



Supporting carers of people with a progressive neurological condition

**Position statement 1
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Prepared by a cross-sector collaborative working group, authors listed below.

Unpaid carers provide round the clock support to people living with a condition that affects the brain and gets worse over time (progressive neurological condition). Caregiving can be rewarding, but can also affect carer health and wellbeing. Carers consistently report many unmet support needs. We believe that carers, academics, service providers, and policymakers need to work together to improve support for carers and offer five pillars of action.

In England, 2.2 million people live with a condition that affects how the brain works, and that gets worse over time.¹ Examples include dementia and brain tumours. Many of these people rely on unpaid carers (family and friends). Neurological or behavioural symptoms such as problems with speaking or memory, or changes in mood and character can be distressing for carers as they can be difficult to predict, complicate care, and affect personal relationships.^{2,3}

In the UK, 60% of people provide unpaid care (physical, practical and emotional support) during their lives.⁴ Carers' support was valued at £530 million per day in the pandemic⁵ or £193 billion a year – more than annual health spending.

Carers need good support to maintain their own health and wellbeing – as well as to provide good quality care. Years

of significant underfunding, coupled with rising demand have combined to push health and social care services to breaking point. Consequently, unpaid carers are needed to fill this void. If carers relinquish their role, or develop health issues themselves, the system becomes further strained. By 2032, there will be a shortfall of 160,000 carers.⁶

Despite previous efforts, it has proven difficult to improve support for carers. This position statement follows from two participatory workshops involving carers, academics, service providers and policymakers held in November 2021.

Jointly we take the position that improvements in support for carers of people with progressive neurological conditions will only happen if stakeholder groups work together. We offer five pillars where such joint action would provide value.



Five pillars for joint action

The following sections present five areas for joint action to improve support for carers of people with a progressive neurological condition. The pillars could also be applicable to other carer groups.

Collaboration, coordination, co-design

With better collaboration between the social care sector, the third sector, and the NHS, we can limit the chances of carers who struggle falling through the net. Although there is good current support available, this can feel fragmented, with different service providers not being aware of each other's efforts. A case manager or carer advocate could provide a coordinating role.^{7,8} Multidisciplinary groups could ensure better integration and continuity of care.⁹ Changes can start small and local. This can help set an example and provide evidence that better collaboration, coordination, and co-design of care pathways can help improve access to support.

Valuing carers

Carers often provide round the clock care. The costs for this, in terms of loss of income from paid work but also costs associated with poorer health and wellbeing, fall primarily on their own shoulders. Yet, lack of funding for carer support is a known issue. What we can do now is acknowledge and enhance the awareness of carer contributions, increasing the visibility of carers. We can start by preparing joint reports for regional use, and/or co-produce research publications highlighting the value carers bring. This can help carers to feel more empowered. While an increase in funding remains essential, working together effectively can help allocate the scarce available resources more efficiently.

Redefine personalised medicine

Personalised medicine is a term that is frequently used to describe advances in targeting treatments for disease using DNA sequencing. However, personalised medicine is about more than this and includes targeted interventions to promote health instead of just managing an illness.¹⁰

We believe that it is time to acknowledge the need for increased focus on the patient and carer, shared decision-making, and what is important to them. Carer support needs are varied and there is no one size fits all.¹¹ We emphasise that personalised care should identify specific needs of carers arising from aspects of diversity, such as gender, race, ethnicity and age (younger or older). Starting at the point of diagnosis of the patient, we should strive to focus on what matters to both patients and carers and create tailored support strategies, reviewing these over time as the needs of both parties change.

Flexible evidence-based support

We need to a) build a better evidence-base for carer support; and b) prioritise evidence-based support, including information materials, over support that has not been proven effective. This is especially important given the scarcity of funds and resources for carers.

Practical barriers to accessing support can include availability of local services, travel time and costs, and leaving the care recipient alone. Telehealth (support delivered over the phone, via the computer or an app) is an established concept that has seen a lot of research attention, yet uptake into support pathways lags behind.

Telehealth may not be suitable or desirable for every carer, but taking a flexible approach to support can help enhance accessibility. We advocate for local evidence-based support where possible, with telehealth available where needed.

Promotion of current support services

Knowledge is power. Many carers do not recognise themselves as carers. Many of those who do, do not know where to get support, or what is available to them locally. Ideally, carers should be informed about available support at the time of diagnosis and before significant issues arise. We especially need to actively engage harder to reach carers who are not accessing support services, such as black, Asian and minority ethnic carers. We want to strive for inclusivity. More research can help to identify barriers and facilitators to support carers from all communities and backgrounds to access formal support.

Summary

To improve support for carers, we need to move away from fragmented approaches and move towards a more collaborative approach with carers at the centre. Our vision is that future support is based on what matters to them as individuals and what is effective in meeting their needs. We strive to provide flexible, accessible, responsive and inclusive support for carers.

As a group, we stand behind the five pillars presented in this position statement and we invite other carers, service providers, academics and policymakers to join our effort.

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The position expressed here is that of the authors and not the University of Leeds.

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Participatory workshops

Two workshops were held online in November 2021 to bring together individuals with an interest in supporting carers, to discuss how we might improve support for carers for people with a progressive neurological condition. All the attendees have contributed to this position statement and are listed as authors.

Each workshop was split into three main sections. The first was a discussion surrounding current carer support and barriers in accessing support. The second part included blue sky thinking exercises, in which attendees were asked to describe their ideal vision of carer support in the future. Finally, participants discussed how the group can work together to improve support.

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