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ar [anhydraddoldebau iechyd meddwl](#)

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MHI 53

Ymateb gan: | Response from: Muscular Dystrophy UK

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## **MDUK's Response to the Health and Social Care Committee inquiry on Mental Health Inequalities**

### **1 Introduction**

Muscular Dystrophy UK (MDUK) welcomes this inquiry into mental health inequalities, particularly recognising how the pandemic has exacerbated existing barriers to accessing suitable mental health support for those with underlying health conditions.

Muscular Dystrophy UK (MDUK) is the charity that brings together more than sixty rare and very rare progressive muscle-weakening and wasting conditions, affecting around 110,000 children and adults in the UK.

### **2 Evidence collection**

Our response and feedback is based on responses we collected through a national survey across the UK looking at the impact of COVID-19 and shielding for people living with a muscle-wasting condition, as well as their families, between March 2020 and February 2021. Over 400 people responded, including in Wales, providing insight into the impact of shielding and disruption to vital clinical appointments. We also heard concerns arising because of the pandemic, such as receiving physical and mental wellbeing support.

Additionally, our response includes feedback from conversations we have had with people with a muscle-wasting condition and neuromuscular healthcare professionals working in Wales through our peer support groups (known as Muscle Groups), the Wales Neuromuscular Network, the Wales Cross-Party Group on Muscular Dystrophy, and through our Muscle Matter webinars.

### **3 Factors contributing to poor mental health**

People with a muscle-wasting condition are often disproportionately affected by poor mental health compared to the general population. Being diagnosed with a muscle-wasting condition can affect every aspect of life and many people tell us they feel isolated because of their condition. Others tell us of their anxiety or depression as they adjust to their diagnosis. Additionally, the impact goes beyond those who have a muscle-wasting condition; families and carers also live with its effects. This is often not recognised when reviewing care and support.

When living with a lifelong, debilitating condition, mental health support is often overlooked as part of holistic care and only offered once an individual is seriously struggling. Whereas, this patient group is constantly needing to adapt to their worsening condition which means they continuously need to re-adapt to each different milestone – for example, they have to eventually face the notion they may be unable to join in with certain social events, to being unable to live independently or go to university, to eventually being fully dependent on carers and facing their mortality.

This has only been exacerbated by the pandemic, as most were shielding and becoming more isolated from society, their social links, and their families. For example, in our survey, 94 percent of respondents in Wales shielded during the pandemic, regardless of whether they received a letter instructing them to do so or not. Of which, 78 percent of respondents said that lockdown and shielding had had a negative impact on their physical health and 78 percent said that lockdown and shielding had had a negative impact on their mental health. Additionally, 33 percent had less access to family carers or care workers because of lockdown or shielding.

Further our survey found that 78 percent of respondents experienced disruption to or delays in accessing specialist muscle clinic appointments, 19 percent said their access to specialist

respiratory care had been affected, disrupted, or delayed, and 16 percent said that access to specialist neuromuscular physiotherapy had been affected, delayed, or disrupted.

Combining the lack of access to specialist physical appointments, and the lack of exercise due to shielding, many people have experienced significant deterioration to their muscles and are now unable to undertake day to day tasks which means they also tend to not leave the house, socialise and some are unable to now work. All these factors combined have led to significant psychological distress. One patient particularly told us that ageing and worsening of his condition has led to him becoming depressed. He was fortunate to have a supportive GP who prescribed him medication for his depression, however (1) providing psychological support is outside of the GP's remit, and (2) he hasn't been able to see a psychologist (as there isn't one to refer him to) to improve his mental health and eventually stop needing the medication. Another patient fed back that they 'felt okay until they start thinking about their future or lack thereof'. Additionally, a healthcare professional told us that the patients' mental health impacts their engagement to keep active and continue to strengthen their muscles. This has a follow-on impact of lacking confidence to go outside which further exacerbates both their physical and mental health.

#### 4 Barriers to accessing mental health services and effectiveness of existing services

Even before the pandemic, accessing mental health support provision for muscle-wasting conditions has been nearly impossible. The Thomas Report<sup>1</sup> (2010) highlighted the lack of psychological support for people with a neuromuscular condition. Similarly, the UK All-Party Parliamentary Group report on access to psychological support for people with neuromuscular conditions<sup>2</sup> (2018) showed that, at the time, many people with a muscle-wasting condition had been struggling to access appropriate psychological support for many years. Some people had accessed counselling or generic psychological support, but, because this is not tailored towards the impact of the condition and its progression, on many occasions that generic support has not had a positive effect. This forced many people to turn to expensive, private psychological support.

In the last ten years, the situation hasn't improved and has only been exacerbated due to the pandemic, as shown in our [Welsh Shine a Light](#) report (2021) which demonstrated the detrimental physical and mental health impact shielding had on people with a muscle-wasting condition. One patient told us that they were referred to a counselling service by their GP, but the service was run by volunteers and due to the pandemic face-to-face meetings were impossible. He was offered telephone sessions but unfortunately the telephone increases his anxiety. As a result, he has been on the waiting list for over 2 years for a face-to-face appointment. During the pandemic, some clinicians have suggested to their patients to access psychological support privately but even then, many patients cannot afford this and the waiting list for this is still years as well.

Overall, these reports particularly identified that the two main barriers in accessing mental health services is:

(1) there is no specialist psychology support to refer patients to (particularly in Southwest and South East Wales), and

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<sup>1</sup> The Thomas Report: Access to Specialist Neuromuscular Care in Wales, Welsh Cross Party Group on Muscular Dystrophy, July 2010: <https://www.muscular dystrophyuk.org/static/s3fs-public/2021-07/PDF-Wales-Cross-Party-Group-Thomas-Report-Access%20to%20specialist%20care-2010.pdf?VersionId=XH4i5EiqMwck3iw5kBH74KhaFYSVuZOO>

<sup>2</sup> All Party Parliamentary Group for Muscular Dystrophy, Access to psychological support for people with neuromuscular conditions, November 2018: [https://www.muscular dystrophyuk.org/static/s3fs-public/2021-07/PDF-Report-MDUK-APPG-Access-to-psychological-support-Mental-Health-Matters-2018.pdf?VersionId=2D2IsWeRqqh51PJFsTzXSOZtCoaihP\\_B](https://www.muscular dystrophyuk.org/static/s3fs-public/2021-07/PDF-Report-MDUK-APPG-Access-to-psychological-support-Mental-Health-Matters-2018.pdf?VersionId=2D2IsWeRqqh51PJFsTzXSOZtCoaihP_B)

(2) general psychologists don't have the upskilling to support someone with a lifelong, debilitating condition.

The Welsh neuromuscular services were working with a psychologist from Bristol to set up peer support groups on coping strategies and mindfulness. However, this stopped due to the pandemic and was unable to address severe mental health disorders. Additionally, those severely struggling were uncomfortable attending a group environment so the most critical were falling through the gaps. They have considered setting these up as a digital tool but there isn't enough staff to set up the digital means.

## 5 Mental health policy gaps in Wales

These are just examples of an overlooked patient group who desperately need access to mental health services. General mental health policy usually focuses strictly on people with a mental health condition (bipolar, anxiety, etc.). This is particularly demonstrable in the Wales Governments' *Together for Mental Health* report (2012) which accounts for all ages but only looks at education, employment, drug and alcohol misuse, and tackling poverty. However, it doesn't refer to people living with chronic conditions. Additionally, in the Welsh Government's *Review of together for mental health: the plan for 2019 to 2022 in response to COVID-19*, it widened their policy remit to include 'vulnerable groups of people and people with additional needs', however the focus in this section remains on people from BAME backgrounds, refugees and asylum seekers. It seems that even with shielding, people deemed clinically extremely vulnerable are still being overlooked, including people with a muscle-wasting condition.

As such, there is a need to incorporate the following into any mental health policy:

- To include people with a lifelong and often progressive condition to ensure they get the appropriate support they need
- Ensure this patient community has access to specialist mental health care when they need it or are referred to more general support who are sufficiently upskilled to handle the complexity of mental health needs associated with having specific condition, such as a neuromuscular condition.
- consider a more holistic approach to mental and physical health, given how dependent they are on each other.

## 6 Recommendations to improve mental health and outcomes

To address the issues we have outlined, we would recommend the following:

**Recommendation 1:** Setting up a Mental Health and Chronic condition lead within the Welsh government to set up the infrastructure to improve patient referral and mental health provision for people living with a lifelong, debilitating condition, such as a muscle wasting conditions.

This support should start from diagnosis and continue throughout their lifespan. Part of this role should entail working with clinical networks, patient organisations and local mental health providers to identify appropriate referral pathways depending on the patient need, set up upskilling sessions to ensure psychologists are able to appropriately support patients, and peer support groups to help those with less severe needs maintain their wellbeing. For example, the Wales Neuromuscular Network is already positioned to easily set up upskilling events so that general psychologists are better equipped to support any patients with a muscle-wasting condition that are referred to them. The Wales Neuromuscular Network was established to advise and support patients, carers, the NHS, and Wales Government to make

