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## Carers of Young People with Mental Health Problems 3



### COVID-19 and UK family carers: policy implications

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Informal (unpaid) carers are an integral part of all societies and the health and social care systems in the UK depend on them. Despite the valuable contributions and key worker status of informal carers, their lived experiences, wellbeing, and needs have been neglected during the COVID-19 pandemic. In this Health Policy, we bring together a broad range of clinicians, researchers, and people with lived experience as informal carers to share their thoughts on the impact of the COVID-19 pandemic on UK carers, many of whom have felt abandoned as services closed. We focus on the carers of children and young people and adults and older adults with mental health diagnoses, and carers of people with intellectual disability or neurodevelopmental conditions across different care settings over the lifespan. We provide policy recommendations with the aim of improving outcomes for all carers.

#### Introduction

March 11, 2021, marked the anniversary of the WHO declaration of the SARS-CoV-2 pandemic.<sup>1</sup> On this date, the global number of recorded deaths from COVID-19 was approximately 2·6 million people, which included more than 124987 deaths in the UK. The UK had the highest number of COVID-19 fatalities in Europe and was one of five nations with the highest overall fatalities globally, with only the USA, India, Brazil, and Russia reporting more deaths from COVID-19.<sup>2</sup>

To reduce and control virus transmission and the subsequent burden on the UK National Health Service (particularly the need for intensive care provision), the UK Government introduced a series of national, regional, and locally enforced lockdowns that included the closure of educational institutions, community facilities (eg, libraries), and all non-essential shops and services. People were instructed to remain at home and, if possible, to work from home, home school, and avoid close physical proximity (physical distancing) with people outside of their immediate household, including relatives, friends, and the general public.<sup>3</sup>

Public health guidelines, including the use of face masks, frequent hand hygiene, and restrictions on individual liberties and freedom of movement, underpinned by an act of Parliament,<sup>4</sup> have co-occurred with a sharp rise in unemployment, households with food and financial insecurity (eg, accessing food banks), and domestic violence.<sup>5-7</sup> Access to, and the delivery of, primary and specialist health and social care services have been impacted by the pandemic and lockdown restrictions, with many health and social care services undergoing rapid alterations to their standard operating procedures. The implementation of remote health delivery, including telephone and online consultations for some and delayed or cancelled assessment and treatments for others, have greatly increased since the pandemic onset.<sup>8-9</sup> These changes occurred at the time that the UK negotiated the final terms governing its exit from the EU, which has had implications for the residency and

employment rights of EU nationals in the UK, including those working in health and social care services.

The adverse mental health and wellbeing sequelae of the COVID-19 pandemic have been widely reported. Data published from nationally representative samples in the UK,<sup>10-12</sup> and elsewhere,<sup>13-14</sup> suggest that the initial weeks and months after the start of the pandemic and first lockdown were associated with deteriorations in mental health, including worsening of depression and anxiety symptoms and increased markers of poor wellbeing (eg, loneliness). The mental health of specific populations has worsened since the start of the COVID-19 pandemic, including children and young people,<sup>15-17</sup> university students,<sup>18</sup> front-line health workers, teachers, and people in minority-ethnic groups.<sup>19,20</sup> However, compared with other groups, there has been considerably less focus on the health impacts and needs of informal (unpaid) family carers.

In this Health Policy, we seek to highlight the needs and issues faced by informal carers during the pandemic and offer recommendations and policy considerations (panel). We convened a diverse group of carers, clinicians, and researchers to share their experiences and thoughts on the impact of COVID-19 on carers. The expertise of this group was focused across the lifespan of children and young people, adult and older adult mental health, and people with intellectual disability or neurodevelopmental conditions, and across different care settings, including the family home.

#### Informal caregiving

In the UK, approximately 26% of the population (around 13·6 million people) have informal caregiving roles. This figure includes a reported 4·5 million new carers since the start of the pandemic.<sup>21,22</sup> Informal carers are engaged in a broad range of duties for people who have physical, mental, and social disabilities, and needs that are linked to older age. Carers are a heterogeneous group, which includes adults caring for children, partners, parents, and siblings, and young people (<18 years) caring

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**Panel: Policy recommendations**

- The ongoing programme of COVID-19 vaccination should recognise informal carers as hidden key workers whose contributions are often as essential as paid front-line health, education, and social care staff. To ensure that carers are no longer hidden from services and overlooked for important health interventions,<sup>62</sup> we recommend an ongoing incentive scheme and national standard for general practitioners to identify informal carers, record contact details, and to implement subsequent effective and targeted support packages
  - Carers have reported unmet needs for emotional, social, practical, and financial support, needs which have increased during the COVID-19 pandemic; we suggest that public health programmes at community and national levels recognise carers as a vulnerable group whose unmet mental and physical health needs have substantial negative implications, not only for carers themselves but also for care recipients and health and social care systems; the inclusion of carer-focused public health messaging and accessible resources to support carers, using different communication mediums, would benefit their wellbeing
  - Ensuring that carers can access freely available information and resources to improve their wellbeing is recommended; developing scalable programmes that help carers improve their mental health should be a priority; for some carers, effective programmes might include wider and larger provision of special funded leave from employers and financial support for carers in so-called gig industries; it is important that employers actively seek to understand the effect of the caregiving roles on the wellbeing of employees; facilitated access to peer networks and prioritised access to mental health support are also indicated
  - The provision of respite care for carers residing with care recipients, who have not had the opportunity to have breaks, should be prioritised; respite care can yield benefits for carers and care recipients, and this will be particularly important given that an increase in the intensity of caregiving roles during the pandemic has left many carers reporting fatigue and burnout
  - The impact on carers who have not been able to visit loved ones in residential care and inpatient psychiatric admissions should not be overlooked and underestimated;
- it is not uncommon for people living with lifelong care needs that affect their everyday behaviour and functioning to reside in a specialist care home facility; ensuring that health and social care providers have sufficient digital resources to adequately facilitate contact between informal carers and care recipients should be prioritised; these assurances need to include identified staff members who can support carers and care recipients who require additional help with using remote access
- Providing families without internet access or devices with access to mobile and portable devices (eg, tablets) will enable many carers to have contact with care recipients they do not reside with and remain involved in their care; the benefits of this contact for care recipients are also recognised
  - To prevent carers feeling forced to choose between maintaining safety in their homes and being supported, the provision of adequate personal protective equipment, regular care staff, and enhanced and rapid COVID-19 testing procedures should be standard
  - Professional cooperation with informal carers to identify optimal approaches and pathways to support care recipients with multiple morbidities to access health and social care is recommended
  - The heterogeneity of carer backgrounds, including ethnicity, socioeconomic status, and family situations, should be acknowledged; for health, education, and social care providers, it should be emphasised that carer needs are not homogenous; a condition-specific (eg, dementia, psychosis, or autism spectrum disorder) approach to examining the needs of carers during the COVID-19 pandemic might be a helpful starting platform and would allow for greater flexibility in understanding how disability-specific issues have impacted carer wellbeing and been impacted by the pandemic and which needs-led support, targeted support, and care options might be needed in the future
  - Partnership working between health, education, and social care providers will reduce the risk of carers (and care recipients) amassing high levels of unmet need that no single provider views as their job to address; efforts must be made to support families and place carers at the centre of care provision

for adults. Although typically a female role, the informal carer role intersects with other attributes, such as ethnicity, age, and social and economic status.<sup>23</sup> Informal caregiving is an essential feature of health and social care systems against a backdrop of scarce financial resources and competing health and care priorities. Competing health and care priorities include an ageing population and increased prevalence of age-related conditions (eg, dementia) and a focus on community-based care for people living with disabilities. However, the wellbeing of caregivers themselves has mostly been neglected.<sup>24,25</sup> This

neglect is despite the large numbers of carers, their unique and valued contribution to the health and wellbeing outcomes of care recipients, and the dependence of health-care providers and society on their contributions. On an almost daily basis, there is a discussion on the rapidly changing landscape of COVID-19, its new variants, vaccination efficacy, roll-out plans and priority groups, and revisions to shielding categories and lockdown restrictions; however, the plight of informal carers has not attracted the same attention of clinical service providers, policy makers, and the wider public.

## General caregiving challenges

### Caregiving and remote access

During the COVID-19 pandemic, there has been a focus on the remote access of health and social care provision and this has additionally highlighted digital poverty and social inequality in the general population.<sup>26–28</sup> Primary care consultations have witnessed a shift from in-person meetings to 90% remote consultations with general practitioners.<sup>29</sup> However, the specific needs of informal carers and remote access have been overlooked.

It is already known that family carers across the life course engage in diverse care activities, including personal and intimate self-care, emotional, social, psychological, financial, and physical health support.<sup>30,31</sup> For care recipients with a broad range of mental health conditions and communication needs (eg, people with psychosis), feedback from carers can be invaluable to health-care providers. The need for this feedback is particularly evident when care recipients might not be motivated to, or not in a position to, communicate or engage with their care and treatment plans because of their age, their developmental phase, or the specific nature of their difficulties (eg, hallucinatory experiences, suspicion and paranoia, and cognitive decline).

Before the COVID-19 pandemic, some family carers might have been invited into face-to-face health provider review meetings. Instead, some families, particularly those not living with care recipients, have been excluded from the invitation process during the COVID-19 pandemic. In informal caregiving relationships, in which the care recipient is residing in separate accommodation (eg, supported housing) from their carer, issues related to insufficient time, regulations about face-to-face contact, and scarce workforce resources have led staff to prioritise appointments with care recipients and not caregivers. Consequently, carers have reported a sense of disconnection from the recipient's care and of abandonment by the service provider.

In households with resident carers and care recipients, implementation of remote access appointments has afforded minimal privacy for carers to explain their experiences and observations pertinent to the care recipient assessment and treatment plans. This privacy is important, particularly if the carer's accounts differ from the care recipient's, and has potential implications for the emotional or physical safety of carers. For some carers, there has been a concern that the health and social care services have not been able to accurately access the care recipient's wellbeing and functioning because the carers have not been able to speak freely and provide their perspective. Additionally, remote access appointments, typically by telephone, do not ordinarily make provision for discussions between three people, which can make providing their perspective harder for carers. For children and young people, parents and carers will often need to make remote sessions happen

(eg, by being available themselves and encouraging the young person to attend). The overall effect is that family carers find it more difficult to advocate with health and social care providers at the time when many care recipients would most benefit from their input over pandemic-related challenges.

### Caregiving and hospital visits

COVID-19 management plans and associated hospital and visiting restrictions have left many carers feeling isolated and fearful about the wellbeing of their care recipient in psychiatric units.<sup>32</sup> This fear is often linked to concerns about hospital-acquired COVID-19 or how the care recipient would tolerate treatments and management strategies for COVID-19 (eg, isolation). With an excess in infection and mortality in hospital settings, these concerns were justified, at least in the initial phase of the pandemic.<sup>33</sup> Restrictions on onsite face-to-face contact and visits have exacerbated these concerns and represent a source of considerable distress to carers. In addition to dealing with the care recipient's psychiatric admission, direct exposure to, or being informed about, a care recipient's upset and puzzlement about the absence of family visits during a hospital admission has been difficult for carers. The absence of family visits is particularly challenging in instances in which care recipients do not have awareness of the pandemic or a shared view of what the virus has meant for organisations, freedom of movement, and infection-control procedures.

Psychiatric inpatient services have sought to use alternative, remote-based methods for informal carers to maintain contact with care recipients. However, the successful implementation of these methods depends on several factors, including the mental state, wellbeing, and receptiveness of the care recipient, availability of staff, and the digital resources and capacity of service providers. The confidence of carers, in participating in varied communication strategies, who themselves vary in demography and technology proficiency is easily overestimated. However, the negative effect on carers who are not able to visit care recipients is underestimated.

## Specific issues across the care recipients' lifespan

### Children and young adults

In general, parents and carers of children and young people have reported a negative impact on their mental health and wellbeing, with observable deterioration after the implementation of national lockdowns and home education. However, some subgroups have shown greater vulnerability to the mental health impacts of the COVID-19 pandemic than other subgroups, including adults in single-caregiver households, families on low incomes, and households with children and young people with special educational needs or neurodevelopmental disorders.<sup>34,35</sup> Many of these subgroups have had to take on roles that might have otherwise been offered by school-based pastoral support and mental health professionals.<sup>36</sup>

As the pandemic unfolded and lockdown measures followed, there has been a public health focus on promoting wellbeing through managing (restricting) food and alcohol consumption and introducing optimal exercise routines. Although laudable and led by evidence that highlights substantial increases in problematic drinking and lifestyle behaviours during lockdown,<sup>37</sup> the confirmed links between obesity and lockdown measures, and the increased risk of death,<sup>38,39</sup> this focus has been complex for people with emerging or established eating disorders.<sup>40</sup>

Carers are often involved in facilitating the positive behavioural change of care recipients using different strategies, including motivational interviewing and anxiety management. With the transfer of specialist eating disorder services to remote access provision, health-care providers have been increasingly reliant on the involvement of family carers to support care recipients with accessing their physical health checks (eg, weight checks and blood tests). This increasing reliance can also affect the caregiving relationship and support needs of the carer.

For individuals, particularly young children and young people, with complex neurodevelopmental needs, such as autism spectrum disorder, intellectual disability, and other neurodevelopmental conditions, their interface with the world is often mediated via their carers. Family carers are frequently the chief negotiators and advocates of which services their child can access, including those in the family home. This liaison with statutory, voluntary, and third-sector service providers can leave carers as *de facto* case managers, which is a considerable responsibility, particularly for single-parent households.

The pandemic and changes to service delivery have increased uncertainty for nearly everyone. However, for specific groups (eg, people with autism spectrum disorder) who depend on routines, consistency, predictability, and familiarity to function optimally in their environments, the effect of these changes on their behaviours and wellbeing and the direct and indirect implications for the wellbeing and needs of informal carers, have not been fully considered.<sup>41,42</sup> For example, it is known that lockdown restrictions on educational access and specialist learning provision, and the cessation of community-based resources (eg, swimming and soft play), which are essential for families in managing the daily and unique challenges of their caregiving role, have left many families feeling desperate and isolated.<sup>43,44</sup> Sources of support (eg, child care, individual help, and educational provision) that parents might have used before the pandemic, and that supported their efforts in managing the effect of their child's complex needs on their wellbeing, have largely disappeared.<sup>45</sup> Compounding this effect, sources of support for carers themselves have also been less available than they were before the pandemic. In addition, some young adults living in supported residential-group settings have returned to their family of origin, initially as

a temporary measure, to minimise the risk of virus transmission. Such developments have provided new challenges and stressors for both carers and recipients.<sup>43,44</sup>

In young children and adults, complex neurodevelopmental needs will often co-occur with other morbidities, including mental health conditions (eg, anxiety or eating disorders) and physical health conditions, which adds to the challenges of the caregiving role.<sup>46,47</sup> Although not exclusive to, or applicable to, all children and adults with complex neurodevelopmental needs, the UK national lockdowns, with their service closures that reduced the population in public places and were associated with an overall quieter and slower daily pace of life, were believed to have led to reductions in common sources of anxiety and stress for some individuals. Thus, the easing of lockdown measures and re-entry into normal life (eg, school) can be linked with mixed emotions for carers. For some carers, the end of lockdown will be a return to old challenges (eg, supporting a young person with mental health difficulties and social vulnerabilities with school attendance). However, understanding of and adherence to lockdown rules has sometimes presented unique challenges for carers, such as care recipients being over-compliant or having an overliteral interpretation of public health guidance. Some families have dealt with situations in which care recipients have chosen not to leave their homes in any permissible circumstances (eg, shopping) or not to see other people, including family carers, as part of their overliteral interpretation of public health guidance. In these situations, family carers have had to create strategies to help care recipients avoid additional health and social disabilities and source creative ways to deliver usual care.

In addition, there are stressors for carers waiting for the start or completion of the diagnostic process for care recipients with complex neurodevelopmental needs. In some geographical areas and services, waiting times for diagnostic assessments, which were already 2–3 years long, have increased during the COVID-19 pandemic.<sup>48</sup> This increase in waiting times partly reflects the transition that services have had to make to adjust to and integrate the collection of diagnostic data using remote methods that were previously gathered across different settings, including the family home and school. Since diagnosis is often a requirement for accessing specialist services and educational support, diagnostic delays exacerbate the stress exposure and strain for carers and the vulnerability of the family unit.

### Older adults

The high number of deaths recorded in UK care homes for older adults was only reported after the initial months following the onset of the pandemic.<sup>49</sup> This statistic also sat alongside the existing, but widely publicised, data and public health messages that COVID-19 differentially affected older adults and those with pre-existing health conditions. It is in the context of this information that

the concern of carers for older adults with underlying health conditions is best understood. This situation is complex for carers of relatives residing in care homes, where policies of no family visits or close contact (eg, hugs) or severely restricted visits (eg, through a bedroom window) have dominated during the pandemic and have been frustrating and distressing. Family carers of these older adults have been exposed to daily media updates on SARS-CoV-2 infections and deaths but have not been able to witness the state of their relatives. For some family carers, their contact has included video conferencing platforms; for other family carers, their relative is not cognitively able to use video conferencing, even with help, and telephone updates from third parties (ie, paid care staff) have had to suffice.

The additional emotional challenges (eg, feelings of loss, grief, and frustration) faced by families of care recipients living with organic conditions, typically dementia-related disorders that impair memory, recognition of others, and communication styles, have had sparse coverage, despite the progressive nature of the condition. These feelings have been complicated by variability in policies for visiting adults in care homes between regions and individual care home providers and by the concern—often backed up by observation—that their relatives deteriorate faster if isolated.<sup>50</sup>

For family carers that reside with care recipients who are older adults with dementia-related conditions, their own risk–benefit calculations have left some declining offers of home care services.<sup>51</sup> This decision is because of fears that formal (paid) carers might change frequently and be a source of infection. Without external home support, family carers have had to fill the role of a formal carer. Additionally, services that care recipients might have accessed outside of the family home (eg, respite care and day centres) have been closed or severely restricted during the COVID-19 pandemic.<sup>52,53</sup> Consequently, family carers have been left supporting relatives, who themselves might have become understimulated and distressed by the losses and changes to their routines brought by the pandemic. Therefore, family carers have had reduced support and an increased caregiving load during the pandemic, including exposure to behavioural changes that can be both challenging and anti-social in adults with dementia-related disorders. Despite this increase in caregiving load, some carers have been reluctant for care recipients to be admitted into specialist care facilities due to fears about being unable to see them or only seeing them just before their death.

Informal carers of older adults have also been affected by digital inequalities and access issues. Some carers (eg, spousal partners) have not had Internet access or have not been confident with its use. Outside of home visits, care has relied heavily on phone-based assessments. This reliance has its limitations on what family carers can report or feel comfortable sharing in the presence of the care recipient. These limitations can include concern

about protecting the reputation and dignity of the care recipient, particularly if sharing information about disinhibited, antisocial behaviours or aggression. Consequently, details about the family experience and needs have been at risk of being missed, unexplored, and misinterpreted, particularly in situations in which the family caregiving relationship was breaking down.

Family carers of older adults with dementia-related conditions provide the bulk of their community-based care and were already overworked and overstressed before the pandemic. Due to concerns around virus transmission and risk of death, COVID-19 and the lockdowns have left many carers of older adults with dementia-related disorders stuck in a vicious cycle of social isolation, adverse impacts on symptoms and behaviours, and sparse or absent social, physical, mental health, and professional support.<sup>54</sup>

### Additional health morbidities

The increased susceptibility of people with physical health morbidities (eg, obesity, diabetes, and respiratory conditions) to COVID-19 is well established, as is the importance of their optimal treatments.<sup>55</sup> Supporting care recipients with multiple morbidities to access the right care has always been a challenge for carers and has been more challenging during the pandemic. The effect of COVID-19 on supporting these care recipients is particularly acute for people from minority-ethnic groups, in whom there has been a sustained spotlight on COVID-19 and its impact. Care for health morbidities is typically met by different health providers (eg, primary care and secondary care) and staff groups and is often across different geographical locations. For many carers, the navigation of these health silos during the pandemic has been problematic.

### Conclusion

Our discussion on the experiences of informal carers during the COVID-19 pandemic is incomplete without acknowledging that carers rarely have options other than to carry on being carers, and the pandemic has not changed this fact. COVID-19 and its impact on community facilities and health, social care, and educational provision have helped to refocus attention on the care and support inequities that carers already had before the pandemic. Health and social care systems remain inextricably linked to, influenced by, and heavily reliant on the simple fact that primary carers are often close family members who continue to provide care irrespective of support they might, or might not, receive from external agencies.

COVID-19 highlighted societal inequalities, including the disproportionate number of COVID-19 deaths of people with comorbidities and people in marginalised communities. These communities include people with intellectual and developmental disabilities, those with severe mental illness, residents in care homes, those

with dementia-related conditions at home, those from minority-ethnic backgrounds, and those living in economically deprived areas.<sup>55,56</sup> Our own experiences, and clinical and research observations during the past 12 months, suggest that families have found themselves locked in virtuous or vicious cycles of functioning. People in virtuous cycles, who were doing well at the start of the pandemic, generally continued along the same trajectory. However, for people who were struggling from the outset of the pandemic, these vicious cycles have mainly continued or worsened.<sup>57</sup> Social inequalities, including living arrangements that are not optimal (eg, living in overcrowded accommodation and no access to green spaces), financial insecurity, and social isolation, have appeared to have key influencing roles on whether families found themselves in vicious or virtuous cycles.

Carers have been resourceful in responding to the immediate challenges of the pandemic and in problem-solving specific issues. However, the adaptations of carers have not been without cost to their own mental and physical health, wellbeing, and family relationships.<sup>58</sup> Much is already known about the psychological health and wellbeing of family carers, predating the pandemic.<sup>59</sup> Ensuring that family carers are not left socially isolated and have opportunities to safely connect with peers should be a priority, and policy makers need to learn from the experiences of caregivers during the COVID-19 pandemic.

Helping families to establish their own so-called closed support bubbles with a small group of other families would have been helpful. These support bubbles could offer a range of functions, including companionship, mutual support, information, and coaching, particularly in single-carer households. These support bubbles could also provide opportunities for supporting blended learning (ie, a combination of in-school and home-based facilitated learning) for school-aged children (ie, aged 5–16 years) when school building access or school provision is disrupted. Data from consultation events with parents and teachers on this type of lockdown model are ongoing and have been encouraging.<sup>60</sup> Disseminating written and audio-based material on how to deal with different family presentations and needs and sharing resources digitally for families with access to technology would also be useful.<sup>61</sup>

Informal carers are a precious and invaluable resource, and the pandemic has highlighted their hidden key worker status. However, it is essential that, as progress is made with the pandemic and vaccination programme, health, social care, and education systems avoid taking carers for granted and inadvertently exploiting their involvement, goodwill, and kinship. Addressing the health and wellbeing needs of carers has never been a central objective of health and social care providers and this needs to change as a matter of priority.

#### Contributors

JO led on the project conceptualisation, implementation, initial drafting, writing coordination, and editing of the Health Policy. CC, GL, TC, AR, KT, and EK contributed to the design, discussion, writing, and editing of the Health Policy and were responsible for searching for articles. DS, JT, MDF, EW, HM, AY, and AD contributed to the design, discussion, writing, and editing of the Health Policy. All authors read and approved the final version.

#### Declaration of interests

We declare no competing interests.

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