SOCIAL, EMOTIONAL AND PSYCHOLOGICAL SUPPORT
Schools work in partnership with the multi-disciplinary team to support children with muscle-wasting conditions, along with their families. For this to be effective, schools must fully understand both the diagnosis and prognosis of the condition, and the physical changes that are likely to take place in the child during his or her time at school. SEN advisors and physical difficulties teaching advisors are employed by the LA, and can offer advice and information. The NCA and healthcare professionals will visit schools to give specific advice. They can also provide information towards the formulating of an EHCP (SEN Statement in Northern Ireland, Co-ordinated Care Plan in Scotland).

4.1 Dealing with diagnosis

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

Most families will have been given an accurate diagnosis and prognosis, but may be unable to emotionally process and deal with the information they have received. Some families choose to tell their child everything about the condition, some say nothing, and others give their son or daughter limited information. There is no right or wrong way. Each family finds their own way of managing this with the support of professionals, as and when needed, for direction and support.

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

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

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

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

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

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

Support for siblings

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

Many siblings can feel left out of what is going on, and may have feelings of loss, jealousy, guilt and anxiety. These are quite normal, as their lives have changed too. If you are concerned about the sibling of a child with a muscle-wasting condition, it is important to raise the subject, in a gentle manner, with the family and agree on an appropriate support plan. Siblings may benefit from having someone to talk to who is outside the family, and it could be helpful for them to know that there is an identified adult in school who can provide them with emotional support. A learning mentor could undertake this role. A book for siblings of children with muscle-wasting conditions is available free of charge from Muscular Dystrophy UK.

Staff support

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

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

Supporting other pupils

The whole-school approach should consider the emotional and psychological needs of all the children. Other pupils might not know the diagnosis, but keeping disability
on the timetable and regularly re-visiting it as a school can highlight and encourage an awareness of the general issues about disability and changing needs. For example, if one pupil needs to use a wheelchair sometimes, but walks at other times, this encouraging of awareness of children’s changing physical needs as a school combines an individual and a wider school approach. Special attention may also need to be paid to the child’s close friends.

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

4.3 The child’s needs

Support for the child’s mental health and wellbeing is essential. Professionals can provide this, but children will often seek support from those people they feel comfortable with at school. It may be that they will ask an ESA or a lunchtime carer searching questions about their condition. Often valuable support for a pupil with a muscle-wasting condition comes from another pupil with a similar condition. Liaison with a NCA/specialist nurse or local paediatrician can provide opportunities for this connection, or events and support groups organised by MDUK.

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

Working towards social inclusion can be difficult and it is important to give children the opportunity to integrate with their peers, without adult supervision. A ‘buddy’ or peer support system can be particularly helpful during break and lunchtimes to promote positive social interaction. Schools should also promote positive role models of disabled people throughout the curriculum.

**Behavioural challenges**

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

**Self-esteem and body image**

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

It is important staff members are aware, and find opportunities to enhance self-esteem by, for example, promoting opportunities to succeed and using positive disabled role models in teaching. The personal, social, health and citizenship education (PSHCE) curriculum may provide opportunities to develop self-esteem through related activities.
Depression and anxiety
All children can experience depression and anxiety. They may show this in a number of ways – lethargy, withdrawal, irritability, and changes in appetite and sleep patterns, lack of interest and loss of school performance. Staff should be aware of this possibility and closely monitor any impact on the child and manage the situation appropriately. These feelings are normal reactions to a progressive condition. If they are sustained over a long period of time, discuss with parents the possibility of seeking professional advice.

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

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

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

Personal care
Menstruation will bring new challenges for both the young woman and the staff involved in her personal care. The subject needs to be sensitively discussed between the pupil and, in most cases, her mother. Ideally this should happen before the start of her periods, so that consideration can be given to adding to the current personal care plan as changes occur. This avoids sudden changes and helps to smooth the process as much as possible.

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

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

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

Key strategies in dealing with a death
- Acknowledge the death, don’t ignore it. Do something to mark the fact that someone has died. Some schools release balloons; others may have a special assembly or pastoral service.
- Tell small groups before telling the
whole school. Be aware of any ‘best friends’ and do something different for them, if needed.
► This is a loss for the class as well as the school. Work out with the class what to do and be led by them and their reactions.
► Don’t change the layout of the classroom immediately, but do acknowledge that the young person isn’t there any more.
► Let teachers and other staff show their emotions and allow them to acknowledge that they are finding it hard. Offer additional support.

Further support:
► Cruse Bereavement Care
  www.cruse.org.uk
► Child Bereavement UK
  www.childbereavementuk.org
► Childhood Bereavement Network
  www.childhoodbereavementnetwork.org.uk
► Child Death Helpline
  www.childdeathhelpline.org.uk
► The Compassionate Friends
  www.tcf.org.uk
► Mind
  www.mind.org.uk
► Samaritans
  www.samaritans.org
► Winston’s Wish
  www.winstonswish.org.uk