

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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ACKNOWLEDGEMENTS

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 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.)

June 2004

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FOREWORD

The Muscular Dystrophy Campaign, with financial support from the DfES Special Educational Needs (SEN) Small Programmes Fund, is pleased to publish *Inclusive Education for Children with Muscular Dystrophy and other Neuromuscular Conditions, Guidance for Primary and Secondary Schools*.

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. But the challenges for child, family and school are great, and overcoming them is no easy task. Inclusion for children with neuromuscular conditions not only means possibly changing the physical environment of a school and having a staff support structure in place, but also re-assessing the fabric of where and how education is delivered for all the pupils in school.

Delivering inclusive education for children with neuromuscular conditions will require working closely with parents and other professionals. An understanding of the specific needs of the child and how these will change is essential. Nothing can be done without detailed knowledge and forward planning. This guidance 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.



Christine Cryne
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 integrated into a mainstream school to receive a good quality of education and support. Research¹, 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.

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.



1. Sue Manning, 2002, *Parental Perspectives on Education Choices for Children with Duchenne Muscular Dystrophy*, MA Dissertation, University of Leeds, Dept of Sociology and Social Policy, Disability Studies.

Children with disabilities are more likely to suffer physical, sexual or emotional abuse than their able-bodied peers². 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.

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. You will also need to be flexible and respond in a positive way to the constant changes faced by working with pupils who have an uncertain future.

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 Family Care Officers.

2. Cross et al 1993, *ABCD: Abuse and Children who are Disabled Resource Pack* NSPCC, Leister, Sullivan/Knutson 1997 – identified as 1.6 – 3.9 times more likely to experience abuse.

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.



PLANNING AHEAD

You should begin planning ahead now 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 their 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 Family Care Officer.

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. Nerve disorders include spinal muscular atrophy and the hereditary motor and sensory neuropathies. The junction between the nerve and muscle (neuromuscular junction) is affected in the myasthenias.

Below is a brief summary of some of the more frequently encountered conditions. For more in-depth information read the Muscular Dystrophy Campaign factsheets available to download from www.muscular-dystrophy.org or call 020 7720 8055 for copies.

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 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.

BECKER MUSCULAR DYSTROPHY (BMD)

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.

MYOTONIC AND CONGENITAL MYOTONIC DYSTROPHY

This is a dominantly inherited condition that increases in severity from one generation to the next. It is not uncommon for the children of affected mothers to have the more serious congenital form. Both boys and girls are equally likely to be affected.

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 could 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 as they get older.

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.

LEARNING NEEDS

Learning difficulties associated with certain neuromuscular conditions do not worsen over time. For boys with Duchenne muscular dystrophy it is usual for the child to have difficulty with language and communication skills.

If a learning difficulty is identified then the pupil's needs should be addressed in the same way as for any other pupil within the school.

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.

2

ACCESS TO SCHOOLS AND THE CURRICULUM

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.

2.1 PRIMARY SCHOOL

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.**

KEY STAGE 1

IDENTIFYING THE PROBLEM

SCHOOL ISSUES	STRATEGIES	RESOURCES
<ul style="list-style-type: none"> Recognition of the problem Diagnosis may only be available after pupil starts school Adapting to rapid physical changes Awareness of progressive nature of many neuromuscular conditions 	<ul style="list-style-type: none"> Find out about the specific condition affecting the pupil from advisory teachers and health professionals Talk to the family and listen to its concerns Be flexible and ready to respond if a pupil's mobility deteriorates rapidly Attend relevant in-service training (INSET) sessions 	<ul style="list-style-type: none"> Family knowledge Information in these Guidelines Muscular Dystrophy Campaign Jennifer Trust for SMA Local support groups CAF Directory www.cafamily.org.uk Internet Professionals' reports

ASSESSING THE PUPIL — PROVIDING A STATEMENT OF EDUCATIONAL NEEDS

ISSUES	STRATEGIES	RESOURCES
<p>Is statutory assessment appropriate or not?</p> <ul style="list-style-type: none"> LEAs delegate budgets to schools, this can eliminate the need for a statement Some LEAs take the position that statementing and reviewing the statement is a process which safeguards the rights of the child 	<ul style="list-style-type: none"> 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 guidance in School Action and School Action Plus Call multi-agency meetings as and when necessary 	<ul style="list-style-type: none"> See Chapter 7 SEN Code of Practice refer to the following pages: 5.43 School Action 5.54 School Action Plus – Request help from outside agencies 5.62 School request to initiate statutory assessment

PHYSICAL LIMITATIONS

ISSUES	STRATEGIES	RESOURCES
<p>Pupil has difficulty with mobility & exercise – signs to look out for</p> <ul style="list-style-type: none"> Struggles to get up from the carpet Falls frequently in the playground Has poor balance Slower when climbing stairs Has difficulty using P.E. apparatus 	<ul style="list-style-type: none"> Seek guidance from physiotherapist on how to help movements Allow pupil extra time to climb stairs Monitor any falls Consult therapists regarding posture/seating concerns Rethink approach to the P.E. curriculum/swimming. Ensure inclusive approach is established 	<ul style="list-style-type: none"> 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 <i>Including Disabled Pupils in Physical Education</i> (English Federation of Disability Sport) Follow physiotherapy programmes
<p>Pupil in a wheelchair</p>	<ul style="list-style-type: none"> Assess school for accessibility; identify safe routes around the building Conduct a risk assessment for safe transfer between chairs, standing frames and toilets Seek guidance from physiotherapist on how to assist movements Begin adaptations prior to pupil starting 	<ul style="list-style-type: none"> 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

<p>Pupil has poor hand movement – watch out for difficulty with recording of work</p> <ul style="list-style-type: none"> ■ Poor handwriting and weak pencil grasp 	<ul style="list-style-type: none"> ■ 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 	<ul style="list-style-type: none"> ■ 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
<p>Pupil suffers from fatigue</p> <ul style="list-style-type: none"> ■ Appears tired in the afternoon sessions ■ Noticeable change in stamina as the week progresses 	<ul style="list-style-type: none"> ■ 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 	<ul style="list-style-type: none"> ■ 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
<p>Pupil has learning difficulties</p> <ul style="list-style-type: none"> ■ Some children will have learning difficulties as well as physical disabilities (those with myotonic dystrophy and some boys with Duchenne muscular dystrophy) 	<ul style="list-style-type: none"> ■ Follow the SEN Code of Practice ■ Develop an Individual Educational Plan (IEP) 	<ul style="list-style-type: none"> ■ See Chapter 1
<p>Communication needs</p> <ul style="list-style-type: none"> ■ Some children may have a very quiet voice and/or be slow to speak 	<ul style="list-style-type: none"> ■ Place at front of class ■ Give time for a response and ensure that class respects the need to wait ■ Consider using a speech amplifier 	<ul style="list-style-type: none"> ■ Speech and Language Therapy Services ■ Advisory teacher ■ CAP and LEA for funding, if appropriate

THE SCHOOL ENVIRONMENT

ISSUES	STRATEGIES	RESOURCES
<p>Creating an accessible environment</p> <ul style="list-style-type: none"> ■ Classrooms ■ Playground ■ Toilet ■ Dining room ■ Cloakroom ■ Hall 	<ul style="list-style-type: none"> ■ 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 	<ul style="list-style-type: none"> ■ 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
<p>Consider equipment needs</p>	<ul style="list-style-type: none"> ■ Assessment needed 	<ul style="list-style-type: none"> ■ See Chapter 6 ■ Advisory teachers and occupational therapists as appropriate
<p>Use, storage and maintenance of specialist equipment</p>	<ul style="list-style-type: none"> ■ Consult with Paediatric Therapy Services staff ■ Risk: assess classroom environment ■ Seek to make reasonable adjustments where necessary ■ Monitor and service equipment 	<ul style="list-style-type: none"> ■ Key worker liaison ■ Occupational therapy and physiotherapy reports ■ Manufacturer's/supplier's guidelines

THE CURRICULUM

ISSUES	STRATEGIES	RESOURCES
Access to curriculum <ul style="list-style-type: none"> National Curriculum 	<ul style="list-style-type: none"> IEP reviews Introduce keyboard skills 	<ul style="list-style-type: none"> See Appendix 1 ICT Advisory teachers ACE Centres BECTA website Educational Psychology Services (EPS)
<ul style="list-style-type: none"> P.E. 	<ul style="list-style-type: none"> Modify curriculum Parallel activities 	<ul style="list-style-type: none"> Disability Sports www.youthsport.net www.teachernet.gov (English Federation of Disability Sport) www.efds.co.uk
Practical activities	<ul style="list-style-type: none"> Differentiation of materials and equipment 	
Performances/concerts <ul style="list-style-type: none"> Consider ways of ensuring full inclusion 	<ul style="list-style-type: none"> Forward planning Consult the pupil, take into account what he or she is comfortable with Discreetly ensure safety of movement 	<ul style="list-style-type: none"> Flexible use of staff and space Clear, unambiguous, written instructions Adequate staffing

ORGANISATIONAL/EMOTIONAL/TEAM WORK

ISSUES	STRATEGIES	RESOURCES
Key worker	<ul style="list-style-type: none"> Identify key worker School Action Plus 	<ul style="list-style-type: none"> See Chapter 3 Named person
Support to staff		<ul style="list-style-type: none"> See Chapter 4
Communication issues <ul style="list-style-type: none"> Home/school liaison Changing information Communication with peer group Communication with pupil Supply and visiting staff to be informed 	<ul style="list-style-type: none"> Share information with all concerned Contact number held centrally in school Create 'Home/School Message Book' Establish system to inform family when transport arrangements are altered Check with family what information they do and do not want the pupil to be told regarding changes in physical ability 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 	<ul style="list-style-type: none"> See Chapter 4 and Appendix 3 Use key worker Keep contact diary Central record of contact numbers 'Home/School Message Book'
Staff training <ul style="list-style-type: none"> Raise awareness Build confidence Provide information for all staff 	<ul style="list-style-type: none"> Liaise with parents on amount of information to be shared Build up a bank of written information Visit other schools attended by children with neuromuscular conditions Invite speakers to staff INSET (from voluntary agencies e.g. Muscular Dystrophy Campaign's Family Care Officers) Appraise modified materials 	<ul style="list-style-type: none"> Muscular Dystrophy Campaign, Family Care Officers Voluntary organisations LEA Support Services EPS

MEDICAL AND THERAPEUTIC ISSUES

ISSUES	STRATEGIES	RESOURCES
<p>Physical management</p> <ul style="list-style-type: none"> ■ 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 	<p>See p.24</p>	<p>See p.24</p>
<p>Personal hygiene</p> <ul style="list-style-type: none"> ■ 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 	<ul style="list-style-type: none"> ■ 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 	<p>See p.24</p> <ul style="list-style-type: none"> ■ Health care professionals involved with the child ■ Local authority Moving and Handling Advisor ■ Muscular Dystrophy Campaign Adaptations Manual ■ Muscular Dystrophy Campaign Family Care Officer
<p>Paediatric therapy and medical issues</p> <ul style="list-style-type: none"> ■ Share information between education and health departments but ensure that this does not infringe data protection or confidentiality 	<ul style="list-style-type: none"> ■ 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 	<ul style="list-style-type: none"> ■ See Chapter 5 ■ SEN Toolkit Section 12 <i>The Role of Health Professionals; The Education of Children with Medical Conditions</i> Rd Alison Closs ISBN 1-85346-569-0 ■ <i>Supporting Pupils with Medical Needs</i> DfES 1996
<p>Hospital admissions</p> <ul style="list-style-type: none"> ■ Child may be admitted to hospital with chest infections ■ Child may require planned surgery 	<ul style="list-style-type: none"> ■ 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 	<ul style="list-style-type: none"> ■ Hospital tuition service ■ Home tuition service ■ Through e-mails/cards/text and telephone contact

POLICIES AND MANAGING RISKS

ISSUES	STRATEGIES	RESOURCES
Child Protection		<ul style="list-style-type: none"> See Chapter 7
Moving and handling	<ul style="list-style-type: none"> Devise policy if one is not already in place Risk assessment 	<ul style="list-style-type: none"> See Chapter 8, Appendix 1 Advisory teacher Examples from other schools
Safe evacuation <ul style="list-style-type: none"> In case of emergency 	<ul style="list-style-type: none"> Review emergency procedures 	<ul style="list-style-type: none"> Consult with local fire service HSE publications <i>Five Steps to Risk Assessment</i>
School uniform		<ul style="list-style-type: none"> See Chapter 7

TRANSPORT

ISSUES	STRATEGIES	RESOURCES
Investigate transport issues <ul style="list-style-type: none"> In most cases LEAs will have clear policies relating to transport for children with SENs which should be made available to parents (8.89 Code of Practice) 	<ul style="list-style-type: none"> Provide dropping-off points to allow easy access to school Consider the venue and access on a planned trip; historical venues may not be suitable. Risk: assess the venue Comply with the Disability Discrimination Act and make reasonable adjustments 	<ul style="list-style-type: none"> 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) Consider an alternative venue with full disabled access for school trips
School trips <ul style="list-style-type: none"> Accessibility of venues for children in wheelchairs Children who usually walk may need to take a wheelchair on school trips 	<ul style="list-style-type: none"> Assess venues for suitability and accessibility Hire adapted vehicles where necessary Ensure suitable toilets are available Complete risk assessment to include any moving and handling issues 	<ul style="list-style-type: none"> Disability Discrimination Act Research venues for trips (pre-visit, Internet, etc) <i>Health and Safety of Pupils on Educational Visits</i> 1998 DES (includes sample model risk assessment forms) HASPEV Forms LEA guidance material

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.



KEY STAGE 2

IDENTIFYING THE PROBLEM

SCHOOL ISSUES	STRATEGIES	RESOURCES
<p>Evaluation of current situation Diagnosis is probably in place</p> <ul style="list-style-type: none"> Assess mobility needs and access issues Is access to education affected by physical difficulties? Are there any learning difficulties? 	<ul style="list-style-type: none"> Gather information Follow Code of Practice guidance relating to School Action and School Action Plus Assess training needs Formulate training plan 	<ul style="list-style-type: none"> Relevant in-service training (INSET) See Chapter 1 Refer to Hull City Council publication, <i>Supporting Children with Medical Conditions</i>, David Fulton publishers, 2004 Professionals' reports
<p>Lack of information about the condition held by school or specific staff in school</p>	<ul style="list-style-type: none"> Ensure all staff have appropriate information and training from advisory teachers and health professionals Look out for relevant in-service training (INSET) opportunities 	<ul style="list-style-type: none"> See Chapter 1 Muscular Dystrophy Campaign factsheets about conditions Internet

ASSESSING THE PUPIL – PROVIDING A STATEMENT OF EDUCATIONAL NEEDS

ISSUES	STRATEGIES	RESOURCES
<p>How will the pupil's needs be met and funded?</p> <ul style="list-style-type: none"> Statutory assessment or delegated funds? Consider whether statutory assessment appropriate or not 	<ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> See Chapter 7 Special Educational Needs Code of Practice Refer to following pages in SEN Code of Practice: <ul style="list-style-type: none"> 5.43 School Action 5.54 Request help from outside agencies through School Action Plus 5.62 School request to initiate statutory assessment DfES/581/2001 effective from 01.01.02

PHYSICAL LIMITATIONS

ISSUES	STRATEGIES	RESOURCES
<p>Increased difficulty with mobility</p> <ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> 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) 	<ul style="list-style-type: none"> 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 <ul style="list-style-type: none"> ■ Mobility around the building ■ Transfers ■ Practical subjects (art, technology, science) 	<ul style="list-style-type: none"> ■ Identify safe routes around the building ■ Risk assess for safe transfer between chairs, standing frames and toilets 	<ul style="list-style-type: none"> ■ 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	See Key Stage 1
Communication needs <ul style="list-style-type: none"> ■ May have a quiet voice and/or be slow to speak 	<ul style="list-style-type: none"> ■ Place at front of class ■ Give time for a response and ensure that class respect the need to wait ■ Consider using a speech amplifier 	<ul style="list-style-type: none"> ■ Speech and Language Therapy Services ■ Advisory teacher ■ CAP and LEA for funding, if appropriate
Physical limitations and reduced stamina <ul style="list-style-type: none"> ■ Suffers from fatigue 	<ul style="list-style-type: none"> ■ 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 	<ul style="list-style-type: none"> ■ 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

ISSUES	STRATEGIES	RESOURCES
Creating an accessible environment <ul style="list-style-type: none"> ■ Entrances/exits ■ Dining room ■ Gym ■ Playground ■ Classrooms ■ Hall ■ Toilets 	<ul style="list-style-type: none"> ■ 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 	<ul style="list-style-type: none"> ■ Install grab rails, handrails, ramps, lifts etc. ■ Ensure adequate space in accessible toilet etc. as required
Moving around the school site during unstructured time <ul style="list-style-type: none"> ■ Dinner breaks & playtimes 	<ul style="list-style-type: none"> ■ 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 	<ul style="list-style-type: none"> ■ 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	<ul style="list-style-type: none"> ■ Assessment needed 	<ul style="list-style-type: none"> ■ See Chapter 6 ■ Advisory teachers and occupational therapists as appropriate
Use, storage and maintenance of specialist equipment	<ul style="list-style-type: none"> ■ Consult with occupational therapists and physiotherapists ■ Risk assess classroom environment and be prepared to make reasonable adjustments ■ Monitor and service equipment 	<ul style="list-style-type: none"> ■ Occupational therapist's and physiotherapist's reports ■ Manufacturer's/supplier's guidelines

THE CURRICULUM

ISSUES	STRATEGIES	RESOURCES
P.E.	<ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> Disability Sports Federation (see Key Stage 1) <i>Success for All</i> CD ROM Physical Education from Lancashire Education <i>Including Disabled Pupils in Physical Education</i> from Manchester Metropolitan University 0161 247 5294 Provide modified P.E. equipment e.g. BOCCIA, Kurling See Davis Sports catalogue for resources
Swimming	<ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> 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 <ul style="list-style-type: none"> Ensure inclusion NOT integration Look at performance areas (podium) 	<ul style="list-style-type: none"> Forward planning Modify performance Adapt/change performance space Consult the pupil and take into account what he or she is comfortable with Adapt or change venue Modify costumes if used Discreetly ensure safety of movement 	<ul style="list-style-type: none"> Flexible use of staff and space Clear, unambiguous, written instructions Adequate staffing

ORGANISATIONAL/EMOTIONAL/TEAM WORK

ISSUES	STRATEGIES	RESOURCES
Staff training <ul style="list-style-type: none"> Raise awareness Build confidence Provide information for all staff 	<ul style="list-style-type: none"> Liase 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 Family Care Officers) Appraise modified materials 	<ul style="list-style-type: none"> See Chapter 5 Muscular Dystrophy Campaign, Family Care Officers Voluntary organisations LEA Support Services Educational Psychology Services (EPS)

MEDICAL AND THERAPEUTIC ISSUES

ISSUES	STRATEGIES	RESOURCES
Physical management <ul style="list-style-type: none"> Moving and handling of pupils with deteriorating muscle strength 	<ul style="list-style-type: none"> 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) 	<ul style="list-style-type: none"> See Chapter 8 and p.24 Manual handling aids may become necessary, e.g. handling belt, hoist Lightweight cutlery recommended by occupational therapist Adult assistance at mealtimes
Personal hygiene and toileting	<ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> ESA job description to reflect changing tasks Appropriate toilet Alternative equipment, e.g. urinal bottle Hygienic disposal facilities (pads etc) Provide suitable hoist
Therapy and use of specialist equipment <ul style="list-style-type: none"> Balance therapy and curriculum needs Seating – school chair no longer appropriate Difficulty moving between chairs Standing becomes difficult Introduction of standing frame Independent use of toilet becomes difficult because of mobility Hoisting may become necessary for transfers and toileting 	<ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> 'Moving and Handling' policy in place, see Chapter 8, Appendix 1 Training in moving and handling techniques 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
Standing frame or other similar equipment <ul style="list-style-type: none"> When and how is a standing frame used? 	<ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> See Chapters 5 & 6
Hospital admissions <ul style="list-style-type: none"> Child may be admitted to hospital with chest infections Child may require planned surgery 	<ul style="list-style-type: none"> Contact 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 	<ul style="list-style-type: none"> Hospital tuition service Home tuition service Through e-mails/cards/ text and telephone contact

POLICIES AND MANAGING RISK

ISSUES	STRATEGIES	RESOURCES
Child Protection		<ul style="list-style-type: none"> See Chapter 7
Moving and handling	<ul style="list-style-type: none"> Devise policy 	<ul style="list-style-type: none"> See Chapter 8
Safe evacuation	<ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> See Chapter 6 Written procedures
School uniforms		<ul style="list-style-type: none"> See Chapter 7

TRANSPORT

ISSUES	STRATEGIES	RESOURCES
<p>Arrival at school (set-down and pick-up arrangements)</p> <ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> School's accessibility plan Staffing implication
Educational trips	<ul style="list-style-type: none"> Risk assessment for trips Select appropriate venue to comply with Disability Discrimination Act Consider transport needs 	<ul style="list-style-type: none"> Disability Discrimination Act Research venues for trips (pre-visit, Internet, etc) <i>Health and Safety of Pupils on Educational Visits</i> 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).

When the recommendations of all agencies have been received, schools can feel overloaded by the demands of all the disciplines. It is worth remembering that each therapist will have an ideal, and it may be necessary to compromise in order to accommodate both curriculum demands and physical management demands.

A PUPIL SUPPORT TIMETABLE

EXAMPLE
(For blank form see Appendix 1)

Pupil

Support Staff

MONDAY	PE	Numeracy	Break	Literacy	Lunch	History	RE	
		◆		◆				
TUESDAY	Literacy	Numeracy		Science		■	Geography	Music
WEDNESDAY	DT	Literacy		Numeracy		■	Science	History
	◆							
THURSDAY	Numeracy	Literacy	Geography	■	Science	ICT		
FRIDAY	Literacy	Numeracy	PE	■	Art	Music		
	◆	◆						

● Powered chair ■ Standing frame ■ Walking with rollator ◆ Specialist chair ● Physical management routine

COMMENTS

Monday

Tuesday

Wednesday

Thursday

Friday

2.2 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.

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.

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.

It is essential that, during this time, an appropriate education/therapy balance continues. This will necessitate increasing flexibility and sensitivity on the part of the school in response to the pupil's changing physical needs.

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

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.



KEY STAGES 3 & 4

IDENTIFYING THE PROBLEM

SCHOOL ISSUES	STRATEGIES	RESOURCES
<p>Knowledge of the medical condition</p> <ul style="list-style-type: none"> How do schools ensure that staff are aware of the educational implications of the condition? 	<ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> Parents Specialist outreach nurse Publications as suggested by advisory/support teachers Local and national support groups DfEE circular 14/96 <i>Supporting Children with Medical Needs</i> Hull City Council publication <i>Supporting Children with Medical Conditions</i>, David Fulton publishers, 2004

ASSESSING THE PUPIL — PROVIDING A STATEMENT OF EDUCATIONAL NEEDS

ISSUES	STRATEGIES	RESOURCES
<p>Consider whether statutory assessment is appropriate or not</p> <ul style="list-style-type: none"> LEAs delegate budgets to schools, this can eliminate the need for a statement Some LEAs take the position that statementing and the review of the statement is a process that safeguards the rights of the child 	<ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> 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

ISSUES	STRATEGIES	RESOURCES
<p>Movement within school</p> <ul style="list-style-type: none"> Pupils with mobility difficulties may move slowly, making them vulnerable in congested corridors Wheelchair users can add to the congestion in corridors Careful planning can minimise these hazards 	<ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> Refer to Hull City Council publication <i>Supporting Children with Medical Conditions</i>, David Fulton publishers, 2004 School Access Plan Advice from therapists Regular maintenance of floors and paved areas

THE SCHOOL ENVIRONMENT

ISSUES	STRATEGIES	RESOURCES
Environmental issues		<ul style="list-style-type: none"> See Chapter 6
Physical management of equipment <ul style="list-style-type: none"> 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? 	<ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> See Chapter 6 Occupational therapy and physiotherapy recommendations Documented instructions on transfers for individual pupils

GENERAL SUBJECT/FACULTY/DEPARTMENTAL ISSUES

ISSUES	STRATEGIES	RESOURCES
How to organise the classroom to accommodate a pupil who uses a wheelchair <ul style="list-style-type: none"> What about pupils who use walking aids or walking frames? 	<ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> Advice from relevant services
Access to all subjects <ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> 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

<p>Homework issues</p>	<ul style="list-style-type: none"> ■ 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 	<ul style="list-style-type: none"> ■ Student planner ■ Information and communication technology (ICT) equipment
<p>Deployment of support staff</p>	<ul style="list-style-type: none"> ■ Vary support staff to prevent emotional overload ■ Ensure all staff involved have access to the same training 	<ul style="list-style-type: none"> ■ Consultation with SENCo ■ Support from Educational Psychology Services (EPS) ■ Support from Family Care Officers
<p>Planned absences</p> <ul style="list-style-type: none"> ■ Hospital appointments, recurring infections, spinal surgery 	<ul style="list-style-type: none"> ■ 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 	<ul style="list-style-type: none"> ■ Hospital tuition service ■ Home tuition service ■ Through e-mails/cards/text and telephone contact
<p>Performances/concerts</p> <ul style="list-style-type: none"> ■ Consider ways of ensuring full inclusion 	<ul style="list-style-type: none"> ■ Forward planning ■ Consult the pupil and take into account what he or she is comfortable with ■ Discreetly ensure safety of movement 	<ul style="list-style-type: none"> ■ Flexible use of staff and space ■ Clear, unambiguous, written instructions ■ Adequate staffing
<p>Educational visits</p> <ul style="list-style-type: none"> ■ Funding for additional staff for residential visits ■ Emergency procedures may need reviewing and adapting 	<ul style="list-style-type: none"> ■ 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 	<ul style="list-style-type: none"> ■ DfES guidance ■ LEA ■ School policies ■ LEA loan equipment
<p>After school clubs</p>	<ul style="list-style-type: none"> ■ Flexible LEA transport 	<ul style="list-style-type: none"> ■ Access to community transport, e.g. Dial a Ride ■ Access to support staff with appropriate training
<p>Work experience</p> <ul style="list-style-type: none"> ■ Refer to physical management routines ■ Refer to personal care routines 	<ul style="list-style-type: none"> ■ Appropriate transport required ■ Assistance from Connexions 	<ul style="list-style-type: none"> ■ Appropriate placement

CURRICULUM ISSUES

ISSUES	STRATEGIES	RESOURCES
<p>English and Modern Foreign Languages (MFL)</p> <ul style="list-style-type: none"> The volume of written work is likely to be the main issue 	<ul style="list-style-type: none"> Maximise use of ICT. Present computer generated worksheets wherever possible. Make these available to the pupil via disc, CD or 'flash drive' Ask educational support assistants (ESAs) to photocopy/scan lesson notes which other pupils will transcribe from the board 	<ul style="list-style-type: none"> Access to ICT hardware Differentiate work tasks within departments at the planning stage
<p>Maths</p> <ul style="list-style-type: none"> Deterioration of hand skills will lead to difficulty in manipulating standard mathematical equipment 	<ul style="list-style-type: none"> Encourage use of specialist maths programmes e.g. Access Maths Reduce the quantity of writing by providing photocopied worksheets rather than copying from text books Ask support assistants to transcribe when copying is unavoidable Provide alternative equipment, e.g. non-slip ruler, safe drawing compass and circle protractor 	<ul style="list-style-type: none"> See Appendix 1 Specialist software (Inclusive Technology) Differentiate work tasks within departments at the planning stage Hope catalogue
<p>Science</p> <ul style="list-style-type: none"> As with other practical subjects, safety will be paramount 	<ul style="list-style-type: none"> Maximise use of ICT. Present computer generated worksheets wherever possible. Make these available to the pupil via disc, CD or 'flash drive' Use of QX3 Computer Microscope Ask ESAs to photocopy/scan lesson notes which other pupils will transcribe from the board Ensure furniture is of appropriate height for wheelchair users Risk assess each practical activity Adapt standard equipment such as Bunsen burners Provide adequate protective clothing e.g. a protective apron for a pupil who remains seated in practical activities Group pupils sensitively to ensure more mobile pupils can collect and manipulate equipment enabling the less physically able pupil to direct activities Ensure appropriate adult support is available when necessary in practical sessions 	<ul style="list-style-type: none"> See Appendix 1 Access to ICT hardware Differentiate work tasks within departments at the planning stage Economatics (Education) Ltd. Liaison between staff Height adjustable furniture (Atkinson Varitech Limited) Timetabling of staff
<p>Design Technology</p> <p>Music</p> <p>Art</p> <p>Drama</p>	<ul style="list-style-type: none"> Maximise use of ICT Ask ESAs to photocopy/scan lesson notes which other pupils will transcribe from the board Ensure furniture is of appropriate height for wheelchair users Risk assess each practical activity Ensure at least one set of equipment is accessible Consider use of alternative/specialist equipment Provide modified or parallel activities 	<ul style="list-style-type: none"> Access to ICT hardware Differentiate work tasks within departments at the planning stage Varitech Atkinson catalogue Liaison between health and safety and subject advisor Homecraft catalogue Advice from advisory/support teacher, subject adviser or occupational therapist

History and Geography	<ul style="list-style-type: none"> ■ 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 	<ul style="list-style-type: none"> ■ Access to ICT hardware ■ Differentiate work tasks within departments at the planning stage ■ Varitech Atkinson catalogue ■ Liaison between health and safety and subject adviser
Physical education	<ul style="list-style-type: none"> ■ Offer alternative or adapted activities ■ Consider swimming as an alternative 	<ul style="list-style-type: none"> ■ Davis Sports catalogue ■ Youth Sport Trust 020 7388 4436 ■ Federation of Disability Sports Organisations 01924 279305 ■ <i>Supporting Disabled People in Sport</i> (Federation of Disability Sports Organisations)

ORGANISATIONAL/EMOTIONAL/TEAMWORK ISSUES

ISSUES	STRATEGIES	RESOURCES
Timetabling <ul style="list-style-type: none"> ■ What must schools do if specialist rooms are upstairs? 	<ul style="list-style-type: none"> ■ 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) 	<ul style="list-style-type: none"> ■ Liaison between heads of faculties, SENCo and member of staff responsible for room allocation ■ Schools Access Plan
Emotional support for staff	<ul style="list-style-type: none"> ■ 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 	<ul style="list-style-type: none"> ■ See Chapter 4 ■ Refer to Hull City Council publication <i>Supporting Children with Medical Conditions</i>, David Fulton Publishers, 2004 ■ <i>Lost for Words</i> A training package for teachers 01482 613423 ■ Local publications from LEA advisory staff

<p>Emotional support for the pupil and the family</p> <ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> See Chapter 4 Bereavement counselling publications
<p>Home school links</p>	<ul style="list-style-type: none"> Establish a workable system 	<ul style="list-style-type: none"> Telephone contact 'Home School Message Book'

MEDICAL AND THERAPEUTIC ISSUES

ISSUES	STRATEGIES	RESOURCES
<p>Physical management</p> <ul style="list-style-type: none"> School needs to consider when, where, by whom and how physical management routines will be implemented 	<ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> Release three members of support staff to receive training Accessible support room School's access strategy Appropriate equipment may include: hoists (ceiling or mobile) and slings, transfer equipment such as slide boards and sheets, height adjustable plinths etc. Timetable for specialist facilities Generic moving and handling training should be provided in accordance with LEA policy – consult with the LEA Health and Safety Officer to access local training School Moving and Handling Policy Pupil specific handling training provided, monitored and updated by relevant healthcare professionals Training log – Excel spreadsheet maintained by nominated staff Maintenance log – Excel spreadsheet updated by nominated staff Intimate care and close personal contact policy – LEA guidelines

<p>Personal hygiene/toileting routines</p> <ul style="list-style-type: none"> 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) 	<ul style="list-style-type: none"> Ensure that staff are aware of all relevant school and LEA policies and adhere to this guidance. Policies should be written if not already in place An individual protocol is required for each pupil, which should be updated to reflect changing needs. This protocol should be respected by all staff Consider use of a 'pupil passport' or 'toilet pass' or a similar method enabling the pupil to give brief written information to staff Ensure the pupil has a means of contacting the relevant member of support staff via the internal telephone system, personal pager or walkie-talkie 	<ul style="list-style-type: none"> See Chapter 1 and p.35 Moving and Handling Policy Intimate Care and Close Personal Contact Policy Refer to DfES and LEA guidelines Refer to the Barnardo's Handbook, or Hull City Council publication <i>Supporting Children with Medical Conditions</i>, David Fulton publishers, 2004, for guidance on intimate care policies Publications as advised by advisory/professional staff Individual Health Care Plan drawn up with guidance from the pupil, parents and relevant health staff Laminated card showing permission has been given to leave lessons on request Support staff timetable to be provided and kept by the pupil and individual subject teachers Provision of, or access to, communication equipment
<p>Physical dependency By this stage most pupils will be physically dependent on adult assistance.</p> <ul style="list-style-type: none"> Use of standing frames Hoisting 	<ul style="list-style-type: none"> Therapy will be ongoing but needs to be balanced with educational needs Clarification with LEA policy necessary Hoisting necessary for all transfers 	<ul style="list-style-type: none"> Risk assess for all transfers Refer to LEA policy re use of standing frame See Physical Management p.35 and Appendix 1 resources
<p>Hospital admissions</p> <ul style="list-style-type: none"> Child may be admitted to hospital with chest infections Child may require planned surgery 	<ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> Hospital tuition service Home tuition service Through e-mails/cards/text and telephone contact

POLICIES AND MANAGING RISKS

ISSUES	STRATEGIES	RESOURCES
<p>Child Protection</p>	<ul style="list-style-type: none"> See Chapter 7 	<ul style="list-style-type: none"> See Chapter 7
<p>Moving and handling</p>	<ul style="list-style-type: none"> See Chapter 8 Risk assessment and moving and handling policies 	<ul style="list-style-type: none"> See Chapter 8, Appendix 1
<p>Emergency evacuation procedures</p>	<ul style="list-style-type: none"> Written procedures Advice from local fire officer 	<ul style="list-style-type: none"> Purchase of evacuation sheets and chairs
<p>School uniform policy</p> <ul style="list-style-type: none"> Pupils sitting in wheelchairs for a large part of the day will be more comfortable in 'jogger bottoms' 	<ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> See Chapter 7 Amend school dress code to reflect needs of pupils who have a special need

<ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> Provide a 'pass' which can be carried by the pupil to indicate he or she has been given special permission to dress outside the school policy 	<ul style="list-style-type: none"> Produce 'permission passes' for relevant pupils
<p>Examination arrangements Special arrangements can be made. The pupil should be familiar with the proposed way of working prior to examinations</p>	<ul style="list-style-type: none"> Information from exam officers in school Practice sessions using scribe or technology prior to exam 	<ul style="list-style-type: none"> Guidance from exam board Back up technology for unexpected technological problems

TRANSPORT

ISSUES	STRATEGIES	RESOURCES
<p>Transport</p> <ul style="list-style-type: none"> Accessible transport is often significantly more expensive. This needs to be taken into account 	<ul style="list-style-type: none"> Home/school transport in accordance with LEA policy NB. Tailgate lift should be used in preference to ramped access to avoid strain on pupil's head An escort may be required according to individual medical needs Shared information 	<ul style="list-style-type: none"> LEA recommended transport contacts
<ul style="list-style-type: none"> Arrival at school (set-down and pick-up arrangements) In accordance with Disability Discrimination Act guidelines schools should have parking spaces designated for disabled use. These spaces are frequently located in the main car park and may not be suitable for set-down and pick-up 	<ul style="list-style-type: none"> Identify a set-down and pick-up point for vehicles carrying disabled students which is close to the school and near ramped access Nominate a member of support staff to receive the pupil on arrival 	<ul style="list-style-type: none"> School's accessibility plan Staffing implication

PERSONAL HYGIENE

You need to take care to ensure that you plan toileting and don't make it a barrier to the child's education.

The need for personal care can change rapidly and a child who may be able to manage personal care and 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

When the recommendations of all agencies have been received, schools can feel overloaded by the demands of all the disciplines. It is worth remembering that each therapist will have an ideal and it may be necessary to compromise to accommodate both curriculum demands and physical management demands.

A PUPIL SUPPORT TIMETABLE

EXAMPLE
(For blank form see Appendix 1)

Name of Pupil _____

Initials of Support Staff _____

MONDAY	PE ●	Maths	Break	English	Lunch	History	RE
TUESDAY	English	Maths		Science ■		Geography	MFL ■
WEDNESDAY	DT ■	English		Maths		Science ■	History
THURSDAY	MFL	English		Geography ■		Science ■	DT
FRIDAY	English ●	Maths		PE		Art ■	Science

■ Standing frame ● Physiotherapy session

COMMENTS

Monday _____

Tuesday _____

Wednesday _____

Thursday _____

Friday _____

3

WORKING TOGETHER ROLES AND RESPONSIBILITIES

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 co-ordinating 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, co-ordinating 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.



TOM

speaking about support staff

I don't think having them there prevented me from making friends. I think it was ... well, it's difficult when they're there most of the time, because the kind of things boys talk about sometimes, we couldn't really. I was quite fortunate at secondary school because they tended to be around less. They'd get my things set up for me, then disappear off to do something else, and come back at the end of the lesson. I was quite independent in the lesson. Once they'd got my stuff out of my bag and set me up next to my friends, they generally left me to it really.

CLASS TEACHER/FORM TUTOR

A class teacher works in a primary school and often has additional responsibility for an area of the curriculum. Primary school classes are usually comprised of pupils of the same age.

Secondary schools allocate pupils to a form tutor who, as well as having pastoral oversight of those children, also works within a particular faculty in the school.

A class teacher or form tutor with responsibility for a pupil with a 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.

EDUCATIONAL SUPPORT ASSISTANT (ESA)

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

EDUCATIONAL SUPPORT ASSISTANT

I started to notice that John was going to the toilet very frequently and spending increasing amounts of time in there. His mother informed me that he was leaking urine and having bowel problems. This was very embarrassing for him and he hadn't wanted to mention it to me. He was given medication to help with the problem. He was finding it difficult to rise from the toilet, even using bars, so an occupational therapist assessed the disabled toilet facilities and a higher toilet seat was provided.

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.

LUNCHTIME ASSISTANT

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.

ADVISORY TEACHERS

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 PSYCHOLOGIST

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.

It is important that you understand all the parents' needs. You might need to consider, for example, involving an interpreter if English is not their first language. And if they have a disability, you need to be aware of how that may affect 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.

FAMILY CARE OFFICER (FCO)

Family Care Officers are health or social care professionals employed by the Muscular Dystrophy Campaign. 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 FCO are available from the Muscular Dystrophy Campaign.

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.

4

EMOTIONAL AND PSYCHOLOGICAL ISSUES



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.

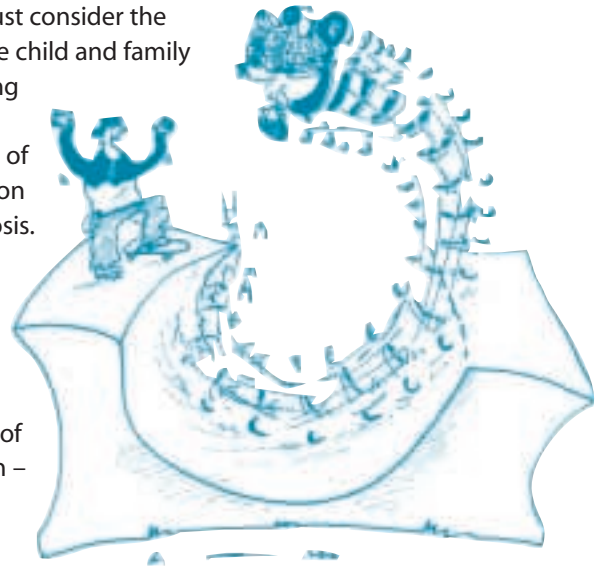


SUPPORTING OTHER PUPILS

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.

Schools must consider the views of the child and family on providing specific knowledge of the condition and diagnosis. Schools should also be aware of the availability of information – not always accurate – on the Internet.



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.

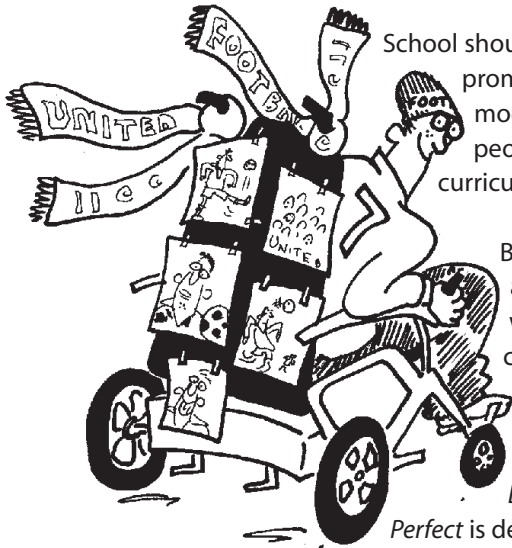
Often the most valuable support for a young person with a neuromuscular condition comes from another young person with a similar illness. Liaison with Family Care Officers or advisory teachers can provide opportunities for this.

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 integration 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.

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.

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.

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.

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.

PERSONAL CARE

Menstruation will bring new challenges for both the young woman and the staff involved in her personal care. The subject

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.

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”¹

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 Employment circular, *Supporting Pupils with Medical Needs*², 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’³ – 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.
4. A standard register for all schools.
5. A smartcard for pupils to carry with them, indicating what help they may need.

Appendix 1 includes a sample blank individual health care plan⁴ 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. Circular 14/98 Department of Education and Employment. *Supporting Pupils with Medical Needs*.

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 P.E., 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 ensure the pupil is

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.

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.

BEN

I used to have physiotherapists come into school. They'd get me out of the chair and put me onto mats and then do the physio and stuff. Sometimes you'd get kids walking past the window thinking 'what's happening there', you know. It was quite embarrassing because you felt different.

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.

SENIOR TEACHER

For James, swimming was a major benefit. Not only for health and mobility reasons but because it was one physical activity which he could access alongside his friends and peers, and this was an enormous boost to his self-esteem.

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/CALLIPERS

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. It is most likely they will need orthopaedic surgery on the ankles and tendons around the feet.

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

EDUCATIONAL SUPPORT ASSISTANT

Richard started to go to the baths with school. A risk assessment had been carried out for this. At first he changed with the boys under the supervision of the male teacher. I accompanied him, but he was able to get in and out of the pool himself. He wore armbands, as these made him feel more secure.

It soon became obvious that he was slowing down, taking a long time to get dressed and needing more assistance. He also needed the wheelchair to get to the school from the bus but there was no room for it on the bus.

Recently, I have been taking him in my car and the wheelchair comes with us. I now help him to change and accompany him in the water. He can join in with the other children if he wants, or do something different with me. He now feels secure, does not get cold while getting changed and we don't have to hurry back on the bus with the other children.

questions and seek reassurance from school staff. Physiotherapists, occupational therapists and Muscular Dystrophy Campaign Family Care Officers 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 a child's operation 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.

6

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

EDUCATIONAL SUPPORT ASSISTANT

Richard used his manual wheelchair during playtimes when he was particularly tired. It did create some problems. Obviously, no child wants an adult following them around the playground as it interferes with social interaction. His friends were allowed to push him but needed instructions on safety as there was a tendency to go too fast and disregard the safety of other pupils.

may ease any access difficulties if these pupils are first in the lunch hall.

PLAYGROUNDS

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 because of weakness in their upper limbs. 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 P.E. 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.

TOM

My first proud moment at primary school was when I did my cycling proficiency. Well, there was a wheelchair one too on stuff like driving. I did that and got a bronze award. I was called out in assembly alongside the people who'd done the cycling tests, so that was good.

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*.¹



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

1. *Adaptations Manual* 2nd Edition, 2004, Muscular Dystrophy Campaign.

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.

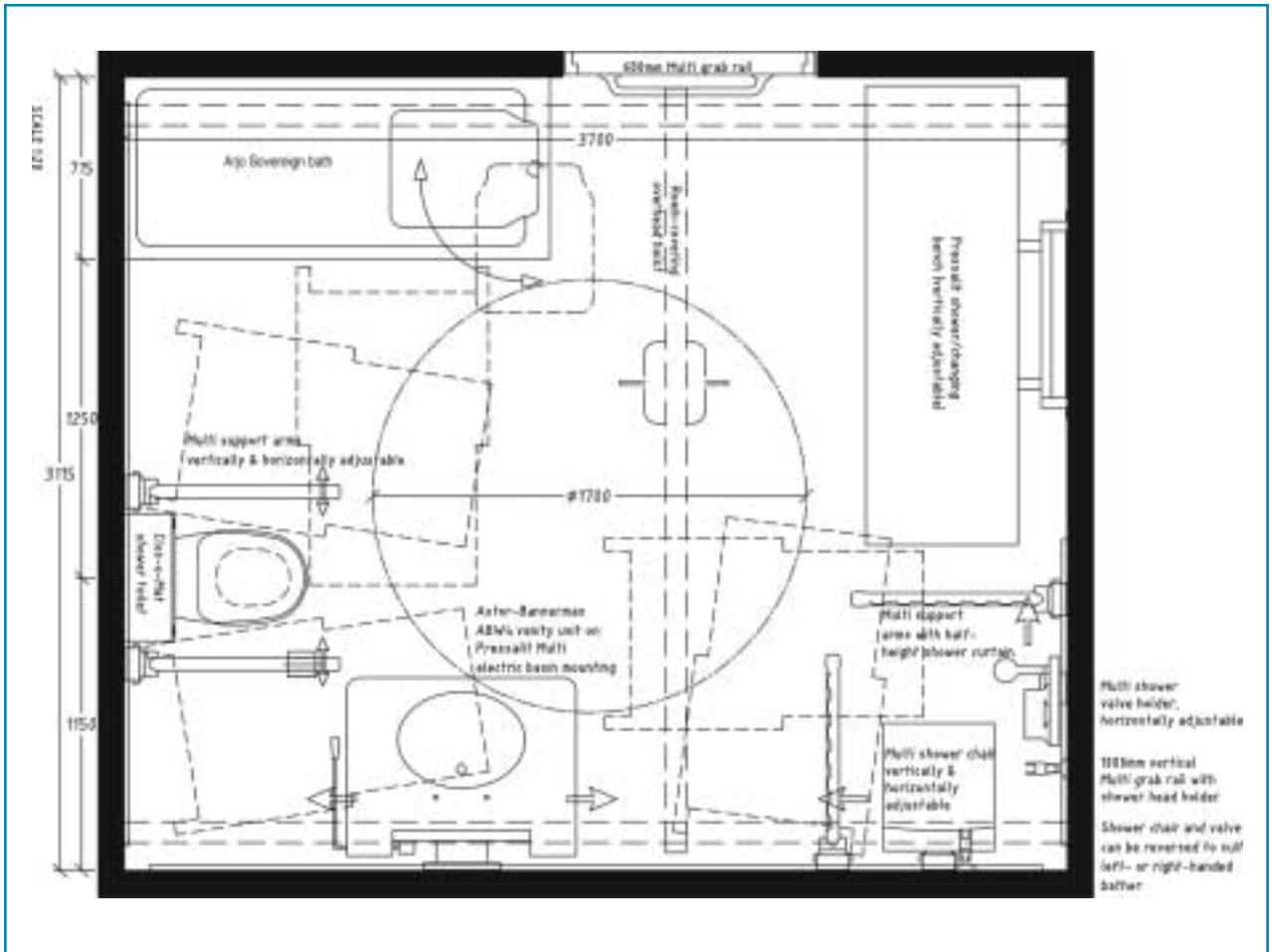
An occupational therapist should be involved with developing design and layout. While the initial impetus for the work may be the needs of a particular child, it is important, where possible, to design a room suitable for all disabled children. This can prove to be cost effective in the long term. Pressalit 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.

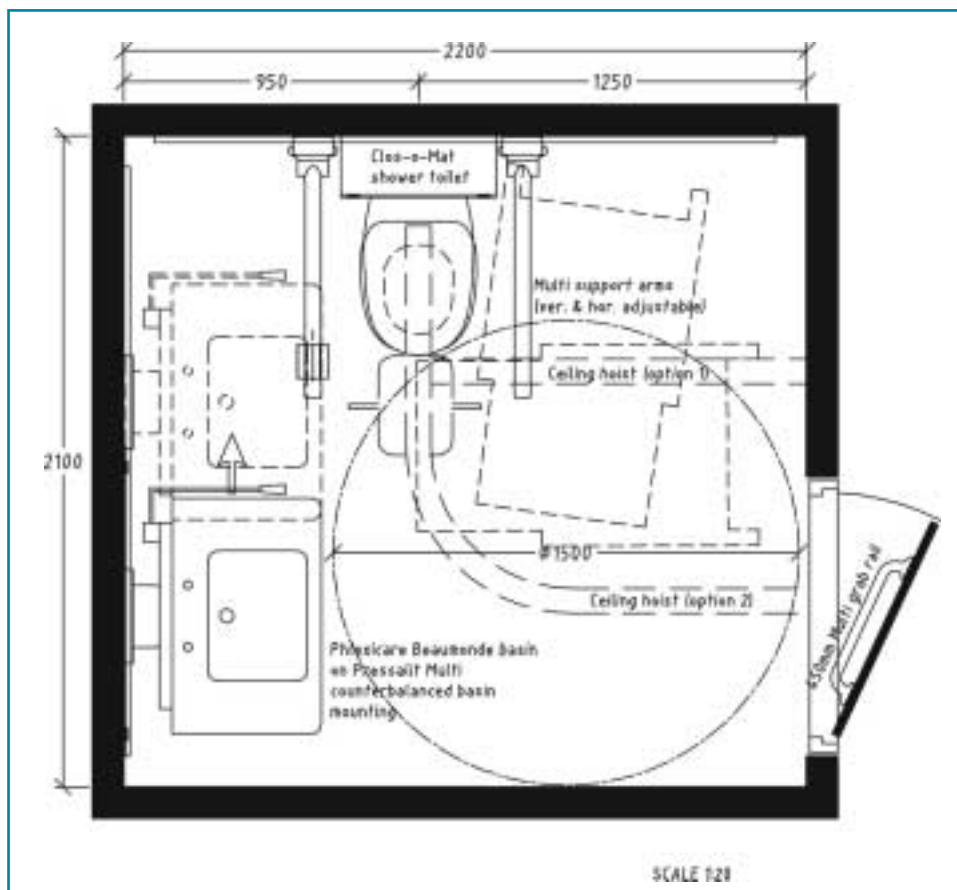
The following layouts from the *Adaptations Manual*, offer examples of appropriate facilities for schools.

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



Below is the possible layout for a toilet and basin area in a small room 2200 by 2100mm.



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.

A PARENT

After the school bus had picked up a number of young people, John spent nearly 45 minutes each way travelling to and from school. By the time he got home or to school he was exhausted.

7.1 SCHOOL'S RESPONSE TO PUPILS WITH SPECIAL EDUCATIONAL NEEDS

The Special Educational Needs Code of Practice¹ 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.

1. Special Educational Needs Code of Practice. November 2001. Ref: DfES/581/2001.

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;
- Set out for parents the procedures for drawing up a statement if it is deemed to be necessary to meet a pupil's special educational needs;
- Explain the timing of the assessment stages within the six month time limit;
- 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.

Inclusion should be a core thread, running through all aspects of school life. It should be intrinsic to the whole school vision and part of the personal philosophy of each member of the school. To be effective and successful, it needs to be part of a long-term plan for whole school improvement.

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.

The personal, social, health and citizenship education (PSHCE) curriculum can be used to encourage all youngsters to recognise right and wrong behaviour. Adult and peer mentoring schemes can also help young people talk in confidence.

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.

8

MOVING AND HANDLING CHILDREN

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 1¹. These can be adapted for use by your school, in conjunction with your local health trust.

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*²).
- 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.

² *5 Steps to Risk Assessment*. HSE Books. 1998. ISBN: 0717615804. www.hsebooks.com



9.1 PARTNERSHIP WORKING MAINSTREAM & SPECIAL SCHOOLS

An LEA's 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 LEA's 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 LEA's 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.

10.1 YEAR 9 TRANSITION PLANNING

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.

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.
- Connexions (see below)
- 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.

10.3 CONNEXIONS

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