

- ▶ Looking at the device's accessibility options will help. Here you will find links to functions such as, for example, filter keys – to stop repetition of letters when a key is held down, or sticky keys – to enable the user to operate a function such as Control-Alt-Delete with one key. The school IT technician can recalibrate a glide pad, which can be activated through lighter touch.
- ▶ Using lightweight devices, such as tablets, which are easier to hold. Their small keyboards also make it easier to use the touchscreen.
- ▶ Exploring different keyboard layouts, such as Dvorak, which has the most used consonants on the right and the most used vowels on the left; it requires less hand movement and keying in a back and forth motion. Or an ergonomic/split keyboard, which enables the user to rest each hand on the sides of the keyboard. With the keys just under their finger span, this reduces forearm movement. There are also many types of keyboard available on the market, which are designed for those with greater dexterity or strength in one hand than the other.

### Options

When hand function is such that using a formal keyboard is not an option, possibilities for activating technology using residual movement can be explored. One such option is the use of the eViacam which has, by the 'Law of Unintended Consequences', been taken from the online gaming community. It was designed to enable a user to play games with both hands and also use a third control with head movement. Enable Viacam (eViacam) is a mouse replacement software that moves the pointer as you move your head which works on standard PCs equipped with a webcam. No additional hardware is required. It's completely free, open source and easy to use.

eViacam is a simple device interface which takes control of the webcam and displays the user's face on the screen. It quickly learns to recognise the face and an algorithm tracks facial movements so that wherever the user looks on the screen the mouse cursor goes. The user looks at the icon of your web browser on the screen and the cursor hovers over it. If there is a switch attached to the computer, which the user can activate, the icon is selected or activated. With an on-screen keyboard, typing is possible. If a switch is not an option, it is possible to use the software's in-built mouse 'dweller'. This automatically issues a left-button single or double click after staying stationary for a set period of time.

- ▶ Mounting the laptop to a wheelchair, so it is held firmly in place. This enables the user, who may have little or no fine motor control of either hand, to achieve independent and effective control of the laptop.
- ▶ Using Speech Empowered Computing, although it needs to be used in quiet environments and the user has to 'train' the system to recognise their voice. They do not respond well to changes in voice as a result of ventilator use. There are paid-for options, as well as free options available on the computer's operating system.
- ▶ Using a Bjoy ring: this is an example of a Bluetooth device with a mercury tilt switch. It replaces the joystick on a powered wheelchair and enables the user to access a computer or communication aid. It can be connected to up to four receivers at a time so can be used to control a wide range of technology including environmental controls.

NB: the more complex systems may require the support of an IT technician to work with the young person and their teachers. It is important to maintain sustainable solutions as the challenges change and technology advances.

### IT vs assistance

For the team supporting a young person with SEND, it can be tempting to promote

independence by using technology that reduces the need for human contact. Many young people who live with complex needs say they enjoy the time others spend with them to support their needs. This may include having someone to scribe in lessons for them, among other care tasks. Don't underestimate the young person's desire to feel empowered, while still enjoying human social contact.

Some young people have also reported that they felt a scribe worked more was quickly and easily for them than technology. Others say they like to have the option to work with a scribe and supplement this with technology. Nevertheless, there needs to be continuity so the scribe can get to know the young person's voice and style. Continuity reduces the energy required to dictate the work, giving more energy for processing and rationalising work.

### Keeping up-to-date

Technology is advancing at such a pace that it is important to keep up-to-date. This may mean continuing to research how best to solve ongoing problems while also looking at new opportunities. There are many sites such as Special World Inclusive Technology ([www.specialworld.net](http://www.specialworld.net)) that provide updates from around the globe. There are always creative solutions.

### References:

[www.abilitynet.org.uk/factsheet/vat-and-computers](http://www.abilitynet.org.uk/factsheet/vat-and-computers)  
[www.muscular dystrophyuk.org/jpt](http://www.muscular dystrophyuk.org/jpt)  
[www.mentalfloss.com/article/52483/6-non-qwerty-keyboard-layouts](http://www.mentalfloss.com/article/52483/6-non-qwerty-keyboard-layouts)  
[www.dvorak-keyboard.com](http://www.dvorak-keyboard.com)  
[www.livingmadeeasy.org.uk/communication/switch-adaptors-for-computer-access-p/bjoy-ring-0117015-1267-information.htm](http://www.livingmadeeasy.org.uk/communication/switch-adaptors-for-computer-access-p/bjoy-ring-0117015-1267-information.htm)  
[www.neater.co.uk](http://www.neater.co.uk)  
[www.speechempoweredcomputing.co.uk](http://www.speechempoweredcomputing.co.uk)  
[www.abilitynet.org.uk/homepage](http://www.abilitynet.org.uk/homepage)  
[www.callscotland.org.uk/about-us](http://www.callscotland.org.uk/about-us)  
[acecentre.org.uk](http://acecentre.org.uk)



## Assessment of ICT skills

Name:	DOB:
NHS (if applicable):	Year group:
Location of assessment:	
Time and date of assessment:	
Consent from parents:	
Present:	

Reason for the assessment:

What technology does the young person currently use?

At home?

At school?

What works well?

Does the young person have support in the classroom?

Describe the support:

What help does the young person receive with homework tasks?

Describe the setting for the assessment:

## Observations

	<b>Suggested solutions:</b>
<p><b>Seating, posture and position:</b></p> <p>What type of chair is the young person using for the assessment?</p> <p>Describe seated position:</p> <p>Does the person use different seating in different classes?</p> <p>Does the posture change if the person, for example, becomes fatigued?</p> <p>Where is the device in relation to the young person? For example, on wheelchair tray/height-adjustable table.</p>	

	<b>Suggested solutions:</b>
<p><b>Arm and function:</b></p> <p>Describe range of movement in the arm:</p> <p>Describe range of movement in the hand:</p> <p>Describe hand use – what are the strengths and difficulties?</p> <p>Right- or left-handed?</p>	

## Observed ICT tasks

	Y	N	Suggested solutions
Monitor at correct height?			
Computer positioned correctly for light source/s?			
Keyboard and mouse in comfortable position?			
<b>Log on</b>			
Knows user name and password?			
<b>Mouse skills</b>			
Holds mouse comfortably?			
Uses L/R hand?			
Can click the left mouse button?			
Can click the right mouse button using middle finger?			
Can double-click the left mouse button?			

## Observed ICT tasks (continued)

	Y	N	Suggested solutions
Can highlight text?			
Can drag?			
Can drag and drop?			
<b>Glide pad skills</b>			
Able to use the glide pad?			
Uses L/R hand?			
<b>Keyboard skills</b>			
Knows alphabet lower case and upper case?			
Knows keyboard layout?			
Can depress individual keys by isolating individual finger?			
Does repeat rate of keys need altering?			
Uses both hands?			
Able to press space bar using thumbs?			
Is able to touch-type?			
Can hold two keys down at once?			
<b>Cursor/pointer</b>			
Is aware that s/he is controlling the cursor/pointer?			
Is able to see and track the pointer?			
Does the speed of the pointer need altering?			
<b>Other skills/issues</b>			
Can start programmes?			
Can move around inside a programme once it is running?			
Does s/he tire easily using computer?			
Issues with frustration/concentration?			
Are staff comfortable with ICT/training issues?			

Any other comments/observations?

Recommendations:

Plan:

Name \_\_\_\_\_

Job title \_\_\_\_\_

Contact details \_\_\_\_\_

References \_\_\_\_\_

Date assessed: \_\_\_\_\_



# Chapter 15

# What to do if you are being bullied

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Many children experience being bullied at school at some point during their school years. It can happen to anyone, for any reason. Sadly, research shows that disabled children are three times more likely to be bullied than non-disabled children.

Bullying is wrong and every child has the right to enjoy school free from bullying.

This guide is to help you understand more about what bullying is, what you can do if your child is being bullied, and who can help you.

### The school's responsibility

Research shows that young disabled people and those with special educational needs are, disproportionately, more likely than their peers to experience bullying.

All schools are required by law to have a behaviour policy with measures to tackle bullying among pupils. Schools are free to develop their own anti-bullying strategies, but they are held clearly to account for their effectiveness through Ofsted.

School staff should support all pupils who are bullied and develop strategies to prevent bullying from happening. To help schools support pupils who are severely affected by bullying, the government has strengthened teachers' powers to tackle poor behaviour and bullying through the Education Act 2011.

The DfE has also updated its advice to schools so that it is shorter and more accessible. It brings together in one place information about schools' responsibilities both to support children who are bullied and to make appropriate provision for a child's needs.

The advice, *Preventing and tackling bullying*, is available at [www.gov.uk/government/publications/preventing-and-tackling-bullying](http://www.gov.uk/government/publications/preventing-and-tackling-bullying)

### When your child asks, "Why me?"

Being bullied at school is something that happens to a lot of children. So if it's happening to your child, he or she is not alone.

Sometimes children who bully pick on other children because they think they're a bit different or because they like different things.

Children who bully may pick on disabled children because it's easier to bully those who have difficulty either speaking up for or physically defending themselves.

They tend to pick on children whom they see as being weaker than they are. They might even do it because bullying others makes them feel better about themselves.

Bullying can take many different forms, such as being called horrible names, being physically hurt or being excluded from things. It can also take the form of nasty text messages, emails or social media messages (this is called cyberbullying).

This can be very upsetting for the child being bullied.

There may be times when a child who bullies might tease a disabled child because they don't understand what it's like to have a disability. They might feel awkward and unintentionally leave them out of things. They might tease in a jokey way, thinking they are being funny, and not realise what they've said has been insensitive and unkind. If the teasing

makes the person feel uncomfortable and unhappy, or if it happens a lot and it's obvious they're not enjoying it, this is more likely bullying rather than light-hearted teasing.

It's important to remember that being bullied because you have a disability is 100 percent wrong and unacceptable. It is not your fault, and you have nothing to be ashamed of. The fact is children who bully don't realise that bullying is actually a sign of weakness. Standing up against bullying shows a person has real courage and inner strength.

### **My child is being bullied – what can I do?**

If your child is being bullied, he or she is probably going through a whole range of emotions right now. They may feel upset, angry, scared, ashamed, lonely and confused. It is completely understandable to feel this way. Here are some things you could tell your child to do.

#### **Tell them to stop and then ignore them**

If a child is bullying you, tell them calmly, 'Stop bullying me. It's not nice and I don't like it.' If they don't stop, then ignore them. Children who bully do it because they like to make other children angry and upset. If a child is bullying you, try to move away and stay calm.

#### **Keep a diary of what is happening**

If the same people keep bullying you, and over a long period of time, keep a diary of what is happening to you. Write down what they said and did, when and where they did it. This will help to show evidence of what is happening to you and that it's serious.

#### **Block them**

If you're experiencing cyberbullying on your phone or computer; keep the texts, emails and screenshots of messages as evidence. You can block accounts on social media, and on some mobile phones too, so they won't be able to send you any more messages. The Diana Award's Anti-Bullying campaign has a useful website on how to stay safe online:

[www.antibullyingpro.com/blog/2015/stay-safe-on-facebook](http://www.antibullyingpro.com/blog/2015/stay-safe-on-facebook)

#### **Tell an adult**

Speak to your parents, carer or another adult you trust about what is happening to you and how it makes you feel. Show them your diary of evidence and any copies of text messages or social media messages they've sent you. Children who bully think you won't tell anyone, so don't let them get away with it – tell someone what is happening to you and as soon as you can.

#### **Tell your school**

Schools take bullying very seriously. All state schools should have an anti-bullying policy that says what they will do to prevent and tackle bullying and how they will support you. Some schools also have a 'buddy' system and anti-bullying ambassadors.

#### **Tell a friend**

If you don't feel ready to speak to an adult or to your school just yet, tell a friend about what's happening to you. Ask if they can support you by joining you at break-time or by coming with you to tell a teacher.

#### **Tell an anti-bullying charity**

If you don't feel able to speak to someone in real life about it, there are organisations out there that can support you. Their names and contact details are listed below.

#### **Don't let it get you down**

Children who bully enjoy making others feel scared and upset. Try not to let it get you down or stop you from doing things you enjoy. Keep studying and doing your best in school, because good grades are something that bullies can never take away from you. Take up a hobby like Powerchair football, or join a group like the Scouts or Girl Guides. Stick with your friends who you trust and are supportive. If your friends don't stick up for you or they become 'frenemies', seek out better friends who won't make you feel rubbish – you deserve better.

Remember – children who bully do it because they think you won't tell anyone and that they will get away with it. So telling someone you are being bullied is a really brave thing to do.

### Remember:

- ▶ lots of children experience teasing and bullying
- ▶ bullying can happen to anyone, for any reason
- ▶ being bullied is not your fault
- ▶ it is your right to enjoy school free from bullying
- ▶ keep a diary of what is happening, as evidence
- ▶ when bullying happens, move away from the situation and keep calm
- ▶ if you're being cyberbullied, don't reply to the messages but keep a copy of them
- ▶ tell someone as soon as you can that you're being bullied – don't suffer in silence
- ▶ bullying someone isn't brave – but taking a stand against bullying is!

### Organisations that can help you

- ▶ ChildLine has a helpline for children. You can ring them on 0800 1111 or visit their website [www.childline.org.uk](http://www.childline.org.uk)
- ▶ The Diana Award's Anti-Bullying campaign has some helpful information about how to deal with bullying. They also train young people to become Anti-Bullying Ambassadors in school [www.antibullyingpro.com](http://www.antibullyingpro.com)

### Did you know?

Bullying can happen to anyone. Famous people who were bullied at school include pop singer and actress Demi Lovato, *Hunger Games* actress Jennifer Lawrence, singer Rihanna, Olympic diver Tom Daley, *Harry Potter* star Daniel Radcliffe, Paralympian Sarah Storey, and singer Taylor Swift!

## Louise's story

### Louise is in her mid-20s and has spinal muscular atrophy

As someone who was bullied for seven of my 15 years of formal education, I'm really pleased to see that [Muscular Dystrophy UK's] Trailblazers have been working on this. I never had a problem with the usual school bullies, they mostly left me alone, or it would be because I was the nearest person rather than a targeted insult. The ones I had the most trouble with were the other kids with disabilities.

The mainstream primary I went to was pretty good, but for some reason kids with disabilities had their lunch, even if it was a packed lunch, in the dinner hall. We sat at the same table in the same places every day. A boy (only other wheelchair user at the school), two years older than me, subjected me to four years of personal insults, threats and physical restraint, holding my arms down so I couldn't eat my lunch. The teaching assistants would sometimes step in, but with the attitude that it was just play gone too far rather than anything more serious. The one time I fought back I was kept inside on breaks for a week.

Needless to say, I often got in trouble for not eating all my lunch as I wanted to get out of there as quickly as possible. Because of this, I was chronically underweight.

At college, my medical equipment was kept in a room, which I had to share with the only other wheelchair user at the college. She had more physical strength than me, and when I needed a lot of help she assumed that I was either being lazy or deliberately awkward. I was quite a shy teen and she and her friends were very loud. Rather than including me in their conversations or leaving me alone, they preferred to misconstrue everything I said and use it as a weapon.

The situation did not improve when we ended up on the same transport. Some days I had to put up with her three times a day. Combined with the usual stress of exams etc., I ended up having panic attacks at least once a day, and often waking up at night having a panic attack, though I didn't know that's what they were until some years later. My respiratory consultant was baffled as to why I would be fine one minute and uncontrollably coughing the next. I only have about one a year now, thank goodness.

As a result of these two experiences, I have a bit of a residual fear of wheelchair users I don't know, or large groups of wheelchair users. As you can imagine, this is not helpful. I would say to schools that they should never remove a child from their peer group unless there is a clear benefit to doing so, and to never assume that children with similar disabilities will automatically be friends.

Find out more about Trailblazers, the young campaigners network within Muscular Dystrophy UK.

Visit [www.musculardystrophyuk.org/trailblazers](http://www.musculardystrophyuk.org/trailblazers) or them [@MD\\_Trailblazers](https://twitter.com/MD_Trailblazers)

# Chapter 16

## Exercise and diet

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### Two reasons to do exercise:

#### It gets me out of maths

#### I can chat with my friends in the physio department

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 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.

#### Exercise

And there are even better reasons for doing exercise. But first, you need to make sure that you are doing the right type of exercise.

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. When your child joins in with PE and games, 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.

#### If my muscles are weak why can't I use weights to make them stronger?

Because the membrane of the muscle is fragile, overworking the muscle by lifting heavy weights could damage it. But there are other active exercises which you can do yourself that are good for you.

#### Why does my physio want me to have hydrotherapy when I just think it's a pain getting undressed and dressed again?

Hydrotherapy is probably the best way to exercise if you have a muscle-wasting condition. The warm water supports your body and relaxes your muscles, which makes stretching exercises much easier. The best thing about hydrotherapy though is being able to move much more freely than you usually can and it's really good fun!

#### What is the point of stretching exercises?

Stretching exercises are perhaps the most important exercises for all ages. Anybody who sits in the same position all the time will get stiff and uncomfortable. If you have a muscle condition, the stiffness can become permanent if the muscles and joints are not moved and stretched. Physios and doctors call this stiffness a 'contracture'. Knees, for example, normally bend right back so that the calf and the back of the thigh meet and they can also straighten up. In muscular dystrophy, there may not be a problem in bending the knee, but sitting in a chair all the time can

make it difficult to straighten up. Joints that don't have a full range of movement can get achy and it's sometimes difficult to find a comfy position in bed. So best to just get on and do those stretching exercises.

### What about my hands and arms?

Hands and arms need to be stretched too. Playing computer games is very important to most kids whether they have a muscle-wasting condition or not. Don't play for long periods of time – take regular breaks. To keep your fingers flexible, ask your physio what you can do (yes – it's more stretches).

### What about my feet?

Looking good is important to many young people. If contractures of the feet and ankle develop, this might make it difficult to wear the sort of trainers or shoes you prefer. Wearing splints every day will keep your feet in the right position so that you can look good (and yes, there are stretches which will help too!). The posture of the upper leg is very important when looking at your foot posture. If your legs flop apart, your feet turn on to their sides (try it!).

### Wheelchairs

Always make sure that your legs are properly supported by your wheelchair.

"I have a powered chair. At first I was a bit anxious about it but now I am really good at using it. Of course, I've had to practise a lot." A caller to Muscular Dystrophy UK's helpline

### Do you need help?

Most youngsters are able to learn to drive a powered wheelchair without too many problems. However, if you are under 18 years of age you may want to learn to control your wheelchair more safely and be more confident and independent.

You wouldn't dream of wearing clothes that didn't fit you properly so why should you put up with a wheelchair that doesn't fit? Having

the right wheelchair makes you feel more comfy and looks better.

Are you comfortable in your chair, or are you leaning over to one side? If you think your chair is too wide ask your physiotherapist or OT for advice.

Do you bend forward to get your arms comfortably on the armrests? Do the armrests dig in? Ask your physio to check the height of the armrests and ask about adjustable ones.

Do you feel tired and want to lie down when you come in from school? Do you find it hard work keeping your head up? Find out about 'Tilt in Space' wheelchairs from your physio or OT to see if they might be suitable for you.

### Resources

The charity Whizz-Kidz runs a scheme called 'Keep on Moving' which has different courses for different ages. Look at the website [www.whizz-kidz.org.uk](http://www.whizz-kidz.org.uk), phone 020 7233 6600, or email [keeponmoving@whizz-kidz.org.uk](mailto:keeponmoving@whizz-kidz.org.uk)

Read Muscular Dystrophy UK's *Wheelchair guidelines* (available online, or by calling Freephone 0800 652 6352).

The Association of Wheelchair Children also provides advice about wheelchairs. It teaches skills that help develop confidence when using a powered or manual chair. Contact the Association on 020 7473 3684 or visit [www.wheelchairchildren.org.uk](http://www.wheelchairchildren.org.uk)

# Chapter 17

## Resources list and glossary

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### Muscular Dystrophy UK publications

*Adaptations Manual 3rd Edition*, Muscular Dystrophy UK, 2016

*A guide for parents: Duchenne muscular dystrophy*

*A guide for parents: children recently diagnosed with a muscle-wasting condition*

*Duchenne Muscular Dystrophy*, Alan Emery, Oxford Medical Publications, 1993. ISBN: 0192623702

*Muscular Dystrophy: The Facts*, Alan Emery, Oxford University Press, 2000 ISBN: 0192632175.

*The 5 Muscular Dystrophies*, Alan Emery, Oxford University Press, 2001. ISBN: 0192632914

*Myotonic Dystrophy: The Facts*, Peter Harper, Oxford University Press, 2002. ISBN: 0198525869

### Relevant charities and organisations

Muscular Dystrophy UK  
61A Great Suffolk Street  
London SE1 0BU  
**020 7803 4800**  
**0800 652 6352**  
[www.muscular dystrophyuk.org](http://www.muscular dystrophyuk.org)

Trailblazers, Muscular Dystrophy UK  
61A Great Suffolk Street  
London SE1 0BU  
**020 7803 4846**  
[www.muscular dystrophyuk.org/trailblazers](http://www.muscular dystrophyuk.org/trailblazers)

ACE Education Advice & Training  
72 Durnsford Road  
London N11 2EJ  
**020 8888 3377**  
[www.ace-ed.org.uk](http://www.ace-ed.org.uk)

Carers UK  
20 Great Dover Street  
London SE1 4LX  
**020 7378 4999**  
**080 8808 7777**  
[www.carersuk.org](http://www.carersuk.org)

Centre for Studies on Inclusive Education (CSIE)  
The Park Centre  
Daventry Road  
Knowle, Bristol BS4 1DQ  
**011 7353 3150**  
[www.csie.org.uk](http://www.csie.org.uk)

Children 1st  
83 Whitehouse Loan  
Edinburgh EH9 1AT  
**0131 446 2300**  
[www.children1st.org.uk](http://www.children1st.org.uk)

Children in Scotland  
Level 1 Rosebery House  
9 Haymarket Terrace  
Edinburgh EH12 5EZ  
**0131 313 2322**  
[www.childreninScotland.org.uk](http://www.childreninScotland.org.uk)

Contact a Family  
209-211 City Road  
London EC1V 1JN  
**020 7608 8700**  
[www.cafamily.org.uk](http://www.cafamily.org.uk)

Council for Disabled Children  
8 Wakley Street  
London EC1V 7QE  
**0207 843 1900**  
[www.councilfordisabledchildren.org.uk](http://www.councilfordisabledchildren.org.uk)

Disability Rights Commission  
**0845 7622633**  
[www.drc.org.uk](http://www.drc.org.uk)

Independent Panel for Specialist Educational  
Advice (IPSEA)  
**0800 018 4016**  
[www.ipsea.org.uk](http://www.ipsea.org.uk)

Disability Rights UK  
Ground Floor CAN Mezzanine  
49-51 East Road  
London N1 6AH  
**020 7250 8181**  
[www.disabilityrightsuk.org](http://www.disabilityrightsuk.org)

ROSPA (Royal Society for the Prevention of  
Accidents)  
RoSPA House, 28 Calthorpe Road  
Edgbaston  
Birmingham B15 1RP  
**012 1248 2000**  
[www.rospace.com](http://www.rospace.com)

## Glossary

CSP	Co-ordinated Support Plan
EHCP	Education health care plan
EPIOC	Electrically powered indoor or outdoor wheelchairs
EP	Educational psychologist
EPS	Educational psychology services
ESA	Educational support assistant
IASS	Information, advice support service
ICT	Information and communication technology
IEP	Individual education plan
IHCP	Individual health care plan
INSET	In-service training
IPSEA	Independent parental special education advice
LA	Local authority
NC	Neurology consultant
NCA	Neuromuscular care advisor
OT	Occupational therapist
PT	Physiotherapist
SEN	Special educational needs
SEND	Special educational needs and disability
SENCO	Special educational needs co-ordinator



## 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.

Find out more here:

[www.musculardystrophyuk.org](http://www.musculardystrophyuk.org)  
[info@musculardystrophyuk.org](mailto:info@musculardystrophyuk.org)  
[@MDUK\\_News](https://twitter.com/MDUK_News)

## Trailblazers

Trailblazers is a UK-wide network of over 700 young disabled people, aged between 16 and 35. We fight social injustices that affect all young disabled people.

Trailblazers hold regional group meetings, where members get to share ideas and experiences, and build friendships. You may also want to consider volunteering or getting involved in our work experience programme.

We've also developed some resources and top tips with the help of our members, to help you live as independently as possible.

We are part of Muscular Dystrophy UK.

Find out more here:

[www.musculardystrophyuk.org/trailblazers](http://www.musculardystrophyuk.org/trailblazers)  
[trailblazers@musculardystrophyuk.org](mailto:trailblazers@musculardystrophyuk.org)  
[@MD\\_Trailblazers](https://twitter.com/MD_Trailblazers)

## Get involved

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 fundraise for us. You may also have contacts that could support our work by, for example, putting Muscular Dystrophy UK forward for a charity of the year partnership.

Muscular Dystrophy UK  
61A Great Suffolk Street  
London SE1

Tel: **020 7803 4800**

Email: [info@musculardystrophyuk.org](mailto:info@musculardystrophyuk.org)

Web: [www.musculardystrophyuk.org](http://www.musculardystrophyuk.org)

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