

MND Association policy briefing: unpaid carers and Covid19

May 2020

Background

Unpaid family carers¹ provide a significant amount of care and support to their loved ones with motor neurone disease (MND)². It makes a huge difference to the experience of those living with MND, and relieves the NHS and Social Care services of additional pressures. However, even under normal circumstances, providing such care can take a physical and emotional toll, which some carers already struggle to cope with and receive very little support for. Prior to the outbreak of coronavirus, we already had concerns that unpaid carers of people with MND were having to provide too high and sustained levels of care without sufficient support due to a poorly funded and unsustainable care system. This will only be exacerbated as a result of the coronavirus outbreak.

The Association is extremely concerned that even greater pressure is now being placed on unpaid carers during the outbreak. Recent research conducted by Carers UK on the impact of coronavirus on carers has found that 70% of unpaid carers are providing more care due to the coronavirus outbreak.³ Carers of people living with MND are likely to be providing more care during this time, especially if the support people with MND normally receive from the health or social care system is being reduced or disrupted. This is reflected in Carers UK's findings, that over a third of unpaid carers are providing more care as a result of local services reducing or closing.⁴ Unpaid carers will have to step-in and fill this gap. The type of care and nature of the caring tasks they need to undertake is likely changing too. It also comes at a time where due to social distancing measures, other family and friends who could potentially assist are not able to. In the meantime, they will be needing to take measures to try and protect themselves and those they care for from contracting the virus. Despite these increased pressures, there is little evidence that support directly aimed at meeting the needs of unpaid carers is increasing.

We are concerned about the combined impact on carers' health and wellbeing that increased pressure, numerous additional challenges, and a lack of extra dedicated support will have. If not addressed, unpaid carers could become exhausted through providing constant care and simply burnout. Worryingly, Carers UK findings indicate that 55% of unpaid carers feel overwhelmed and are worried that they are going to burn out in the coming weeks.⁵ Now more than ever, the role that unpaid carers play to support their families and friends with MND should be properly valued and their needs supported in full. There is a clear need for national and local government and

¹ Informal unpaid care can be carried out by a variety of people including but not limited to family members, friends and other acquaintances. For ease, we shall use the term unpaid carer throughout this briefing as an overarching term.

² The Association's most recent [Improving MND Care Survey \(2019\)](#) found 33% of carers spent more than 100 hours per week caring.

³ [Carers UK, Caring behind closed doors: forgotten families in the coronavirus outbreak](#) (April 2020) p.6

⁴ Carers UK, p.6

⁵ Carers UK, p.6

others to act and do more to support unpaid carers during this time and going forward.

This briefing summarises the key issues for unpaid carers of people with MND during this challenging time and makes recommendations for urgent action in the following areas:

- Self-isolation, shielding and testing
- Coronavirus Act 2020
- Financial issues
- Welfare benefits
- Access to Personal Protective Equipment (PPE)
- Health and wellbeing

Summary of key issues being faced by unpaid carers of people with MND

Self-isolation, shielding and testing

There has been a lot of worry and confusion within the MND community regarding shielding and social distancing, with many being unsure about whether they can register as extremely clinically vulnerable⁶ as MND is not listed as a condition. The exception is in Northern Ireland, where MND has been added to the clinically extremely vulnerable guidance by name.⁷ In Wales, people living with MND can be added to the list if their GPs assess them as extremely vulnerable. In England, there is a process of self-referral that people with MND can attempt. Many carers will have taken on the responsibility of trying to ensure the person they care for is added to the extremely clinically vulnerable list so they can access additional support and follow extreme shielding measures.

MND is already listed as a condition as part of the wider social distancing guidance⁸, and people with MND can be added to the extremely vulnerable shielding group if they are experiencing respiratory symptoms. In both instances unpaid carers will be supporting people with MND to adhere to those measures. This will come with their own set of challenges. It may add to the pressure and stress that unpaid carers already feel that the person they care for is well looked after and kept safe. It may also produce a set of challenges and obstacles in ensuring the person with MND they care for can receive safe and effective care while adhering to the social distancing or shielding measures. In addition, there are concerns around how long unpaid carers will have to shield or self-isolate with the person they care for, especially as lockdown and social-distancing measures may begin to change in the future. Normal life will not resume for carers and those they care for and further clear guidance will need to be made in this regard.

Adhering to these measures may also impact on the amount of and type of care that unpaid carers are now needing to provide, as in some instances paid carers are

⁶ [Gov.uk: Guidance on shielding and protecting people who are clinically extremely vulnerable from COVID-19](#)

⁷ [NI Direct: Guidance on shielding for extremely vulnerable people](#)

⁸ [Gov.uk: Guidance on social distancing for everyone in the UK](#)

unable to conduct the care they would normally provide due to illness or lack of protective equipment. As unpaid carers' responsibilities subsequently increase, maintaining their own wellbeing will become more of a challenge.

A related problem has been access to supermarkets and food delivery slots, which is due to a number of factors:

- some unpaid carers will not want to visit the supermarket out of fear that they could contract the virus and bring it home to the person living with MND
- some carers may not be able to leave the person they care for as they require constant care
- unpaid carers who themselves have pre-existing health conditions or disabilities may be unable to queue and shop for prolonged periods of time
- some may not be able to rely on others to collect essential items on their behalf.

A combination of these factors have made it difficult for carers to access essential supplies. Carers UK has found that 64% of carers are having some or significant problems accessing food.⁹ Therefore, it is essential that the Government and supermarkets introduce provisions beyond those already made so that unpaid carers can still access food and other supplies. It has been clarified by Government that carers can now access the NHS and Royal Voluntary Service, stating anyone with caring responsibilities can self-refer themselves if the support on offer helps them to continue their caring role.¹⁰ Beyond this though, there is anxiety around unpaid carers not having anything to prove they are unpaid carers in order to access further support. A form of national registration system or being able to have an identification card or similar are some of the suggestions being made at the moment.

Finally, as the UK's capacity to test for Covid19 increases, priority should be given to unpaid carers alongside NHS and Social Care staff. This would provide carers with the clarity they need so they can follow the correct self-isolation measures and reduce the amount of stress and anxiety they may feel in potentially contracting the virus and passing it on to someone with MND. Testing has now been introduced in England for unpaid carers who have symptoms of Coronavirus.

Recommendations:

- Ensure local and national Governments have systems in place so that unpaid carers can access food and essential supplies, including enabling unpaid carers to access priority supermarket opening times and delivery slots, or support from volunteers who could do shopping on their behalf
- Enable unpaid carers to be tested for Covid19, irrespective of whether symptoms are present, as a priority so they know they are safe to care for their loved one with MND or whether they will need to self-isolate

⁹ Carers UK, p.18

¹⁰ Communication from Helen Whately MP, Minister of State for Care, May 2020. Further information about the scheme is here: <https://volunteering.royalvoluntaryservice.org.uk/nhs-volunteer-responders>

- The UK Government, Welsh Parliament and Northern Ireland Executive should develop a national registration/identification system for unpaid carers, which they could then use to access support.

Coronavirus Act 2020

The Coronavirus Act 2020¹¹ suspends parts of the Care Act (2014) in England and the Social Services and Wellbeing Act (2014) in Wales, by changing the duties of Local Authorities to meet the eligible needs of disabled people and their carers¹². The legislation regarding social care and carers is framed differently in Northern Ireland, but they will be seeking alignment.

In relation to measures relating to carers as part of the Coronavirus Act it:

- removes the duty to carry out carer's assessments i.e. that a Local Authority *must* carry these out
- removes the requirement to follow eligibility criteria
- removes the duty to provide services, and care and support plans (unless in relation to the Convention on Human Rights – see next point)
- states the Human Rights Act must be followed for people who need services and for carers
- allows for the prioritisation of care services to those deemed by the Local Authority as in most need.¹³

Although the Coronavirus Act is a UK-wide piece of legislation, responsibility for health, social care and public health is devolved to the national governments in Wales and Northern Ireland. Both Wales and Northern Ireland have produced their own sets of guidance on a variety of provisions.¹⁴ And whilst Social Care and provisions for carers are administered via Health and Social Care Trusts in Northern Ireland, rather than by Local Authorities, they may introduce similar measures to those being implemented by some Local Authorities across the rest of the UK.

Although we acknowledge the social care system is already overstretched and now under increased pressure due to Covid19, we believe the changes set out in the Coronavirus Act could have serious implications for unpaid carers and those they support. Even prior to this current crisis, the Association's 2019 Improving MND Care Survey found that as many as 76% of carers had not had a carers assessment.¹⁵

Some carers are already reporting that their support plans are being changed or reduced, which is increasing the amount of pressure they are being put under. It is important that carers' rights are not being eroded when they are being relied on now more than ever. The decisions that Local Authorities make in no longer having to follow some elements of the Care Act in England or Social Services and Wellbeing

¹¹ [Gov.uk: What the Coronavirus Bill will do](#)

¹² [Carers UK has produced a useful policy summary of the Coronavirus Act and unpaid carers](#)

¹³ There are many more provisions under the Coronavirus Act, however for the purposes of this briefing the ones specifically or more likely to impact on unpaid carers have been highlighted

¹⁴ Northern Ireland: <https://www.health-ni.gov.uk/coronavirus> and Wales: <https://gov.wales/coronavirus-legislation-and-guidance-law#CoronavirusAct2020>

¹⁵ [Improving MND Care Survey 2019](#)

Act in Wales must be proportionate, so that unpaid carers are not placed under even greater pressure with even less support. It is vital that Local Authorities continue to assess carers' needs during this time.

Following the Coronavirus Act, the UK Government produced advice for unpaid carers on Covid19.¹⁶ The specific purpose of the guidance is to help unpaid carers to make plans in case they, or the person they care for, develop COVID-19. To do this the guidance advises carers to create an 'emergency plan' with the person they care for, including details of ongoing medication and treatment the person with care and support needs is receiving. Some carers of people with MND may not be able to put contingency plans in place as they do not have other family members or friends to rely on who could help with caring responsibilities in their place. Carers UK's research has indicated that only 21% of carers felt confident that they had a contingency plan in place in case of emergency.¹⁷ With MND, some elements of someone's care may be too complex to assist with without proper training. And without being able to get support from other family or friends, social care services cannot necessarily be relied upon to fill the gap due to already being overstretched. As one carer told us¹⁸,

“Government guidance for unpaid carers, threw the onus once again back on individual carers. All were advised to create an emergency plan should they fall sick themselves. As ever, unpaid carers were not supported with a standardised template to fill in, rather that unpaid carers mobilised themselves to share best practice and shared their own plans. Given the increased workload on unpaid carers at this time this lack of practical support showed that government were removed from unpaid carers' responsibilities.”

More generally, the guidance advises carers to take extra precautionary measures by only providing essential care and ensuring they follow the NHS hygiene advice for people at higher risk. However, there seems to be very little guidance aimed at meeting the needs of unpaid carers themselves, beyond signposting to a few but limited further sources of information. Even before the crisis, the Association's Improving MND Care Survey 2019 found that 51% of carers would value practical support.¹⁹ There is a clear need for better information about the different sources of support and services they can access during the outbreak. Where this doesn't exist, it should be invested in as a priority.

There may be learning to be had from the advice for unpaid carers that has been produced in Northern Ireland, which has had input from unpaid carers themselves and generally has a stronger emphasis and focus on more practical support.²⁰ It also includes emergency and contingency plan templates.²¹

¹⁶ [Gov.UK: Guidance for those who provide unpaid care to friends or family](#)

¹⁷ Carers UK, p.17

¹⁸ Direct quote via email exchange, May 2020

¹⁹ [Improving MND Care Survey 2019](#).

²⁰ Department of Health, Northern Ireland. [Covid-19: Advice for informal \(unpaid\) carers and young carers during Covid-19 pandemic](#)

²¹ <https://www.health-ni.gov.uk/publications/carers-documents>

Recommendations:

- The enactment of easements in relation to social care and cares permitted by the Coronavirus Act should be closely monitored in respect to the impact on unpaid carers
- If certain Local Authorities choose to relax measures to support unpaid carers under the Coronavirus Act, they should ensure there is other support available from local agencies or in the community that can help and signpost accordingly
- Support for carers that has been lost through the Coronavirus Act should be reinstated as soon as possible, and improved overall
- Further dedicated information, guidance and advice should be produced for unpaid carers, aimed at meeting their own particular needs – this should be informed by carers themselves
- When the UK Government, Welsh Parliament and Northern Ireland Executive turn to making future recovery plans, these must ensure they include the needs of unpaid carers
- In the long-term, the UK Government, Welsh Parliament and Northern Ireland Executive should improve the support that is available to unpaid carers on a permanent basis.

Financial issues

Unpaid carers are likely to be experiencing increased financial difficulty during the coronavirus outbreak. The extra costs of caring are going to increase with the need to spend more on food, household bills (such as heating) and other essentials during this time. Carers UK's research has found that 81% of carers said they were spending more at the moment, and some of the biggest reasons for the increase in spend were food and bills.²²

There are multiple factors that affect each of these increased costs. Taking food as just one example, many unpaid carers are unable physically go shopping and are using alternative supermarkets and local shops instead, which have increased costs such as tending to have higher-priced items and delivery charges compared with bigger supermarkets. By not being able to physically go to the shops, the ability to choose cheaper or near to date items which normally help stretch a food budget is not possible. Availability of items pose a challenge, from basics such as flour for baking through to more specialist hygiene supplies, and carers are having to source these through different suppliers, meaning increased delivery charges and costs as opposed to the supermarket pricing of these items.

Many unpaid carers will also be struggling to manage both care and work commitments, whilst perhaps having to negotiate reduced hours or giving up work entirely due to social distancing measures. Worryingly, Carers UK's research on the impact of coronavirus has found that almost a fifth of carers reported either having lost or given up their job or being unable to work because of the social distancing

²² Carers UK, p.10

rules.²³ We anticipate that particular difficulty will be faced by those who are also key workers and are made to go to work, despite caring for someone with MND.

Recommendations:

- Employers should ensure that their employees who are unpaid carers can be supported to remain in their job for as long as possible – and be flexible so that carers can continue to undertake their caring role
- As society begins to leave the lockdown and return to work, particular guidance and advice for unpaid carers should be produced by the UK Government, Welsh Parliament and Northern Ireland Executive to ensure unpaid carers and the people they care for continue to be protected
- Paid care leave and flexibility policies should be introduced by the UK Government to better support carers to manage their work and care responsibilities.

Welfare benefits

The Association is pleased to see the Government has changed the eligibility criteria for Carers Allowance during the Covid19 pandemic. We are particularly pleased to see easements in relation to the requirement to provide a minimum of 35 hours of care per week. The Government laid an amendment to the Carers Allowance regulations, which came into effect on 30.03.2020, which means that carers who have to take a temporary break in care due to needing to self-isolate or from having coronavirus itself will not have their Carers Allowance stopped. We welcome this provision and believe it could help carers who cannot provide their loved one with MND with the usual level of care through no fault of their own.

The Government also confirmed that providing emotional support counts towards the Carers Allowance threshold of 35 hours of care a week. This comes with the Government acknowledging that many carers and disabled people will fall into the 'self-isolating' group and that therefore instead of providing the usual face-to-face care, many carers will only be able to provide that contact on the phone, or via online methods, such as skype, facetime etc. This may benefit some unpaid carers of people with MND who are unable to see them at the current time to carry out their caring role, but who are nonetheless supporting them in other ways.

However, the Association is disappointed that there have not been any moves to increase the rate of Carers Allowance during this time, despite the increasing costs that unpaid carers will inevitably face and the additional pressure they are being placed under. Carers Allowance currently only provides £67.25 a week, which is the lowest benefit of its kind. This must be increased immediately, with a view to properly reviewing Carers Allowance once the immediate response to the coronavirus outbreak is over.

²³ Carers UK, p.12

Recommendation: The UK Government must urgently review and substantially increase the rate of Carers Allowance to a level that truly accounts for and values the contribution that unpaid carers make.

Access to PPE

We are hearing of cases where paid care workers are not wanting to visit people living with MND because they do not have the right protective equipment or feel they are at risk of passing on the virus. Similarly, we are aware of instances where family members are not wanting to let paid carers into their homes without the correct PPE. Whilst this is being done with the best intentions for the person living with MND, the gap in care this creates is needing to be filled by unpaid family carers, which is increasing the strain they are being placed under.

There are different pieces of guidance across the UK. In Wales the focus for the supply of PPE has been on supporting the health and social care workforce and is based on advice from Public Health Wales. At present, this does not include provision for unpaid carers. However, Northern Ireland seems to be ahead, especially in relation to those receiving direct payments. In terms of unpaid carers specifically the advice is to discuss the correct type and usage with their named worker in their Health Trust.²⁴

Recommendations:

- Local Authorities and Clinical Commissioning Groups should ensure access to PPE for social care staff, including those paid for via Continuing Healthcare (CHC), Direct Payments and Personal Health Budgets
- Local Authorities in England and Wales should ensure unpaid carers have access to their own PPE. This could be through local hubs, as is already the case in Scotland.

Health and wellbeing

The Association is concerned about the impact that the coronavirus outbreak will have on unpaid carers' physical and mental health.

Prolonged self-isolation and social distancing will have an impact on unpaid family carers during this time, who may already be feeling socially isolated. It may distance them from any support groups or services they do currently access if they have not already been reduced or closed. It may also impact on their ability to have breaks and respite from their caring responsibilities during this time, which is often needed to ensure they can maintain their own health and wellbeing so they can continue to provide care for their loved one with MND. The Association's 2019 Improving MND Care Survey already found that as many as 62% of carers had not had any respite.²⁵ Not being able to have a break from caring can have a significant emotional impact.

Many carers will also have their own health needs and wider familial circumstances to manage. The 2019 Improving MND Care Survey found that 24% of carers had a

²⁴ [Department of Health, Northern Ireland](#)

²⁵ Planned break from a couple of hours to a few days. [Improving MND Care Survey 2019](#).

disability or long term health condition, rising to 44% for those aged over 75.²⁶ For young families and those of working age we know there are additional challenges for unpaid carers during this time, who are needing to care for children who are now at home from school and/or manage their commitments to paid employment through working at home. For family carers who are of older age, there will be some caring tasks they physically won't be able to undertake themselves safely and/or they may have their own additional needs to manage, which will be put under greater strain at this time.

Bereavement will also be a key issue for unpaid carers during the outbreak. Unfortunately, it has already been the case that some people with MND have died after contracting Covid19. As this has happened, some carers may have had to deal with difficulties in end of life care provision²⁷ and organising practical arrangements following their loved one's death. With social distancing measures in place, carers who lose loved ones will be unable to grieve in normal ways and will be coming to terms with bereavement without their normal support network. In particular, funereal arrangements will be difficult under lockdown and social distancing measures. And there are slight differences in provisions relating to funerals across the UK. In England attendance is essentially limited to close family, whereas in Wales the determining factor is the number of people who can attend and maintain social distancing measures. Northern Ireland also has its own guidance on funerals.²⁸ Overall, there should therefore be dedicated investment in and promotion of grief and bereavement services during this time.

Overall, if the health and wellbeing of unpaid family carers are not sufficiently supported during this time, this could lead to a deterioration of the situation as carers burnout and increased demand is placed on Local Authorities and the NHS at a time when they are already struggling to cope with the impact of the epidemic.

Recommendations:

- When developing their plans for who is at most need in their communities during the pandemic, Local Authorities in England and Wales and Health and Social Care Trusts in Northern Ireland must take on board the needs of unpaid carers
- Local Authorities in England and Wales and Health and Social Care Trusts in Northern Ireland should publish information so it is clear where carers can access local support to manage their own needs during the pandemic
- The UK Government, Welsh Parliament and Northern Ireland Executive should provide dedicated funding to Local Authorities and Health and Social Care Trusts so they can invest further in support services specifically for

²⁶ [Improving MND Care Survey 2019](#).

²⁷ Some sources are suggesting that some carers are needing to take on more palliative care responsibilities during this time: https://www.theguardian.com/society/2020/apr/18/families-expected-to-provide-palliative-care-during-coronavirus-pandemic-nhs?CMP=share_btn_tw

²⁸ Coronavirus (COVID-19): guidance for bereaved about funeral arrangements: <https://www.nidirect.gov.uk/articles/coronavirus-covid-19-guidance-bereaved-about-funeral-arrangements>

unpaid carers during the pandemic, to support their mental health and wellbeing during this time.