INCLUSIVE EDUCATION
FOR CHILDREN WITH MUSCULAR DYSTROPHY AND OTHER NEUROMUSCULAR CONDITIONS

GUIDANCE FOR PRIMARY AND SECONDARY SCHOOLS
SECOND EDITION

supported by
Muscular Dystrophy Campaign
Norwich Union
an AVIVA company
DEVELOPING THE GUIDANCE

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

The working party comprised health, education and care professionals, parents, and staff from specialist voluntary organisations such as the Muscular Dystrophy Campaign and the Jennifer Trust for Spinal Muscular Atrophy. Young people with neuromuscular conditions were also interviewed and their experiences at school are incorporated into these guidelines. The work was carried out over a year in the Yorkshire and Humberside region but the guidance is applicable nationally.

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

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The Muscular Dystrophy Campaign, in addition to acknowledging the support of the Department for Education and Skills (DfES) in funding this project, would also like to thank the local teachers, parents and young people who so willingly gave their time and effort to make this document possible.

It is hoped that through their experience, other schools will be empowered to improve the lives and educational experiences of children with a neuromuscular condition, enabling them to reach their full potential.

We also wish to thank: Christine Langham; Martin Patrick; Barry Young; the North of England Group of the National Network of Advisory Teachers for Physically Impaired Pupils; ESPD Frederick Holmes School, Hull; Wakefield Local Education Authority; Muscular Dystrophy Campaign Family Care Officers; Moving and Handling Team, Education, Bradford; the Wakefield West/Eastern Wakefield NHS Primary Care Trust; the Leeds Teaching Hospitals NHS Trust; Beckfoot School, Bingley, West Yorkshire and St. Lukes C of E Primary School, Beeston, Leeds for contributing materials to the guidelines.

We wish to thank Cathy Szeplaki for her contribution to this second edition.

We would particularly like to acknowledge the Wakefield Special Educational Needs Support Service for children with physical disabilities who contributed personal as well as professional time in writing the guidance materials – ‘beyond the call of duty.’ We also thank the Minsthorpe Centre in South Elmsall, Pontefract, which proved an excellent venue for the working party meetings, and Martin House Children’s Hospice which provided the venue for the interviews with young people with neuromuscular conditions.

We would especially like to thank the young people with neuromuscular conditions who were interviewed. (Their names have been changed to protect their identity.)

January 2007
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**RESOURCES – USEFUL ORGANISATIONS, ADDRESSES, BIBLIOGRAPHY GLOSSARY**
The Muscular Dystrophy Campaign is pleased to publish the second edition of *Inclusive Education for Children with Muscular Dystrophy and other Neuromuscular Conditions, Guidance for Primary and Secondary Schools*.

The first edition was very well received by the teaching community and since its publication, 5,000 copies have been distributed. Recognising the continuing need for accessible information about inclusive education for children with a neuromuscular condition the Muscular Dystrophy Campaign, helped by generous support from Norwich Union, is proud to present this second edition.

This new and improved edition reflects feedback and contributions, for which we are grateful, from the thousands of teachers and parents who read and used the original publication. This second edition also features updated information in line with recently published and relevant academic papers.

Most children with neuromuscular conditions can be fully included at their local mainstream school and will receive the best education there, enabling them to reach their full potential. The challenges for child, family and school are, however, enormous, and overcoming them is no easy task. Inclusion for children with neuromuscular conditions not only means the possibility of changing the physical environment of a school and having a suitable support structure in place but also re-assessing the fabric of where and how education is delivered for all the pupils at that school.

Delivering inclusive education for children with neuromuscular conditions requires parents and professionals to work closely together. An understanding of the specific needs of the child and how these are likely to change over time is essential, as little can be done without detailed shared knowledge and forward planning. This publication is designed to help you with that process. Getting it right is a rewarding experience for all involved and will greatly enrich any school and community as well as the lives of the family that you are helping.

Philip Butcher
Chief Executive
Muscular Dystrophy Campaign
Inclusive Education for Children with Muscular Dystrophy and other Neuromuscular Conditions, Guidance for Primary and Secondary Schools is written for schools, special educational needs advisors, teachers and educational support assistants who have children with muscular dystrophy or other neuromuscular conditions in their school. The guidance may also be 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 to also mean carer.)

This guidance has been written within the context of current legislation and in line with the DfES SEN 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. Supporting materials can be found in the appendices. Appendix 1 has materials for teachers. Appendix 2 is aimed at parents and includes a checklist to help them choose appropriate educational provision for their child. Appendix 3 has a range of literature about neuromuscular conditions and disability which is aimed at pupils and can be used with them by teachers.

Materials can be photocopied or downloaded from the Muscular Dystrophy Campaign website. Booklets for pupils can also be ordered (free of charge) from the Muscular Dystrophy Campaign.
At any given time, there are approximately 2,500 children with muscular dystrophy or a neuromuscular condition attending schools in the UK. Children with neuromuscular conditions live throughout the country and occur within all ethnic communities. But, because of the low number and geographical spread of these children, most schools will have no prior experience of educating a child with a neuromuscular condition or knowledge of how to fully include him or her in the life of the school.

Unlike many other children with physical disabilities, the needs of most children with a neuromuscular condition will change during their time at school, as their muscle strength deteriorates. This change could be very rapid and schools need to be prepared and ready to deal with every eventuality. A child may be mobile and active when he or she enters the school, for example, but could be an electric wheelchair user needing help with toileting, eating and other personal care, by the time he or she leaves.

Most children with a neuromuscular condition can be fully included into a mainstream school to receive a good quality of education and support. Research\(^1\), however, has found that some children with a neuromuscular condition start their education at a mainstream school but then transfer to a special school because, as their condition progresses, their needs are not met and their families receive insufficient support.

To help integration, it is essential 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.

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**PUT THE CHILD’S NEEDS FIRST**

In addition to enabling a child to fulfil his or her academic potential, school 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.

Children with disabilities are more likely to suffer physical, sexual or emotional abuse than their able-bodied peers\(^2\). Lack of inclusion in a school and poor disability awareness among teachers and pupils can cause feelings of low self-esteem and self-image, making the acceptance of poor quality care, even neglect and abuse, more likely. Because of the physical weakness of children with a neuromuscular condition and the physical care they require, these pupils may be subjected to bullying and unable to resist abuse.

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**EDUCATION SUPPORT ASSISTANT**

David’s mother told me that he knew all about his muscles weakening. But he recently said that he could not understand what was happening to him as the only thing wrong with him was one weak leg, yet his other leg and back were also bothering him. At the time, I could tell him nothing, just offer reassurance. I spoke to the SENCo who referred this to his mother. Apparently she had explained things but he had been too young to really understand the facts so she explained it to him again.

Last week he was upset because two boys told him he was going to die in his twenties. This is not something his mother had told him. I reassured him that none of us knew when we were going to die and referred it again to the SENCo. In both cases I made sure that David agreed to me speaking to the SENCo. I need to keep his trust and am very careful not to pass on any information without his knowledge.

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WORKING TOGETHER
Clear communication between home and school is vital and goes beyond the requirements of normal home/school liaison. Building up a knowledge of all staff who may be in contact with the pupil will assist this process. School staff will need to work closely with the parents throughout the time their child is in school and think through the messages communicated to pupils. It is important to establish what parents have told the child about his or her condition and what they wish school staff to say.

Good staff training can produce positive outcomes and experiences for pupil, parents and staff alike. It is essential to be a good listener when working with pupils and families. The ability to be flexible and respond positively to the constant changes faced by working with pupils who have uncertain futures is essential.

Think through your 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 know how to look up words such as muscular dystrophy or Duchenne 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 messages if questions are asked.

As well as special educational needs coordinators (SENCos) and other educational professionals, there are more people who can help and support you, including social workers, health professionals, physiotherapists, occupational therapists, specialist nurses and Muscular Dystrophy Campaign Care Advisors.

PLANNING AHEAD
Careful planning is needed to anticipate the needs of the child. Adaptations to the school and even to the curriculum will 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 primary to secondary school, secondary school to further or higher education, work or other day provision.

SENIOR TEACHER
When James arrived at the school we were aware that he would present us with a challenge. We were all totally committed, however, to meet his needs and very optimistic about our ability to do so. Hindsight may have proved us to be a little naïve!

My aim as Special Education Needs Co-ordinator was to pre-empt James’ physical deterioration and have equipment and resources available before they were absolutely essential. The introduction of specialist seating in the early stages, along with access ramps and storage space for a wheelchair, did not present us with any difficulties. However, I had no idea how complicated it was to provide the more radical and expensive equipment.

The school already had a disabled toilet with wide access and supporting handrails and this, on first inspection, was considered adequate. But it quickly became clear that it was not large enough to accommodate James’ wheelchair, hoist and support assistant. The toilet was a normal flush toilet and there was no shower. Providing the right facility took almost a year and, as time went on, I felt that James suffered because of my determination to provide the best for him. I also had several grey hairs and had developed a thick skin.

We did eventually succeed in establishing a really lovely bathroom area. All of the equipment is specially designed and mobile, both laterally and horizontally, so it can be used by other children with different abilities. As well as being functional and attractive it allowed James a lot of independence as well as sustaining his self-esteem. There is sufficient space for safe and comfortable manoeuvring and the ceiling hoist addresses moving and handling issues in line with health and safety guidance.

Attempting to anticipate the rapidly changing needs of children like James in a mainstream setting is never easy. Seeing the level of independence that he was able to achieve was well worth it. One can never be too well prepared!
1.1 DIAGNOSIS
Some children will have a diagnosis of their condition as they begin school life, others will still be having investigations and tests, and some will only begin to show signs and symptoms when they are already at school. It may be that school staff will be the first to recognise a problem, perhaps during P.E. 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 while many children have co-ordination and movement difficulties, the majority will not have a neuromuscular 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 an identified neuromuscular problem it is vital to:

- Find out accurate information about the specific condition and what is likely to happen in the future.
- Discuss the child’s health with his or her family, while being aware that they may find it difficult to pass on information, especially about the future.
- Gain information from specialist advisory teachers, health professionals and your local Muscular Dystrophy Campaign Care Advisor.

1.2 NEUROMUSCULAR CONDITIONS
The term ‘neuromuscular conditions’ describes a very wide range of disorders that have in common a weakness caused by an abnormality in either the nerves (neuro) or muscles. A very small number may be cured by appropriate treatment, others can be kept in check by drugs. Although a great deal can be done to manage many of the conditions, there is no specific treatment and muscle strength deteriorates. Many have a genetic basis – a gene fails to produce one of the proteins needed for normal muscle function. In some cases, there is no family history of the condition.

Amongst the commonest neuromuscular conditions are the muscular dystrophies. There are many different types with a very wide range of severity. There are also disorders affecting nerves including spinal muscular atrophy and the hereditary sensory neuropathies which cause muscle weakness. The junction between the nerve and muscle (neuromuscular
Becker muscular dystrophy is also an X chromosome condition and a milder variant of DMD. Some of the problems experienced by children with BMD will be similar to those observed in children with DMD, but they are not likely to be as severe or occur as early in life.

**SPINAL MUSCULAR ATROPHY (SMA)**

SMA is a genetically inherited condition causing weakness of the muscles. It affects both boys and girls. The severity of the condition depends on the type of SMA and age of onset.

Type I is the most severe form of SMA. Children with Type I tend to be weak and lack motor development. They cannot sit unaided and have trouble breathing, sucking and swallowing. Sadly, most do not survive beyond their first birthday.

Type II is slightly less severe. Children with Type II SMA may be able to sit unaided, or even stand with support, and do not usually have feeding or swallowing difficulties. They are, however, at an increased risk of complications from respiratory infections. Some children will not outlive childhood.

Type III is milder. Children with Type III SMA can stand and walk but may outgrow their muscle strength. Many end up needing to use a wheelchair. Type III affects children after 18 months of age, but can surface even in adulthood.

Detailed information can be found on The Jennifer Trust for Spinal Muscular Atrophy website www.jtsma.org.uk. Tel: 0870 7743651.

**DUCHENNE MUSCULAR DYSTROPHY (DMD)**

Duchenne muscular dystrophy is the most common of the childhood onset muscular dystrophies. It is a serious condition caused by a fault on the X chromosome which means that almost exclusively boys are affected. Their mothers may be carriers and there are some girls with the condition. About 100 boys with DMD are born in the UK each year and there are approximately 1,500 boys with the condition living in the UK at any one time.

DMD is often characterised by late walking (after 18 months). Other signs can be calf hypertrophy (enlarged calves), muscle weakness in the lower limbs which causes loss of balance and difficulties in getting up from the floor or using stairs. As the condition progresses, a distinctive walk emerges with the boy walking on his toes, his abdomen pushed forward, to compensate for the increasing weakness of the hip and pelvic muscles. Further problems may arise, such as contractures (stiffness) of the heels and ankles, which could require surgery.

Some children with DMD also have learning difficulties. These are rarely severe and don’t worsen with time, unlike the muscle weakness. In those children where it is a problem, language and communication skills (see page 10) are often the main difficulty.

From the age of nine, most children lose their ability to walk and become full-time wheelchair users. Once in a wheelchair, further causes for concern are: scoliosis (curvature of the spine), cardiac problems, chest infections, weakness in the shoulders, arms and hands and, at a later stage, respiratory problems. The condition is severe enough to shorten life expectancy.
A main feature of this condition is myotonia or muscle stiffness (delayed relaxation of the muscle after it has contracted), often worse in cold conditions, and more a nuisance than a disability. However, there can be muscle wasting and weakness, particularly in the face, neck, lower leg and forearms. Affected individuals may also experience smooth muscle problems leading to trouble with the gut, bowel and bladder (pain, similar to that in Irritable Bowel Syndrome, is not unknown).

Significant features, particularly in congenital myotonic dystrophy, are learning difficulties (which can be severe), tiredness, lethargy and cataracts at an unusually early age. The heart may also be affected and experts recommend cardiac monitoring of both adults and children. It is unlikely, however, that one individual would have all the symptoms and problems associated with such a variable and complex condition.

**CONGENITAL MUSCULAR DYSTROPHIES (CMD)**

These are a collection of different muscular dystrophies typified by babies displaying weakness at birth or soon after (although, on occasion, CMD may be diagnosed a little later). This condition varies considerably according to the type of CMD a child has and some children will have a more severe form than others.

Early life problems can include floppiness (hypotonia), poor head control, contractures, respiratory problems, swallowing and feeding difficulties. Some children may also have learning difficulties. A number of children will never walk while others, although delayed for several years, do manage to walk though they may lose this ability as they grow older.

**FACIOSCAPULOHUMERAL MUSCULAR DYSTROPHY (FSH)**

FSH is an inherited condition that can affect boys and girls. Initial symptoms are muscle weaknesses in the face and shoulders which make it difficult to raise the arms and a ‘winging’ of the shoulder blades becomes apparent. The weakness of the facial muscles may affect speech, communication and feeding. The lower leg and the muscle that raises the foot may also be affected, causing a tendency to trip up.

FSH is progressive but very variable; a rule of thumb is, the earlier the symptoms the faster the progression. Although a minority of children with FSH will experience complete loss of walking, many only need to use a wheelchair for long distances or to prevent fatigue. Some people may also have hearing loss.

**LIMB-GIRDLE MUSCULAR DYSTROPHIES (LGMD)**

These are a group of progressive muscle conditions affecting both boys and girls. The limb girdle muscular dystrophies are so called because generally they cause weakness in the shoulder and pelvic girdle. Weakness in the legs is usually noticed before that of the arms. Progression is variable and some children may experience only mild symptoms. Another form of LGMD does, however, involve the heart and breathing.

**CONGENITAL MYOPATHIES**

This group of conditions cause muscle weakness and affects boys and girls. The possibility of respiratory problems is also a common factor. Depending on which particular type of myopathy a child has, there may be additional factors to consider such as scoliosis, cardiac problems, and contractures.

**HEREDITARY MOTOR AND SENSORY NEUROPATHIES (HMSN)** also known as Charcot Marie-Tooth (CMT)

HMSN has a variable inheritance pattern and may be first noticed in childhood, when it affects the small muscles of the hand (influencing fine motor movement) and the feet (creating features such as high arches, foot drop and ‘club foot’). In Types I and II, the high arched foot may be the most noticeable feature, although there can be progressive muscle weakness later in life. People with the condition often experience balancing difficulties and some complain of pain. Type III can be severe and scoliosis may develop, causing the individual to need a wheelchair later in life.
MYASTHENIA GRAVIS
This is not a genetic condition. The body’s immune system produces antibodies that damage the neuromuscular junction, causing weakness. It can occur at any age. 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 the child’s smile look like a snarl. The arms and legs may be weak and, in severe cases, there can be problems with breathing muscles.

CONGENITAL MYASTHENIA
This condition, which is very rare, can be difficult to distinguish from Myasthenia Gravis (above). 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.

1.3 KEY ISSUES FOR THE CONDITIONS

MOBILITY AND PHYSICAL ACTIVITY
Some children with neuromuscular conditions will be walking and independently mobile while others may be wheelchair users. Children whose condition fluctuates, may alternate between walking and using a wheelchair for short periods of the day. As their muscle weakness deteriorates, however, they may need to use a wheelchair all the time and this change can happen quickly.

FALLING/LOSING BALANCE
There will be some children who, while able to walk, will be at risk of losing their balance and falling because of their muscle weakness. This will worsen as they become older and their condition deteriorates; some of these children will then become wheelchair users.

Children with neuromuscular conditions use a variety of mobility aids, including lightweight self-propelled wheelchairs, adapted tricycles, indoor-only, outdoor-only or indoor/outdoor electric wheelchairs. They may use these aids for part or all of the day and for longer periods of time as their condition worsens.

FATIGUE
Fatigue is likely to be a problem for children with a neuromuscular condition. Physical fatigue can affect a child’s behaviour as well as his or her ability to concentrate, learn and access a full curriculum. Fatigue can be influenced by health related issues, physical exertion and changes to routine. The level of tiredness can fluctuate from day to day, and even within the day. It may become more of an issue with increasing age.

UPPER LIMB FUNCTION
The upper limbs are often affected by a neuromuscular condition and can cause many limitations for the child. Hand function, power and manipulation skills may be compromised, impacting on many activities. (See Chapter 5)
PERSONAL CARE AND COMFORT

Moving and handling
There are likely to be moving and handling issues for many children. The appropriate professionals (physiotherapist, occupational therapist, moving and handling advisor or advisory teacher) need to be consulted for advice specific to the child’s needs, and a strategy to manage this throughout the school should be agreed and implemented.

Seating, standing, comfort and positioning
Appropriate seating, comfort and positioning for a child with a neuromuscular condition is important. Solutions may include using specialist equipment and, for some children, a standing frame will be appropriate. The child’s therapist should assess each piece of equipment and school staff will need training on its safe use and positioning. (See Chapter 5)

Temperature control
Staff need to be aware that temperature changes can affect the mobility of children with neuromuscular conditions. They are less able to generate body heat and are, therefore, susceptible to a cold environment both inside and outdoors. A child with balance problems may also encounter difficulties in the playground during windy, icy and snowy conditions.

Eating and swallowing
Some children with neuromuscular 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 lungs – this is called aspiration. If this happens regularly, the child could be more prone to chest infections and find it hard to put on weight.

Other children with neuromuscular conditions find that they can only eat very slowly due to the shape of their mouths or weakness in their chewing and swallowing muscles. Some children may have weakness in their arms and upper limbs which affects their ability to feed themselves. Eating a meal can, therefore, take a long time and food may become cold and unappetising. Height adjustable tables, arm supports and adapted cutlery can assist children and help them maintain independence.

It is important to discuss with the pupil and parents how to manage the situation and it may involve getting support from a speech and language therapist and/or an occupational therapist on appropriate management.

Some children use 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 be self-conscious. To prevent any embarrassment, other pupils should be told about the tube and why it is necessary.

A gastrostomy tube (g-tube) offers a more permanent method of supplementing nutrition by sending food straight into the stomach. This can reduce problems and ensure that the child 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 health care professionals and the school Special Educational Needs
Co-ordinator (SENCo). Feeding needs should be included in the individual's Health Care Plan.

Toileting
Thought needs to be given to the toileting needs of any disabled pupil. As a minimum they will require an accessible toilet. A full-time wheelchair user will need hoisting facilities and sufficient circulation space to allow safe moving and handling on and off the toilet when being assisted by a carer.

Consideration should be given to what assistance the child needs and who is the most appropriate person to provide it. Because of their mobility needs, children may take longer to go to and from the toilet and some may be unable to wait and need to use toileting facilities immediately.

This is a complex, private and personal issue for the pupil. A sensitive and caring discussion should take place with the pupil and parents to work out how to effectively manage the situation. Schools may again need to work in collaboration with healthcare professionals who can advise and support.

SELF-IMAGE AND EMOTIONAL WELL-BEING
A neuromuscular condition is likely to impact on a child’s self-image and emotional well-being. All children will be aware of what makes them different, and the things they can and can’t do. Some children will be continually adjusting to the deterioration in their abilities. There will be particular issues for those losing the ability to walk (or other functional skills) and/or coming to terms with the life-limiting nature of their condition.

Children with a neuromuscular condition may be very thin or overweight and be self-conscious about this. Children who are underweight might need extra nutrition and support (see section 1.3) and those who are overweight may benefit from a dietitian’s advice.

Scoliosis or curvature of the spine is common as the trunk muscles become weak and this can also affect a child’s self-image.

Children with neuromuscular conditions, like other pupils, will mature and wish to explore their sexuality. (See Chapter 4, page 48)

LEARNING ABILITIES IN DUCHENNE MUSCULAR DYSTROPHY
Since Duchenne named the condition, it has been realised that children and young people with Duchenne muscular dystrophy can find some aspects of learning more difficult.

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 have an IQ score one point lower than their peer group, which means that they score within the average range. However,
about nineteen percent will have a more significant difference with a score in the 70’s, and some individuals 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 and reading skills, limited verbal memory, reduced attention and poor social and interpersonal behaviour skills. These are the ‘hidden problems’ of Duchenne and can be overlooked when the principle concerns seem to focus on physical skills and access.

It has been suggested that about half of children with Duchenne are thought to present with a form of developmental dyslexia and 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 non-contextual aural information, which is not accompanied by kinaesthetic or visual re-enforcement, so they may find it difficult to repeat back verbal information presented only once.

Evidence points to a reduction in digit span which is a measure of short-term memory. It involves testing the number of digits a person can absorb and recall in a correct sequence after hearing or seeing them. A child needs to recall approximately six digits in order to utilise phonics and if this is not possible the strategies employed in the classroom need to focus on memory development.

The social interaction difficulties can manifest as the child 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 the caregivers.

These children and young people are, however, skilled in areas such as rote memory, which does not require mental manipulation; long term memory is effective and intact. These skills need to be nurtured in educational and clinical settings to facilitate effective compensation.

Research undertaken with the mothers of children with Duchenne shows that high stress levels are experienced due to difficulties associated with their child’s poor social skills. Increasing parental stress can often compound the worsening behaviour of the child. Thus a cycle develops which needs to be acknowledged and managed in the early years.

All involved in education and care giving must be mindful that the difficulties experienced by children with Duchenne are far reaching and go beyond physical difficulties. Consequently accurate Assessment is essential to enable the most effective and accessible teaching techniques are employed to deliver the national curriculum. Any assessment needs to look at the child’s academic skills, verbal abilities, working memory and attention span.

Suggested strategies for use in the classroom:
- Breaking aural information and instructions into chunks
- Frequent checking the child’s understanding of information.
Mixed media presentation with emphasis on visual and kinaesthetic learning
Memory improving strategies
Phonological awareness as used with the dyslexic population.

Each strategy should be employed in a way, which does not alienate the child who is already learning that he is different to his peers.

Additionally, parents need to be supported through the process of assessment so that they can carry through the suggested management techniques at home.

COMMUNICATION NEEDS
Delay in language development has been reported in boys with Duchenne muscular dystrophy. Pupils may have difficulties with verbal memory, struggling to retain and process complex spoken information. This can have a significant impact on their social life, affecting their ability to build and maintain friendships.

Pupils with specific facial weaknesses – such as those found in the FSH and myotonic muscular dystrophies – may encounter language difficulties because of lack of strength in the muscles used for articulation. When facial weakness is present, non-verbal facial expressions can be affected and this can interfere with a pupil’s communication skills. A child with severe facial weakness may, for example, find it impossible to smile or show emotion in the usual way. In these circumstances careful and sensitive explanations to other pupils are necessary to assist the child’s social development.

Children may also have quiet voices due to the weakness of respiratory and upper airway muscles.
This chapter provides guidance on how to fully include all pupils 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:

- establish a positive and inclusive ethos
- take into account any increasing difficulty the pupil may experience in moving his or her body, and
- address 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. An inclusive school ethos successfully managed, together with an accessible curriculum and environment, can create 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 environment with appropriate equipment | Chapter 6 |
| Clear understanding of the health, personal care and changing needs of pupils with a neuromuscular 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 concentrates on the needs and changes within and beyond the curriculum at the various key stages.
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 a neuromuscular condition may enter school in a wheelchair, (those with SMA or congenital muscular dystrophy, for example) those with Duchenne muscular dystrophy and other forms, will be walking. These children should be encouraged to join in activities as far as they are able.

Difficulties with gross motor activities will become more noticeable over time and schools must be ready to respond to these changes. Initially, for example, a child may have difficulty running and climbing steps, and later he or she might experience problems getting up from the floor. Placing items of furniture nearby will help a child to move unaided from floor to standing. Providing a chair as an alternative to sitting on the floor, helps a child move from the sitting to standing position, should this become difficult.

Advice from an occupational therapist and/or a physiotherapist can be invaluable in deciding what type of equipment will help maintain independence.

Within the infant stage the use of a variety of pencil grips, sloping desks and calculators will be beneficial to the child as fine motor operations become more difficult because of poor hand control.

For pupils with neuromuscular conditions the full diagnosis may not be apparent until after they have started school. The first difficulties that a teacher might notice include:

- struggling to get up from the carpet
- frequent falls in the playground
- poor balance
- slow when climbing stairs
- difficulty using apparatus in P.E. lessons
- tiredness during the afternoon session
- a noticeable change in stamina over the week
- poor handwriting because of weak pencil grasp

Teachers often notice how different one child's mobility is compared to another's and this can help with diagnosis. If you have concerns about a child's mobility you need to make the appropriate referral. It is important to remember, however, that while many children have co-ordination and movement difficulties the majority will not have a neuromuscular condition.
### Recognizing the Problem

<table>
<thead>
<tr>
<th>SCHOOL ISSUES</th>
<th>STRATEGIES</th>
<th>RESOURCES</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Recognition of the problem</td>
<td>• Find out about the specific condition affecting the pupil from advisory</td>
<td>• Family knowledge&lt;br&gt;• Information in these Guidelines&lt;br&gt;• Muscular</td>
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<tr>
<td></td>
<td>health professionals&lt;br&gt;• Talk to the family and listen to its concerns</td>
<td>Dystrophy Campaign&lt;br&gt;• Jennifer Trust for SMA&lt;br&gt;• Local support groups&lt;</td>
</tr>
<tr>
<td></td>
<td>• Be flexible and ready to respond if a pupil’s mobility deteriorates rapidly</td>
<td>• CAF Directory&lt;br&gt;• <a href="http://www.cafamily.org.uk">www.cafamily.org.uk</a>&lt;br&gt;• Internet&lt;br&gt;• Professionals’</td>
</tr>
<tr>
<td></td>
<td>• Attend relevant in-service training (INSET) sessions</td>
<td>reports</td>
</tr>
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<tr>
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<td></td>
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<td></td>
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<td>many neuromuscular conditions</td>
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</table>

### Assessing the Pupil — Providing a Statement of Educational Needs

<table>
<thead>
<tr>
<th>ISSUES</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Is statutory assessment</td>
<td>• Assess whether the child’s physical condition is affecting his or her</td>
<td>• See Chapter 7&lt;br&gt; • SEN Code of Practice refer to the following pages:</td>
</tr>
<tr>
<td>appropriate or not?</td>
<td>learning/mobility&lt;br&gt;• Monitor, record and review the situation&lt;br&gt;</td>
<td>5.43 School Action&lt;br&gt;5.54 School Action Plus – Request help from</td>
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### Physical Limitations

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### Key Stage 1

#### Identifying the Problem

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### Resources

- CAF Directory
- www.cafamily.org.uk
- Internet
- Professionals’ reports
- Muscular Dystrophy Campaign
- Jennifer Trust for SMA
- Local support groups
- See Introduction, Chapters 1 & 6
- Handrails at child height on staircases/steps outdoors
- Benches in the playground for the pupil to sit down during break time
- Specialist seating funded by either education or health departments
- Read Including Disabled Pupils in Physical Education (English Federation of Disability Sport)
- Follow physiotherapy programmes
- See Chapter 6
- Occupational therapist and advisory teacher survey site to overcome obstacles to mobility
- Ensure wheelchair tray is adequate to allow pupil to use this where suitable height tables are not available
- Specialist seating may be needed for use in classroom
- Training in moving and handling for all adults engaged in supporting pupils with neuromuscular conditions
### Pupil has poor hand movement – watch out for difficulty with recording of work
- Poor handwriting and weak pencil grasp

- Contact occupational therapist for advice/resources to address difficulties with recording work
- Use simple, modified tools such as sloping board, handhugger pencils, fingertip ruler
- Consider alternative recording methods using information and communication technology (ICT), introduce keyboard skills at an early stage

- See Chapters 1, 5, Appendix 1 ICT resource material
- Need for specialist equipment
- Follow occupational therapy programmes
- Taskmaster Ltd info@taskmasteronline.co.uk
- Philip and Tacey Ltd (See Resource list)
- Sloping desks. Contact horizon&magnifiers.co.uk

### Pupil suffers from fatigue
- Appears tired in the afternoon sessions
- Noticeable change in stamina as the week progresses

- Monitor changes in stamina
- Introduce new concepts in the mornings where possible
- Allow extra time to complete tasks in the afternoons
- Allow rest periods, provide suitable location
- Extend educational support assistant (ESA) provision
- Monitor changes during the day and as the week progresses

- See Chapters 3 & 5
- School Functional Assessment Therapy Skill Builders by Psychological Corporation 1998
- Additional funding/support to cater for increasing fatigue
- Use ‘Pupil Support Timetable’ where increased level of adult support may be required

### Pupil has learning difficulties
- Some children will have learning difficulties as well as physical disabilities (those with myotonic dystrophy and some boys with Duchenne muscular dystrophy)

- Follow the SEN Code of Practice
- Develop an Individual Educational Plan (IEP)

- See Chapter 1, page 10
- Speech and Language Therapy Services
- Advisory teacher
- CAP and LEA for funding, if appropriate

### Communication needs
- Some children may have a very quiet voice and/or be slow to speak

- Place at front of class
- Give time for a response and ensure that class respects the need to wait
- Consider using a speech amplifier

- See Chapters 6
- Advisory teachers and occupational therapists as appropriate

### THE SCHOOL ENVIRONMENT

#### ISSUES

#### STRATEGIES

- Undertake a school access audit of the whole site
- Ensure that the child’s current needs are catered for
- Seek to plan for the future
- Discuss an access plan with the LEA
- Start developing required adaptations

- See Chapter 6
- Specialist advice from advisory teachers, Paediatric Therapy Services, LEA’s planning department
- Improve access to school building, e.g. grab rails, handrails, ramps, minor adjustments to the cloakroom and door openings

#### RESOURCES

- See Chapter 6
- Advisory teachers and occupational therapists as appropriate

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**GUIDANCE FOR SCHOOLS**
### THE CURRICULUM

#### ISSUES

<table>
<thead>
<tr>
<th>Access to curriculum</th>
<th>Practical activities</th>
<th>Performances/concerts</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Curriculum</td>
<td></td>
<td>Consider ways of ensuring full inclusion</td>
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<tr>
<td></td>
<td></td>
<td>Modify curriculum</td>
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<td></td>
<td></td>
<td>Forward planning</td>
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<td></td>
<td></td>
<td>Consult the pupil, take into account what he or she is comfortable with</td>
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<tr>
<td></td>
<td></td>
<td>Discreetly ensure safety of movement</td>
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</tbody>
</table>

#### STRATEGIES

<table>
<thead>
<tr>
<th>IEP reviews</th>
<th>Introduce keyboard skills</th>
<th>Differentiation of materials and equipment</th>
<th>Modify curriculum</th>
<th>Parallel activities</th>
<th>Forward planning</th>
</tr>
</thead>
</table>

#### RESOURCES

<table>
<thead>
<tr>
<th>See Appendix 1 ICT</th>
<th>Advisory teachers</th>
<th>ACE Centres</th>
<th>BECTA website</th>
<th>Educational Psychology Services (EPS)</th>
</tr>
</thead>
</table>

| Disability Sports | www.youthsport.net | www.teachernet.gov (English Federation of Disability Sport) | www.efds.co.uk |
|--------------------|---------------------|------------------------------------------------------------|

<table>
<thead>
<tr>
<th>Flexible use of staff and space</th>
<th>Clear, unambiguous, written instructions</th>
<th>Adequate staffing</th>
</tr>
</thead>
</table>

### ORGANISATIONAL/EMOTIONAL/TEAM WORK

#### ISSUES

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<tr>
<th>Key worker</th>
<th>Support to staff</th>
<th>Communication issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identify key worker</td>
<td>School Action Plus</td>
<td>Share information with all concerned</td>
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<tr>
<td></td>
<td></td>
<td>Contact number held centrally in school</td>
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<td></td>
<td></td>
<td>Create ‘Home/School Message Book’</td>
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<tr>
<td></td>
<td></td>
<td>Establish system to inform family when transport arrangements are altered</td>
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<tr>
<td></td>
<td></td>
<td>Check with family what information they do and do not want the pupil to be told regarding changes in physical ability</td>
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<tr>
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<td></td>
<td>Explain in simple terms to peer group the pupil’s physical difficulty to ensure that others do not bump/push into him or her, or damage specialist equipment</td>
</tr>
</tbody>
</table>

#### STRATEGIES

<table>
<thead>
<tr>
<th>Liaise with parents on amount of information to be shared</th>
<th>Build up a bank of written information</th>
<th>Visit other schools attended by children with neuromuscular conditions</th>
</tr>
</thead>
</table>

#### RESOURCES

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<th>Muscular Dystrophy Campaign, Family Care Officers</th>
<th>Voluntary organisations</th>
<th>LEA Support Services</th>
<th>EPS</th>
</tr>
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<table>
<thead>
<tr>
<th>See Chapter 3</th>
<th>Named person</th>
<th>See Chapter 4</th>
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<table>
<thead>
<tr>
<th>See Chapter 4 and Appendix 3</th>
<th>Use key worker</th>
<th>Keep contact diary</th>
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<table>
<thead>
<tr>
<th>Central record of contact numbers</th>
<th>‘Home/School Message Book’</th>
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## MEDICAL AND THERAPEUTIC ISSUES

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<tr>
<th>ISSUES</th>
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</table>
| **Physical management**       | ▪ Pupils with neuromuscular conditions will have physical management routines which may involve supervised/assisted walking (during ambulant phase), powered chair, specialist seating systems, standing frame, assisted stretches, toileting needs, eating and drinking needs  
▪ School needs to consider when, where, by whom and how these will be implemented | See page 24                                                                                                           |
|                               | See page 24                                                                                           | See page 24                                                                                           |
| **Personal hygiene**          | ▪ The need for personal care can change rapidly and a child able to manage personal care and toileting at one time may not be able to do so later. The ESA should be sensitive and aware of the likelihood of this change, and ready and able to support it  
▪ For a child in a wheelchair and those with a significant degree of muscle weakness, help will be needed with personal care and toileting | Discuss with family the best ways of meeting the child’s needs  
▪ Develop whole school plan for managing personal hygiene needs  
▪ Ensure all staff involved with personal hygiene are aware of the plan and child protection issues  
▪ Ensure necessary adaptations have been completed and equipment is available | See page 24                                                                                                           |
|                               | ▪ Hold regular meetings to share information  
▪ Inform external agencies of named key worker within school  
▪ Inform parents of how to access key worker  
▪ Ensure there is a balance between education and therapy | ▪ Health care professionals involved with the child  
▪ Local authority Moving and Handling Advisor  
▪ Muscular Dystrophy Campaign Adaptations Manual  
▪ Muscular Dystrophy Campaign Family Care Officer | See Chapter 5  
▪ SEN Toolkit Section 12 The Role of Health Professionals; The Education of Children with Medical Conditions  
Rd Alison Closs ISBN 1-85346-569-0  
▪ Supporting Pupils with Medical Needs DFES 1996 |
| **Paediatric therapy and medical issues** | ▪ Share information between education and health departments but ensure that this does not infringe data protection or confidentiality | ▪ Contact relevant hospital tuition service  
▪ Liaise with family re warning signs and prevention strategies  
▪ With planned admissions, liaise with family about keeping up to date with work  
▪ With emergency admissions, liaise with family re current situation and when their child will be well enough to require work  
▪ Assist in maintaining school friendships | Hospital tuition service  
▪ Home tuition service  
▪ Through e-mails/cards/text and telephone contact |
| **Hospital admissions**       | ▪ Child may be admitted to hospital with chest infections  
▪ Child may require planned surgery | ▪ Hospital tuition service  
▪ Home tuition service  
▪ Through e-mails/cards/text and telephone contact |
### POLICIES AND MANAGING RISKS

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<td>▶ See Chapter 7</td>
</tr>
<tr>
<td>Moving and handling</td>
<td>Devise policy if one is not already in place</td>
<td>▶ See Chapter 8, Appendix 1, Advisory teacher, Examples from other schools</td>
</tr>
<tr>
<td>Safe evacuation</td>
<td>In case of emergency</td>
<td>▶ Consult with local fire service, HSE publications <em>Five Steps to Risk Assessment</em></td>
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<tr>
<td>School uniform</td>
<td></td>
<td>▶ See Chapter 7</td>
</tr>
</tbody>
</table>

### TRANSPORT

<table>
<thead>
<tr>
<th>ISSUES</th>
<th>STRATEGIES</th>
<th>RESOURCES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Investigate transport issues</td>
<td>Provide dropping-off points to allow easy access to school</td>
<td>▶ Allocate a marked parking space for disabled use and ensure it is kept free (use traffic cones, if necessary, to reserve the place before the start and end of school)</td>
</tr>
<tr>
<td></td>
<td>Consider the venue and access on a planned trip; historical venues may not be suitable. Risk: assess the venue</td>
<td>▶ Consider an alternative venue with full disabled access for school trips</td>
</tr>
<tr>
<td></td>
<td>Comply with the Disability Discrimination Act and make reasonable adjustments</td>
<td></td>
</tr>
<tr>
<td>School trips</td>
<td>Assess venues for suitability and accessibility</td>
<td>▶ Disability Discrimination Act, Research venues for trips (pre-visit, Internet, etc)</td>
</tr>
<tr>
<td></td>
<td>Hire adapted vehicles where necessary</td>
<td>▶ Health and Safety of Pupils on Educational Visits 1998 DES (includes sample model risk assessment forms)</td>
</tr>
<tr>
<td></td>
<td>Ensure suitable toilets are available</td>
<td>▶ HASPEV Forms</td>
</tr>
<tr>
<td></td>
<td>Complete risk assessment to include any moving and handling issues</td>
<td>▶ LEA guidance material</td>
</tr>
</tbody>
</table>
KEY STAGE 2

As the child moves through Key Stage 2 from National Curriculum Year 3 to Year 6 (from seven to 11 years old), children with muscular dystrophy and other neuromuscular conditions who are wheelchair users are likely to become more aware of the differences between themselves and other pupils. This awareness has implications for their self-image.

A child with Duchenne muscular dystrophy, while usually still ambulant, will become weaker. Walking will become limited and both 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.

By the end of Key Stage 2 most pupils with Duchenne muscular dystrophy will be using a wheelchair. Adult support will be needed in a wider range of areas than previously, especially with transferring from classroom chairs to wheelchairs and when energy levels dip in the afternoon. Increased levels of supervision will also be required at breaks and lunchtimes, and an accessible toilet should be provided.

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 make the move from paper/pencil recording to typing before the child’s upper body strength becomes significantly weaker. As the difficulties increase, some pupils may present challenging behaviour. Some children with Duchenne muscular dystrophy have specific learning difficulties. See page 10.
## IDENTIFYING THE PROBLEM

### SCHOOL ISSUES

**Evaluation of current situation**
- Diagnosis is probably in place
- Assess mobility needs and access issues
- Is access to education affected by physical difficulties?
- Are there any learning difficulties?

### STRATEGIES

- Gather information
- Follow Code of Practice guidance relating to School Action and School Action Plus
- Assess training needs
- Formulate training plan

### RESOURCES

- Relevant in-service training (INSET)
- See Chapter 1
- Refer to Hull City Council publication, *Supporting Children with Medical Conditions*, David Fulton publishers, 2004
- Professionals' reports

**Lack of information about the condition held by school or specific staff in school**

### STRATEGIES

- Ensure all staff have appropriate information and training from advisory teachers and health professionals
- Look out for relevant in-service training (INSET) opportunities

### RESOURCES

- See Chapter 1
- Muscular Dystrophy Campaign factsheets about conditions
- Internet

## ASSESSING THE PUPIL – PROVIDING A STATEMENT OF EDUCATIONAL NEEDS

### ISSUES

**How will the pupil's needs be met and funded?**
- Statutory assessment or delegated funds?
- Consider whether statutory assessment appropriate or not

### STRATEGIES

- Look at Disability Discrimination Act guidance
- Look at how your LEA funds pupils; apply for appropriate funds
- Follow Code of Practice guidance relating to School Action Plus
- Seek accurate assessments from all professionals involved

### RESOURCES

- See Chapter 7
- Special Educational Needs Code of Practice
- Refer to following pages in SEN Code of Practice:
  - 5.43 School Action
  - 5.54 Request help from outside agencies through School Action Plus
  - 5.62 School request to initiate statutory assessment
- DfES/S81/2001 effective from 01.01.02

## PHYSICAL LIMITATIONS

### ISSUES

**Increased difficulty with mobility**
- As muscle strength deteriorates, the pupil may become progressively weaker and walking is affected when he or she can no longer bear weight effectively
- Previously ambulant children may need to use a wheelchair to access playtimes and trips
- Most pupils with muscular dystrophy will not be ambulant at the end of this stage

### STRATEGIES

- Provide assistance up and down steps
- Provide discreet educational support assistant (ESA) supervision during unstructured times
- Encourage buddy system during unstructured playtimes
- Identify and forward plan to introduce the use of a wheelchair when necessary
- Plan for possible progression from manual chair to an electrically powered indoor or outdoor chair (EPIOC)

### RESOURCES

- Install handrails and ramps in appropriate places, move pegs, look at door handles
- School to implement buddy system
- Guidance from Paediatric Therapy Service
- Wheelchair training from appropriate professionals
### Pupil in a wheelchair
- Mobility around the building
- Transfers
- Practical subjects (art, technology, science)
- Identify safe routes around the building
- Risk assess for safe transfer between chairs, standing frames and toilets
- Occupational therapist and advisory teacher survey site to overcome obstacles to mobility
- Ensure wheelchair tray is adequate to allow pupil to use this where suitable height tables are not available
- Specialist seating may be needed for use in classroom
- Moving and handling training for all adults engaged in supporting pupils with a neuromuscular condition

### Pupil has poor hand movement
See Key Stage 1

### Communication needs
- May have a quiet voice and/or be slow to speak
- Place at front of class
- Give time for a response and ensure that class respect the need to wait
- Consider using a speech amplifier
- Speech and Language Therapy Services
- Advisory teacher
- CAP and LEA for funding, if appropriate
- See Chapter 1, page 10

### Physical limitations and reduced stamina
- Suffers from fatigue
- Plan in advance, consult with therapists
- Allow rest periods, provide suitable location
- Extend ESA provision
- Monitor changes during the day and as the week progresses
- School Functional Assessment Therapy Skill Builders by Psychological Corporation 1998
- Additional funding/support to cater for increasing fatigue
- Use ‘Pupil Support Timetable’ (Chapter 2) where increased level of adult support may be necessary

### THE SCHOOL ENVIRONMENT

<table>
<thead>
<tr>
<th>ISSUES</th>
<th>STRATEGIES</th>
<th>RESOURCES</th>
</tr>
</thead>
</table>
| Creating an accessible environment
  - Entrances/exits
  - Dining room
  - Gym
  - Playground | Revise the school’s access audit to ensure the child’s current and future needs are addressed in consultation with advisory teachers, health professionals, and personnel from planning depts | Install grab rails, handrails, ramps, lifts etc.
  Ensure adequate space in accessible toilet etc. as required |
| Moving around the school site during unstructured time
  - Dinner breaks & playtimes | Risk assess site
  Share information (e.g. dinner supervisors to be made aware of care plan and trained in use of equipment)
  Awareness of health and safety issues versus developing independence – such as the need for increased but non-intrusive supervision – particularly when child is ambulant but falling | Care plan and appropriate equipment
  Provide sufficient lunchtime supervision and review regularly
  Provide seating in the playground
  Make use of wheelchair at playtimes |
| Equipment needs | Assessment needed | See Chapter 6
  Advisory teachers and occupational therapists as appropriate |
| Use, storage and maintenance of specialist equipment | Consult with occupational therapists and physiotherapists
  Risk assess classroom environment and be prepared to make reasonable adjustments
  Monitor and service equipment | Occupational therapist’s and physiotherapist’s reports
  Manufacturer’s/supplier’s guidelines |
## THE CURRICULUM

<table>
<thead>
<tr>
<th>ISSUES</th>
<th>STRATEGIES</th>
<th>RESOURCES</th>
</tr>
</thead>
</table>
| **P.E.** | - Adopt an inclusive approach to mainstream P.E. curriculum  
- Modify P.E. curriculum  
- Consult with paediatric therapists  
- Seek support and advice if a P.E. lesson is causing concern for class teacher | - Disability Sports Federation (see Key Stage 1)  
- Success for All CD ROM  
- Physical Education from Lancashire Education  
- Including Disabled Pupils in Physical Education from Manchester Metropolitan University 0161 247 5294  
- Provide modified P.E. equipment e.g. BOCCIA, Kurling  
- See Davis Sports catalogue for resources |
| **Swimming** | - Plan in advance and complete risk assessment of swimming and changing facilities, equipment needed and temperature of the pool and changing area  
- Allow additional time if necessary for dressing/undressing  
- Ensure personal dignity and privacy is considered  
- Provide adequate staffing levels to ensure safety while in the pool, also for transfers and changing time  
- Ensure hoist is available, if necessary  
- Identify and research transport to pool, vehicle and escorts; seek to build in flexible arrangements | - Pool with hoisting facilities  
- Increase opportunities to swim, through flexible timetabling or plan visits to a hydrotherapy pool  
- Additional adult assistance in pool  
- Suitable transport |
| **Performances/concerts** | - Ensure inclusion NOT integration  
- Look at performance areas (podium) | - Flexible use of staff and space  
- Clear, unambiguous, written instructions  
- Adequate staffing |
| **ORGANISATIONAL/EMOTIONAL/TEAM WORK** | | |
| **Issues** | **Strategies** | **Resources** |
| **Staff training** | - Liaise with parents on amount of information to be shared  
- Build up a bank of written information  
- Visit schools attended by children with neuromuscular conditions  
- Invite speakers to staff INSET (e.g. from voluntary organisations, Muscular Dystrophy Campaign’s Care Advisors)  
- Appraise modified materials | - See Chapter 5  
- Muscular Dystrophy Campaign, Family Care Officers  
- Voluntary organisations  
- LEA Support Services  
- Educational Psychology Services (EPS) |
## MEDICAL AND THERAPEUTIC ISSUES

<table>
<thead>
<tr>
<th>ISSUES</th>
<th>STRATEGIES</th>
<th>RESOURCES</th>
</tr>
</thead>
</table>
| **Physical management**  
- Moving and handling of pupils with deteriorating muscle strength  
- Personal hygiene and toileting  
- Therapy and use of specialist equipment  
- Standing frame or other similar equipment  
- Hospital admissions |  
- Risk assess and devise safe written procedures, in consultation with the child’s physiotherapist  
- Training by a qualified person  
- Assistance at mealtimes (to help fetch, carry and cut up food)  
- Identify suitable toilet; plan for the provision of a disabled toilet if one is not available  
- Ensure ESA’s job description includes specific reference to catering for pupil’s personal needs  
- Identify and request hoist when necessary  
- See ‘Physical Management’ p 24  
- Provide chair with arms for additional support  
- Pupil needs adult assistance transferring between chairs  
- Standing frames can be timetabled where appropriate  
- Adult assistance transferring between chair and standing frame  
- Access to a disabled toilet (hand rails, urine bottles and adult assistance)  
- Risk assess for safe transfer  
- See Chapter 8 and page 24  
- Manual handling aids may become necessary, e.g. handling belt, hoist  
- Lightweight cutlery recommended by occupational therapist  
- Adult assistance at mealtimes  |  
- See Chapter 8 and page 24  
- Appropriate toilet  
- Alternative equipment, e.g. urinal bottle  
- Hygienic disposal facilities (pads etc)  
- Provide suitable hoist  
- ‘Moving and Handling’ policy in place, see Chapter 8, Appendix 1  
- Funding for specialist equipment (health and education departments)  
- Provide hoist  
- Follow advice of Paediatric Therapy Services  
- Use ‘Pupil Support Timetable’ to monitor balance of therapy and education  |  
- See Chapters 5 & 6  |  
- Hospital tuition service  
- Home tuition service  
- Through e-mails/cards/text and telephone contact  |
### Child Protection

- Devise policy

### Moving and handling

- Risk assess and make appropriate arrangements for safe exit having consulted with fire officer, health and safety officer etc; ensure all staff are fully conversant with procedures

### Safe evacuation

- See Chapter 6
- Written procedures

### School uniforms

- See Chapter 7

### TRANSPORT

#### Arrival at school (set-down and pick-up arrangements)

- In accordance with Disability Discrimination Act guidelines schools should have designated parking spaces for disabled use. These spaces are frequently located in the main car park and may not be suitable for set-down and pick-up

- Identify a set-down and pick-up point for vehicles carrying disabled pupils which is close to school and near ramped access

- Nominate a member of support staff to receive the pupil on arrival

- School's accessibility plan
- Staffing implication

#### Educational trips

- Risk assessment for trips
- Select appropriate venue to comply with Disability Discrimination Act
- Consider transport needs

- Disability Discrimination Act
- Research venues for trips (pre-visit, Internet, etc)
- *Health and Safety of Pupils on Educational Visits* 1998 DES (includes sample model risk assessment forms)
- HASPEV Forms
- LEA guidance material
**PERSONAL HYGIENE**

The need for personal care can change rapidly and a child who is able to manage personal care and toileting at one time may not be able to do so later. School staff should be sensitive and aware of the likelihood of this change, and be ready and able to support it.

**PHYSICAL MANAGEMENT**

Pupils with neuromuscular conditions will have physical management routines. Schools need to consider when, where, by whom and how these will be implemented.

- Liaise with parents and other agencies
- Identify support staff. Ensure a back-up system is in place with trained staff to cover absences. Nominate a key worker from the trained staff to communicate between all those involved
- Identify areas for physical management routines which are private and where there is appropriate and accessible space, equipment and facilities
- Consideration must be given to other users of specialist facilities
- Relevant members of support staff to receive training

Most pupils who have a neuromuscular condition are likely to require a combination of the following physical management strategies:

- Supervised/assisted walking (during ambulant phase)
- Powered chair
- Specialist seating system
- Manual chair
- Standing frame
- Assisted stretches
- Toileting needs
- Eating and drinking

The timetable on page 25 gives an example of how the physical management routine can be incorporated into a school day, assuming most toileting will happen at lunchtime and breaks. The majority of transfers between chairs and equipment should take place after toileting to minimise handling.

For a pupil with a neuromuscular condition there is likely to be a number of external professionals guiding the staff. It might be useful for ESAs to keep a record of every professional's involvement and contribution. Support staff should highlight any activities that have not been implemented, to provide an accurate record of physical management.

This timetable also informs teaching staff of the physical activity which will be incorporated into their lesson and is helpful in recording how staff have catered for the pupil's individual needs.

An example of a 'weekly overview' is given overleaf 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 occupational therapist or physiotherapist
- Use of standing frame
- Wheelchair training
- Specific IEPs for learning difficulties

It is important to keep a record of what has actually been achieved against the plan. Information should be recorded about the child's physical abilities and the assistance required for each activity. Some grids and checklists that you may wish to use or adapt are available in *Including Children with Physical Disabilities* by Mark Fox (David Fulton Publishers, 2003).
## A PUPIL SUPPORT TIMETABLE

| Pupil Support Staff |

<table>
<thead>
<tr>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
<th>Friday</th>
</tr>
</thead>
<tbody>
<tr>
<td>Powered chair</td>
<td>Standing frame</td>
<td>Walking with rollator</td>
<td>Specialist chair</td>
<td>Physical management routine</td>
</tr>
</tbody>
</table>

### COMMENTS

Monday

Tuesday

Wednesday

Thursday

Friday
2.2 SECONDARY SCHOOL

PHASE TRANSFER IS A KEY TIME
Pupils with Duchenne muscular dystrophy between the ages of 11 and 13 are likely to become totally reliant on an electric wheelchair for independent mobility. They may also have associated specific learning difficulties (see page 10).

All moving and handling should only be carried out after a risk assessment and will probably involve using a hoist and slings. The correct equipment needs to be provided.

KEY STAGES 3 AND 4
Mobility difficulties have implications for access to specialist teaching rooms. A school is expected to make reasonable adjustments to ensure full access to the curriculum. As the physical management of a pupil becomes more complex, access to the full range of the National Curriculum can be compromised. It may be necessary to establish a modified curriculum that works with the pupil’s strengths and interests to ensure that the secondary phase continues to provide a positive preparation for adult life.

During this educational stage many young people become increasingly aware of their deteriorating condition and prognosis. Parents and school must liaise closely to establish exactly how much the pupil is to be told and how his or her questions should be answered.

Schools may wish to consider establishing a support network for the pupil and those staff and peers who work closely with him or her to help deal with this emotionally challenging time.

There are issues common to all subject areas and these should be agreed by the senior management team and adopted by all departments.
### IDENTIFYING THE PROBLEM

<table>
<thead>
<tr>
<th>SCHOOL ISSUES</th>
<th>STRATEGIES</th>
<th>RESOURCES</th>
</tr>
</thead>
</table>
| Knowledge of the medical condition | ■ Special Educational Needs Co-ordinator (SENCo) to collate information and organise in-service training (INSET)  
■ Provide general information about the condition to the departments through whole school INSET  
■ Provide pupil specific information to relevant teaching and support staff through an individual health care plan (IHCP)  
■ Review INSET needs regularly to ensure new staff are fully briefed | ■ Parents  
■ Specialist outreach nurse  
■ Publications as suggested by advisory/support teachers  
■ Local and national support groups  
■ DfEE circular 14/96 Supporting Children with Medical Needs  
■ Hull City Council publication Supporting Children with Medical Conditions, David Fulton publishers, 2004 |

### ASSESSING THE PUPIL — PROVIDING A STATEMENT OF EDUCATIONAL NEEDS

<table>
<thead>
<tr>
<th>ISSUES</th>
<th>STRATEGIES</th>
<th>RESOURCES</th>
</tr>
</thead>
</table>
| Consider whether statutory assessment is appropriate or not | ■ Assess whether the child's physical condition is affecting his or her learning/mobility  
■ Monitor, record and review the situation  
■ Follow the Code of Practice  
■ Follow School Action and School Action Plus guidance  
■ Call multi-agency meetings as and when necessary | ■ See Chapter 7  
■ SEN Code of Practice refer to following pages;  
■ 5.43 School Action  
■ 5.54 Request help from outside agencies through School Action Plus  
■ 5.62 School request to initiate statutory assessment |

### PHYSICAL LIMITATIONS

<table>
<thead>
<tr>
<th>ISSUES</th>
<th>STRATEGIES</th>
<th>RESOURCES</th>
</tr>
</thead>
</table>
| Movement within school | ■ Ensure pupils and support staff are aware of the most accessible route to each subject area  
■ Allow the pupil to leave class a couple of minutes before other pupils to avoid adding to congestion in the corridors or suggest the pupil waits a few minutes to avoid the rush; ensure homework tasks are recorded  
■ Ensure staff are aware of evacuation procedures for all pupils  
■ Check that handrails are in place on all external and internal steps  
■ Check that all staircases have handrails on each side  
■ Check for sunken mat wells which can cause trip hazards for ambulant pupils and obstacles for wheelchair users | ■ Refer to Hull City Council publication Supporting Children with Medical Conditions, David Fulton publishers, 2004  
■ School Access Plan  
■ Advice from therapists  
■ Regular maintenance of floors and paved areas |
### Physical management of equipment
- When and how is a standing frame used?
- When should the powered wheelchair be used?
- Who decides whether or not the ambulant pupil should use his or her wheelchair?

### STRATEGIES
- Negotiate with physiotherapist and pupil
- Try to use the standing frame in lessons when other pupils are standing
- Timetable standing before or after break to allow time for transfers and minimise loss of teaching time
- Consider availability of support staff
- Consider proximity of classroom to specialist toilet/support facilities with regard to movement to and from the classroom, and the possible need for toileting as a result of being in the standing frame
- Use a sensitive approach and discuss any pros and cons with the pupil, parents and relevant health staff – respect the pupil’s views

### RESOURCES
- See Chapter 6
- Occupational therapy and physiotherapy recommendations
- Documented instructions on transfers for individual pupils

### GENERAL SUBJECT/FACULTY/DEPARTMENTAL ISSUES

#### ISSUES
- How to organise the classroom to accommodate a pupil who uses a wheelchair
- Access to all subjects

#### STRATEGIES
- Arrange the furniture to allow for a clear path in and out of the classroom
- Take any sensory impairment into account when allocating tables. Does the pupil need to face the teacher or the board?
- Try to encourage sensible storage of walking aids so that they don’t create a trip hazard for staff or pupils
- Encourage other pupils to keep aisle clear of bags and coats

#### RESOURCES
- Advice from relevant services
- Risk assessment policy and guidance
- Subject/advisory teachers
- Advisory or support services for pupils with physical disabilities
- Networking with other subject specialists, professional associations and internet groups
- Networking with colleagues working in similar fields
- Appropriate, accessible storage facilities

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**THE SCHOOL ENVIRONMENT**

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<tr>
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<th>RESOURCES</th>
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</thead>
<tbody>
<tr>
<td>Environmental issues</td>
<td></td>
<td>See Chapter 6</td>
</tr>
<tr>
<td>Physical management of equipment</td>
<td>Negotiate with physiotherapist and pupil</td>
<td>See Chapter 6</td>
</tr>
<tr>
<td></td>
<td>Try to use the standing frame in lessons when other pupils are standing</td>
<td>Occupational therapy and physiotherapy recommendations</td>
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<td></td>
<td>Timetable standing before or after break to allow time for transfers and minimise loss of teaching time</td>
<td>Documented instructions on transfers for individual pupils</td>
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<td></td>
<td>Consider availability of support staff</td>
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<tr>
<td></td>
<td>Consider proximity of classroom to specialist toilet/support facilities with regard to movement to and from the classroom, and the possible need for toileting as a result of being in the standing frame</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Use a sensitive approach and discuss any pros and cons with the pupil, parents and relevant health staff – respect the pupil’s views</td>
<td></td>
</tr>
</tbody>
</table>

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**GENERAL SUBJECT/FACULTY/DEPARTMENTAL ISSUES**

<table>
<thead>
<tr>
<th>ISSUES</th>
<th>STRATEGIES</th>
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</thead>
<tbody>
<tr>
<td>How to organise the classroom to accommodate a pupil who uses a wheelchair</td>
<td>Arrange the furniture to allow for a clear path in and out of the classroom</td>
<td>Advice from relevant services</td>
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<td>Take any sensory impairment into account when allocating tables. Does the pupil need to face the teacher or the board?</td>
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<tr>
<td></td>
<td>Try to encourage sensible storage of walking aids so that they don’t create a trip hazard for staff or pupils</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Encourage other pupils to keep aisle clear of bags and coats</td>
<td></td>
</tr>
</tbody>
</table>

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**Access to all subjects**

- Safety must be a primary concern and a risk assessment for each practical activity is required. This should be updated to take into consideration the pupil’s changing physical ability. A high-risk activity should not necessarily result in the pupil being excluded
- Risk assessments should be carried out to ENABLE, not prevent, pupils from carrying out tasks
- Staff should acknowledge and recognise the differences between unconventional and unsafe ways of doing things

### STRATEGIES
- Head of department/subject teachers carry out risk assessments in consultation with their school’s health and safety representative
- Advice for teachers regarding differentiation of tasks and/or equipment to take account of physical limitations
- Advice for support staff regarding supporting pupils in specific subject areas
- Ensure that pupils can access equipment by providing individual sets of equipment stored at an accessible height
- Enlist peer support where possible by organising small group work
- Support staff working under the direction of the pupil

### RESOURCES
- Risk assessment policy and guidance
- Subject/advisory teachers
- Advisory or support services for pupils with physical disabilities
- Networking with other subject specialists, professional associations and internet groups
- Networking with colleagues working in similar fields
- Appropriate, accessible storage facilities
| Homework issues | Consider when it is given  
Give out homework tasks at the start of a lesson so those pupils leaving the room early have an accurate account of what they need to do  
Acknowledge that a pupil may have physiotherapy after school and fatigue may therefore be an issue | Student planner  
Information and communication technology (ICT) equipment |
|---|---|---|
| Deployment of support staff | Vary support staff to prevent emotional overload  
Ensure all staff involved have access to the same training | Consultation with SENCo  
Support from Educational Psychology Services (EPS)  
Support from Family Care Officers |
| Planned absences | Hospital appointments, recurring infections, spinal surgery  
Catch-up facilities to compensate for work missed, support staff photocopy pupils’ work or note-take in lesson  
Access to home/hospital tuition service when appropriate  
Assist in maintaining school friendships | Hospital tuition service  
Home tuition service  
Through e-mails/certs/cards/text and telephone contact |
| Performances/concerts | Consider ways of ensuring full inclusion  
Forward planning  
Consult the pupil and take into account what he or she is comfortable with  
Discreetly ensure safety of movement | Flexible use of staff and space  
Clear, unambiguous, written instructions  
Adequate staffing |
| Educational visits | Funding for additional staff for residential visits  
Emergency procedures may need reviewing and adapting  
A physical access audit including personal care facilities should be carried out prior to a visit  
Risk assessments  
Deployment of trained support staff  
School transport  
Portable equipment, such as hoists, may be needed  
Medical cards with precise information may need translating into a foreign language for overseas trips | DfES guidance  
LEA  
School policies  
LEA loan equipment |
| After school clubs | Flexible LEA transport | Access to community transport, e.g. Dial a Ride  
Access to support staff with appropriate training |
| Work experience | Refer to physical management routines  
Refer to personal care routines | Appropriate transport required  
Assistance from Connexions | Appropriate placement |
<table>
<thead>
<tr>
<th>CURRICULUM ISSUES</th>
<th>STRATEGIES</th>
<th>RESOURCES</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>English and Modern Foreign Languages (MFL)</strong></td>
<td>Maximise use of ICT. Present computer generated worksheets wherever possible. Make these available to the pupil via disc, CD or 'flash drive'</td>
<td>Access to ICT hardware</td>
</tr>
<tr>
<td>The volume of written work is likely to be the main issue</td>
<td>Ask educational support assistants (ESAs) to photocopy/scan lesson notes which other pupils will transcribe from the board</td>
<td>Differentiate work tasks within departments at the planning stage</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Maths</strong></td>
<td>Encourage use of specialist maths programmes e.g. Access Maths</td>
<td>See Appendix 1</td>
</tr>
<tr>
<td>Deterioration of hand skills will lead to difficulty in manipulating standard mathematical equipment</td>
<td>Reduce the quantity of writing by providing photocopied worksheets rather than copying from text books</td>
<td>Specialist software (Inclusive Technology)</td>
</tr>
<tr>
<td>Children with Duchenne muscular dystrophy may have specific problems.</td>
<td>Ask support assistants to transcribe when copying is unavoidable</td>
<td>Differentiate work tasks within departments at the planning stage</td>
</tr>
<tr>
<td></td>
<td>Provide alternative equipment, e.g. non-slip ruler, safe drawing compass and circle protractor</td>
<td>Hope catalogue</td>
</tr>
<tr>
<td></td>
<td></td>
<td>See Chapter 1, page 10</td>
</tr>
<tr>
<td><strong>Science</strong></td>
<td>Maximise use of ICT. Present computer generated worksheets wherever possible. Make these available to the pupil via disc, CD or 'flash drive'</td>
<td>See Appendix 1</td>
</tr>
<tr>
<td>As with other practical subjects, safety will be paramount</td>
<td>Use of QX3 Computer Microscope</td>
<td>Access to ICT hardware</td>
</tr>
<tr>
<td></td>
<td>Ask ESAs to photocopy/scan lesson notes which other pupils will transcribe from the board</td>
<td>Differentiate work tasks within departments at the planning stage</td>
</tr>
<tr>
<td></td>
<td>Ensure furniture is of appropriate height for wheelchair users</td>
<td>Economatics (Education) Ltd.</td>
</tr>
<tr>
<td></td>
<td>Risk assess each practical activity</td>
<td>Liaison between staff</td>
</tr>
<tr>
<td></td>
<td>Adapt standard equipment such as Bunsen burners</td>
<td>Height adjustable furniture</td>
</tr>
<tr>
<td></td>
<td>Provide adequate protective clothing e.g. a protective apron for a pupil who remains seated in practical activities</td>
<td>(Atkinson Varitech Limited)</td>
</tr>
<tr>
<td></td>
<td>Group pupils sensitively to ensure more mobile pupils can collect and manipulate equipment enabling the less physically able pupil to direct activities</td>
<td>Timetabling of staff</td>
</tr>
<tr>
<td></td>
<td>Ensure appropriate adult support is available when necessary in practical sessions</td>
<td></td>
</tr>
<tr>
<td><strong>Design Technology</strong></td>
<td>Maximise use of ICT</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ask ESAs to photocopy/scan lesson notes which other pupils will transcribe from the board</td>
<td>Access to ICT hardware</td>
</tr>
<tr>
<td></td>
<td>Ensure furniture is of appropriate height for wheelchair users</td>
<td>Differentiate work tasks within departments at the planning stage</td>
</tr>
<tr>
<td></td>
<td>Risk assess each practical activity</td>
<td>Varitech Atkinson catalogue</td>
</tr>
<tr>
<td></td>
<td>Ensure at least one set of equipment is accessible</td>
<td>Liaison between health and safety and subject advisor</td>
</tr>
<tr>
<td></td>
<td>Consider use of alternative/specialist equipment</td>
<td>Homecraft catalogue</td>
</tr>
<tr>
<td></td>
<td>Provide modified or parallel activities</td>
<td>Advice from advisory/support teacher, subject adviser or occupational therapist</td>
</tr>
</tbody>
</table>
### History and Geography
- Maximise use of ICT. Present computer generated worksheets wherever possible. Make these available to the pupil via disc, CD or ‘flash drive’
- Ask ESAs to photocopy/scan lesson notes, maps, diagrams etc. which other pupils will transcribe from the board or books
- Consider use of digital camera to record field work
- Ensure furniture is of appropriate height for wheelchair users
- Risk assess field visits

### Physical education
- Offer alternative or adapted activities
- Consider swimming as an alternative

### ORGANISATIONAL/EMOTIONAL/TEAMWORK ISSUES

<table>
<thead>
<tr>
<th>ISSUES</th>
<th>STRATEGIES</th>
<th>RESOURCES</th>
</tr>
</thead>
</table>
| **Timetabling**
- What must schools do if specialist rooms are upstairs?
- Allocation of form rooms to ground floor if possible
- Allocation of subject classrooms to ground floor rooms wherever possible for pupils with mobility difficulties
- When specialist teaching facilities are located in upstairs classrooms, equivalent provision must be made if access to upstairs classrooms via lifts is not possible
- Time practical lessons to overflow into break period if time is limited
- Proximity of specialist toilet facilities (personal care facilities)

| **Emotional support for staff**
- Staff working with pupils who have a deteriorating condition may develop a close relationship with that pupil. A support network within school may be needed
- Establish a formal and informal route for staff to discuss their concerns
- INSET regarding loss and bereavement to help staff deal with issues arising from working with a pupil who has a deteriorating condition
- Try to ensure that support staff do not become too isolated. This is particularly true in a small school where the support staff team is also small

| Access to ICT hardware
| Differentiate work tasks within departments at the planning stage
| Varitech Atkinson catalogue
| Liaison between health and safety and subject adviser

| Davis Sports catalogue
| Youth Sport Trust 020 7388 4436
| Federation of Disability Sports Organisations 01924 279305
| Supporting Disabled People in Sport (Federation of Disability Sports Organisations)

| Liaison between heads of faculties, SENCo and member of staff responsible for room allocation
| Schools Access Plan

See Chapter 4
Refer to Hull City Council publication *Supporting Children with Medical Conditions*, David Fulton Publishers, 2004
Lost for Words A training package for teachers 01482 613423
Local publications from LEA advisory staff
### Emotional support for the pupil and the family
- When a pupil with a deteriorating condition loses skills, he or she will experience emotional changes which may be reflected in his or her behaviour, attitude and work.
- Ensure all relevant staff have access to information and training relating to loss and bereavement.
- Establish a clear route for passing on information offered by the pupil.
- Ensure the pupil is aware that some things said in confidence to staff must be passed to their team leader.
- Maintain good communication links with the family. Be sensitive in your approach but ensure that the family is made aware of the pupil’s worries and ask how it would like to deal with these situations.
- Encourage staff to be open when dealing with ‘difficult’ questions but cautious about giving more information than is needed at that time.
- Maintain good communication links with the family. Be sensitive in your approach but ensure that the family is made aware of the pupil’s worries and ask how it would like to deal with these situations.
- Ensure the pupil is aware that some things said in confidence to staff must be passed to their team leader.
- Maintain good communication links with the family. Be sensitive in your approach but ensure that the family is made aware of the pupil’s worries and ask how it would like to deal with these situations.
- Encourage staff to be open when dealing with ‘difficult’ questions but cautious about giving more information than is needed at that time.

### Home school links
- Establish a workable system.
- Telephone contact.
- ‘Home School Message Book’.

### MEDICAL AND THERAPEUTIC ISSUES

<table>
<thead>
<tr>
<th>ISSUES</th>
<th>STRATEGIES</th>
<th>RESOURCES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical management</td>
<td>School needs to consider when, where, by whom and how physical management routines will be implemented.</td>
<td>Identify support staff. Ensure that at least three staff are trained to cover absences. Nominate a key worker from the trained staff for ease of communication. Identify areas for physical management routines ensuring privacy and access to appropriate space, equipment, facilities etc. Consideration must be given to other users of specialist facilities. Training and instruction on implementing the physical management routine in accordance with current moving and handling regulations. Maintain a training log to record initial and ongoing training received. Keep a record of equipment maintenance.</td>
</tr>
</tbody>
</table>
### Personal hygiene/toileting routines
- Are support staff covered by LEA insurance with reference to handling pupils and child protection issues?
- Should pupils with neuromuscular conditions be expected to conform to normal routines or be allowed to go to the toilet on request?
- How do we ensure that supply staff and new teachers are aware of existing/agreed procedures?
- What should teachers do if the pupil needs to go to the toilet and a support assistant is not in that lesson?
- For girls the onset of puberty and the start of periods will create new challenges and issues to be addressed (See Chapter 4)

### Physical dependency
By this stage most pupils will be physically dependent on adult assistance.
- Use of standing frames
- Hoisting

### Hospital admissions
- Child may be admitted to hospital with chest infections
- Child may require planned surgery
- Catch-up facilities to compensate for work missed, support staff to photocopy pupils’ work or note take in lesson
- Access to home/hospital tuition service when appropriate
- Assistance in maintaining school friendships

### POLICIES AND MANAGING RISKS

<table>
<thead>
<tr>
<th>ISSUES</th>
<th>STRATEGIES</th>
<th>RESOURCES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child Protection</td>
<td>See Chapter 7</td>
<td>See Chapter 7</td>
</tr>
<tr>
<td>Moving and handling</td>
<td>See Chapter 8, Appendix 1</td>
<td></td>
</tr>
<tr>
<td>Emergency evacuation procedures</td>
<td>Written procedures, Advice from local fire officer</td>
<td>Purchase of evacuation sheets and chairs</td>
</tr>
<tr>
<td>School uniform policy</td>
<td>Encourage parents to purchase clothing appropriate to their child’s physical needs but in the same colour and as near to the style of the school dress policy as possible</td>
<td>See Chapter 7, Amend school dress code to reflect needs of pupils who have a special need</td>
</tr>
</tbody>
</table>
Many pupils with physical disabilities prefer to wear trousers with elasticated waists to aid independence or to help with their physical management routine.

- Girls often choose trousers to protect their dignity when being transferred from one position to another.

- Specialist footwear may be recommended to accommodate splints or improve gait. This is not always available in appropriate colours.

**Examination arrangements**

Special arrangements can be made. The pupil should be familiar with the proposed way of working prior to examinations.

- Information from exam officers in school
- Practice sessions using scribe or technology prior to exam

**TRANSPORT**

<table>
<thead>
<tr>
<th>ISSUES</th>
<th>STRATEGIES</th>
<th>RESOURCES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transport</td>
<td>- Home/school transport in accordance with LEA policy <strong>NB. Tailgate lift should be used in preference to ramped access to avoid strain on pupil’s head</strong>&lt;br&gt;- An escort may be required according to individual medical needs&lt;br&gt;- Shared information</td>
<td>- LEA recommended transport contacts</td>
</tr>
<tr>
<td>Arrival at school (set-down and pick-up arrangements)</td>
<td>- Identify a set-down and pick-up point for vehicles carrying disabled students which is close to the school and near ramped access&lt;br&gt;- Nominate a member of support staff to receive the pupil on arrival</td>
<td>- School’s accessibility plan&lt;br&gt;- Staffing implication</td>
</tr>
</tbody>
</table>
PERSONAL HYGIENE
Care needs to be taken to plan ahead for the child’s toileting needs.

The child’s personal care needs can change rapidly. A child who may be able to manage care and personal toileting at one time might not be able to do so later. The ESA should be sensitive and aware of the likelihood of this change, and ready and able to support it.

Fluid intake is a problem as children may not drink in order to avoid going to the toilet and can become dehydrated as a result.

Puberty brings on specific issues such as menstruation.

ORGANISING THE TEACHING AREAS
How can I organise my classroom to accommodate a pupil who uses a wheelchair?

- Arrange the furniture to allow for a clear path in and out of the classroom
- Take any sensory impairment into account when allocating tables. Does the pupil need to face the teacher or board?
- Encourage sensible storage of walking aids so that they don’t create a trip hazard for staff or pupils
- Encourage other pupils to keep aisle clear of bags and coats

PHYSICAL MANAGEMENT
Pupils with neuromuscular conditions will have significant physical management needs. Schools should consider when, where, by whom and how these will be met.

- Liaise with parents and other agencies
- Identify support staff. Ensure that at least three staff are trained to cover absences. Nominate a key worker from the trained staff to relay communication to all those involved
- Identify an area for physical management routines that is private and has appropriate and accessible space, equipment and facilities
- Consideration must be given to other users of specialist facilities
- Arrange to release three members of support staff to receive training

Most pupils who have a neuromuscular condition are likely to require a combination of the following physical management strategies:
- Powered chair
- Specialist seating system
- Standing frame
- Assisted stretches
- Toileting needs

The timetable on page 36 gives an example of how the physical management routine can be incorporated into a school day, assuming most toileting will happen at lunchtime and breaks. The majority of transfer between chairs and equipment should take place after toileting to minimise handling.

For a pupil with a neuromuscular condition, there is likely to be a number of external professionals guiding the staff. It might be useful for ESAs to keep a record of every professional’s involvement and contribution. Support staff should highlight any activities that have not been implemented to provide an accurate record of physical management. This timetable also informs teaching staff of the physical activity that will be incorporated into their lessons and is helpful in recording how staff have catered for the pupil’s individual needs.

An example of a ‘weekly overview’ is given overleaf with completed tasks highlighted. A blank copy, that can be photocopied, is included in Appendix 1.

Things to be recorded on the form include:
- Mobility and postural needs (changes in seating from wheelchair to specialist chair)
- Therapy input of occupational therapists and physiotherapists
- Use of standing frame
- Wheelchair training
- Specific IEPs for learning difficulties (see page 10)
## A PUPIL SUPPORT TIMETABLE

### Name of Pupil

### Initials of Support Staff

<table>
<thead>
<tr>
<th>MONDAY</th>
<th>PE</th>
<th>Maths</th>
<th>English</th>
<th>History</th>
<th>RE</th>
</tr>
</thead>
<tbody>
<tr>
<td>TUESDAY</td>
<td>English</td>
<td>Maths</td>
<td>Science</td>
<td>Geography</td>
<td>MFL</td>
</tr>
<tr>
<td>WEDNESDAY</td>
<td>DT</td>
<td>English</td>
<td>maths</td>
<td>Lunch</td>
<td>Break</td>
</tr>
<tr>
<td>THURSDAY</td>
<td>MFL</td>
<td>English</td>
<td>Geography</td>
<td>Science</td>
<td>DT</td>
</tr>
<tr>
<td>FRIDAY</td>
<td>English</td>
<td>Maths</td>
<td>PE</td>
<td>Art</td>
<td>Science</td>
</tr>
</tbody>
</table>

- ■ Standing frame
- ● Physiotherapy session

### COMMENTS

Monday

Tuesday

Wednesday

Thursday

Friday
3.1 EDUCATION STAFF

Teamwork is the only way to provide an effective school response to meeting the changing needs and abilities of pupils with neuromuscular 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. Learning targets should be based on academic, not physical, ability and the school ethos ought to ensure the continuing development of social skills and self-esteem throughout school life.

HEAD TEACHER

The head teacher is responsible for the organisation, management and control of the school, and works in close partnership with the school’s governing body. The Disability Discrimination Act requires the head teacher and governing body to consider how to provide access to a full, broad and balanced curriculum as well as to the school itself.

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, but a small primary school may have relatively few staff and the head teacher could also have direct teaching commitments or additional co-ordinator responsibilities.

SPECIAL EDUCATIONAL NEEDS CO-ORDINATOR (SENCO)

Every school has a designated member of staff who is responsible for coordinating special educational needs provision within the school. This person is called the special educational needs co-ordinator (SENCo). Working with the head teacher, senior managers and colleagues, the SENCo should be closely involved in the strategic development of SEN policy and provision. He or she will also have responsibility for the day-to-day operation of the school’s SEN policy, coordinating provision for pupils with SEN, particularly through School Action and School Action Plus (SEN Code of Practice). The SENCo often has line management responsibility for educational support assistants (ESAs) who work in classes or alongside individuals to ensure that pupils with SEN have full access to the curriculum. The SENCo may also organise training opportunities for ESAs and teaching colleagues as appropriate.
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 neuromuscular condition should understand how the condition will affect the pupil's learning. She or he will supervise the ESA designated to work alongside the pupil in their lessons, and liaise with parents, the SENCo and a range of outside agencies.

There has been a considerable increase in the number of ESAs, especially those working with children who have physical difficulties. An ESA will work closely with the class teacher. They also spend considerable time working directly with the individual child to help him or her be as independent as possible, while managing a deteriorating medical condition. An ESA will support different curriculum areas which have been identified by the school and the Local Education Authority (LEA). The number of hours an ESA works will reflect the changing needs and physical condition of the pupil.

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 neuromuscular 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 and toileting. Supervision should be discreet so that the pupil's dignity and privacy are respected and he or she is able to interact with his or her peers without a constant adult presence.

An advisory teacher has specific responsibility for co-ordinating the LEA's response to pupils who have physical and medical difficulties. Advisory teachers work alongside teachers and LEA officers. They may also have contact with planning departments and other specialist services.

Advisory teachers work with occupational therapists, physiotherapists and voluntary agencies, and maintain close contact with parents. Advisory teachers are concerned with the overall well-being 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.

Educational psychologists (EPs) are qualified and experienced teachers with an honours degree (or equivalent
accredited qualification) in psychology, and a post-graduate qualification. 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 including 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 well-being of pupils by, for example, offering advice and support on developing a pupil’s self-esteem as well as guidance on issues such as bereavement and bullying (potentially significant areas for pupils with a neuromuscular condition).

**SCHOOL NURSE**

The school nurse can be a valuable resource to coordinate and disseminate healthcare information. The role of the school nurse varies in different authorities and schools but many secondary schools will 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 with a neuromuscular condition in the school so he or she can liaise, when necessary, with other healthcare professionals.

**SCHOOL MEDICAL OFFICER**

Clinical medical officers (CMOs), also known as school doctors or community paediatricians, specialise in the care of pupils and young people from birth to 19 years of age. As well as routine healthcare and immunisations, they are responsible for the developmental screening of young children. Following the diagnosis of a neuromuscular condition, the CMO will advise the education authority and possibly request a statutory assessment. CMOs review a pupil’s progress throughout his or her school life. They may refer the pupil to the Paediatric Therapy Service and also take part in the review process if a statement is in place.

When a pupil is nearing the end of his or her school career the CMO will liaise with Connexions, health authority, education department and social services.

**EDUCATION WELFARE OFFICER**

Education welfare officers (also known as education social workers) work closely with schools and families to resolve attendance issues and promote effective working relationships between home and school. They help parents meet their responsibility to secure education for children and young people, and promote regular school attendance. Each school maintained by the local education authority 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.

**LEARNING MENTOR**

Learning mentors are often used when a young person becomes disaffected with school and/or has a problem which is hindering the learning process. They aim to help the pupil through his or her difficulties whether they are academic, social or emotional. The learning mentor tends to work with a pupil outside of the classroom.

Learning mentors are part of the Excellence in Cities programme, established to improve standards in education within inner city areas. The scheme is funded by the Government and aims to have over 3000 learning mentors in place by the end of 2004.
A learning mentor should:

- talk and listen to young people individually
- work with the pupil to identify problem areas, such as social, emotional, behavioural, attendance or learning
- agree targets with the young person in the areas to be worked on
- maximise learning potential
- liaise with teachers and other agencies
- keep records of meetings and progress

The learning mentor is an additional source of help for both pupils and teachers – helping the pupil make the most of what is on offer and supporting teaching staff in achieving the best results for individuals and classes.

**PARENT PARTNERSHIP SERVICES**

The Parent Partnership Service provides impartial information and guidance for parents of pupils with SEN on how SEN procedures are implemented by schools and LEAs. The service aims to support and empower parents so they can play an active role in their child’s education. The service can also mediate if parents find themselves in disagreement with a school or LEA.
3.2 WORKING WITH PARENTS AND THE CHILD

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

Strong and clear communication links between home and school are essential for an effective working relationship to develop. This may mean regular planned meetings or a ‘home/school meeting book’. It is important to remember that many parents can 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 both extremely stressful as well as emotionally and physically demanding.

As many of the neuromuscular conditions are genetic, parents may also be affected. If they have a disability, obviously it is helpful to know how it affects them.

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 communications between school and home.

Religious and cultural groups deal with medical conditions and disability in a variety of ways. Most neuromuscular conditions are genetic, and this can be a sensitive issue for families. At the time of diagnosis all parents are offered genetic counselling through the local health services, but some families will 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 outcome of his or her illness, particularly when the condition is life shortening. They may also not be in favour of some medical treatments.

At times, schools may need to take the initiative with parents and discover what has been said to the young person. 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 need to be aware that a young person in secondary school may have access to the Internet and use it to find out about his or her condition and the illness pattern. Parents and teachers need to be aware of this possibility, as information learnt by this route could come as a terrible shock to the pupil, and put the school in a difficult position.

It can be challenging for school staff to respect the views of parents, especially where they are different to their own. It is crucial however, for the well-being of the young person, that both parents and school discuss the issues around knowledge and treatment to develop a combined approach.

Work with the child and listen to his or her needs. Children can also become weary of the number of professionals they encounter, each making decisions about their life. It is particularly important, as children become older and more aware of their physical differences, that they are encouraged to participate and contribute to discussions about their education.
3.3 HEALTH AND SOCIAL CARE PROFESSIONALS

Health and care professionals will work with you in a multidisciplinary way.

**OCCUPATIONAL THERAPISTS**

Occupational therapists (often called OTs) work with children to promote independence. They enable pupils to reach their full potential by reducing, where possible, the impact of the condition on the child, family and carers.

OTs view each child as an individual, and OT programmes are shaped to the specific needs of the child, his or her family and the school setting. The aim of an OT programme is to improve quality of life and maximise participation in activities at home, school and in the community.

OTs look at a range of self-care skills, including toileting, bathing, eating, and dressing. They will also advise on upper limb and fine motor movements such as scissors skills and pencil/crayon grasp.

OTs can advise on appropriate equipment and adaptations for maximum independence. This may include advice on seating, wheelchairs, hoisting, moving and handling and the use of other specialised equipment both in school and at home.

**PHYSIOTHERAPISTS**

Physiotherapists help children reach their maximum physical potential. They aim to minimise the development of contractures and deformity through a programme of stretches (and exercises, where appropriate). Physiotherapists can prescribe specialist equipment and aids such as orthoses, wheelchairs and standing frames. They can also give advice on moving and handling issues.

A key role of the physiotherapist is to maintain and monitor respiratory function and advise on techniques to assist with breathing, such as exercises and methods of clearing secretions.

**MUSCULAR DYSTROPHY CAMPAIGN CARE ADVISORS**

MDC Care Advisors are health or social care professionals funded by the Muscular Dystrophy Campaign and some NHS Trusts. They are experienced in the management of neuromuscular conditions and can offer practical, specialist advice and information to the school, family and child. They also provide a training service to professionals as well as support to families and people with a neuromuscular condition.

They are based primarily within hospitals, usually within a specialised neuromuscular service. Contact details of your nearest MDC Care Advisor are available from the charity.

**SOCIAL WORKER**

Social workers are sometimes also called care managers, because they are responsible for assessing the needs of a child and family and arranging provision of care. They can offer advice on respite care, carer’s support, benefits and social services. Social workers may also be involved with child protection issues. They can be hospital based or in local social services departments.

**DIETITIAN**

Dietitians may be based in a hospital or community setting. They provide advice on specialist diets, weight loss, weight gain and nutritional requirements.

**SPEECH AND LANGUAGE THERAPIST (SALT)**

A speech and language therapist assists children with speech, language and/or communication difficulties. Speech and language therapists are concerned with all issues relating to communication, including articulation, understanding of language and communication disorders. They are usually employed by the health authority, but sometimes by LEAs.

Speech and language therapists work with pupils in clinics and at school to ensure they can fully express themselves. They also work closely with dietitians and other therapists, and can offer advice if a child has difficulty with biting, swallowing and chewing.
Schools work in partnership with the medical team to support children with neuromuscular conditions and their families. For this to be effective, schools must fully understand both the diagnosis and prognosis of the condition, and the changes that will take place in the child during his or her time at school. Special educational needs advisors and physical difficulties teaching advisors are employed by the LEA and can offer advice and information, alongside condition specific support groups. The Muscular Dystrophy Campaign Family Care Officers and other healthcare professionals will also visit schools to give specific advice.

4.1 DEALING WITH DIAGNOSIS

Parents handle the diagnosis of a neuromuscular condition in a variety of ways. Where the prognosis of the condition is life-limiting to childhood or early adulthood there is likely to be a range of reactions, with some parents coping better than others. What all parents must face, however, is living with their child’s deteriorating condition. Coming to terms with a diagnosis is not necessarily a static situation. It is often a period of fluctuating emotions for the entire family, and this could continue for a long time. Some feelings may resurface as the condition progresses and the child begins to lose specific skills.

Families will almost certainly have been given an accurate diagnosis and prognosis, but may be unable to deal with the information they have received. Consequently, the child could be told different things. Some families tell their child everything about the condition, some say nothing, and others give their son or daughter limited information.

Families are likely to have strong views on what their children should and should not know about the 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 also need to ascertain what the parents’ views are about sharing information, and explain what could happen if information is not disclosed. Difficulties can arise, for example, if an older child searches the Internet for information about his or her condition. Similarly, schools need to be aware of how much the affected child’s siblings understand about the situation.

Agree with the parents 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 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

SUPPORT FOR THE FAMILY
The family should have access to support from a specialist medical team, local health and social care professionals, the condition specific support group and other families in similar situations. In addition, they may be receiving psychological support, accessed via their doctor or a clinical/educational psychologist. Children with life-limiting neuromuscular conditions might also get support from their local children’s hospice, where they may go for respite care and to meet other children with the same condition.

Families may sometimes choose not to divulge information about all the people working with their child. If you feel that a family is not receiving appropriate support, you should discuss with them the possibility of a referral, and perhaps offer to work alongside the other professionals supporting them. Some education authorities have educational and psychological services that support individual children and their families. These services may include a physical difficulties teaching support service which can offer help from the point of diagnosis. If such a service exists in your authority then consider whether a referral is appropriate.

SUPPORT FOR SIBLINGS
It is important to remember that the siblings of children with a neuromuscular condition will have needs of their own. Older siblings may well be aware of the diagnosis and prognosis, although this is not always the case. Even younger children will be aware that 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. If you are concerned about the sibling of a child with a neuromuscular condition you should raise the subject, in a sympathetic 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 neuromuscular conditions, *Hey, I’m Here Too* is available free of charge from the Muscular Dystrophy Campaign.

STAFF SUPPORT
Having a child in the classroom with a life-limiting and deteriorating 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 situation. 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 carers – who may develop a close relationship with the child and be asked searching questions.

Staff working closely with the child, as well as those who have suffered bereavement or have children of a similar age, may be particularly affected by a child with a deteriorating 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 ought to be made aware of general issues about disability and changing needs, for example, their classmates might need a wheelchair sometimes, but walk at others. Special attention may need to be paid to the child’s close friends.

A book for 11-14 year old pupils about disability – Same but Different – is included in Appendix 3. Copies are available free of charge from the Muscular Dystrophy Campaign. The book is not specifically about neuromuscular conditions.

4.3 THE CHILD’S NEEDS
Psychological support for the child is invaluable. 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 a learning support assistant or a lunchtime carer searching questions about their condition.

Often the most valuable support for a young person with a neuromuscular condition comes from another young person with a similar illness. Liaison with MDC Care Advisors or advisory teachers can provide opportunities for this.

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 and 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.
School should also generally promote positive role models of disabled people throughout the curriculum.

Books and materials aimed at children with neuromuscular conditions are included in Appendix 3. 

Everybody’s Different, Nobody’s Perfect is designed for 4-10 year olds, and Thinking about you is aimed at 11-14 year olds. This information as a colourful booklet, is also available free of charge from the Muscular Dystrophy Campaign. A leaflet DMD – On the Ball aimed specifically at 11-14 year old boys with Duchenne muscular dystrophy is also available free of charge from the Muscular Dystrophy Campaign.

BEHAVIOURAL CHALLENGES

Children with neuromuscular conditions need the same structure and discipline in class as everyone else. The usual positive classroom management strategies should be employed in line with school pastoral policy. But it is important to acknowledge and understand that a young person with a neuromuscular condition may have limited ways of expressing his or her feelings and could behave in an angry, frustrated, stubborn or withdrawn manner. Help the young person 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.

SELF-ESTEEM AND BODY IMAGES

Some children with a neuromuscular 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 very limited and they could have a poor body image.

Some neuromuscular conditions cause weakness of the facial muscles, affecting facial expressions. Pupils and staff can sometimes respond to these facial expressions in a negative way. Appropriate steps need to be taken to address this issue.

Staff need to be aware of the importance of enhancing self-esteem by 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 circle time and other related activities. See Chapter 7 – personal, social, health and citizenship education policy.

DEPRESSION AND ANXIETY

All children can experience depression and anxiety. They may show this in a number of ways – lethargy, withdrawal, irritability, 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’s performance and relationships in school.

These feelings are a normal reaction to a deteriorating condition, but if they are sustained over a long period of time then discuss with parents the possibility of seeking professional advice.

RICHARD

When you get older, people seem to look at you more than when you were younger. They seem to back away more and I know some people who get upset by this. Adults can be patronising and talk down to you like a child. I don't think they would do that with other teenagers. Sometimes I would keep my feelings inside at school and feel miserable and depressed, but when I got home I'd spout it all off to my mum.

SEXUALITY AND RELATIONSHIPS

Young people with neuromuscular conditions will have the same teenage anxieties and experiences as others their
age, including hormonal swings, spots and wet dreams! 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. (Visit www.after16.org.uk, and see ‘Friends and Beyond’.)

A young person with a neuromuscular condition will 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?’ ‘can I 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 physical reason why a young person with a neuromuscular condition should not have sex.

A young person’s view of his or her sexual attractiveness is linked to how he/she perceive his/her body. Young people with neuromuscular conditions frequently have a poor body image and, while it is possible to help them develop their own individual style and improve their confidence, it is not possible to change their underlying neuromuscular physique. Young people with deteriorating neuromuscular conditions will constantly be readjusting to a changing body image.

Contact A Family (CAF) has produced a booklet for teachers called ‘Sex and Relationship Education for Young People’. See the Resources list at the back of the guidelines for CAF’s contact details.

RICHARD

I used to feel angry because I wanted to do what the others were doing but I felt much better once I started to concentrate on the things I could do. When I did well in my work it proved I could do things, and it felt like more of an achievement. It was important for me to be praised because that motivated me to try.

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 with the family and young woman, prior to the start of her periods, and consideration given to menstrual hygiene and the use, storage and disposal of sanitary products.

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 help to deal with it 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 DEALING WITH 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 a child, before it happens. 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 neuromuscular conditions will have received support from their local children’s hospice and this will continue for the family and siblings after the child has died.

There will be other circumstances when the school may have to deal with loss and bereavement and the whole school plan should be broad enough to cover this.
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.
- Tell small groups before telling the whole school. Be aware of any ‘best friends’ and do something different for them.
- This is a loss for the class as well as the school. Work out with the class what to do.
- Don’t change the layout of the classroom immediately, but acknowledge that the young person isn’t there.
- Let teachers and other staff show their emotions and allow them to acknowledge that they are finding it hard. Give everyone ‘permission’ to feel sad or cry in front of the class.
5.1 INDIVIDUAL HEALTH CARE PLAN

"Good communication between local health authorities and school staff is important for ensuring that pupils receive the health-related support they need, to get the most from school life"  

Pupils with a chronic illness need a range of support in school. To help establish all the appropriate requirements for their needs, teachers must first understand the medical condition and the impact it will have on school life. The Department of Education and Skills guidance, Managing Medicine in Schools and Early Year Settings, provides a good starting point and includes a practice guide to help schools.

It is good practice to draw up an individual health care plan (IHCP) for every child with a medical condition. This should summarise the pupil’s condition, identify emergency situations and detail the procedures to follow. Schools should then agree with parents how frequently the IHCP will be jointly reviewed (the recommendation is at least once a year).

Some education authorities issue students with ‘smartcards’ – these contain information about the child’s condition and are accessible to all school staff when required. Several voluntary organisations (for example, the Jennifer Trust for SMA and the Myotonic Dystrophy Support Group) also produce their own medical information cards, carried by people with the relevant condition.

A written agreement between school and parents clarifies for everyone – staff, parents and pupil – the help that a school can provide and receive.

A model national health/school communication plan would provide:

1. A named teacher in every mainstream school, who has responsibility for the medical/health needs of pupils.
2. A named health professional for every mainstream school.
3. A standard health care plan for pupils with an illness or disability.
5. A smartcard for pupils to carry with them, indicating what help they may need.

Appendix 1 includes a sample blank individual health care plan currently used by an LEA/health trust. Permission has been granted for this form to be used in other localities.

1. University of York, November 2000, Improving Health/School Communication for Pupils with Special Health Care Needs. Social Policy Research Unit. The research findings include guidance for health and education professionals on providing consistent, effective communication on medical care.
2. Department of Education and Skills, and Department of Health 2005, Managing Medicine in Schools and Early Year Settings.
3. York Local Education Authority has smartcard guidelines. Contact Sarah Withernick: 01904 554332.
4. Wakefield West/Eastern Wakefield NHS Primary Care Trust.
5.2 MEDICAL EMERGENCY

It is unlikely that a child with a neuromuscular condition will have a medical emergency at school. If there were an emergency situation, however, it should be handled in the same way as for any other pupil. The parents should be notified if the child is unwell and an ambulance called for a medical emergency.

5.3 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 neuromuscular conditions will be walking and independently mobile while others will be wheelchair users. A child’s condition can fluctuate and deteriorate; children who are walking might need to rest and/or also use a wheelchair for part of the day. As muscles weaken the child may need to use the wheelchair full-time. This transition can occur quickly.

Splints and callipers also aid mobility.

A standing frame helps to stretch muscles and can be used to provide a change of posture. The back, hips and legs are held in a position which prevents shortening of the muscles, curvature of the spine and maintains good functioning of internal organs. In addition, standing frames enable a prolonged stretch to calves, hamstrings and hip flexor muscles.

A child can feel awkward using a standing frame, particularly in a classroom during lesson time. How and when to introduce a standing frame needs to be sensitively handled and planned, and should be discussed with the child’s physiotherapist. It may also need to be talked about, in a matter of fact way, with the class, and the benefits of its use explained to pupils.

UPPER LIMB FUNCTION
Many neuromuscular conditions cause weakness in the upper limbs. This may not always be apparent on first meeting or seeing a child – particularly if he or she is using an electric wheelchair – and 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 severe cases, for example, a child may not be able to raise his or her hand in response, or call for the teacher’s attention. In this situation, another method of communicating with the teacher will need to be devised.

Hand function is essential for writing. 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 which are too low, for example, will cause a child difficulties. A paediatric occupational therapist can provide a full assessment and advise on ways to maximise a child’s upper limb functional abilities.

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 an outdoor coat.

A pupil might find it impossible to reach for objects in the classroom, so ensure that all work tools and books are easily accessible. Using heavy textbooks and/or objects could also cause difficulties.

Children who are still mobile 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 the spine. Encourage pupils in secondary schools to use lockers rather than carry heavy bags between classrooms. Support staff can help by fetching and carrying equipment or simple aids, such as writing slopes. Extra pen grips can help the pupil with his or her hand function. A full occupational therapy assessment will identify what aids would be most helpful.

**EATING/SWALLOWING**

Some children with neuromuscular 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 lungs – this is called aspiration. If this happens regularly, the child could be more prone to chest infections and find it hard to put on weight.

Other children with neuromuscular 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 and it may be necessary to ask advice from a speech and language therapist and/or occupational therapist on appropriate management.

Some children use 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.

Other children will be fitted with a gastrostomy tube (g-tube) which sends food straight into the stomach. This can reduce problems and ensures 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 health care 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, refer the pupil to a speech and language therapist or advisory teacher who can offer assessment and treatment.

Writing may be difficult but simple aids, such as writing slopes and extra pen grips, can assist the pupil with hand function. Adapted computers or mobile arm supports may also help maximise a pupil’s abilities. An occupational therapist or advisory teacher can give a full assessment.

**CONTINENCE**

The majority of children with neuromuscular conditions will not have a problem with continence. Children with Duchenne muscular dystrophy, however, can have ‘overexcited bladders’, which means they need to empty them regularly and therefore require more frequent toileting.

**EDUCATIONAL SUPPORT ASSISTANT**

The standing frame is already in school and will be set up for Ali shortly. It can be adjusted so that he will be supported at an angle, and his weight won’t be on his feet. Initially, he will be in it for ten minutes, and then we’ll build up to two 30-minute sessions a day. He will be able to work while he’s in it as a work surface is provided.

I think Ali will resent being in the standing frame as he’ll feel embarrassed in front of his friends. The benefits of using the frame will need to be carefully explained to him.
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 sufficient fluid 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.

Some children will avoid going to the toilet regularly because they are self-conscious about asking for assistance. This can become more of an issue as children develop into self-aware adolescents. Staff need to be sensitive while trying to establish if this is causing difficulties. You can seek help and guidance for continence problems with the child’s healthcare team. In some cases it may be necessary to consult a specialist continence advisor.

5.4 STAYING HEALTHY

DIET/EXERCISE
Any excessive weight gain will put an additional burden on already weakened muscles. It can be difficult, however, for a child to lose weight when he or she has limited mobility and suffers from fatigue. As a general principle, encourage exercise within the child’s own capabilities. It may be necessary to seek advice and guidance from the healthcare professionals involved with the child.

Swimming is an excellent form of exercise and should be encouraged for all children.

While some children with neuromuscular conditions can be prone to putting on excessive weight others may well 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 notice that a pupil is putting on, losing, or not gaining sufficient weight, then they should alert the healthcare professionals involved with the child so this can be addressed. Dietitians and speech and language therapists can support the child with this issue.

It is important to encourage children to drink plenty of fluids as this helps to prevent urine infections and dehydration. Some children with a neuromuscular condition 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.

SLEEP AND TIREDNESS
Children with neuromuscular conditions often have disturbed sleep patterns. They may need turning and repositioning in bed many times during the night. As a result they can be exhausted in the day, and this affects their concentration and ability to work effectively. Schools need to be aware that a pupil can become tired more easily and may need a place to rest or ‘chill out’ for a while.

Many neuromuscular conditions affect respiratory function so it is important to alert health professionals if a child complains of frequent headaches (especially in the morning), increased tiredness or if you become aware of a changing level of concentration (see Section 5.5).

PHYSIOTHERAPY
Physiotherapy is an essential part of managing any neuromuscular condition. Following the diagnosis, the parents will receive advice on an appropriate physiotherapy regime. This may involve stretches, exercises and hydrotherapy as well as advice on respiratory care. The
programme will sometimes need to be carried out within the school. It can be incorporated into P.E. or games lessons and specialist equipment, such as a standing frame may be required.

**HYDROTHERAPY/SWIMMING**
Children with neuromuscular conditions benefit from hydrotherapy sessions, if these are available. Swimming is also an excellent form of exercise, and all children should be encouraged to swim, whenever possible. Swimming provides a supported medium for movement (helping to maintain a range of movement in the joints) and assists with respiratory care.

Certain factors should be considered when arranging a swimming session for a child with a neuromuscular condition: how accessible is the pool? Are lifts and hoists available, if needed, to transfer the pupil safely? Is there extra space available, if help is required, for dressing and undressing? Remember that a child requiring full assistance will take longer to get changed before and after a swimming session.

The temperature outside and in the pool is also important. Children with neuromuscular conditions do not generate the same level of body heat as others and are more sensitive to cooler temperatures. Consider the warmth 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 to avoid any potential psychological difficulties.

**5.5 MEDICAL TREATMENTS**

**STEROIDS**
It has been known for some time that steroids have an effect on muscle strength in boys with Duchenne muscular dystrophy. Steroids will not cure the condition but, when used with boys who are still walking, they can stabilise or even improve muscle strength for a while, allowing the boys to be mobile 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.

Steroids are usually administered at home by parents and their usage is closely monitored by the boy’s healthcare team. If a pupil is using steroids, the school should be provided – by parents, therapists or the school medical officer – with an information sheet.

**ORTHOTICS/SPLINTS/CALLIPPERS**
Some children may be required to wear orthoses. The most common type is the ankle-foot orthoses (AFO) which keeps the ankle and foot in a good position.

The orthoses will be prescribed by the pupil’s physiotherapist or medical team and supplied through the NHS.

Larger orthoses, such as lightweight callipers, may be needed by some children. These enable and assist independent mobility and are known as knee-ankle-foot orthoses (KAFOs). The child's physiotherapist can advise on their usage. Other different types of walking aid may also be required.

**SURGERY**
Pupils with a neuromuscular condition may require certain forms of surgery. 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. More than one operation on the spine may be needed to insert rods into the back to accommodate the child's growth. This type of surgery is not without significant risk and the child, parents and siblings, will be understandably anxious before the operation. The pupil may ask questions...
and seek reassurance from school staff. Physiotherapists, occupational therapists and MDC Care Advisors can all help.

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

When a child returns home after surgery, it may help him or her to do some schoolwork. Home tuition may be necessary for a short while with phased school entry as the child becomes stronger. After spinal surgery pupils are likely to tire more easily so it may be advisable to build up to returning to school full-time.

Existing equipment will need re-adjusting after spinal surgery as his or her position and shape will change:

- **Wheelchair**, seating and tray. Check the child has a head rest.
- **Table heights** within the classrooms and dining hall may need adjusting to accommodate the child's altered position and upper limb function.
- **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, need to have good 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.

**RESPIRATORY/VENTILATION**

This is a very important area of healthcare for pupils affected by a neuromuscular condition. Some children have very weak respiratory muscles and are carefully monitored by healthcare professionals. Early treatment of coughs, colds and respiratory infections is necessary as such children can become ill quite quickly. All staff need to be extra vigilant and parents should be alerted if the child becomes acutely unwell. A child may also need chest physiotherapy to help him or her clear any secretions.

Respiratory complications may mean a pupil has to spend time away from school and this 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, may be difficult to get going in the morning and his or her concentration and well-being will be affected. If a change is noticed it is worth alerting parents. Ventilation equipment aids effective breathing and the medical team may decide that night time ventilatory 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 the child is sleeping, some children may need extra assistance during the day. A portable ventilator can be attached to a wheelchair and the child accesses it via a nasal mask. If a child needs this level of support at school then careful planning and training of all involved staff is essential. It may at first seem a daunting task, but 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 the Muscular Dystrophy Campaign.
ENVIRONMENTAL CONSIDERATIONS

Any adaptations to the school should be guided by the Special Educational Needs and Disability Act 2001 and discussed with all agencies involved in the pupil’s well-being, to ensure his or her ongoing needs are met.

What do we need?
How do we get it?
Who pays?
Where do we go for advice?

The answers to these questions vary between LEAs but sources of help and information include:

- LEA Special Educational Needs Section
- LEA Advisory and Support Services
- LEA department responsible for building services
- School medical services
- Paediatric Therapy Services
- Social Services
- Voluntary agencies and support groups (for example, the Jennifer Trust for SMA)
- Muscular Dystrophy Campaign Family Care Officers

6.1 ACCESS AND EVACUATION

Careful consideration should be given to the school environment for a pupil with a neuromuscular condition. What a child needs will vary depending on his or her level of physical impairment and could change as the condition deteriorates. A child who is mobile 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
- Circulation space in classrooms and corridors
- Ramped access to emergency exits
- An evacuation plan in case of emergency or fire

ACCESS TO THE SCHOOL

Organise a site inspection of the school to ensure that it is fully accessible. Meeting the needs of a child with a neuromuscular condition may mean altering and adapting the school site.

Ramps provide wheelchair access, and step lifts (which can be used internally and externally) could also be an option (see Resource list).

An ambulant child may need handrails on steps and stairs, both inside and outside the building. Check that there are no
unnecessary obstacles blocking access to stairs. Uneven ground surfaces and mat wells could be trip hazards and cause difficulties for a wheelchair user.

Circulation 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, thereby avoiding congestion in corridors. Lunchtimes can also be very busy and it may ease any access difficulties if these pupils are first in the lunch hall.

PLA YGROUNDS
The playground needs to be assessed for accessibility and possible adaptations. Benches prevent fatigue in ambulant children by providing them with a chance to rest, and allow 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.

Consider the playground’s location, as exposed north facing sites can be windy and cold which may cause difficulties for pupils with neuromuscular conditions (see Chapter 5).

STORAGE
Think about storage space for equipment. Pupils will need to store special equipment – such as standing frames, mobile arm supports and hoists – in a safe, secure place. 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 near the school entrance.

ACCESS TO THE CLASSROOM
Ensure that there is 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.

Electric wheelchairs provide a pupil with freedom and independence. They can be quite large, particularly the adult sizes or those with tilt in space or sit to stand options, but they are very easy to manoeuvre and pupils become proficient at handling them.

A height adjustable table (see Resource list) can ensure a pupil’s comfort by supporting his or her arms and assisting hand function. Upper limb weakness is associated with many neuromuscular conditions, so it is essential that table and tray height are correct, allowing the pupil to rest his or her elbows on a supportive surface. This stabilises the upper limb girdle, maximising upper limb and hand 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 aid upper limb function. An occupational therapist or advisory teacher can help by assessing a pupil’s level of functioning.

ACCESS TO THE DINING HALL
Some pupils with neuromuscular conditions can be very self-conscious at lunchtime if they cannot eat independently due to upper limb weakness. Many children are too embarrassed to ask for assistance or do not want help eating in front of their friends. This means the pupil may have an inadequate and/or poor diet.
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? This could be difficult for children with upper limb weakness.

A height adjustable table may be needed for the pupil’s comfort and to assist hand function when eating. Specially adapted cutlery and crockery can also help pupils be independent, although they may be reluctant to use them in front of others.

Some pupils may prefer to eat in private – and this will need to be arranged – but still sit and socially interact with friends during lunchtime.

Every situation is unique but careful discussion with the pupil and parents will help find a workable solution. An occupational therapist or advisory teacher can also offer advice and support.

**EVACUATION ISSUES**

A full risk assessment, and health and safety review, is recommended to develop emergency evacuation procedures for pupils with disabilities. All staff should be aware of the evacuation procedures for pupils who are wheelchair users and the pupils, themselves, should also be informed as they may feel vulnerable and anxious about their personal safety in an emergency situation.

All emergency exits should be checked for accessibility. Although lifts should not be used in the event of a fire, an Evacuation Chair can overcome any difficulties (see Resource list).

The Fire Safety Officer, from the local fire service, can offer advice and help with safety and evacuation procedures.

### 6.2 EQUIPMENT

**WHEELCHAIRS**

It is important to establish which type of wheelchair a pupil will be using.

Some pupils may use a self-propel wheelchair for short periods of time. This helps them conserve energy and allows them to travel longer distances. Other pupils will use an electric powered chair full-time. If a child is using a manual wheelchair (one that can be pushed), staff need basic training on how to collapse the chair and use it safely.

Extra cushions and supports can be used with a wheelchair and it is essential that staff involved with the care of a pupil know where these are placed, as they help maintain a good seating posture. Information on this should be available either from the issuing authority, the pupil’s parents, physiotherapist or occupational therapist.

A pupil using an electric powered indoor-outdoor wheelchair (EPIOC) will have passed a safety test but it is essential, nevertheless, to encourage the child to act responsibly in school. A wheelchair proficiency scheme organised by the Royal Society for the Prevention of Accidents (see Resource list) promotes safe use of powered wheelchairs and could be incorporated into a PE or games lesson. Other schemes may also be available locally through Disabled Living Centres, wheelchair services or occupational therapy and physiotherapy departments.

Storage space for equipment that is not continuously in use (for example, standing frames or manual wheelchairs) needs to be available.

Parents should be alerted if staff notice a fault with any equipment the child uses, so they can inform wheelchair services of
necessary repairs. Some pupils may have a privately owned electric wheelchair, which is funded by their family or a charity. Repair and maintenance of these chairs is the sole responsibility of the family.

When a child is being transported in his or her wheelchair, ensure the vehicle’s clamping and security system complies with current safety standards and that restraints are worn and fitted correctly.

Many neuromuscular conditions weaken the neck muscles, and children can be at higher risk of whiplash injuries. It is vital that a headrest is fitted to the child’s wheelchair whenever he or she is travelling to prevent neck injuries should the vehicle brake suddenly.

**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). Standing frames are prescribed by the pupil’s physiotherapist as part of the child’s physical management programme.

If a standing frame is used in school, staff will need guidance from the physiotherapist on its usage.

How and when to introduce a standing frame into the timetable needs to be sensitively planned and managed. It is essential that activities are provided for the child while he or she is standing and, ideally, the frame should be used when other pupils are also standing. Many standing frames have trays or can be placed next to a height adjustable table to enable good hand function.

**SPECIAL SEATING**

Weakness of the trunk muscles in pupils with neuromuscular conditions can cause problems with the spine (see Chapter 5), so special consideration should be given to the seating position of these children. Some pupils will need a different school chair 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 children will have seating inserts in their wheelchairs, which provide postural support and prolong functional ability. They may also have special cushions to aid comfort and prevent pressure problems. Certain wheelchair seating systems will have a safety harness. This should always be worn as it helps the pupil’s postural control.

Staff need to be aware of the correct seating position for the pupil, especially if they are involved with transferring and handling him or her. Specialist teaching and therapy staff can offer advice and help staff feel more familiar and confident with the equipment.

An occupational therapist or physiotherapist, 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 and his or her muscle strength changes.

**HEIGHT ADJUSTABLE TABLE**

A pupil needs to be seated well to maximise his or her upper limb function. He or she 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 (see Resource list). If pupils choose to work on their wheelchair tray, ensure it is big enough for workbooks, keyboards and recording equipment.
HOISTS/SLINGs
Special equipment is needed to safely transfer a pupil. An appropriately trained professional should carry out a full moving and handling assessment. A method of hoisting the pupil is most likely to be recommended.

There are two main types of hoists:
- **Mobile hoists**, which can be moved from one location to another. They can be electric or manually operated and will require their own storage space.
- **Tracking hoists**, which are electrically operated, and use a fixed tracking system. They are especially recommended for toileting and 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. A one-piece sling designed specifically for people with neuromuscular conditions (often referred to as ‘the md sling’) is available from most specialist manufacturers. It 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.

A pupil may require different slings as his or her condition changes. Schools will need at least two slings so they can be regularly laundered.

A full description of all aspects of hoisting is included in the Muscular Dystrophy Campaign’s *Adaptations Manual*.

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 staff should have training in the use of equipment and this should be an essential component of the induction process (See Chapter 2).

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. Indoor/outdoor electric wheelchairs are heavy so ensure that those used by pupils do not exceed the maximum weight the lift can carry. 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 steps (see Resource List).

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

TOILET AND PERSONAL HYGIENE REQUIREMENTS
A toilet or washroom 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.

Many 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. Female urinals (uri-bags) are available on prescription. They are small and compact, and can be very helpful, particularly on school trips. See www.uribag.com.

Part M of the building regulations states that an accessible toilet should be a minimum of 1500 x 2000mm. While these measurements are adequate for adult public toilets, schools will need more space and perhaps a changing and physiotherapy area.

A full and comprehensive guide on building adaptations – with in-depth measurements and information – is available in the Adaptations Manual. The Manual includes advice on key design criteria, as well as fittings and equipment which are:

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 with arm weakness, who cannot transfer out of their wheelchairs and need to be hoisted

2. **Suitable for the needs of carers.**
   
   EC rules have recognised the importance of protecting the carer’s back.

3. **Able to withstand regular and heavy use** (for multi-use facilities).
   
   The facilities must be robust and suitable enough for the heaviest and most disabled people.

4. **Attractive.**
   
   The equipment should be attractive and easy to clean.

5. **Good value for money.**
   
   The cheapest equipment is not always the best buy. The most expensive equipment often proves more economical in the long term.

   An occupational therapist should be involved with 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 (see Resource list).

   Consider not only the size and layout of the toilet, but also how it is accessed from an outside corridor.

   The following layouts from the Adaptations Manual, offer examples of appropriate facilities for schools.

   School bathroom facility with a room size 3700 x 3115mm, incorporating the following features:

   - space on both sides of the toilet for wheelchair and carer access
   - sideways basin movement to within reach of the toilet
   - movement of supportive products for individual needs
   - turning circle of 1700mm, to allow complete turning of a large mobile hoist or wheelchair
   - shower chair with space away from the corner for assisted showering which can be used independently left or right handed
   - height-adjustable bath
   - Pressalit Care shower/changing bench
TRANSPORT

Pupils with neuromuscular conditions who receive transport to and from school will need an adapted vehicle. For wheelchair users this will mean travelling in wheelchair accessible vehicles with ramps or tailgate lifts. These must conform to safety standards and have secure, well-maintained anchorage/clamping systems which fix the wheelchair in place.

A headrest should be attached to the pupil’s wheelchair when travelling, to prevent whiplash injuries should the vehicle suddenly stop. Headrests also help maintain head balance in pupils with severe neck muscle weakness. Safety harnesses should always be secured and worn correctly as they help weak pupils maintain postural balance.

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 changes.

All the above points need to be considered when planning school trips.

Pupils with neuromuscular 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 a neuromuscular condition will need accessible transport to participate in, and benefit from, after-school clubs and activities.
The Special Educational Needs Code of Practice encourages schools to use a graduated approach in meeting pupils' needs and enabling them to access the curriculum.

If staff are concerned that a child may have special educational needs they should talk to the parents and discuss what action the school is considering.

Once a school has identified that a pupil has special educational needs, the teachers and SENCo should devise interventions to support the pupil (in addition to those already in the school curriculum).

The school may intervene if the pupil:

- is making little or no progress, even when teaching is targeted at his or her identified area of weakness;
- is finding it difficult to develop literacy and numeracy skills;
- has persistent emotional and behavioural difficulties which are not resolved by the school’s usual behaviour management techniques;
- has physical or sensory difficulties and, even though specialist equipment is provided, still makes little or no progress;
- has communication and/or social interaction difficulties and, despite the provision of a differentiated curriculum, continues to make little or no progress.

The school must decide what form of intervention is most appropriate for each pupil by assessing how the current strategies being used to meet the pupil’s learning needs could be more effective. During this process the pupil is described as being at School Action on the graduated approach.

An important part of School Action is collecting and seeking all known information about the pupil from people involved with him or her. This information will provide the basis for planning appropriate interventions and the SENCo should facilitate the process of collection. All collected information should be added to the pupil’s individual record in case a statutory assessment is requested in the future.

An Individual Education Plan (IEP) or a Group Education Plan should be drawn up to include specific targets based on the pupil’s areas of need. This plan should be monitored carefully and reviewed at regular intervals. Parents should be consulted about its contents and management and kept fully informed of the action being taken to help their child, and any outcomes.

If, despite the IEP, a pupil still does not make progress then the school can seek help from outside agencies such as Educational Psychology Services or Special Educational Needs Support Services. When outside agencies provide advice to the school for a specific pupil, that child is described as at School Action Plus. It is good practice for a school to seek permission from the pupil’s parents for external agency involvement.

When considering the progress of a pupil with a neuromuscular condition, the following areas should be considered (whether or not there is a statement):

- How the child’s physical condition is affecting his or her learning/mobility;
- How the situation is being monitored, recorded and reviewed;
- Is the SEN Code of Practice being followed (School Action 5.43)?
- Are multi-agency meetings called as and when necessary?
- Requesting help from outside agencies through School Action Plus (5.54);
- Should the school request a statutory assessment (5.62)?

### 7.2 STATUTORY ASSESSMENT — THE LEGAL FRAMEWORK

“The special educational needs of the great majority of children should be met effectively within mainstream settings through Early Years Action and Early Years Action Plus or School Action and School Action Plus, without the LEA needing to make a statutory assessment. In a very small number of cases the LEA will need to make a statutory assessment of special educational needs and then consider whether or not to issue a statement.” SEN Code of Practice, Chapter 7.

An increasing number of LEAs in England and Wales are following Government advice and delegating all education funding into schools. It is likely, therefore, that there will be fewer statements of special educational needs by LEAs in the future. However, some LEAs believe that the process of a statutory assessment and review of the statement safeguards the rights of the child. Even in LEAs that no longer issue statements for most children with special needs, pupils with neuromuscular conditions continue to be statemented to ensure their changing needs are met.

A pupil can be referred for a statutory assessment by:
- Parents
- A school or educational setting
- Another agency involved with the child’s care, such as medical or social services

**REQUESTING A STATUTORY ASSESSMENT**

The request for a statutory assessment is made to the LEA and each child must be considered on an individual basis. On receiving the request the LEA must, under section 323(1) or 329A(3) of the Education Act 1996, issue a notice and:
- Write to parents informing them that the LEA is considering whether or not to make a statutory assessment;
- Set out for parents the procedures for a statutory assessment if it is deemed to be necessary;
- Name an LEA officer who can give the parents more information;
- Inform the parents of their right to present written and/or oral evidence to the LEA on why they believe their child should or should not be assessed. (The LEA must set a time limit for receipt of parental views, not less than 29 days.);
- Encourage parents to submit evidence, stressing the importance of their contribution;
- Give parents information about the local Parent Partnership Service which can provide details of other sources of independent advice such
as regional mediation services, voluntary organisations and a local support group;

- Ask the parents (if the LEA decides to proceed with a statutory assessment) whether they would like the LEA to consult anyone else, in addition to the professionals it will approach for educational, medical, psychological and social services advice;
- Inform parents that any private advice or opinions they have, or can obtain, will be taken into account.

The LEA must comply with a parental request for statutory assessment unless:

- The LEA has already made a statutory assessment within six months of the date of the request;
- The LEA concludes, after considering all the information, that a statutory assessment is not necessary. This decision must be made within six weeks of the request being received.

The LEA should consider the case for statutory assessment of a child’s special educational needs when the evidence before it suggests that the child’s learning difficulties have not responded to school interventions or advice from external specialists, and he or she may require special educational provision which cannot be supplied using available resources.

If the LEA refuses to carry out a statutory assessment the parents can appeal against the decision at the Special Educational Needs and Disability Tribunal (SENDIST). LEAs must ensure that parents are aware of their right of appeal and the time limits for lodging such an appeal. LEAs must also ensure that parents are informed of the availability of regional mediation services such as Parent Partnership Services and local disagreement resolution agencies.

**MAKING A STATUTORY ASSESSMENT**

If an LEA decides to make a statutory assessment, it must seek advice from education services, medical officers, psychologists and social services plus the pupil’s parents and any additional professionals they wish the LEA to contact. Where appropriate, the LEA will also seek the views of the child. Responses should be submitted within six weeks.

Once the LEA has received the advice, it then decides whether to issue a statement of special educational needs to make provision for the child. This decision must be made within 10 weeks of serving the notice, under section 323(4) or 329A(7) of the Education Act 1996.

If the LEA decides to issue a statement then, within two weeks of this decision, a proposed statement must be sent to the parents, along with the advice received during the assessment. It is also good practice to send copies of the proposed statement to all those who contributed advice.

If the LEA decides not to issue a statement it is good practice to issue a note in lieu of a statement.

In summary, parents should receive written notification of the outcome of the statutory assessment within 12 weeks of the start of the process and 18 weeks after the initial request for assessment.

There may be circumstances which prevent normal timescales from being met, such as school holidays or missed medical appointments. The LEA should explain the circumstances for delay to parents.

**STATEMENT OF SPECIAL EDUCATIONAL NEEDS**

A statement should clearly state what provision is required to meet each of the child’s identified needs.

In some cases, a school will require extra resources to provide for all the needs specified in a pupil’s statement. The LEA may provide monies for this from central funds or delegate additional funding to the school.
ANNUAL REVIEWS

The aim of the annual review is to ensure that parents, pupil and professionals regularly assess whether the objectives and provision set out in the statement are still relevant and effective.

ARRANGING AN ANNUAL REVIEW

The LEA must write to schools two weeks before the beginning of each term, listing all pupils requiring an annual review.

The school must invite to the annual review:
- Parents
- Social worker and residential care worker (or foster carer if the child is looked after by the local authority)
- Relevant teachers
- An LEA representative
- Anyone else specified by the LEA
- A representative from Connexions (for pupils in year 9 and above)

It may also be appropriate to invite educational psychologists, representatives from health and social services, and any other professionals involved with the pupil.

Prior to the meeting, the head teacher should request written views from all those invited. The school should also ensure that the pupil’s views are recorded. These reports must be circulated to those attending the meeting at least two weeks before the date of the review.

There are four parts to an annual review:
- Collection and collation of information
- Annual review meeting
- Head teacher’s report
- LEA review of the statement, in the light of information received, and decision whether to amend the statement

The meeting should consider the pupil’s development over the past year in relation to each identified special educational need, and his or her progress towards meeting the objectives in the statement. The meeting must then make recommendations to the LEA based on whether:
- The statement is still appropriate
- The pupil’s special educational needs have changed
- The placement is still appropriate

If there is a difference of opinion at the meeting, then all views should be recorded and sent to the LEA. The LEA must then decide whether the statement is still appropriate, based on the evidence submitted at the annual review. If the statement is no longer appropriate it must be either amended to reflect changing needs or ceased.

7.3 THE SPECIAL EDUCATIONAL NEEDS AND DISABILITY ACT 2001

The Special Educational Needs and Disability Act 2001 gives pupils a greater right to mainstream education. It also extends and amends the Disability Discrimination Act 1995 (DDA) to cover all aspects of education and prevent discrimination in access for pupils with disabilities.

The duties in the DDA – to meet the special educational needs of individual children – dovetail those that exist as part of the SEN framework. Children with a disability have special educational needs if they have any difficulties accessing education and/or if they need any special educational provision, additional to or different from what is normally available.

Legislation defines disability discrimination as:
- Treating disabled pupils (or prospective pupils) less favourably, for a reason relating to their disability, without justification
- Failing to take reasonable steps to ensure that disabled pupils (or prospective pupils) are not placed at a substantial disadvantage, without justification

The two key disability discrimination duties identified are:
- Not to treat disabled pupils less favourably
- Take reasonable steps to avoid putting disabled pupils at a
substantial disadvantage (known as the reasonable adjustments duty)

Reasonable adjustments may require:
- Amending policies, procedures or practices
- Ensuring that staff are aware and adequately trained
- Ensuring that facilities are in place

The reasonable adjustments duty is limited by a number of considerations. The responsible body is not required to provide auxiliary aids and services (as these can be provided through the SEN framework) or make alterations to the physical features of the school (these will be covered through planning duties).

Planning duties place requirements on LEAs and schools to draw up accessibility strategies and plans, respectively. These should aim to increase access to physical environments, the curriculum and information.

LEAs must produce a strategy of how this will be developed across the authority and the school’s accessibility plan will be assessed during Ofsted inspections.

The planning duties also update the requirements of government bodies to provide information in their annual report about arrangements for pupils with disabilities.

**PHYSICAL ACCESS**

Funding for developing direct physical access is available from the Schools Access Initiative, part of the Standards Fund. Each LEA decides how to spend this money within the ‘accessibility remit’. It is accepted that some schools, because of the building layout, will never be fully accessible. These schools must, however, develop inclusive strategies and any new buildings should be fully accessible.

**CURRICULUM**

All aspects of the curriculum need to be considered in developing a more inclusive approach. This could mean using specialist laboratories or purchasing equipment to improve access in a particular curriculum area.

**INFORMATION**

Signage around the school and information sent from school to parents and other stakeholders must be accessible.

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**7.4 SCHOOL GUIDELINES AND POLICIES**

All schools have a range of policies and procedures; some are formal, written policies and others are not. Below are some specific policies which may need to be monitored and adapted for pupils with neuromuscular conditions.

**CHILD PROTECTION POLICY**

A named person in every school is responsible for child protection policy. Disabled young people are recognised as being at higher risk of abuse. Staff should report any concerns they have about abuse, and disclosures made by a young person should be treated seriously and reported to the named person.

Those young people whose personal care is undertaken by others are at a higher risk of abuse and may fear repercussions if they raise their concerns.

**DISCIPLINE POLICY**

Although all schools have a discipline policy, its ethos is individual to schools and often tailored to the needs of pupils. A whole school policy is uniform throughout the school, and rules and guidelines are often displayed in classrooms to ensure that all pupils are aware of them.

Like all policies, a discipline policy should be applicable to everyone in the school. Staff sometimes find it difficult to apply a discipline policy to a pupil with...
disabilities. This can cause behavioural problems in the child and make him or her feel isolated and different. Some forms of punishment are, however, more appropriate than others.

Young people with neuromuscular conditions may be facing difficult and challenging changes in their lives. These changes can manifest themselves in school as behavioural difficulties and it may be necessary, as with any pupil, to investigate the cause of the behaviour, and liaise with parents and/or identify a mentor for the pupil (see Chapter 4).

ANTI-BULLYING POLICY

An anti-bullying policy should be consistent and apply to everyone. This type of policy is most effective when it offers clear guidance and provides practical strategies to deal promptly with incidents.

Pupils with limited mobility may be more vulnerable to verbal and physical abuse, but bullying can be reduced with good organisation and appropriate resources.

Practical strategies include:

- Managing movement around the school to reduce the areas where bullying could occur
- Educating pupils on how a bully operates
- Making all pupils aware of how the school responds to bullying
- Using drama or PSHCE work to highlight bullying
- Providing peer group support systems
- Encouraging vulnerable pupils to speak out should an incident occur
- Providing safe sanctuary areas during unstructured periods of the day
- Educating pupils via programmes (for example, Kidscape)
- Maintaining good quality record keeping
- Giving a clear message to children about the serious implications of bullying for physically vulnerable pupils
- Making all staff aware of the particular issues for children in wheelchairs (being taken where they don’t want to go, for example, or having the motor element of their wheelchair turned off when they are unable to turn it back on)
- Involving parents in a constructive way

POSITIVE BEHAVIOUR POLICY

A code of behaviour should apply to all school pupils – not just those who are able-bodied – and ensure their well-being. Where a positive behaviour policy is in place, the reward scheme should be wide enough to encourage participation among all pupils.

PERSONAL, SOCIAL, HEALTH AND CITIZENSHIP EDUCATION POLICY

Schools need policies to cover PSHCE issues, including sex/relationship education and drugs education. A school might wish to consider developing a policy specifically to address the needs of children with physical difficulties.

SCHOOL UNIFORM POLICY

When developing a school uniform policy, consider pupils who have special needs and amend the school dress code to reflect these differences.

‘Jogger bottoms’ are recommended for pupils sitting in wheelchairs for a large part of the day or those who need assistance with toileting. The elasticated waists aid independence and helps with physical management.

Girls in wheelchairs often choose trousers to protect their dignity when being transferred from one position to another.

Specialist footwear may be recommended to accommodate splints or improve gait. This is not always available in appropriate colours.
Two pieces of legislation affect the moving and handling of pupils in school: the Health and Safety at Work Act 1974 recommends that a moving and handling policy is developed to cover those who need help (children with special needs, for example) and those who will be doing the moving and handling; the Manual Handling Operations Regulations 1992 place a legal obligation on employers and employees to avoid lifting wherever possible, when moving and handling objects or people.

Most children with a neuromuscular condition will need to be moved and handled as they become unable to support some or all of their weight. They may need help with toileting, for example, or altering their position in the wheelchair, or require assistance transferring to therapeutic equipment, such as a standing frame.

Schools need to plan ahead and develop a moving and handling strategy to address this need and ensure pupils are safely transferred.

When a pupil requires moving and/or handling, the school should carry out a risk assessment to identify the correct procedures. This assessment should be reviewed annually to keep up with the pupil’s changing physical ability.

**HOW TO ASSESS THE RISKS**

**Step 1:** Look for the hazards  
**Step 2:** Decide who might be harmed and how  
**Step 3:** Evaluate the risks and assess whether existing precautions are adequate or more should be done  
**Step 4:** Record the findings  
**Step 5:** Review your assessment and revise if necessary

**TRAINING**

Training should be provided for all staff involved in moving and handling pupils. The LEA can advise which agencies to approach.

**EQUIPMENT**

Health professionals can recommend aids, and moving and handling equipment, but it is the school’s responsibility to ensure it is correctly maintained.

**RISK ASSESSMENT FORMS**

Contact your LEA for risk assessment forms. Examples of joint health/education risk assessment, and moving and handling forms are provided in Appendix 1. These can be adapted for use by your school, in conjunction with your local health trust.

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1. Wakefield LEA and Wakefield West/Eastern NHS Primary Care Trust
GOOD PRACTICE GUIDELINES

- Ensure that provision/support for moving and handling is incorporated into existing health and safety policy, or becomes a separate policy.

- Identify a named individual (the person responsible for health and safety, for example) to act as co-ordinator of moving/handling concerns and policy.

- Avoid, as far as possible, moving/handling operations that put an employee at risk.

- Carry out risk assessments of all moving/handling operations and decide on the appropriate procedures for each situation (follow recommendations in 5 Steps to Risk Assessment).

- Use appropriate equipment to reduce the risk of injury to pupils and staff.

- Provide training for staff, which covers the key elements of safe handling procedure, via the LEA or an external agency.

- Always give consideration to the privacy, dignity, independence and views of the pupil being moved.

- Obtain written consent from parents which indicates their recognition and approval of the physical management of their child.

- Review procedures annually.

- Ensure that equipment is maintained and checked according to Lifting Operations and Lifting Equipment Regulations 1998 (Nos. 9 and 10).

- Review emergency/fire drill procedures and consult with the local fire service, if necessary.

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9.1 PARTNERSHIP WORKING
MAINSTREAM & SPECIAL SCHOOLS

An LEAs specialist teaching service offers a variety of support to children with neuromuscular conditions in mainstream schools, although how this support is organised can vary between authorities.

Some LEAs have a specialist team, often known as the Physical Difficulties Support Service, while others co-ordinate outreach work between special and mainstream schools. The form of this outreach partnership is likely to be unique to the LEA and can take a variety of approaches. It may, for example, encourage staff from mainstream schools to look at systems in special schools or staff from special 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 LEAs SEN department should be the first point of contact for any school which has pupils with a neuromuscular condition 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 conditions¹, 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.

All hospital teaching units are in the process of becoming schools and, as such, will be subject to Ofsted inspections.

One of the most important roles of the hospital teacher is providing 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 and 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 home tuition a week.

¹. Access to Education for Children and Young People with Medical Needs, DfES, 2001
9.3 RESPITE/HOSPICE CARE

RESPITE CARE
Depending on whether they meet the local authority's eligibility criteria (usually linked to the severity of the child's disability), a family 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.

RESPITE CARE
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.

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 so that the parents can have an uninterrupted night's sleep on a regular basis.

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, 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 its own carers, rather than use those provided by the local authority. In this case, it will receive payments directly from its local authority to fund the care.

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

Children's hospices offer care and support to children with a short life expectancy and their families. They provide respite care, emergency care, symptom control and terminal care. The hospice is a 'home from home', catering sensitively to the family's individual needs.

Telephone support is available 24 hours a day and care can also be provided in the home, if required.

When a child dies, bereavement support is available to parents, siblings and grandparents for as long as it benefits the family.

Professionals working with families may also contact the hospice for help and advice. Further information is available at www.childhospice.org.uk.
The aim of transition planning should be to prepare young people for employment, training or further education. It should also encourage them to contribute to community life and become independent and autonomous. Developing social relationships is important in helping pupils make their own decisions about the future.

**CHECKLIST**

Transition planning should:

- Ascertain the young person's views and aspirations, and how these can be met
- Determine what information is required to help the pupil make informed choices and decisions
- Help parents support their children through the process
- Ensure the curriculum meets physical/health/educational aspirations
- Determine whether work experience is appropriate and help facilitate a placement
- Ensure the pupil has appropriate life skills
- Be flexible enough to accommodate exam arrangements and early college placement

Schools should invite to the year 9 annual review meeting:

- Pupil
- Parents
- SENCo
- Relevant members of teaching and support staff
- Social services
- Staff from Connexions
- LEA officers, educational psychologists and advisory teachers, as appropriate
- Local college staff, if necessary
- Paediatric/medical services

**10.2 MAKING CHOICES**

Although they have the right to free education up until the age of 19, young people with neuromuscular conditions will need to decide whether or not to continue with their education. In making this decision, they should have the same educational choices as other pupils: stay at the school they currently attend, move to another school or sixth form, go to a further education or residential college, aim for higher education or undertake open learning. To make an informed choice, the young person may also need help and advice about work, independent care support and direct payments.
Connexions is a support service for young people in England between 13 and 19 (or between 13 and 25 if the young person has a disability). It offers advice, guidance and personal development opportunities in further/higher education, training and employment, and helps young people make a smooth transition to adulthood.

Connexions personal advisers work closely with schools and young people.

By Year 9 they have usually contacted pupils with special educational needs and their families. Prior to meeting a young person they will have received information from the school, but will also expect the pupil and his or her family to contribute. Personal advisers also attend transition planning meetings to help ensure that agreed strategies are implemented to meet goals.

The same procedures apply to a young person attending a residential school but are likely to be carried out jointly between the personal adviser working with the school and another in the home area. If a pupil wishes to stay at school or attend a residential college then these options should be explored with the personal adviser at the earliest opportunity.

Support from a personal adviser continues after the young person has made the transition to college, sixth form or a work based learning provider.

The next major transition point usually occurs at 18 or 19 and personal advisers should ensure that those young people with more severe difficulties can access an appropriate package of support, whatever their move may be. Personal advisers can offer advice and support for those individuals who wish to move on to higher education, employment and/or training. If they have not already been contacted, the personal adviser may involve social services and a range of other agencies at this stage.

www.connexions-direct.com

There are many sources of help available for young people some of which are specifically aimed at children with disabilities:

- The Family Fund has a website for young people with disabilities as well as parents, carers and professionals. It includes advice on finance, housing, learning, work and a directory of useful organisations. www.after16.org.uk.

- Department of Health – www.gov.uk-transition – see ‘Getting it Right For Young People’

- The National Bureau for Students with Disabilities (Skill) promotes opportunities in education, training and employment for young people with disabilities. www.skill.org.uk.

- Advisory Centre for Education (ACE) is an independent organisation offering advice to parents about state education in England and Wales for 5-16 year olds. www.ace-ed.org.uk.

- A care manager or social worker at the local social services (or social work) department.

- Connexions (see below)
APPENDIX 1 – RESOURCES FOR TEACHERS

1. INFORMATION COMMUNICATION TECHNOLOGY – SOLUTIONS FOR PUPILS WITH MUSCULAR DYSTROPHY

2. PUPIL SUPPORT TIMETABLE

3. INDIVIDUAL HEALTH CARE PLAN

4. RISK ASSESSMENT AND INDIVIDUAL MOVING AND HANDLING CARE PLAN

   SECTION A
   1 — PERSONAL PROFILE
   2 — RISK ASSESSMENT OF TASKS
   3 — RISK ASSESSMENT SUMMARY
   4 — TASK ANALYSIS SUMMARY

   SECTION B (DETAILED ASSESSMENT)
   — RISK ASSESSMENT FORM

All these materials can be photocopied or downloaded from www.muscular-dystrophy.org
INFORMATION COMMUNICATION TECHNOLOGY – SOLUTIONS FOR PUPILS WITH MUSCULAR DYSTROPHY

This is not a definitive guide as new technology regularly appears on the market. You may choose to stick to something you know and can use with minimal support and training.

As their physical condition deteriorates, some pupils will feel more in control using pen and paper. Be guided by what they tell you is useful.

<table>
<thead>
<tr>
<th>Writing aids</th>
<th>Supplier</th>
<th>Price</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Desktop PC</td>
<td>Widely available</td>
<td>£350 and upwards</td>
<td>Solid&lt;br&gt;Easy to upgrade&lt;br&gt;Does not need to be moved once in correct position&lt;br&gt;Good for home use&lt;br&gt;Full range of software available&lt;br&gt;A miniature keyboard can be attached</td>
<td>Takes up room&lt;br&gt;Not portable&lt;br&gt;Needs to be on an accessible surface</td>
</tr>
<tr>
<td>Laptop</td>
<td>Widely available</td>
<td>£400 and upwards</td>
<td>Portable&lt;br&gt;Mains connection not required&lt;br&gt;Full range of software available&lt;br&gt;Alternative ‘mice’ and keyboards can be attached</td>
<td>Vulnerable to damage&lt;br&gt;Designs and models regularly altered and superseded&lt;br&gt;Battery life ranges from 30 minutes to four hours&lt;br&gt;Batteries often fail through poor management&lt;br&gt;May need repositioning when moved&lt;br&gt;May not be safe to use on wheelchair tray</td>
</tr>
<tr>
<td>Alphasmart</td>
<td>Inclusive&lt;br&gt;Don Johnston&lt;br&gt;Special Needs&lt;br&gt;www.donjohnston.co.uk&lt;br&gt;Key Tools&lt;br&gt;www.keytools.com</td>
<td>Inexpensive compared to laptop (case, win cable and angled rest need to be ordered separately)</td>
<td>Available with ‘Smart Applets’ such as Co-Writer&lt;br&gt;Lightweight&lt;br&gt;Simple to use&lt;br&gt;Impossible to lose files&lt;br&gt;Easy to manage files (delete and transfer)&lt;br&gt;Can print direct from machine&lt;br&gt;Dedicated word processor&lt;br&gt;Transfers files directly to PC&lt;br&gt;Uses standard 3 x AA batteries (no need to charge)&lt;br&gt;Robust keyguard available&lt;br&gt;Infra-red version available</td>
<td>One size display&lt;br&gt;Small screen&lt;br&gt;No tilt, requires separate angled rest (£25 – 30)&lt;br&gt;Limited to eight files&lt;br&gt;Price of cases, rests and software can almost double the cost</td>
</tr>
<tr>
<td>Writing aids</td>
<td>Supplier</td>
<td>Price</td>
<td>Advantages</td>
<td>Disadvantages</td>
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<tr>
<td>DANA</td>
<td>Don Johnston Special Needs</td>
<td>Slightly more expensive than Alphasmart</td>
<td>Simple to use, Lightweight, Difficult to lose files, Can print direct from machine, Larger screen than Alphasmart, Some formatting possible, Touch screen and stylus pen, Palm-top technology – additional software available, 25 hour battery life, batteries can be re-charged quickly through PC, Screen can be changed from landscape to portrait, Hand doesn't have to move very far to write (letters written on top of each other), Memory cards replaceable, USB ports for printer and data transfer, Infra-red, easy printing, Bridges gap between Alphasmart and PC, Easy to learn keyboard shortcuts</td>
<td>Stylus pen is easy to lose and hard to pick up and hold, Requires file management skills, Time needed to get used to it, Fiddly menus</td>
</tr>
<tr>
<td>Tablet PC</td>
<td>Widely available</td>
<td>£800 – 1500</td>
<td>Lightweight, Full capability of PC, Infra-red data transfer, Screen can be changed from landscape to portrait, On-screen keyboard and writing pad, Freehand drawings can be inserted into word processor, Battery life 6 – 8 hours, Alternative mouse and keyboard can be attached, Stand can be used as a screen</td>
<td>Needs training to use, Writing pad not fluid and needs practice, Small screen, Requires USB peripherals</td>
</tr>
<tr>
<td>Miniature keyboard AT/PS2/USB/ Wireless/Infra-red</td>
<td>Widely available CPC</td>
<td>£49 – 89</td>
<td>Same size as laptop keyboard, Easily positioned with laptop</td>
<td>No separate keypad for numbers</td>
</tr>
<tr>
<td>Web cams (Web cams are now built into laptops)</td>
<td>Widely available</td>
<td>Low cost</td>
<td>Can be used:  ■ with microscopes and telescopes  ■ for still images  ■ for video conferencing over the Internet (with MS Messenger)  ■ so pupils can chat with friends while e-mailing (Could help to alleviate isolation during later stages of the condition.)  ■ around the school to allow pupils to see what's happening in inaccessible rooms/buildings</td>
<td>Requires good ICT skills and imaginative staff</td>
</tr>
<tr>
<td>Flexible arms to hold webcams</td>
<td><a href="http://www.flexstand.com">www.flexstand.com</a></td>
<td>Low cost</td>
<td>Helps position camera at 'odd' angles. Pupils can view images through their laptops and tell support staff what they want to photograph</td>
<td>Requires help to position the arm</td>
</tr>
<tr>
<td>Writing aids</td>
<td>Supplier</td>
<td>Price</td>
<td>Advantages</td>
<td>Disadvantages</td>
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<tr>
<td>Digital cameras</td>
<td>Widely available</td>
<td>Low cost</td>
<td>Use on desktop tripod connected directly to a laptop to operate remote capture Use a remote (up to 12 feet) handheld switch</td>
<td>Pupils may be unable to position camera as their condition deteriorates. Remote switches need to be directed at camera</td>
</tr>
<tr>
<td><strong>Software</strong></td>
<td></td>
<td></td>
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<tr>
<td>Clicker</td>
<td>Crick software <a href="http://www.cricksoft.com">www.cricksoft.com</a></td>
<td>£120</td>
<td>Helps reading, comprehension, vocabulary, spelling. Structured writing tasks prompt memory. Speeds up writing as pupil can input whole words and phrases. Grids available from Cricks website at no cost</td>
<td>Requires LSA/teacher support to produce grids. Staff not familiar with the programme often fail to recognise its potential</td>
</tr>
<tr>
<td>ClozPro</td>
<td>Crick software</td>
<td>£90</td>
<td>Easy for support staff to use Text can be imported from a word processor and activities designed for individual students. Support for comprehension and reading. Cuts down typing time</td>
<td>Requires word processing knowledge and some computer skills to make best use of software</td>
</tr>
<tr>
<td>2Investigate (incorporating Junior Video Toolbox)</td>
<td>2Simple <a href="http://www.2simple.com">www.2simple.com</a></td>
<td>£39 SU</td>
<td>Simple to use. Access to paint, graph and database software</td>
<td>Aimed at Key Stage 2 pupils (but ideal for those with learning difficulties)</td>
</tr>
<tr>
<td>Access Maths 4</td>
<td>ACE Centre, Oxford</td>
<td>Contact Ace direct</td>
<td>Geometry and drawing programme for pupils of all physical abilities. ‘Measuring’ with on-screen ruler</td>
<td>Support and teaching staff need to learn how to use the programme Requires good mouse control</td>
</tr>
<tr>
<td>MyTobii</td>
<td>SmartBox Ltd</td>
<td>£12,000 (but price will drop)</td>
<td>The MyTobii system allows the user to communicate and control a PC, just by looking at the screen. Allows people with very limited movement who previously had no workable means of input full control of a PC</td>
<td>Very expensive</td>
</tr>
<tr>
<td>Dasher</td>
<td>Cambridge University</td>
<td>Free</td>
<td>Allows user to type 20-30 words a minute with just minimal mouse movement</td>
<td></td>
</tr>
<tr>
<td>USE</td>
<td>Madhouse Software</td>
<td>£490</td>
<td>Assistive access software aimed at people with very limited movement that relies on sophisticated scanning and switch use.</td>
<td>User needs support to customise grids</td>
</tr>
<tr>
<td>Writing aids</td>
<td>Supplier</td>
<td>Price</td>
<td>Advantages</td>
<td>Disadvantages</td>
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<tr>
<td>Co-writer</td>
<td>Don Johnston Special Needs</td>
<td>£149 SU</td>
<td>Adds word prediction, grammar and vocabulary support capabilities to any word processor or e-mail programme For each pupil or assignment, a dictionary/dictionaries are designated as the source for predicted words FlexSpell – support for struggling writers who use phonetic spelling Easy to support</td>
<td>Pupil must work between two windows One sentence at a time posted to text in word processor (could also be considered an advantage) Keyboard shortcuts cannot be used while Co-writer is running Pupils may need help setting up topic dictionaries</td>
</tr>
<tr>
<td>Voice recognition software</td>
<td>Widely available</td>
<td>£60 +</td>
<td>Speech converted to text at normal talking speed Corrections can be made</td>
<td>Good reading skills required to complete training Good knowledge of Windows needed Works more efficiently if pupils correct mistakes as they happen Requires 'boom mike' for independence</td>
</tr>
</tbody>
</table>

**Mice**

<table>
<thead>
<tr>
<th>Glide pad</th>
<th>Widely available</th>
<th></th>
<th>Common to most laptops, cursor controlled by applying light pressure with finger Can be adjusted to user's pressure Control software available to customise pads (e.g. scroll, double click, click and drag)</th>
<th>Can be accidentally knocked or brushed Two fingers on the glide pad cause unpredictable results (machine can crash)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tablet pad</td>
<td>Widely available</td>
<td></td>
<td>Greater accuracy Pad replicates screen (similar to touch screen) Can trace round graphics (e.g. simple maps)</td>
<td>Wired pen Mouse buttons on pad are small and can be clicked inadvertently Experienced mouse users may find it difficult adjusting</td>
</tr>
<tr>
<td>Trackerball</td>
<td>Widely available</td>
<td></td>
<td>Requires less space Greater control Available in wide range of shapes and sizes Can be programmed</td>
<td>Looks very different to conventional mouse Cheap versions tend to be unreliable</td>
</tr>
<tr>
<td>Writing aids</td>
<td>Supplier</td>
<td>Price</td>
<td>Advantages</td>
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<tr>
<td>Headpointer + software</td>
<td>Widely available</td>
<td>£200 – several hundreds</td>
<td>Accurate movements with minimal head control, using software Discreet Mouse clicks by dwelling on objects</td>
<td>Doesn't work well outside Interference possible from reflective surfaces (e.g. glass frames and jewellery) Requires additional mouse software</td>
</tr>
<tr>
<td>Ergonomic arm rests</td>
<td>View on <a href="http://www.techdis.ac.uk">www.techdis.ac.uk</a></td>
<td>£50+</td>
<td>Greater movement</td>
<td>Difficult to set up, not truly portable Difficult to keep arm comfortable</td>
</tr>
<tr>
<td>Boom mike (for use with voice recognition software)</td>
<td>Widely available</td>
<td></td>
<td>Allows independent access to PC and prevents need for headsets</td>
<td>Difficult to get in right position Needs to be high quality to work with software</td>
</tr>
<tr>
<td>USB Flashdrive</td>
<td>Widely available</td>
<td></td>
<td>Large storage capacity allows work to be transported between home and school Lightweight and small (same size as a pen) Work can be transferred between any PC (Windows ‘98 and above)</td>
<td>Pupil may not be able to use it independently Easily lost Must use ‘safe removal’ before removing from Windows XP</td>
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</table>

**Useful additional ICT skills**

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<tr>
<th>General accessibility</th>
<th></th>
<th>Refer to the accessibility options in Windows, for example, to slow the mouse speed and keyboard repeat rates</th>
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<tbody>
<tr>
<td>Virtual Learning Environments</td>
<td>If designed with accessibility for all in mind (all actions are simple and mouse clickable), these web spaces allow children with muscular dystrophy to control their pace of learning, log on to collect and post homework, see results and work collaboratively</td>
<td></td>
</tr>
<tr>
<td>Podcasts of lessons</td>
<td>Some schools are already using this functionality. It allows students to catch up on missed lessons by making the lesson available on the school website, which the student can then download to their iPod or MP3 player</td>
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# PUPIL SUPPORT TIMETABLE

**Pupil:**

**Support staff:**

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<th>MONDAY</th>
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<th>TUESDAY</th>
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<th>WEDNESDAY</th>
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<th>THURSDAY</th>
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<th>FRIDAY</th>
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</table>

- Powered chair  □ Standing frame  + Walking with rollator  ◆ Specialist chair  ★ Physical management routine

## COMMENTS

**Monday**

**Tuesday**

**Wednesday**

**Thursday**

**Friday**
INDIVIDUAL HEALTH CARE PLAN FOR _______________________

Action to be taken:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Follow-up care:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

(Following any emergency action, please inform school nurse to allow evaluation and assessment of individual care plan/school staff training needs.)

Disposal of waste: Waste must be disposed of as agreed in risk assessment. School staff must protect themselves from body fluids/products.

I understand that I must deliver _____________________________________________ personally to (agreed member of staff) and accept that this is a service that the school is not obliged to undertake.

Signature(s): ___________________________ Date: ___________________________

Relationship to pupil: ___________________________

Head teacher: ___________________________ Date: ___________________________

School nurse: ___________________________ Date: ___________________________

Copy to: parents, school, child health records

© Wakefield West/Eastern NHS Primary Care Trust
SECTION A – RISK ASSESSMENT AND INDIVIDUAL MOVING AND HANDLING CARE PLAN

<table>
<thead>
<tr>
<th>Child’s name:</th>
<th>Date of birth:</th>
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<tr>
<th>Assessment date:</th>
<th>Review date:</th>
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<thead>
<tr>
<th>Assessors</th>
<th>Name</th>
<th>Signature</th>
<th>Designation</th>
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<tbody>
<tr>
<td>1.</td>
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<td>2.</td>
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</table>

This form is only to be used and completed by those who are conversant with their local health and education authorities’ policies on moving and handling.

Q1. Is a moving and handling risk assessment required? **Yes/No**
   - If ‘Yes’, the remainder of this form should be completed.
   - If ‘No’, assessors should move on to Q2 and sign below.

Q2. Is a moving and handling risk assessment required in the near future? **Yes/No**
   - If ‘Yes’ please state review date.

Signed: Name:

Designation: Date:
MOVING AND HANDLING – PERSONAL PROFILE

Child's name: __________________________ Date of birth: __________________________

Diagnosis: __________________________ Assessment date: __________________________

Height: __________________________ Weight: __________________________

Please tick below as appropriate:

**Understanding:**
- Age appropriate
- Limited
- Not known

**Compliance:**
- Co-operative
- Unco-operative
- Unpredictable

**Level of dependence:**
- Totally dependent
- Needs assistance to transfer
- Some sitting balance
- Unable to weight bear on lower limbs

**Minimal active participation**
- Needs assistance in some situations
- Full sitting balance
- Able to weight bear in standing

**Other relevant problems:**
- Epilepsy
- Fatigue
- Fear
- Other: __________________________

- Fragility
- History of falls
- Muscle spasms
- Skin condition
- Pain
- Sensory loss

**List equipment and appliances normally used by child:**

________________________________________________________

________________________________________________________

________________________________________________________

**Hoisting:**

Has the use of a hoist been considered? Yes/No

If hoisting is inappropriate, please state reasons:

________________________________________________________

________________________________________________________

________________________________________________________

Signed: __________________________ Name: __________________________

Designation: __________________________ Date: __________________________
# MOVING AND HANDLING – RISK ASSESSMENT OF TASKS

Child’s name: ___________________________ Date of birth: ___________________________

Please comment where appropriate

<table>
<thead>
<tr>
<th>TASK</th>
<th>LEVEL OF RISK to child (tick)</th>
<th>LEVEL OF RISK to carer (tick)</th>
<th>CONTROL MEASURE to reduce risk</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>High</td>
<td>Med</td>
<td>Low</td>
</tr>
</tbody>
</table>

* To action

1. **Change of position**
   - (a) In bed
   - (b) On floor

2. **Support**
   - (a) Standing
   - (b) Walking

3. **Transfers**
   - (a) Floor < - > chair
   - (b) Chair < - > chair
   - (c) Chair < - > stand
   - (d) Floor < - > stand

4. **Mobility aids**
   - (a) Walking frames
   - (b) Trikes
   - (c) Other

5. **Special equipment**
   - (a) Standing frames
   - (b) Corner seats
   - (c) Lying boards
   - (d) Special seating
   - (e) Other

6. **Daily care needs**
   - (a) Potty
   - (b) Toilet
   - (c) Changing couch
   - (d) Shower/bath

7. **Transport**
   - (a) In/out of car
   - (b) In/out of car seat

8. **Special environments**
   - (a) Hydrotherapy
   - (b) Swimming pool
   - (c) Riding
   - (d) Other

Signed: ___________________________ Name: ___________________________

Designation: ___________________________ Date: ___________________________
## MOVING AND HANDLING – RISK ASSESSMENT SUMMARY

<table>
<thead>
<tr>
<th>Child’s name:</th>
<th>Date of birth:</th>
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</thead>
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</tr>
</tbody>
</table>

### SUMMARY OF ASSESSMENT

<table>
<thead>
<tr>
<th>Operations covered by this assessment:</th>
<th>Overall priority for remedial action (circle as appropriate)</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>Nil Low Med High</td>
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<tr>
<td></td>
<td>Remedial action to be taken:</td>
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<table>
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<tr>
<th>Locations:</th>
<th>Date of assessment:</th>
<th>Date by which action to be taken:</th>
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<tr>
<th>Assessor’s names:</th>
<th>Signatures:</th>
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1. 1. 2. 3.

### Section A – Preliminary

1. **Q1** Do the operations involve a significant risk of injury? **YES NO**
   - If ‘Yes’ go to Q2. If ‘No’ the assessment is complete. If in doubt, answer ‘Yes’.

2. **Q2** Can the operation be avoided/mechanised at a reasonable cost? **YES NO**
   - If ‘No’ go to Q3. If ‘Yes’ proceed and check the result is satisfactory.

3. **Q3** Are the operations clearly within the guidelines set out by the appropriate moving and handling policies? **YES NO**
   - If ‘No’ go to Section B (see separate sheet(s)). If ‘Yes’ go to Section C.

### Section B – See more detailed assessment (if undertaken)

### Section C – Overall assessment of risk

<table>
<thead>
<tr>
<th>Q</th>
<th>What is the overall assessment of risk of injury?</th>
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<tbody>
<tr>
<td></td>
<td>Insignificant <strong>Low Med High</strong></td>
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If not, go to Section D.

### Section D – Remedial action

<table>
<thead>
<tr>
<th>Q</th>
<th>What remedial steps should be taken, in order of priority?</th>
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**FINALLY**

- Complete the summary above.
- Decide your priorities for action.
- Compare with other moving and handling assessments.
- TAKE ACTION – AND CHECK IT HAS THE DESIRED EFFECT.
## MOVING AND HANDLING – TASK ANALYSIS SUMMARY

<table>
<thead>
<tr>
<th>Task</th>
<th>Methods to be used</th>
<th>Equipment needed</th>
<th>Date of risk assessment/ review</th>
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**Signed:**

**Name:**

**Designation:**

**Date:**

© Wakefield LEA
# SECTION B – MOVING AND HANDLING – RISK ASSESSMENT FORM

<table>
<thead>
<tr>
<th>Child’s name:</th>
<th>Date of birth:</th>
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**TASK:**

Questions to consider (If the answer to a question is ‘Yes’ place a tick against it, and then consider the level of risk) | Level of risk (Tick as appropriate) | Possible remedial action |
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<tbody>
<tr>
<td><strong>Tick</strong></td>
<td><strong>Low</strong></td>
<td><strong>Med</strong></td>
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**The task – does this involve**

- Holding loads away from the trunk
- Twisting
- Stooping
- Reaching upwards
- Large vertical movements
- Long carrying distances
- Strenuous pushing or pulling
- Unpredictable movement of loads
- Repetitive handling
- Insufficient rest or recovery time
- A work rate imposed by a process

**The loads – are they**

- Heavy
- Unstable/unpredictable
- Difficult to grasp
- Fragile

**The working environment – are there**

- Constraints on posture
- Constraints on space
- Poor floor surfaces
- Variation in levels of floors
- Hot/cold/humid conditions
- Poor lighting conditions

**Individual capability – does the job**

- Require unusual strength of repetition
- Constitute a health hazard to those with health problems
- Constitute a hazard to those who are pregnant
- Require special information or training

Signed: Name:  
Designation: Date:
APPENDIX 2 – RESOURCES FOR PARENTS

PARENTS’ CHECKLIST

All these materials can be photocopied or downloaded from www.muscular-dystrophy.org/publications
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 or special schools in your area. Senior specialist staff in these schools should advise parents about the:

- 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 neuromuscular 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. No school will be able to do everything and you may need to make hard choices. Don’t be daunted. What you are looking for is a school which your son or daughter likes and that will work in partnership with you to provide him or her with the best educational experience possible.

LOOKING AT WRITTEN INFORMATION (PROSPECTUS) ABOUT THE SCHOOL

- Does the prospectus indicate what, if any, facilities are available for disabled pupils?
- Does the prospectus welcome disabled pupils and is there space in the application form to detail your child’s special needs?

LOOKING AT THE SCHOOL BUILDINGS

You should tour the building with a senior specialist advisor at the school.

- 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 a pupil in a wheelchair?
- 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?

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 that allows him or her to use the lift independently)?

Is there privacy for toileting? Are the toilets adapted to meet your child’s needs? Is a closimat 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 move around the dining hall? Are there adjustable tables? Are the counter and cash desk at the right height? Can the dining staff hear what pupils in wheelchairs 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 in wheelchairs? 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 who are wheelchair users?

What building work is likely in the future?

**ACCOMMODATING YOUR CHILD’S NEEDS IN THE SCHOOL**

How will your child’s care and learning needs be assessed and monitored? How will you be involved in planning the provision for your child?

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 LEA or by therapists?

Can lessons be re-timetabled to take account of your child’s needs?

Are children with disabilities segregated because of support needs? Do teaching staff rely on educational support assistants 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? What is this likely to be? How many support staff are involved with each pupil? How often is this provision reviewed?
What academic needs will the educational support assistants address?

What care and support needs will the educational support assistants 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 staff, for example, monitor how fast children want to eat? Do they respect the child's instructions? Is enough 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 self-care needs, such as toileting? Do trained staff understand the need for discretion to maintain the child's dignity (respecting confidentiality, for example, by leaving the pupil alone and returning when summoned)? What happens if the child needs changing? (Some children wear pads and can soil themselves without realising it. Other children may have an accident.) Is the right equipment available?

When the educational support assistants are absent, is somebody else trained to step in?

What records will be kept for informing staff 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 enable your child to access the full curriculum?

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 educational support assistant check that homework is recorded properly? Are staff 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 an educational support assistant record the homework for them?

Will work be provided if your child is unwell for a long period? Will notes of missed lessons be available? From pupils or support staff? (LEAs provide cover which can be used for this purpose.)

SPORTS AND P.E.

Will your child have full access to P.E., including swimming? Is there an inclusive P.E. policy? Is specialist equipment available?

Will your child have an opportunity to participate in team sports with other pupils with disabilities?

What is the swimming provision at the school? Is there access to an indoor heated swimming pool with hoists and/or a warm pool, private changing area, wheel through showers? Is swimming timetabled to allow enough time to get changed? (Swimming is a particularly valuable form of exercise because mobility is easier in the water, but the school must be committed to making swimming accessible.)
INFORMATION AND COMMUNICATION (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, microwaves, talking clocks) to make technology fully accessible?

- Can the educational support assistant 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? Are staff prepared for disabled pupils at after-school activities?

- Are disabled pupils included in school trips? What transport arrangements are available?

- What support is available for residential trips? What cover is offered? Are parents expected to offer cover?

WORK EXPERIENCE

- Are there resources/funds available to facilitate work placements for pupils with disabilities (for example, provision of taxis, use of support staff as Access to Work assistants)?

- Does the school positively promote work placements to pupils with disabilities and encourage work placement contacts to consider them?

- Is a member of staff responsible for access audits/risk assessments of placement providers or do they accept assertions that premises are wheelchair accessible?

- Are the staff involved in placement development fully trained in disability awareness?

- If a work placement is not possible, are there alternative courses and units of accreditation available to your child?

HOMEWORK

- How is homework differentiated – by task or time spent? Pupils can be tired at the end of the school day and extra time does not always help.

- Is there a supervised homework club or the opportunity to do homework at lunchtimes?

PASTORAL CARE

- What is the school's anti-bullying policy?

- Will pupils be made aware of your child's needs – why some children use wheelchairs and standing frames, for example? Are pupils aware of the safety issues?

- Who is responsible for mentoring pupils facing emotional difficulties? Does the school use external sources such as Muscular Dystrophy Campaign Family Care Officers and/or outreach teams, 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 special educational needs co-ordinator in case of problems?
GETTING TO SCHOOL

☐ How long will your child be on transport in the morning? Could he or she attend later? Are there alternative methods of registration if he or she arrives late, to avoid signing a late book (for example, letting the educational support assistant sign the register)?

☐ Does the school phone parents when transport arrangements change due to emergencies, fire drills or bad weather?

SCHOOL GOVERNANCE AND PARENTAL CHOICE

☐ What criteria are there 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 special educational needs?

☐ How do you appeal if you don't get a place for your child at this school?

USEFUL READING

Help in the Classroom

The Motor Impaired Child

Taking Action! Your Child's Right to Special Education
APPENDIX 3 – MATERIALS FOR PUPILS

FOR PUPILS WITH A NEUROMUSCULAR CONDITION:

1. EVERYBODY’S DIFFERENT, NOBODY’S PERFECT (4-10 YEAR OLDS)
   Revised for UK publication by the Muscular Dystrophy Campaign Information
   Department, 2004.
   Reprinted with permission of the Muscular Dystrophy Association of the United States.

2. THINKING ABOUT YOU (11-14 YEAR OLDS)
   Extracts from DMD – On the Ball

FOR OTHER PUPILS:

3. SAME BUT DIFFERENT
   Written by Leigh Chambers

All these materials can be photocopied or downloaded from
www.muscular-dystrophy.org/publications
Everybody's different, nobody's perfect. Look around you’ll see that people can be small or tall, thin or big. Perhaps some of your friends and relatives don’t see too well and wear glasses to help them.

Maybe some of your friends break out in a rash when they eat certain foods (this is called an allergy). And I bet you've noticed that some people use a wheelchair or scooter to get around.

Well, some children can’t run as fast as others can. They get where they’re going, but it takes them longer to get there. Their legs are not so strong and they also have a harder time jumping, running, climbing stairs or just keeping up when they are playing with their friends.

This is because they have a muscle weakness and it's caused by a number of conditions – some are called muscular dystrophy. That’s what you have and that’s why you’re different.
WHAT DO WE KNOW ABOUT MUSCULAR DYSTROPHY?

We know that muscular dystrophy affects children. We know that it makes their muscles weak. We know that it is not their fault that they have it and we know that scientists are working for a cure. We also know that muscular dystrophy doesn't change your other abilities. You can still see, hear, smell, taste and talk, just like all your friends. In fact, some of the cleverest children have muscular dystrophy.

So you see, even though you may not run as fast as others, there are lots of things you can do just as well as everyone else can.

WHAT THINGS?

Well, thinking things and things you can do with your hands instead of your legs. Things like reading, drawing or games that you can play sitting down.

Hobbies, like collecting or building things (such as models), or using a computer or playing video games with your friends. Doing well at school does not depend on having strong legs. You can also be a good friend and fun to be around.

WHAT CAN YOU BE THE BEST AT?

By now you can see that everybody is different and nobody's perfect, because we are all good at some things and not so good at others.

That goes for everybody, and for you too!

You may not believe that children with muscular dystrophy can be involved in sports. Well, I know of at least one who is. Players aren't the only ones who are active in sports. There are also team managers and coaches. The boy I'm talking about is a coach/manager for a football team. He goes to all the games and is a big part of the team so they really can't do without him. I know a girl with muscular dystrophy who runs a newspaper at her school. And a boy who works as a dj spinning and mixing different sounds. All three use a wheelchair!
SO WHAT IF IT GETS HARD FOR YOU TO WALK?

WHAT ABOUT THAT?

Well, keep your legs well stretched (sometimes a physiotherapist or your parents will have to help you stretch them) and keep on walking as long as you. This will keep you on your feet longer than just saying 'oh, what's the use, it's too much trouble,' and giving up.

Don’t forget, you are a special person and should feel proud of what you can do, especially if you have to work hard to do it.

Even after it gets really hard to keep walking, there are other ways to help you take those important steps such as using splints (sometimes called orthoses).

Splints are like extra muscles, except you wear them outside your legs. They are made especially to fit and are light, comfortable and easy to put on and take off. They don’t even show when you wear them under a pair of trousers.

When you use splints your own muscles don’t have to work as hard, and they don’t get tired so quickly. With splints, you can stand, walk and do lots of things.

There are other ways of being helped when you have muscular dystrophy. Doctors can help keep you as healthy as possible, even when your muscles are weak. Physiotherapists can help you do your exercises to keep your muscles stretched out.

Occupational therapists (sometimes called OT for short) can teach you new ways to do everyday things like getting dressed, eating, playing and doing your homework. And social workers can help you and your family understand that everybody’s different, nobody’s perfect, and handle the kind of differences that having muscular dystrophy means.
It's no fun being so different that you can't run off and play the way you want to. But playing isn't all running and there are lots of things you can do well. You can help yourself by understanding that it is normal to be afraid and have angry feelings about being different. Everybody's different and everybody feels that way sometimes.

It sometimes helps to talk about these feelings with someone close to you. It's always easier to get rid of a bad feeling by sharing it with someone, like your mum or dad, or a good friend.

**BUT HOW CAN YOU HELP YOURSELF?**

And you can help yourself by realising that you're not alone because there are lots of people working with you. There are a lot of people who are interested in you and who love you because, just like them, you are different.
THINKING ABOUT YOU

When you were younger it was the adults around you who made decisions on your behalf. But now, like many young people, you are growing up and discovering that your goals and ideas are important and that there are things you may want to change. Perhaps you are feeling more confident and capable about making up your own mind about life.

Maybe you want to have more fun, gain new freedoms and responsibilities, or you may want to be more involved in decisions about your health. Independence often begins with people taking on this sort of responsibility. You may also be exploring ‘real life’ thoughts and feelings that you haven’t yet shared with anyone else.

All this can be exciting, but sometimes a ‘bad patch’ can leave you feeling a bit uncertain. Talking with other people about how you feel can help. By sharing your thoughts you will find there is a lot of information available and loads of great ideas to help you solve any problems or worries you might have.

This booklet will start you off. So, if you are between 11 and 14 years old and have a neuromuscular condition, then this is for you.

If you want further information about your condition call the Muscular Dystrophy Campaign Information Officer on 020 7720 8055, or email info@muscular-dystrophy.org. Everything discussed will be confidential.
Feeling good about yourself

Feeling shy? 
Want to be more confident? 
Just be yourself!

This is good advice, but what if you don’t feel confident enough to ‘be yourself’? You may compare yourself unfavourably to other people like celebrities or even your friends.

Self-esteem is about feeling good about yourself and who you are. And it matters. It matters a lot!

Self-esteem means you can enjoy being with a group of people you don’t know and feel comfortable. It allows you to have a laugh with your friends – even if you’re the butt of the joke. And people with a high level of self-esteem are usually more assertive too (that is, letting other people know what you want and what your opinions are without going into a strop!).

So, how do you ‘get’ self-esteem? Well, by being both proud of who you are and valuing yourself. One way you can begin to build your self-esteem is by developing your own style and looks.

Everyone wants to look good (even though some people don’t appear to care – think ‘grunge’). Film stars and models always seem to look good but, remember, it’s their job to look great, they have lots of people to help them and they get paid tons of cash. The rest of us have to be realistic about our appearance and there are some things we can’t change. Remember the song – Nobody’s Perfect? So, be positive and concentrate on the good things about yourself. You may have a nice smile, great teeth or great hair gel (= great hair).

Get the books
If you need any help, a book written just for boys called Style Blitz by Helen Thomas has ideas and tips on looking your best. It gives you tips on getting rid of acne (as if!) and hints about shaving and personal hygiene. Anita Naik has also written a very helpful book called Self-Esteem (it’s part of the Wise Guides series). Try your local library for a copy.

One way of dealing with those people who want to ‘pat you on the head’ or ignore you (sometimes called the ‘does he take sugar?’ syndrome, because they don’t think disabled people can speak for themselves) is to be direct, and speak up with a suitable comment. To be able to do this takes confidence, so practice in the safety of your own room, well away from others and you’ll soon gain the confidence to make yourself heard.

HOT TIP
Begin by writing down the problem or difficulty.

Break down the ‘problem’ into achievable chunks or bites by asking yourself:
- When is it due in?
- What help do I need?
- Where can I get help?
- Where do I want to do the work – at home, at school, at a friend’s house?
- How much time should I give to each part?
- Keep checking that you are on course and, if necessary, make changes.

A useful saying that can remind you how to use this technique, is ‘if you want to eat an elephant – eat it a bit at a time!’ It just means, break down a problem and tackle it bit by bit.

HOT TIP

Everybody feels a little scared at some point in their lives – it could be while wheelchair abseiling over a cliff or when watching a horror film! But you can also feel nervous about a big event, where you may be the centre of attention. Perhaps you have to give a speech at school or deal with a difficult situation and you may feel that if you are not absolutely perfect, people will make fun of you.

One solution is to be positive and imagine it not as a ‘problem’, but a ‘challenge’. Once you start thinking in this way many of your fears will go away and you will give yourself a genuine ‘can-do attitude’. You might find it hard to think like this and try to deal with your worries yourself, but this might not be such a good idea. It can be really helpful to talk to someone else, perhaps a friend, a teacher, an older brother or sister or even your parents. All these people can offer support and understanding. Talk, talk and talk is the best advice around.

If you really feel that you can’t talk about a fear that you have, then apply the strategy that we talked about in the bullying section. You can raise the problem (oops, challenge) as a topic that you have recently read about in a book or seen on a television show, and then you can openly discuss it with someone you trust who can help. Talking will make it easier to give the challenge a sense of proportion. Not being perfect at something is not a disaster and very likely your worries are needless.

When trying something new, like learning a foreign language or taking up a new hobby, you may quickly feel frustrated and drop it because your skills don’t match up to expectations. In these situations your confidence can take a knock, but remember to have that ‘can-do attitude’ and set yourself realistic weekly or monthly targets.

Think about what you want to achieve. An example could be a school project about a subject you know nothing about. Your ultimate goal is to submit a thoroughly researched and well-written project to your tutor and be confident of receiving a good mark.

A tip for those who find that their short-term memory is not too great: use ‘post it’ notes around your room. Stick them on your schoolbooks. Stick them on the mirror. It’s a great idea to help jog your memory.

Get the idea?

By applying this method to difficult or complex matters you will have a sense of purpose, know where you are going and therefore stand a good chance of succeeding.

There are lots of books around to help you, so if you want to find out more about stress try ‘Stress – find out how to handle it’, (part of the Wise Guides Series) by Anita Naik £3.99. Struggling with feelings – try www.youngminds.org.uk.
Bullying stresses people out and can spoil lives. Even the milder forms of bullying such as name-calling or excluding people from groups can be very upsetting. It is a deliberate and hurtful act that could happen to the same person over and over again. Sometimes it happens to people who are a bit different, but most of the time there is no obvious reason. The best thing to do in all cases of bullying is to take rapid action. Unfortunately, people who are being bullied are often reluctant to talk about what is happening to them and they may even keep it a secret. Why? Well, people often feel upset or ashamed to admit that they have been singled out for this type of treatment. They often think ‘Why me? What have I done? What have I said? Perhaps they (the bullies) took something I said the wrong way’.

If you know someone who is having a bad time because of a bully, can you do anything about it? If you have experienced bullying yourself you probably know what action to take. But if the person being bullied doesn’t want to talk about it, what can you do?

One strategy is to read a book or story about bullying or perhaps you can remember a TV show about this kind of hurt. You can then bring up the subject by talking about the book or programme – how good the story was, the difficulties the main characters faced, their dilemmas and the choices they made. You can also use this strategy to talk to your parents, teachers and friends about other embarrassing, complex, personal subjects. Remember that bullying is nothing to feel ashamed about and schools take it very seriously.

There are other people who can help:

The site www.bullying.co.uk offers advice and strategies on dealing with bullies (including text message bullying). It also gives advice to parents and schools and has information about the current legal position on bullying.

Two recent novels that feature bullies and bullying are ‘Traitor’ by Pete Johnson and ‘4 days ‘till Friday’ by Pat Moon. Your local or school library will probably have copies.

You have probably heard about Childline. It offers a 24-hour helpline for children and young people. Call 0800 1111 (if you find it difficult to use an ordinary phone you can use textphone on 0800 400 222) and talk to them about any problem, including bullying. The call is confidential (no-one else will know) and they will offer advice and help. www.childline.org.uk.

Kidscape is a charity that works to keep kids safe. It takes bullying very seriously and offers help to any kids being bullied. Its helpline is 020 7730 3300 www.kidscape.org.uk.
What’s on your plate?

Experts say that we all need to eat healthily from a wide range of foods but...

Too much of a ‘good thing’?
Foods high in sugar and fat are very tasty, and because they are tasty it is easy to eat a lot of them! But they are loaded with calories. If you eat more calories than you burn up, the result is too much fat. So, as well as cutting down on obvious high calorie foods watch out for those hidden calories too.

How good is your diet?
We all know that what we eat affects our health, but do we manage to eat healthily? Try this short quiz to see how you score:

1. What do you usually start the day with?
   a. Sugar coated cereal
   b. Toast with lashings of butter or margarine and some other spread
   c. Nothing much
   d. Cereal with very little or no sugar
   e. Toast with a thin scraping of butter or margarine

2. Do you use…?
   a. Skimmed milk  b. Semi-skimmed milk  c. Whole milk (full fat)

3. At lunchtime do you…?
   a. Have a packed lunch with just sandwiches and fruit
   b. Have a packed lunch as above with crisps and/or a biscuit (including chocolate!)
   c. Just have a drink and crisps and/or a biscuit

4. What is the drink you have most often?
   a. Ordinary fizzy drinks/squash
   b. Diet or low calorie fizzy drinks/squash
   c. Milk
   d. Water
   e. Pure fruit juice

5. If you are hungry between meals what are you most likely to reach for?
   a. Biscuits  b. Fruit
   c. Sweets  d. Bread/toast  e. Crisps

see page 2.7 for scores
Many people would think that the above equation doesn’t balance, but you can eat healthy food while on the move as long as you choose carefully.

**Baguettes/pitta breads/wraps** with salad/cold meat/egg/tinned tuna (in brine or water). If you can’t do without mayo use a low calorie version but remember that even these are high in calories so only have a teaspoon. You can also use pickles and relish to add lots of flavour.

**Jacket potatoes** with baked beans/low fat cheese/prawns/tuna in brine. But don’t add butter or margarine, although reduced fat margarine would be OK.

**Pizza** At home get pizza bases and make your own pizzas rather than getting the high fat, high calorie take-away types. If you are eating out, try to choose the pizza with less cheese and more veggies.

**Beans on toast** is a nutritious quick snack that is high in fibre; this means it will keep you feeling fuller for longer than other snacks.

**Sausage & mash** – but make the mashed potato with skimmed milk and don’t add butter or margarine. Try to have only one or two thin sausages and cut them into halves or thirds, then stick them into the pile of mash so they look like more sausages! Reduced fat sausages can taste good too.

**Pasta** with sauce is very popular and can be quite low in calories. Just boil the pasta then add a ready-made tomato based sauce with tinned sweet corn and/or tuna. To spice it up add a little chilli sauce or a small amount of chopped salami. Try to avoid the creamy, cheesy sauces.

**Chilli con carne** is very good especially when made with lean meat and plenty of vegetables, kidney beans and tomato puree. Try it with cumin as well as chilli powder.

**Soups** can be really tasty and fill you up without too many calories. There are many ready-made ones, both fresh and tinned, which are low fat. Look at the nutrition label and choose vegetable soups or reduced fat soups, and again try to avoid the creamy ones.

Even a ‘fry up’ needn’t be a plate of grease! Try thick sliced potatoes fried (the thicker the slices the less fat they absorb). Grill a lean rasher of bacon with tomatoes and mushrooms and serve with baked beans and lightly buttered toast. (A good tip – you mustn’t be able to see your teeth marks in the butter!)

**Lower calorie puds**

Any type of fresh fruit or frozen or tinned fruits in their own juice (not syrup)

Diet yoghurts (low calorie)

Sugar free jellies

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**Fibre – why eat it?**

Fibre means you feel fuller for longer and it keeps the bowel healthy. The bowel is a large muscle which must be given work to do to keep functioning properly, and the fibre in your diet is what this muscle uses to exercise! As the fibre is pushed through the bowel by the muscle, it acts like a sponge and absorbs water. That’s why it’s important to drink plenty of fluids but make sure it’s water or a low calorie drink because sweet fizzy drinks will add calories to your diet. You can increase your fibre by eating high fibre breakfast cereals, wholemeal bread, beans and pulses (try lentils and chickpeas), and, of course, fruit and vegetables.
Pack a punch with your packed lunch!

Lunch is an important meal. If you don’t refuel in the middle of the day you could well end up over-eating after school because you’re so hungry. By choosing a balance of foods you can feel full without having too many calories.

**Sandwich fillings**

Grated cheese (use only a little), a slice of lean meat, tinned fish (in brine or water), prawns. Always have a vegetable in the sandwich, for example, grated carrot, sliced peppers, cherry tomatoes, cress, sprouted alfalfa, shredded Chinese leaves, baby spinach as well as all the traditional salad vegetables. If you need mayonnaise choose the low calorie variety.

Have lots of fruit – grapes, peeled citrus fruit, apples, pears and banana are excellent. To help you get your five a day you could make up a big mixed fruit salad, but remember to squeeze a little lemon juice over it to prevent it going brown.

If you like yoghurts get the diet types or at least the low fat ones. And for something else sweet try a fruit bun or scone with a little jam (but not butter) or have a few dried apricots or raisins.

Try to have crisps only a couple of times a week and at other times try some homemade popcorn (you can buy the kernels at most supermarkets) and pop them yourself. Pour a little vegetable oil in a large saucepan and when the oil is hot, sprinkle a single layer of kernels on the bottom. Put the lid on the pan and as soon as you hear the first ‘pop’, turn down the heat and shake the pan occasionally until the popping has died down. Add salt to taste and eat.

Finally, drink water or low calorie squash and unsweetened fruit juices.

**Quiz answers, what did you score?**

<table>
<thead>
<tr>
<th>Scores for questions</th>
<th>1. a.2  b.1  c.1  d.3  e.3</th>
<th>2. a.3  b.2  c.1</th>
<th>3. a.3  b.2  c.1</th>
<th>4. a.1  b.3  c.2  d.4  e.2</th>
<th>5. a.1  b.3  c.1  d.2  e.1</th>
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</thead>
<tbody>
<tr>
<td>Scores</td>
<td>15+ excellent</td>
<td>10-15 very good</td>
<td>under 10 improvements are definitely needed to this diet!</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Remember that eating healthily doesn’t mean you have to eat boring food. You *can* eat the things you like, just don’t eat too much of them and balance them out with healthy foods. Why not experiment with unfamiliar foods and new recipes? A little imagination can make a big difference to what’s on your plate.

**Vitamin in the spotlight**

Vitamin A is essential for good eyesight and healthy skin (it is used as a medicine for some people with acne). You can get Vitamin A from the orange substance, called beta-carotene, which is in fruit & vegetables.

There are many more vitamins and minerals – C, E, B, calcium and iron – and you can find out about them and about the food we eat from books and the Internet. Try ‘How does my diet affect me’ by Patsy Westcott for starters!
Exercises

And there are even better reasons for doing exercises. But first, you need to make sure that you are doing the right type of exercise.

Q. If my muscles are weak why can't I use weights to make them stronger?
A. 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.

Q. Why does my physio want me to have hydrotherapy when I just think it's a pain getting undressed and dressed again?!
A. Hydrotherapy is probably the best way to exercise if you have a muscle condition. The warm water supports your body and relaxes your muscles, which makes stretching exercises much easier. The best thing about hydro though is being able to move much more freely than you usually can and it's really good fun!

Q. 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!!

Q. What about my hands and arms?
A. Hands and arms need to be stretched too. Playing computer games is very important to most kids whether they have a muscle 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!).

Q. What about my feet?
A. 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!).
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

If you are 13+ and interested in getting involved with Whizz-Kidz then it is interested in getting involved with you. It has set up a Board (a group of people who meet regularly with a common purpose) to give young people a say in the organisation. Whizz-Kidz wants the Board to let them know what it is doing right and how it could improve in the future. Even better than telling someone else what to do, Board members have also taken part in television and radio interviews, had stories published in national magazines and newspapers, attended functions and media events and generally had a good time.

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. 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, phone 020 7233 6600, or email keeponmoving@whizz-kidz.org.uk

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 occupational therapist for advice.

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 occupational therapist and see if they might be suitable for you.

Do you bend forwards 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.

Chair Tips Chair Tips Chair Tips Chair Tips

Always make sure that your legs are properly supported by the wheelchair.
There are over eight and a half million disabled people in the UK. That means that about one in seven of us has a disability. There are lots of kinds of disability and they can affect people of all ages and backgrounds.

People become disabled in several ways. Some people are born with a disability and some people become disabled through accidents. Their bodies are changed in ways that cannot be repaired. While some infectious diseases (such as HIV, AIDS or Polio) can cause disability, the disability itself isn’t catching. Nobody has ever ‘caught’ a disability from someone else.
Being 'disabled' generally means that some parts of your body work differently. When you see a person in a wheelchair, for example, it’s likely that he or she has a problem with his or her legs or back, which means that walking is difficult. But not all disabilities are obvious from looking. How would you know, for example, if somebody were hard of hearing? Or diabetic (a condition where there is too much sugar in the blood)? Or dyslexic (has difficulty reading and writing)? Yet each of these people has a disability which, in a small or large way, affects the way they live.

We’re all better at some subjects than others. Being disabled doesn’t mean that you can’t still be clever or successful. In fact, there have been many successful disabled people throughout history. (Read our interview with actress, Julie Fernandez, for more information about making it to the top with a disability.)

The media (newspapers, magazines and television) frequently portrays an image of disabled people that is not always flattering or accurate. They are often seen as victims or people to feel sorry for. When the same images are used over and over again they can be very unhelpful. Most disabled people don’t want pity. They just want to be treated equally, like everybody else. And they should be, even when they do things that are wrong. Disability is no excuse for being nasty or committing a crime.

There’s more to a disabled person than being disabled – it’s only one part of who they are. Being disabled makes a person different, but it doesn’t make them that different. We all want the same things, whether or not we’re disabled – to have good friends, enjoy ourselves, be successful, and fall in love – in short, to be happy.

Disabled people often say that the environment and attitudes of other people disable them more than their own disability. By this they mean that because society is not fully accessible for disabled people, they are prevented from participating in it as fully as non-disabled people.

And the way they are sometimes treated by non-disabled people can also act as a barrier.

Think about it. Have you ever been stared at because you looked a bit different? (Perhaps you were wearing some dodgy clothes or having a bad hair day!) Can you remember how it made you feel? You probably felt uncomfortable, self-conscious, perhaps even scared.

Now think, have you ever stared at a disabled person because they looked a bit different? And it’s not just staring that disabled people have to deal with. Often people will be rude to them, ask personal questions about their disability or talk about them as if they’re not there. How would you like it?

Disabled people aren’t ashamed of their disability. Sometimes disabled people talk about having a ‘disabled identity’ and actively campaign on issues that are particularly important to them, such as civil rights and equal access.
Julie was born in London in 1974. From the ages of 12 to 18 she attended Lord Mayor Treloar’s College in Hampshire, a boarding school for disabled people. She has appeared in *The Office*, *Eldorado* and *Dangerfield*. Julie has also worked as a presenter on *Wish You Were Here? From the Edge* and *The Politics Show*. She has brittle bone disease and is a wheelchair user.

**What are your memories of school?**
I didn’t go to a mainstream school as my brittle bone disease was very severe when I was younger and it would have been too dangerous for me. I was very lucky and went to a fantastic boarding school for disabled children. It catered for all our needs – we did lots of sports, went on field trips and even had our own driving instructor! The teachers there helped us believe that we were good enough to do anything we wanted to. We were taught never to use our disability as an excuse not to work hard and get on in life.

**So you weren’t bullied then?**
Yes, I was bullied by other disabled students.

**How did that make you feel?**
Bullying is never nice. It’s the weak person’s game. I told my parents who stepped in and spoke to the relevant teacher. It was dealt with and stopped. As I became older I became more confident and would smile and laugh back at people if they made remarks. I think that’s the best way to react to anything a bully says, show them that you’re not affected.

**Did you find it difficult, as a disabled person, to become an actress?**
Extremely difficult. The media’s attitude is that you have to be perfect to be on television, which doesn’t help. They used to tell me at auditions that I was good but that my disability would frighten viewers. And very often they cast non-disabled actors as disabled characters. That makes me angry as there are many good disabled actors.

I’ve had people be rude to me, or sarcastic, or over-friendly – the lot. I was even told once that I should be grateful for being given a job. You have to be strong. Sometimes you need to help people understand their own fears about disability as well as proving that you’re capable.

**Have people ever treated you like David Brent did in The Office?**
The older I’ve got the less it happens and I also don’t give people the opportunity to behave that way. Comedy has a wonderful way of breaking down barriers and *The Office* helped. It made people stop and think about their own behaviour. Beware all those David Brents!

**Do you think the Disability Discrimination Act will make a difference?**
I think it will help and encourage disabled people to move into a range of fields of work. And the more disabled people there are working, the more non-disabled people will be used to having us around and so hopefully become more relaxed.

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**JULIE SAYS:**
Even if you think you’re not affected by disability now, you may be in the future. As we get older, parts of our body don’t work so well and many elderly people often have a disability. So, it’s simple really. Just treat other people how you would like to be treated – because one day it may be you.
There are two main types of school – mainstream school and special needs school. A mainstream school is open to all children. A special needs school is for children and young people who need more support and help with their education to reach their full potential.

In the past, disabled and non-disabled pupils would have gone to separate schools but now there is much more inclusion (everybody studying together). Wherever possible, changes have been made to mainstream schools so that disabled pupils can attend.

Disabled pupils need to be able to move around as freely as their friends not just to get to their lessons or lunch but also in case they need to leave the building quickly in an emergency. Ramps and lifts help, and mean they are safe.

A lot of disabled people can still take part in physical education or games because the exercise can be adapted to suit them. Pupils with mobility or co-ordination difficulties, for example, can still play wheelchair football, hockey or tennis.

Almost everyone hates exams. They make you feel stressed out, under pressure and you have to remember a lot of information. Think how much harder that would be if you couldn’t read the exam papers properly or write down the answers easily, or if your brain just works differently to other people’s. That’s why some disabled people need help and support when they are sitting exams. They might need extra time because it takes them longer to think and write essays or their disability may make them tired. This is not cheating, it just evens the situation up, so that they have the same chance as everyone else to do well.

**THINK ABOUT IT**

Which buildings or classrooms in your school would be difficult to get into in a wheelchair?

How many steps are there into the school and inside the school?

If you couldn’t see, how would you navigate around the school?

Go on, try it!

Are there any classrooms or spaces which are difficult to hear in?

If you were deaf and working alone, how would you know if the fire bell rang?
Some disabled people need certain things to help them move around school or follow lessons.

If they have difficulty in walking then they may need a wheelchair to help them get around. Some disabled people use manual wheelchairs and push the chair forward by turning the wheels themselves. Others use a wheelchair which is powered by an electrically charged battery. These wheelchairs can go quite fast and are steered by the disabled person, using a sort of gearstick. Riding in one of these can be good fun, but they are definitely not toys! They can be dangerous, so if you want to know more about them, ask the wheelchair user how they work.

Certain wheelchair users may also be able to walk, and only use a wheelchair when they’re feeling tired. Others may need to use a wheelchair more as they get older or change from a manual wheelchair to an electric one.

Some disabled people need help to walk. They may wear special supports for weak parts of the body, like a brace to keep their back straight or support for a leg or arm. These braces aren’t painful to wear but they do mean that the disabled person can’t run or walk fast.

There are other things which disabled children at your school might need to help them, such as hearing aids, large print books or spending extra time with a teacher. Some disabled pupils may need a carer to come to school with them to help them with personal things that they find difficult to do, such as eating, going to the toilet and taking medication.

They may also need to spend time away from school going to the hospital for check-ups.

Everybody likes to be independent, including disabled people, but sometimes we all need a little help. If you think a disabled schoolmate might need help opening a door, for example, or getting down stairs in a wheelchair, then don’t be afraid to ask them if you can do anything. It may be that they are fine and would prefer to do it themselves, but they could also need assistance and be grateful of some help!
BULLYING

Bullying can make people's lives a misery. Whether it's name-calling, physical abuse or intimidation, it can be very upsetting. It makes the person being bullied feel upset, frightened and ashamed.

Often bullies pick on people who are a bit different – such as somebody who has a disability – and who they think they can easily intimidate. Most bullies are weak characters who get a kick out of thinking they can make people unhappy and control their lives.

Those being bullied often don't say anything because they're too scared or distressed. Sometimes they hope that it all might go away if they just keep quiet and do what the bully wants. Unfortunately, this isn't usually the case.

The most important thing about bullying is to deal with it quickly, before it escalates. Anyone who is being bullied, whether they are disabled or not, needs a friend. So, if you think you know someone who is being intimidated, try talking to him or her – maybe ask them how they are, what they did at the weekend. They might not want to talk at first, but at least they'll know that someone is interested.

The best way to be a friend to them, though, is by telling someone about the bullying. It doesn't matter who you tell – it could be your teacher, parents or grandparents – as long as you tell someone. Ideally, the bullies should be caught red-handed so if you know where it's happening (the toilets, for example, or the changing rooms) then let a teacher know.

DISCRIMINATION

The Disability Discrimination Act (DDA) was passed in 1995 as a way of trying to end the discrimination that many disabled people face in their daily lives. The DDA makes it illegal (with a few exceptions) to treat a disabled person less favourably than other people because of their disability.

FOR MORE INFORMATION ON

The rights of disabled people and DDA
- Disability Rights Commission – www.drc-gb.org

Bullying
- www.bullying.co.uk, an award winning charity, offers advice on dealing with bullying
- Call 0800 1111 or visit www.childline.org.uk for confidential advice and help
- Get Connected has a free helpline and email service helping young people find the best solutions to their problems. Visit www.getconnected.org.uk or call free on 0808 808 9994
- www.kidscape.org.uk has advice and help for children being bullied


Five Steps to Risk Assessment, Health and Safety Executive (HSE). Can be ordered from www.hsebooks.co.uk.


Guide to the Handling of Patients, National Back Pain Association, 16 Elmtree Road, Teddington, Middlesex, TE11 8ST. 020 8977 5474.


Manual Handling Guidelines. Flash Ley Resource Centre, Hawksmoor Road, Stafford, ST17 9DR. 01785 356830.


Supporting Support Assistants, A Practical Handbook for SENCos in Mainstream, Primary and Secondary Schools, Stephanie Lorenz, Downright Press, SEN Marketing, 618 Leeds Road, Outwood, Wakefield, WF1 2LT. 01924 871697.
MUSCULAR DYSTROPHY AND NEUROMUSCULAR CONDITIONS ORGANISATIONS

Muscular Dystrophy Campaign
7-11 Prescott Place
London SW4 6BS
Tel: 020 7720 8055
Email: info@muscular-dystrophy.org
Web: www.muscular-dystrophy.org

Children Living with Inherited Metabolic Diseases (CLIMB)
CLIMB Building
176 Nantwich Road
Crewe CW12 6BG
Tel support: 0870 7700 326
Web: www.climb.org.uk

CMT United Kingdom
PO Box 5089
Christchurch
BH23 7ZX
Tel: 0870 7744 314
Email: secretary@cmt.org.uk
(Hereditary Motor and Sensory Neuropathy, also known as peroneal muscular atrophy and Charcot-Marie-Tooth disease)

Duchenne Family Support Group
78 York Street
London W1H 1DP
Tel: 0870 241 1857
Helpline: 0870 606 1604
Email: info@dfsg.org.uk
Web: www.dfsg.org.uk

FSH Support Group
8 Caldecote Gardens
Bushey Heath
Herts WG23 4GP
Tel: 020 8950 7500
Web: www.fsh-group.org

The Jennifer Trust for Spinal Muscular Atrophy (JTSMA)
Elta House
Birmingham Road
Stratford on Avon CV37 0AQ
Tel: 0870 774 3651
Helpline: 0800 9753100
Email: jennifer@jtsma.org
Web: www.jtsma.org.uk

Mitochondrial Myopathies – Information Point
Web: www.communicate.co.uk/ne/mitolinks

Myasthenia Gravis Association
First Floor
Southgate Business Centre
Normanton Road
DERBY DE23 6UQ
Tel: 01332 290 219
Web: www.mgauk.org

Myotonic Dystrophy Support Group
35A Carlton Hill
Nottingham NG4 1BG
Tel: 0115 987 0080
Email: mdsg@tesco.net
Web: www.mdsuk.org

Myotubular Trust
10 Penshurst Close
Chalfont St Peter
Buckinghamshire SL9 9HB
Tel: 078 1320 0298
Email: contact@myotubulartrust.com
Web: www.myotubulartrust.com

Nemaline Myopathy
5 Cairnbank Gardens
Penicuik
Midlothian EH26 9EA
Tel: 01968 674998
Web: www.nemaline.org

Parent Project UK
Epicentre
41 West Street
London E11 4JL
Tel: 020 8556 9955
Email: info@ppuk.org
Web: www.ppuk.org
OTHER ORGANISATIONS

Advisory Centre for Education (ACE)
22 Highbury Grove
London, N5 2DQ
020 7354 8318 www.ace-ed.org.uk

Carers' National Association
20-25 Glasshouse Yard
London, EC1A 4JT
020 7490 8818
Carers' National Helpline: 0808 8087777

Centre for Studies on Inclusive Education (CSIE)
Room 2S 203, S Block, Frenchay Campus,
Coldboar Lane, Bristol, BS16 1QU
0117 344 4007 www.inclusion.org.uk

Children's Hospice website: www.childhospice.org.uk

Contact A Family
209-211 City Road, London, EC1V 1JN
020 7608 8700 www.cafamily.org.uk

Council for Disabled Children www.ncb.org.uk

Disability Law Services
Ground Floor, 39-45 Cavell Street,
London, E1 2BP
020 7791 9800

Disability Rights Commission 08457 622633

Disabled Living Centres Council
Redbank House, 4 St Chad's Street,
Manchester, M8 8QA
0161 834 0144 www.dicc.org.uk

The Family Fund Trust
(For families with severely disabled children)
PO Box 50, York, YO1 9ZX
Tel 01904 621115

Independent Panel for Special Educational Advice (IPSEA), 6 Carlow Mews,
Woodbridge, Suffolk, IP12 1EA
0800 0184016 www.ipsea.org.uk

Mobility Information Service
National Mobility Centre,
Unit B1, Greenwood Court,
Cartmel Drive, Shrewsbury,
Shropshire, SY1 3TB
01743 4603072 www.mis.org.uk

RADAR (Royal Association of Disability and Rehabilitation), 12 City Forum, 250 City Road, London
020 7250 3222 www.radar.org.uk

Royal Society for the Prevention of Accidents (ROSPA), Cannan House,
Priory Queensway, Birmingham, B4 6B
www.rospa.com

Skill – The National Bureau for Students with Disabilities, 336 Brixton Road,
London, SW9 7AA
020 7274 0565 www.skill.org.uk

Winston's Wish
(Information and advice for young children who have been bereaved.) www.winstonswish.org.uk

Moving and Handling Aids
Pil-E-Slide Manual Handling Equipment
Ergo-ike Associates,
Elmsleigh, Featherbed Lane, Oldbury on Severn,
South Gloucestershire, BS35 1PP
01454 417961

Select Health Care
Unit 9, Midland Business Centre, Midland Road,
Higham Ferrers, Northants, NN1 0BD
01933 411729

Vari-Tech, Atkinson Vari-Tech Ltd,
Sett End Road North, Shadsworth
01254 678777 e-mail: sales@vari-tech.co.uk
www.vari-tech.co.uk

Westholme Ltd
Newcombe Street, Elland, West Yorkshire
01422 260011

Equipment
Electronic Fire Door Stay
Fireco Ltd, Newall House,
31–32 High Street, Brighton, BN2 1RP
01273 624054

Evac-Chair, Evac-chair International Ltd.
Paraid House, Weston Lane
Birmingham, B11 3RS
Tel 0121 7066744

Philip and Tacey Ltd
North Way, Andover, Hants, SP10 5BA
www.philipandtacey.co.uk

Pressalit Care Ltd
Riverside Business Park, Leeds Road,
Ilkley, West Yorkshire, LS29 8JZ
01943 607651

Super–Four Adjust a Hite table systems
Panilet Tables, Unit 17,
Dragon Court, Crofts End Road,
St George's, Bristol, BS5 7XX
www.panilettables.co.uk

Lifts
Terry Group Ltd
Longridge Trading Estate
Knutsford, Cheshire, WA16 8PR
01565 650376 www.terrylifts.co.uk
BIBLIOGRAPHY


Booth et al (2000). The Index for Inclusion, Bristol Centre for Studies on Inclusive Education.


DfEE (2001). The Special Needs and Disability Act, Norwich, HMSO.


DfES (2001b). Promoting Children's Mental Health within Early Years and School Settings, Nottingham, DfEE Publications.


FURTHER READING: LOSS AND BEREAVEMENT

- Coping with Bereavement, A handbook for teachers, John Holland, Cardiff Academic Press, St.Fagin's Road, Fairwater, Cardiff, CF5 3AE. 01222 554909.
- Lost for Words, A training package for teachers, Learning Services, Kingston upon Hull, 01482 613423.
- Positive Responses to Death – A Strategy for Schools (by Winston's Wish), Clara Burgess Centre, Gloucestershire Royal Hospital, Gloucester GL1 3NN.
- Supporting Bereaved Students in Primary and Secondary Schools, Practical Advice for Staff, National Council for Hospice and Palliative Care Services and Kings College London. Contact: Clarissa Jones 020 7520 8299, c.jones@hospice-spc-council.org.
- The Social Curriculum, Death and Bereavement: Guidance for Schools, Essex County Council Learning Services, PO Box 47, Chelmsford, CM2 6WN.
- Lost for Words, A training package for teachers, Learning Services, Kingston upon Hull, 01482 613423.
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GLOSSARY

CAP Communication aids project
CMO Clinical medical officer
DDA Disability Discrimination Act
DfEE Department for Education and Employment
DFES Department for Education and Skills
EPOC Electrically powered indoor or outdoor wheelchairs
EPs Educational psychologists
EPS Educational Psychology Services
ESA Educational support assistant
HASPEV Health and safety of pupils on educational visits
ICT Information and communication technology
IEP Individual education plan
IHCP Individual health care plan
INSET In-service training
LEA Local education authority
MFL Modern foreign languages
OT Occupational therapist
SEN Special educational needs
SENCo Special Educational Needs Co-ordinator

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YOUNG PAVEMENT ARTISTS COMPETITION
AN ARTS COMPETITION FOR 4 – 19 YEAR OLDS

The Young Pavement Artists Competition, which was launched in 1986, captures young people’s enthusiasm for art with a novel canvas – the pavement. An innovative arts initiative, this annual event engages schools, youth groups and communities, encouraging young people to meet, draw, unlock their imagination and have fun. Each year the participants have to capture in chalk their interpretation of the chosen environmental theme.

As well as encouraging children to develop their drawing skills, the competition raises awareness of disability and environmental issues, as well as vital funds for the Muscular Dystrophy Campaign, the national charity leading the fight against muscle disease.

Participation in the project will encourage children to think in new, inclusive and original ways and supplement their classroom learning. The website offers full competition details, as well as specifically developed free downloadable lesson plans and topic ideas that support art, geography, citizenship, science and global citizenship for 5-16 year-olds, helping teachers to deliver the national curriculum in engaging ways.

Please apply for further information about how you can take part in the competition by logging onto www.muscular-dystrophy.org/pavementart. Or, for general queries, please contact the events team on 020 7720 8055 or at art@educationconnections.co.uk.
BE PART OF THE MUSCULAR DYSTROPHY CAMPAIGN

The Muscular Dystrophy Campaign is the largest national charity focusing on muscular dystrophy and related muscle diseases and supports over 60 different neuromuscular conditions. It has pioneered the search for treatments and cures for over 45 years, and provides practical, medical and emotional support to people affected by these diseases.

More than 30,000 people in the UK have muscular dystrophy or a related condition, and 150,000 people are indirectly affected as relatives and carers. There are no cures or treatments which prevent the breakdown of muscle but increased knowledge has improved the quality of people's lives and – in many cases – length of life.

We rely entirely on donations from individuals, charitable trusts and foundations, statutory funding bodies and corporate partners to finance the valuable work we do. If you would like to contribute to our fight against muscular dystrophy and related muscle diseases, please email donations@muscular-dystrophy.org.

Joining the Muscular Dystrophy Campaign is easy, and it's free (unless you are joining from overseas). By becoming a Member, you will receive Target md magazine quarterly. It's packed with up-to-date research news, features and information. You'll be the first to know about research advances for the condition you're interested in, and you'll have the chance to get involved – through meeting other local Members, campaigning to influence health and social care providers and the Government, or fundraising. To become a Member, please email membership@muscular-dystrophy.org, or call us on 020 7720 8055.

Do you want to get involved with the work of the Muscular Dystrophy Campaign? We are always looking for people willing to donate their time, experience or expertise to help in a variety of ways. There are opportunities to volunteer at head office, to work as a media volunteer or campaigner, to work in the regions with support groups or help with fundraising. If you can help in anyway, please get in touch using the contact details below.

Together we're stronger

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Email: info@muscular-dystrophy.org
Web: www.muscular-dystrophy.org

Registered Charity No: 205395

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