

**Muscular
Dystrophy UK**

Fighting muscle-wasting conditions



Missing out

The case for care advisor provision in
London and the South East

August 2016



1. Executive summary

This report draws on the views and experiences of individuals and families affected by muscle-wasting conditions, as well as specialist neuromuscular health professionals from the London and the South East Coast Neuromuscular Clinical Network.

There are a number of serious concerns regarding the provision of neuromuscular care advisor and care co-ordinator support in London and the South East Coast area for individuals and families affected by muscle-wasting conditions. The co-ordination of care that a neuromuscular care advisor provides is vital for this patient group to ensure they are able to access both specialist and community services, which will improve their quality of life.

There are currently 61 NHS-funded care advisor and clinical nurse specialist roles across the UK, supporting the 70,000 people living with muscle-wasting conditions, as well as their families. However, there are no neuromuscular care advisor and just seven clinical nurse specialists based at the eight specialist neuromuscular centres in London. These centres provide healthcare not only for the estimated 9,000 people in London who are affected by muscle-wasting conditions, but also for a significant number of the further 5,000 in the South East Coast area of England. This region has no specialist neuromuscular centre at all.

Up until June this year, King's College Hospital NHS Foundation Trust funded one care advisor. However, the previous post-holder has now left the role and there is an ongoing gap in care for patients, with no recurrent funding guaranteed.

In effect, this means that 13 percent of the UK's care advisor and clinical nurse specialist support is based in London and the South East Coast. This, even though 27 percent of the 70,000 people in the UK affected by muscle-wasting conditions live in the region. The current level of care advisor support in the region needs to be more than doubled. This will ensure patients in the region are receiving an equitable level of care advisor support, compared with other regions of the UK.

In addition, with no neuromuscular centre in the South East Coast region, people affected by muscle-wasting conditions living in the area have to travel long distances to London to receive specialist healthcare.

Recommended immediate action:

NHS England to provide funding as a matter of urgency for three neuromuscular care advisor roles at King's College Hospital NHS Foundation Trust, Barts Health NHS Trust and The Royal Free NHS Foundation Trust. This will ensure they are adhering to the NHS neurosciences specification for adults.

It is also vital that Clinical Commissioning Groups (CCGs) in the South East Coast fund a neuromuscular care advisor role as there is no specialist neuromuscular centre in the region.

2. Background

Neuromuscular care advisors provide practical and emotional support for families affected by muscle-wasting conditions. They also offer advice and information, supporting physical and emotional wellbeing through regular clinics, and educating other local health professionals.

Neuromuscular care advisors work with statutory service providers, education authorities and other professionals to provide a regional point of contact for information and advice. They are there for those affected by muscle-wasting conditions, as well as their families and the professionals working with them. They also empower people to advocate for the provision of appropriate locally-based services and facilities to meet their needs.

Care advisors are often the first and most vital point of contact for an individual and their family when diagnosed with a muscle-wasting condition. Common key areas of work for a care advisor include:

- ▶ playing a key role in specialist neuromuscular and transition clinics
- ▶ co-ordinating the care of patients between clinic appointments and, in so doing, helping to avoid unplanned admissions
- ▶ maintaining links with local specialist clinicians to ensure information about newly-diagnosed patients – both children and adults – is passed on
- ▶ conducting home, school, tribunal and workplace visits
- ▶ liaising with schools and the workplace
- ▶ acting as a resource for other professionals, e.g. teachers, to promote best practice in the care and support of people with muscle-wasting conditions
- ▶ taking the lead in organising local information days for patients, carers and professionals.

While the number of NHS-funded neuromuscular care advisor roles across the UK has continued to rise since 2011, there still remains a huge gap in London and the South East Coast region. There is currently no care advisor role based in London to co-ordinate the care of patients living in the South East.

There are seven clinical nurse specialists based in London, who are available to attend clinic appointments. However, owing to clinical commitments, they cannot provide the level of practical support in between appointments that neuromuscular care advisors can. This means that although excellent specialist consultant-led neuromuscular healthcare is available in London, there is currently no capacity to offer the highest level of care co-ordination in the community.

Clinical nurse specialists

Neuromuscular clinical nurse specialists are required to focus on the clinical need of patients, and do not have the capacity to offer the level of community care co-ordination that neuromuscular care advisors have. This means they might be unable to keep track of a patient's care outside of clinics. In turn, if there were to be a change in a person's condition, this could not only leave the patient vulnerable, but also have a severe impact on the NHS via the cost burden of an unplanned emergency admission.

This leaves the estimated 14,000 individuals with muscle-wasting conditions, living in London and the South East, facing a huge gap in the expert care they require. This can lead to potentially avoidable complications in their health, owing to a lack of co-ordination.

3. The national picture

The gap in neuromuscular care advisor support in London and the South East is further highlighted by looking at the number of NHS-funded care advisor roles now in post in other areas of the UK. There are 61 neuromuscular care advisor and specialist neuromuscular nurse roles spread across the UK.

Table 1 (Appendix 1) shows that on average in other areas of the UK there is a care advisor for every 1,665 people with muscle-wasting conditions. By contrast, in London and the South East Coast, although there are seven clinical nurse specialists in post, there are no care advisors to support the estimated 14,000 people with muscle-wasting conditions who live in the region.

To ensure the service in London and the South East Coast meets the standard being set elsewhere in the UK, an additional seven neuromuscular care advisor roles would have to be funded. While this is a long-term goal, there is an urgent need for funding to be provided for three neuromuscular care advisor roles in the current year. These would be based at King's College Hospital, Barts Health and the Royal Free. A fourth neuromuscular care advisor role funded by South East Coast CCGs is also vital.

4. Investment

One full-time neuromuscular care advisor role costs the NHS around £30,000 - £40,000 (NHS Band 7) per annum, which would require a potential total investment of £249,627 a year to cover the cost of seven care advisor roles.

However, a recent audit of unplanned emergency admissions of people with muscle-wasting conditions, across London and the South East¹ found that 37.5 percent of admissions were preventable, with a further 4.9 percent possibly preventable. The 2012 audit found that the most common measures that could have been taken to prevent admissions included:

- ▶ surveillance of a patient's condition (29.9 percent)
- ▶ access to neuromuscular services (25.7 percent)
- ▶ having an emergency plan in place (15.5 percent).

¹http://www.cnmd.ac.uk/documents/AIAU_NMD_Emg_Adm_Audit_2012.pdf / *Unplanned admissions of neuromuscular patients*

These are all key factors in a care advisor's provision of care to people with muscle-wasting conditions.

By ensuring that the seven care advisors are funded, this co-ordination of care of patients outside of clinics could substantially reduce the number of unplanned emergency admissions for people with muscle-wasting conditions. This currently costs the NHS **£15.9m** per year.

This figure is based on the fact that it is estimated that for people with muscle-wasting conditions, there are a total of 5,485 unplanned emergency admissions a year in London and the South East². Each admission costs an average of £2,890.18, which leads to expenditure of £15,850,820 a year.

5. Funding

There are two main funding avenues to secure the long-term funding of seven neuromuscular care advisor roles in London and the South East. These involve trust funding and CCG funding, and are outlined below.

Trust funding

Health professionals have told Muscular Dystrophy UK that five of the required seven neuromuscular care advisor/co-ordinator roles should be based at neuromuscular centres in London. These roles could be individually funded by the following trusts:

- ▶ University College Hospitals London NHS Foundation Trust, Queen Square (neurosciences centre)
- ▶ Barts Health NHS Trust (neurosciences centre)
- ▶ The Royal Free NHS Foundation Trust (neurosciences centre)
- ▶ King's College Hospital NHS Foundation Trust (neurosciences centre)
- ▶ Evelina Children's Hospital, part of Guy's and St Thomas' NHS Foundation Trust (paediatrics neurosciences centre).

Three of these centres, (Barts Health, The Royal Free and King's College Hospital) are of high priority as they are not currently adhering to the neurosciences specification.

In addition, there should be two clinical nurse specialist roles to be funded by:

- ▶ St George's (neurosciences centre)
- ▶ King's College Hospitals (neurosciences centre).

²<http://hub.muscular-dystrophy.org/wp-content/uploads/2014/08/Invest-to-Save-report.pdf> / *Invest to Save Report*

All of these centres are designated NHS England neurosciences and paediatric neurosciences centres. This means that they should abide by what is set out as necessary for a neuromuscular service to provide in the NHS England's neurology service specification³. The service specification outlines the importance of a multi-disciplinary team in providing care, and specifically mentions the importance of a care co-ordinator as a part of that team.

The care of all patients should be led from a regional specialist neuromuscular centre with a specialist multi-disciplinary team (MDT) providing regular local clinics. The specialists MDT team should comprise of neuromuscular consultants, neuromuscular physiotherapist, neuromuscular nurse, occupational therapist, speech and language therapist (SALT), dietician, psychologist and neuromuscular care co-ordinator.

2013/14 NHS Standard Contract for Neurosciences: specialised neurology (adult)

Clinical Commissioning Group (CCG) funding

Two further neuromuscular care advisor roles could be funded by CCGs clustering in this region. This is necessary, as there are no specialist neuromuscular centres in the South East Coast region (Kent, Surrey East and West Sussex) that could host and fund a care advisor role themselves. This leaves the responsibility with CCGs to fund the roles.

As care advisors have a community outreach element to their roles, there is a precedent for them to be funded by CCGs. This has been achieved by CCGs clustering across the East of England to fund three care advisor roles, based at Addenbrooke's Hospital in Cambridge, but covering different areas of the East of England. CCGs in South and West Yorkshire have also clustered to permanently fund three specialist neuromuscular physiotherapist roles, which have the remit to work with community physiotherapy teams.

In this model, CCGs split the cost of the role funding between them, based on the patient population the role will benefit. For example, in Yorkshire, Sheffield CCG took the lead in funding the two South Yorkshire physiotherapist roles.

Families in the South East Coast region, as well as those in the East of England and Yorkshire and Humber, are spread out across the region with great distances to travel to a neuromuscular centre.

Even without a neuromuscular centre nearby, people living with muscle-wasting conditions receive better co-ordination of care from care advisors. This includes encouragement to attend clinic appointments, the option of home visits, and a local health professional who can advocate for their care.

Care advisor support has dramatically improved the healthcare people receive in the East of England. Addenbrooke's Hospital in Cambridge recently received a Muscular Dystrophy UK Centre of Clinical Excellence award, owing to its growing stature in better healthcare provision for a larger cohort of patients.

³<https://www.england.nhs.uk/wp-content/uploads/2013/06/d04-neurosci-spec-neuro.pdf> / *NHS standard contract for neurosciences*

Key next steps for CCGs to consider clustering to fund neuromuscular care advisors:

- ▶ identify where best to house CCG-funded neuromuscular roles in the South East Coast
- ▶ work with NHS England commissioners to establish which CCG groups in the region already cluster to fund roles, similar to those in Yorkshire
- ▶ create a funding plan/business case for CCGs to create neuromuscular care advisor roles
- ▶ gather support from relevant CCGs to split-fund a neuromuscular care advisor role in line with their population of people living with muscle-wasting conditions
- ▶ ensure roles are funded as soon as possible.

6. Case studies

Muscular Dystrophy UK regularly hears from individuals and families living with muscle-wasting conditions who have difficulty getting vital healthcare owing to the lack of care advisor support:

Sulaiman Khan, from Woodford Green, who has congenital muscular dystrophy:

“Being unable to access the support of a care advisor has had a hugely negative impact on my healthcare. It has meant that outside of my clinic appointments, I have no-one to help co-ordinate my care between all the different health professionals that I need to see in the community.

“This is a big issue as in between clinic appointments my condition often changes, which can be in the form of potentially life-threatening chest infections. Without the support of a care advisor to advise me on the best methods to ease these infections, I usually end up having lengthy hospital stays. In the past year, I have even been rushed to hospital in an ambulance because of these infections, and the lack of co-ordination of care I receive to ensure they are better managed in the community.”

Phillippa Farrant, from Eastbourne, whose son Dan has Duchenne muscular dystrophy:

“Despite receiving expert healthcare from neuromuscular teams throughout Dan’s life, we have never been able to benefit from the support of a neuromuscular care advisor. This lack of support has meant that sometimes Dan and I have struggled to access all of the services he needs, in a timely manner.

“Not being able to access these services can have a hugely damaging effect on our lives, and you do not always feel supported. Especially for Dan, whose health can drastically change at any moment with respiratory and cardiac implications to his condition.

“Having access to a neuromuscular care advisor that we could speak to about these changes and help plan for them would be hugely beneficial for our quality of life and Dan’s healthcare.”

Romina Puma, from London, who has facioscapulohumeral muscular dystrophy (FSHD):

"I haven't really been able to access a care advisor, but I think if I did it would be really helpful. I can think of several occasions where speaking to a care advisor could have helped. I really struggled with being rehoused; it took me over a year doing it by myself and I'm sure with the help of a care advisor, it would have been much quicker. They could help with other things like getting the right support such as aids in the house, or knowing where to go for therapies."

Sue Elsegood, from London, who has limb girdle muscular dystrophy:

"I think care advisors are very important and it would be lovely if I had access to one. A care advisor would have much more overall knowledge of the support available, or what equipment might help you, than a non-specialist would. If you're not seeing a specialist then, to be honest, you're lucky if you get the right information. You can ask friends with similar conditions or if you happen to ask doctors the right questions you can get snippets of information."

Glen Cady, from London, who has facioscapulohumeral muscular dystrophy (FSHD):

"Having access to a care advisor would be very beneficial as it would give you a central point to contact, especially for information. You have the internet, library, doctors' surgeries, hospitals, word of mouth. With all these sources of information, a care advisor would be so much better as a source of information and so much easier."

For individuals and families living with muscle-wasting conditions, who have access to a regional care advisor, the benefits are clear. This demonstrates the vital need for permanent, continued funding of a care advisor role. This makes it even more concerning that the role based at King's College Hospital has been lost.

Parents of Luke (13), from Kent, who has Duchenne muscular dystrophy:

"Being parents of a child with a complicated condition like Duchenne muscular dystrophy, we are faced with a growing number of decisions to make on our son's health and wellbeing. We have to deal with a wide range of medical and practical issues, including physiotherapy, access issues for wheelchairs, the correct type of wheelchairs, access and access equipment outside, around the home and at school. We have to deal with physiotherapists, occupational therapists, our GP, cardio specialists and neuromuscular specialists.

"Luke's condition affects every aspect of normal life, both day and night, and at the same time we have to take Luke's emotional wellbeing into account. As Luke's condition is progressive, we are having to adapt and take on new challenges at every step. We can honestly say that without the support of our care advisor, who is able to provide advice not only to us but also to the health professionals who may not have had to deal with muscular dystrophy before, Luke would not have had the same care that he has received.

"As parents, we have received first-class expert advice from someone who has first-hand experience of dealing with the issues surrounding muscular dystrophy and who can provide support to help us personally deal with our feelings."

7. Next steps/actions

1. Muscular Dystrophy UK is calling for funding for seven neuromuscular care advisor roles, in the long term. Seven care advisor roles are needed to ensure that London is on par with the level of care advisor support available in other regions of the UK.
2. Muscular Dystrophy UK is calling for the urgent funding of three care advisor roles, based at King's College Hospital, Barts Health and the Royal Free, by the end of 2016.
3. Muscular Dystrophy UK is calling for trust service managers, NHS England and CCG commissioners to meet with Muscular Dystrophy UK and members of their neuromuscular team to address this gap in expert care.
4. Muscular Dystrophy UK is calling for CCGs in the South East Coast region to cluster and fund care advisor roles that will support the 5,008 people in the region who are living with muscle-wasting conditions.
5. Muscular Dystrophy UK is calling for King's College Hospital to commit to providing permanent, ongoing funding for the care co-ordinator role based at the Trust.

Appendix 1: Table 1

Region	Number of people with a muscle-wasting condition	Number of care advisor roles	Number of people with muscle-wasting conditions per care advisor role
Scotland	5,984	3	1,994
Wales	3,432	4	858
Northern Ireland	1,992	7*	285
North East	3,101	2	1,550
North West	8,141	3	2,713
Yorkshire and Humber	6,076	4	1,519
East Midlands	5,122	3	1,707
South West	6,064	4	1,516
East of England	6,628	3	2,209
London and the South East	13,888	1	13,888
Thames Valley and Wessex	4,769	4	1,192
West Midlands	6,235	4	1,559

*Six of the seven Northern Ireland care advisor roles are neurological care advisors, so do not exclusively see neuromuscular patients.

Appendix 2: Table 2

Region	Number of people with a muscle-wasting condition	Number of clinical nurse specialist roles	Number of people with muscle-wasting conditions per clinical nurse specialist role
Scotland	5,984	1	5,984
Wales	3,432	0	N/A
Northern Ireland	1,992	3	664
North East	3,101	2	1,550
North West	8,141	4	1,035
Yorkshire and Humber	6,076	0	N/A
East Midlands	5,122	0	N/A
South West	6,064	0	N/A
East of England	6,628	0	N/A
London and the South East	13,888	7	1,984
Thames Valley and Wessex	4,769	3	1,589
West Midlands	6,235	1	6,235

Appendix 3: Table 3

Differences between neuromuscular care advisor and clinical nurse specialist roles

Care advisor	Clinical nurse specialist
Based in the community – covering an area, may link in with neuromuscular clinics in a region.	Based in hospital/neuromuscular clinic setting.
Provides advice and information to support that given by neuromuscular team.	Involved in direct care and treatment management.
Signposts and liaises with local services to ensure patients/families get the best support from what is available locally.	Liaises with care advisor regarding needs at discharge, as well as support for community-based care.
Provides home visits if required.	Manages inter-hospital in-patient transfers.
Links with local education/workplace to provide support information regarding condition.	Monitors treatments, makes adjustments.
Supports with <i>Access to Work</i> , PIP, ESA and other, if needed, and support if appeal.	Helps with supporting information for applications for PIP/ESA, etc.
Works with community stakeholders and patient groups to improve access and service provision in local/regional area.	Works with commissioners/stakeholders for service evaluation to improve access and care provision at a hospital level.
Provides additional information and deals with questions post-diagnosis (where appropriate).	Provides genetic and new diagnosis counselling.
Helps patient/family with ways to adjust to living with long-term condition – offers practical ideas, support, signposting.	Manages patient in acute situations – liaises with local emergency services and with medical team regarding potential admission or transfer.
Provides community link for transition between paediatric and adult services.	Helps with transition of patients from paediatric to adult services.
Supports in preparation for transition to senior education from primary school – educational support regarding the muscle-wasting condition.	Provides information to local hospital, GP/therapies.
Offers support following crisis/emergency admission.	
Supports family after bereavement – family support.	
Offers support re information about hobbies and social interaction – e.g. sports facilities for disabilities, volunteering, etc.	