

**Muscular  
Dystrophy UK**

Fighting muscle-wasting conditions



LC  
AMBU

**Ambulance action: improving emergency care  
for people with muscle-wasting conditions**

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## FOREWORD

Carrie is a disability blogger and freelance writer. She is also a member of Muscular Dystrophy UK's (MDUK's) Trailblazers, a network of young disabled people who campaign for change and, through lived experience, are experts in what life is like for young disabled people.

**“I live with the progressive condition, Ullrich congenital muscular dystrophy, resulting in contractures of the joints, a severe ‘S’ shaped scoliosis, and respiratory decline. I lost the ability to weight-bear at the age of 10, and now use an electric wheelchair to get around.**

**“Having endured several bouts of acute pneumonia, a collapsed lung and pleurisy, ambulances, A&E and hospital wards are all too familiar to me. Throughout my life, I have, on many occasions, required support from the emergency services. Each time it is necessary to relay every detail of my disability, and how it affects me. Worryingly, there is an apparent lack of basic knowledge about muscle-wasting conditions and their diversity.**

**“I cannot complain about the care and conscientiousness of the paramedics, nurses and doctors who have treated me over the years. However, I am concerned that I may someday be in a position where I’m unable to verbally communicate and answer their questions regarding my condition. For instance, it can be dangerous to give people with my condition supplementary oxygen, as we retain carbon dioxide. Failure to communicate this information can put lives at risk.**

**“To avoid such situations, it is vital that emergency care plans for people with a muscle-wasting condition, who are at a high-risk of needing emergency care, are made available to ambulance services.**

**“It is clear that work needs to be done to ensure people, like myself, who are living with a muscle-wasting condition, can access the emergency care we need to save our lives in a crisis. This is why MDUK’s Ambulance Action campaign is so important.**

**“I urge anyone reading this report, whether you have a muscle-wasting condition or you’re involved in the provision of emergency care, to contact Muscular Dystrophy UK to find out how to get involved.”**

Read more about Carrie in her online blog: [www.lifeontheslowlane.co.uk](http://www.lifeontheslowlane.co.uk)



## EXECUTIVE SUMMARY

Muscle-wasting conditions are rare and in some cases, owing to a heightened risk of health complications, can put people at an increased risk of requiring emergency care.

Some people with a muscle-wasting condition will have specific care needs, and it's vital emergency services are aware of them. When ambulance services do not have this information, the person they are treating is at risk of receiving unsafe and dangerous care.

There are some great examples of neuromuscular healthcare teams and ambulance services taking action to ensure people with a muscle-wasting condition get the emergency care they need. However, too many people find themselves in situations where the health professionals treating them don't have the knowledge required to provide the right care.

In the past decade, MDUK has supported two NHS audits in the south east of England, of unplanned admissions of people with neuromuscular conditions. After the first audit, MDUK produced a range of emergency alert cards and care plans to help improve healthcare support in an emergency. We surveyed 52 people with muscle-wasting conditions, as well as their family members, about their experiences of emergency care.

### Key findings in this report include:

- alarming accounts of people being treated by A&E staff and ambulance crews who lacked knowledge of how to provide the right care. More than 70 percent of respondents thought A&E staff didn't have a basic understanding of their condition and emergency care needs. More than half (55 percent) believed that the ambulance crews who treated them didn't have this knowledge.
- a postcode lottery in emergency care for people with muscle-wasting conditions. It cannot be right that the ability to receive safe and effective emergency care could depend on where you live. There are examples of neuromuscular healthcare teams and ambulance services working effectively on emergency care planning. But too often ambulance services don't have access to the emergency care plans of people with muscle-wasting conditions, who are likely to need their support.
- a need for MDUK to work more effectively with neuromuscular healthcare teams to ensure people with muscle-wasting conditions get the care they need in emergency situations. More than 90 percent of people who responded to our emergency care survey did not have an MDUK alert card when they received emergency care.

These findings highlight the need to take action to ensure the lives of people with muscle-wasting conditions aren't lost because of a lack of knowledge within emergency care. That is why MDUK has developed this report to share best practice and encourage discussion about how best to ensure that no matter where in the UK a person with a muscle-wasting condition lives, they can access the highest standard of emergency care.

We are calling on the government, NHS trusts and ambulance services to take action to make this a reality.

## RECOMMENDATIONS

### 1. Supporting neuromuscular healthcare teams – government and NHS England

Take action to ensure that neuromuscular healthcare teams have the staffing and resources they need to develop emergency care plans for everyone who needs one.

Having a clear and well-documented emergency care plan ensures that people with muscle-wasting conditions get the care they need. There is also evidence that having an emergency care plan is one of the most important measures in preventing expensive, unplanned hospital admissions for people with muscle-wasting conditions.<sup>1</sup>

### 2. Developing ambulance service flagging systems – NHS trusts

Work together with all NHS ambulance services and specialist neuromuscular services to ensure a 'red flagging' system is in place to alert ambulance crews to the emergency care needs of people with muscle-wasting conditions, who are likely to need their support. Call handlers are alerted to the fact that someone at a high risk of requiring specialist emergency care lives at the address the ambulance has been called to. This information can then be shared with ambulance crews.

Many ambulance services are able to receive emergency care plans via a secure email inbox. This information can then be added to the service's 'flagging' system. Another option is to give people an emergency care plan to keep at home. An alert can then be added to the service's flagging system, ensuring ambulance crews are aware that the person they are treating has a patient-held care plan.

We encourage ambulance services and the NHS to work to develop new approaches to make it easier for ambulance crews to access care records or individual care plans for people with rare conditions.

### 3. Improving emergency health professionals' knowledge of muscle-wasting conditions – ambulance services

Work with MDUK to ensure their ambulance crews and A&E staff have a basic understanding of muscle-wasting conditions.

MDUK has produced a range of online modules, which support health professionals to improve their knowledge of how to provide the best possible care for people with muscle-wasting conditions. This includes our introductory online module. After completing this course, participants are able to understand what muscle-wasting conditions are, the common ways they can affect a person's body, and the range of health professionals involved in providing care.

We can also work with specialist clinicians to provide tailored study days on muscle-wasting conditions for emergency care staff. We would also welcome a partnership to produce an online training module specific to the provision of emergency care.

<sup>1</sup> Scalco, S. R. et al (2017). *Re-Audit on Unplanned Admissions in Patients with Neuromuscular Diseases*. MRC Centre for Neuromuscular Diseases. Available at: <https://bit.ly/2FIGsml>

#### 4. Increasing awareness of MDUK's alert cards – neuromuscular healthcare teams

Work with MDUK to ensure that, where applicable, everyone with a muscle-wasting condition receives one of our alert cards.

MDUK has produced a range of condition-specific alert cards that outline symptoms and treatment needs that a non-specialist clinician would need to know when treating a person with that condition.

#### Background

People living with one of the more than 60 rare or very rare progressive muscle-weakening and wasting conditions often face the challenge of being treated by health professionals who don't fully understand their care needs. This can have potentially fatal consequences in emergency care situations. For example, it can be life threatening for a person with Duchenne muscular dystrophy to receive supplementary oxygen during a respiratory crisis.

MDUK has heard from people across the UK who found that the ambulance crews and A&E staff treating them didn't have the knowledge to provide the best possible care. In response to this, we worked with specialist clinicians, ambulance services and people with muscle-wasting conditions to develop new initiatives and resources to improve emergency care.

#### Alert cards

Alert cards enable anyone with a muscle-wasting condition, and their families, to easily inform emergency healthcare professionals of the vital and specific care needs of the person they are treating. These credit-card sized booklets cover a wide range of condition-specific symptoms and treatment needs. They also include important contact information for the person's specialist neuromuscular and respiratory teams. There is widespread recognition of the benefits of our alert cards among both health professionals and people with muscle-wasting conditions; we have distributed over 20,000 of these since 2009. At the time of publication, we have alert cards that cover the following conditions:

- Duchenne muscular dystrophy
- Charcot-Marie-Tooth disease (CMT)
- Becker muscular dystrophy
- limb girdle muscular dystrophy
- myotonic dystrophy types 1 and 2
- spinal muscular atrophy (SMA) (types 1,2,3)
- congenital muscular dystrophy
- facioscapulohumeral muscular dystrophy (FSHD)
- undiagnosed muscle-wasting conditions (for people who have been diagnosed but the specific condition is yet to be identified)
- oculopharyngeal muscular dystrophy (OPMD)
- inclusion body myositis (IBM)
- GNE myopathy.

Please contact us at [info@muscular dystrophyuk.org](mailto:info@muscular dystrophyuk.org) to order some of our alert cards.

Jeanette Charlton from Cambridgeshire was able to use one of MDUK's alert cards to make sure her husband, who has myotonic dystrophy Type 1, received excellent emergency care:

“Two years ago my husband became unwell, experiencing a rising temperature, severe coughing and symptoms of delirium. After his condition worsened over a couple of days, I called 111 and, in addition to describing his current symptoms, used Muscular Dystrophy UK's alert card to describe the specific issues that affect adults with his condition.

“Paramedics arrived within an hour and stayed until my husband's symptoms were stabilized; and organised two out-of-hours visits from doctors during the night. In addition to this, the GP phoned the next morning and visited the house later that day.

“My husband would not have accessed the outstanding care he received if I had not been able to use Muscular Dystrophy UK's alert card. The card gave me the information I needed to ensure the emergency services knew how to provide the right care. I think that alert cards are particularly beneficial for families who may lack the confidence, skills or resources to access the care they need.”

### Ambulance service flagging systems

We have looked at how to build on the success of our alert cards in ensuring people with muscle-wasting conditions receive the care they need in emergencies. MDUK is working to ensure that the emergency care needs of people with muscle-wasting conditions are made available to ambulance crews through ambulance service flagging systems. The priority is for this support to be made available to people identified by their specialist neuromuscular healthcare team as being at a high risk of needing emergency care.

Ambulance service flagging systems work slightly differently across the UK. The most widely used model involves neuromuscular healthcare teams sharing emergency care plans with a person's local ambulance service. This is then added to the ambulance service's flagging system, and their care plan is linked to their address. When a 999 call is received from a person's address, the call operator is aware they have an emergency care plan and is then able to share this with the health professionals responding to a call.

## FINDINGS FROM THE AMBULANCE ACTION PROJECT

### Experience of people with muscle-wasting conditions

People from across the UK have been in touch with MDUK to share their experiences of emergency care. Overwhelmingly, people have found that the emergency care staff treating them have been conscientious and committed to providing the right care. But this has frequently coincided with a lack of understanding of muscle-wasting conditions and the specific care needs of the person they were treating.

### Here are some of these accounts of emergency care:

- “Daniel has had emergency admissions where doctors have ignored what I have said about the need to contact and involve his neuromuscular healthcare team. Without the right specialist support, he won’t get the care he needs. On one occasion he wasn’t put on the right antibiotics for the respiratory problems he had, which can turn into a very serious problem for someone with Duchenne.”**  
Phillippa from Eastbourne, whose son Daniel has Duchenne muscular dystrophy
- “The paramedics didn’t have an understanding about my condition and care needs. Emergency care staff need to be educated about muscle-wasting conditions like congenital muscular dystrophy so they can make sure people like me get the right care.”**  
Vicki from Berkshire, who has congenital muscular dystrophy
- “Neither the ambulance or the Accident and Emergency department had the piece of plastic needed to feed oxygen through my ventilator circuit. At one point I literally thought to myself ‘am I going to die because nobody can find the correct piece of plastic tubing?’”**  
Charlotte from Nottingham, who has myofibrillar myopathy
- “After reading your advice I was able to advise the paramedics about oxygen and muscular dystrophy, which they weren’t aware of.”**  
Tracie from Coventry, whose father has limb girdle muscular dystrophy type 2
- “Fergal’s experience of emergency care shattered my confidence in the support we would receive should the need arise again. However, all family members now carry Muscular Dystrophy UK alert cards and through our specialist nurse the ambulance service is aware of any issues our son may have.”**  
Mary from Omagh, whose son Fergal has Duchenne muscular dystrophy

### Working together to improve emergency care

MDUK is currently working with nine of the UK’s 13 ambulance services, alongside people with muscle-wasting conditions and specialist health professionals, to agree action to improve emergency care.

We have found that ambulance services have the technology in place to ensure that emergency care plans are made available to paramedics and first responders before they respond to a

call. The number of people whose details need to be added to ambulance services' flagging systems is relatively small, with most regions estimating it to be in the low hundreds.

There are challenges to developing services' flagging systems to benefit people with muscle-wasting conditions. For example, agreement is required on: which group of people will have information added; the type of information that will be added to the flagging system; the format used to add information; timescales for reviewing information once it's added; and who will be permitted to add information. Despite these challenges, there are examples across the UK of neuromuscular healthcare teams and ambulance services working together to improve emergency care for people with muscle-wasting conditions.

## London

The London Ambulance Service NHS Trust 'Coordinate my Care' patient electronic record system is used by the service to ensure people's personalised urgent care plans are available 24/7 to all those who care for them. Neuromuscular healthcare teams are now able to add patients to a list of people who should automatically be treated as high-priority cases when 999 or 111 calls are received from their addresses.

Ambulance crews can also access individualised care plans, meaning that people added to the system have the security of knowing that paramedics have the right information to give them the care they need.

 **At London Ambulance Service we gain considerable benefit from having access to Electronic Palliative Care Coordination Systems and being able to share knowledge about patients with specialist needs.**

**"Our long-standing use of the Coordinate My Care system allows us rapid access to critical information about a patient, helping us to provide the right care, at the right time and in the right place. Coordinate My Care provides access to both a person's preferences for care and specialist information from multidisciplinary teams. This supports our clinicians when making complex decisions and improves patient outcomes."**

Georgina Murphy-Jones, Macmillan Paramedic Programme Lead at London Ambulance Service

## West Midlands

The neuromuscular healthcare team at the Robert Jones and Agnes Hunt Orthopaedic Hospital in Oswestry have developed a 'traffic light' system for identifying people at high risk of needing emergency care. People's emergency care plans are then shared with the West Midlands Ambulance Service NHS Foundation Trust. Call handlers are able to identify if somebody has one of these plans and will inform the medics attending that call. Ambulance crews are then able to contact their colleagues and retrieve this information.

## Northern Ireland

MDUK has been working with the Northern Ireland Ambulance Service Health and Social Care Trust, the neuromuscular healthcare team in Belfast, and patient representatives to improve emergency care. There is now a flagging system in place, which ensures that ambulance crews are made aware

if the person with a muscle-wasting condition, who they are treating, has a patient-held emergency care plan. They can then view this when they arrive at the person's address.

## East Midlands

Some muscle-wasting conditions can cause weakness in the muscles required to move air in and out of the lungs, leading to respiratory difficulties. It is therefore essential that emergency healthcare professionals have the knowledge they need when treating people at risk of potentially fatal respiratory complications.

The neuromuscular healthcare team at Nottingham University Hospitals NHS Trust and the East Midlands Ambulance Service NHS Trust are working together to make sure vital information is shared. The emergency care plans of people with complex respiratory needs are made available to ambulance crews through the ambulance service's flagging system. The information is first sent to them by the respiratory nurse working with this group of people.

 **The patients I work with have complex respiratory difficulties and often rely on breathing equipment. Supporting them to manage their condition requires a high-level of clinical knowledge, as they often have specific clinical needs.**

**“For example, some patients with a muscle-wasting condition require non-invasive ventilation rather than direct oxygen. If paramedics are unaware of this it could lead to serious respiratory complications. These individuals are often at high risk of needing emergency care, and that is why it is essential that their emergency care needs are highlighted to ambulance crews.”**

Juliet Colt, Specialist Neuromuscular Home Ventilation Nurse at Nottingham University Hospitals NHS Trust

## Unplanned admissions

As shown in shown in the comments from health professionals, an emergency care plan can make a crucial difference in an emergency. An emergency care plan provides concise, relevant, rapidly accessible clinical recommendations for use in an emergency. Not having one can be a considerable barrier to ensuring that people receive the emergency care they need. In 2017, MDUK collaborated with the MRC Centre for Neuromuscular Diseases and the Department of Health on a project to re-audit data<sup>2</sup> from an earlier 2012 audit<sup>3</sup> on unplanned admissions for people with muscle-wasting conditions.

Unplanned hospital admissions relating to muscle-wasting conditions across four specialised commissioning groups were examined: London, South Central, South East Coast and the East of England. In total, 576 unplanned admissions were reviewed, for 395 people with muscle-wasting conditions.

The re-audit found that, while there had been improvements in reducing unplanned admissions, there was only a clear emergency care plan in place for five of the admissions reviewed. The study also identified that having an emergency care plan was one of the factors that could have prevented unplanned admissions.

<sup>2</sup> Scalco, S. R. et al (2017). *Re-Audit on Unplanned Admissions in Patients with Neuromuscular Diseases*. MRC Centre for Neuromuscular Diseases. Available at: <https://bit.ly/2FIGsml>

<sup>3</sup> Jaffer, F. et al (2012) *Audit of unplanned admissions in neuromuscular patients: a collaborative audit*

As well as helping to deliver better outcomes for people with muscle-wasting conditions, emergency care planning can help save the NHS money. Given that a week's stay as an inpatient in a specialist NHS ward is over £13,000<sup>4</sup>, unplanned admissions of people with muscle-wasting conditions are contributing to unnecessary costs to healthcare services<sup>1</sup>. This is in addition to increasing the risk of people with muscle-wasting conditions being provided with inadequate and harmful treatment; this will not only have an impact on the individual but will also lead to further care and treatment costs.

MDUK is committed to working with neuromuscular healthcare teams and NHS commissioners to ensure that services have the staff and resources they need to provide effective emergency care planning.

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## **Getting the emergency care you need should not depend on where you happen to live.**

A failure to take account of an individual's emergency care needs can have potentially fatal consequences. Neuromuscular healthcare teams across the UK need to work with ambulance crews to ensure they have the information required to provide the best possible emergency care for people with muscle-wasting conditions.

One potential barrier to effective emergency care planning is the risk that some neuromuscular clinical teams are overstretched by providing care in the here-and-now. They may also lack the staffing and resources to develop and share emergency care plans with ambulance services. The Government and NHS commissioners must take action to address these issues.

MDUK is committed to working with people with muscle-wasting conditions, along with their families, healthcare professionals and the NHS, to address the gaps in care highlighted in this report.

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<sup>4</sup>[www.muscular dystrophyuk.org/assets/0002/4945/Muscular\\_Dystrophy\\_Campaign\\_Invest\\_to\\_Save\\_Report.pdf](http://www.muscular dystrophyuk.org/assets/0002/4945/Muscular_Dystrophy_Campaign_Invest_to_Save_Report.pdf)

## GET INVOLVED

If you have been affected by any of the issues raised in this report, and would like to share your story and get involved with our Ambulance Action campaign, please get in touch with us at [info@musculardystrophyuk.org](mailto:info@musculardystrophyuk.org) or call 020 7803 4826.

### What are muscle-wasting conditions?

There are about 60 forms of muscular dystrophy and related neuromuscular conditions. These conditions cause muscles to weaken and waste over time, leading to increasing disability. The conditions may affect not only the muscles in the limbs, but also those of the heart and lungs, sometimes significantly shortening life expectancy.

Many of the conditions are low incidence, rare conditions, with some regarded as very rare or ultra-orphan. Muscular dystrophy and related neuromuscular conditions can be genetic or acquired and, while there has been exciting progress in developing new medicines, overall there remains a lack of effective treatments or cures available.

### About Muscular Dystrophy UK

Over 70,000 young children and adults live with muscle-wasting conditions in the UK today. There's no cure, it limits and, in many cases, shortens lives. Muscular Dystrophy UK funds pioneering research into treatments and cures to improve lives today and transform those of future generations. We offer information, advice and support to help people live well with a muscle-wasting or associated condition. And we're driving change to see better care so that people can stay active, independent and connected.

## TO FIND OUT MORE GO TO:



Helpline: 0800 652 6352



Research Line: 020 7803 4813



[info@musculardystrophyuk.org](mailto:info@musculardystrophyuk.org)

Muscular Dystrophy UK, 61A Great Suffolk Street, London SE1 0BU  
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