



you care for them, we care for you

The experiences of unpaid carers during the Covid-19 pandemic

*March 2020
to March 2022*



Executive Summary

The Covid-19 pandemic had an enormous impact on the health and wellbeing of many people across the UK, and unpaid carers were affected more than most.

During the pandemic, Carers' Resource staff witnessed powerful evidence of the struggle and suffering of carers across Bradford, Harrogate and Craven.

This study draws together the experiences of hundreds of unpaid carers, and dozens of staff and volunteers who support carers, to reveal how the closing of services, limiting of primary and secondary care, and restrictions on everyday routines, really affected carers during these unprecedented times.

Key findings include:

- **The pandemic intensified and compounded many of the issues already faced by carers.**

Many carers were not accessing support before the pandemic, for a range of reasons. The unpaid caring role is often unrecognised in professional health and social care settings. This was true before and continued during the pandemic. Carers themselves often struggle to identify themselves as carers, which is a barrier to accessing support. The pandemic exacerbated these issues; made it harder to access support, and isolated carers further.

- **Those who were new to caring during the pandemic found it even more difficult to access services than those who were already on a care pathway.**

Carers reported widely differing experiences of social care and NHS services. If carers were waiting for health or social care support before the pandemic hit, or became in need during the pandemic, they were more likely to struggle to access services, as there was a priority for very high-risk cases relating to Covid.

- **The pandemic had an effect on the physical and mental health of many carers.**

Around two-thirds of carers surveyed said the pandemic had taken a toll on their physical and mental health.

- **The specific needs of unpaid carers were not considered in the development of lockdown restrictions.**

Carers reported difficulties, even with everyday tasks such as food shopping, due to the severe restrictions which did not take into account the needs of unpaid carers and their caring responsibilities. Isolating households and shielding left carers and cared-for people with sometimes dangerously low levels of daily support and necessities.

- **The effects of the pandemic are still being felt by carers.**

Health and social care services have not returned to pre-pandemic ways of working and can still be difficult to access. Many cared-for people and their carers are vulnerable and remain fearful of infection. Many cared-for people need more support than they did pre-pandemic, which is difficult to access. The economic climate will have a more profound effect on carers than the wider population.

This study makes a number of recommendations, which can be summarised as follows:

1

Recognition that there needs to be a sustained campaign to encourage unpaid carers to recognise their role, and that asking for support as a carer is an acceptable thing to do.

2

An increased focus on the need for a break from caring, and funding to support it.

3

Greater recognition of the role and needs of, unpaid carers in any future public health campaigns.

4

At a local level there needs to be a greater recognition of the carer's role in health and care settings.

5

Work needs to be undertaken in primary care settings to embed the Quality Markers for carers to ensure that all carers are registered as such with their GP.

6

Agencies and organisations need to be creative in enabling carers to be consulted, and to engage in the co-design of services.



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Introduction

Carers' Resource offers information, advice and a wide range of support services to unpaid carers across the Bradford, Harrogate and Craven districts, covering a total population of over 600,000. The organisation continued to deliver services to unpaid carers throughout the Covid-19 pandemic, and therefore became aware of the unbearable levels of stress and exhaustion many carers were experiencing.

Carers' Resource exists to support the carer; to ensure that they get the support they need in order to be able to continue their role and that carer strain is kept to a minimum. However, carers are primarily concerned with getting the services and support they need for the person they care for. And therefore support for the carer and support for those in need of care are often intertwined and this investigation illustrates how difficult it can be to distinguish between the 2 sets of need.

Most people in the UK were affected by the pandemic, lockdowns and restrictions; but some were affected worse than others. Carers' Resource staff and volunteers knew the pandemic was having a disproportionate impact on unpaid carers. Even as the last of the restrictions were being lifted in spring 2022, the full impact on unpaid carers was still emerging.

Carers' Resource was keen to gather a more robust picture of the unpaid carer experience through the pandemic; to capture their own stories and develop key messages for the ears of NHS England, local authorities, and the national Department of Health and Social Care.

In January 2022, NHS England & NHS Improvement's Commitment to Carers Programme commissioned 30 rapid-learning projects, each of which was to evaluate different aspects of carers' experiences.

This research is part of that commission; it examines in detail how the pandemic affected the support received by unpaid carers, including from primary and secondary health services, and carers' experiences of the vaccine rollout.

The report draws on the insights and suggestions identified by unpaid carers, Carers' Resource staff and volunteers, and aims to drive change; develop best practice; and ensure that support and services are more responsive to the needs of unpaid carers in the future.

How the study was conducted

Unpaid carers, largely from the districts of Bradford, Craven and Harrogate, were asked to complete an online questionnaire, which would be the primary source of quantitative data. A number of qualitative, semi-structured interviews with unpaid carers explored experiences in greater depth.

Online surveys and in-depth interviews were also carried out with Carers' Resource staff and volunteers. Day-to-day over the past two years, they heard from, and supported, unpaid carers in dealing with the range of issues they faced. By participating in this survey, staff and volunteers were able to advocate for those carers who could not, or did not want to, participate in this study directly.

Introduction

The surveys and interviews were conducted from mid-February 2022 to the end of May 2022. Interviews were largely carried out by telephone or video call, although participants were offered the opportunity to meet face to face.

Carers were invited to take part through the Carers' Resource newsletter, mailing list and social media channels, and through word of mouth by staff and volunteers.

Who participated

327 people took part in the online questionnaire. 321 of these were unpaid carers.

89% of respondents were unpaid carers before the pandemic began.

13% said they had only just become a carer immediately before the pandemic.

11% of respondents took on caring responsibilities after March 2020.

27% of respondents had been a carer for more than ten years. Older respondents were more likely to have been a carer for longer.

Those aged 25-34 were most likely to say they became a carer during the pandemic.

98% of respondents who were over 65 years of age look after a single family member. A higher proportion of younger respondents support more than one person.

Many cared-for people have multiple conditions and a number have very complex needs. There were differences amongst the age cohorts, but the most common conditions included:

- Memory loss and dementia
- Mental health conditions
- Intellectual disability and learning difficulties
- Physical disability

Further information about the unpaid carers who completed a questionnaire, and who they care for, and the limitations of the survey, can be found in the appendices.



Support & services available to carers before the pandemic

In order to establish a baseline to understand the impact of the pandemic, all survey participants were given a list of the support and services that might be available to unpaid carers to help them in their care role. Carers were asked which of these services they had used regularly before the pandemic. Staff and volunteers were asked which services they thought were typically available pre-pandemic. The results were as follows:

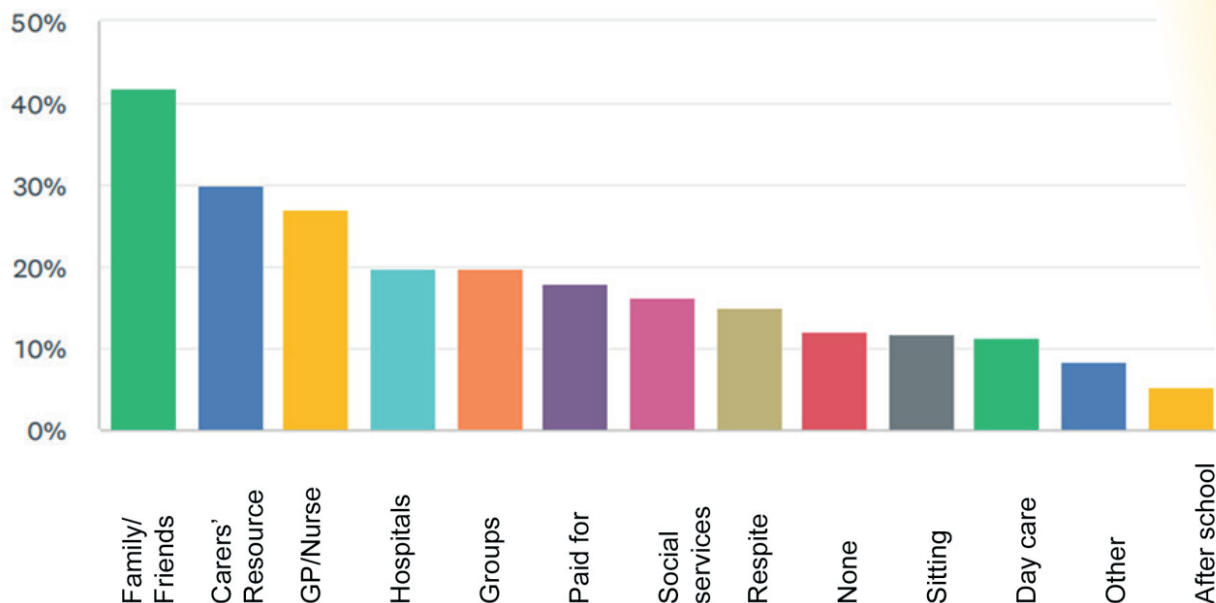


Chart 1: services and support accessed pre-pandemic

42% of respondents said they received some support from family, friends or neighbours pre-pandemic; 47% accessed primary and secondary health care.

Of the support designed to help them in their unpaid carer role, 30% said they did use Carers' Resource, and 20% said they went to support groups.

Of the more formal and statutory services, 16% said they received support from social care, and similar percentages used paid-for care (18%), respite care (15%), day care (11%) and sitting services (12%).

Other support and services identified included: School/college; religious support, churches, mosques and temples; third sector organisations, e.g. Dementia Forward, Harrogate Easier Living Project, MIND, Saneline and CALM; Financial and emotional support; food banks, food poverty campaign groups, community organisationst; activity or social groups for the cared-for person.

Many carers described minimal support even pre-pandemic

12% of respondents said they received no support or services prior to the pandemic. Many face-to-face interviewees also described having no or low levels of support before the pandemic began. Many services had been cut before the pandemic, with local authority and care services reducing support due to constraints on their budgets.

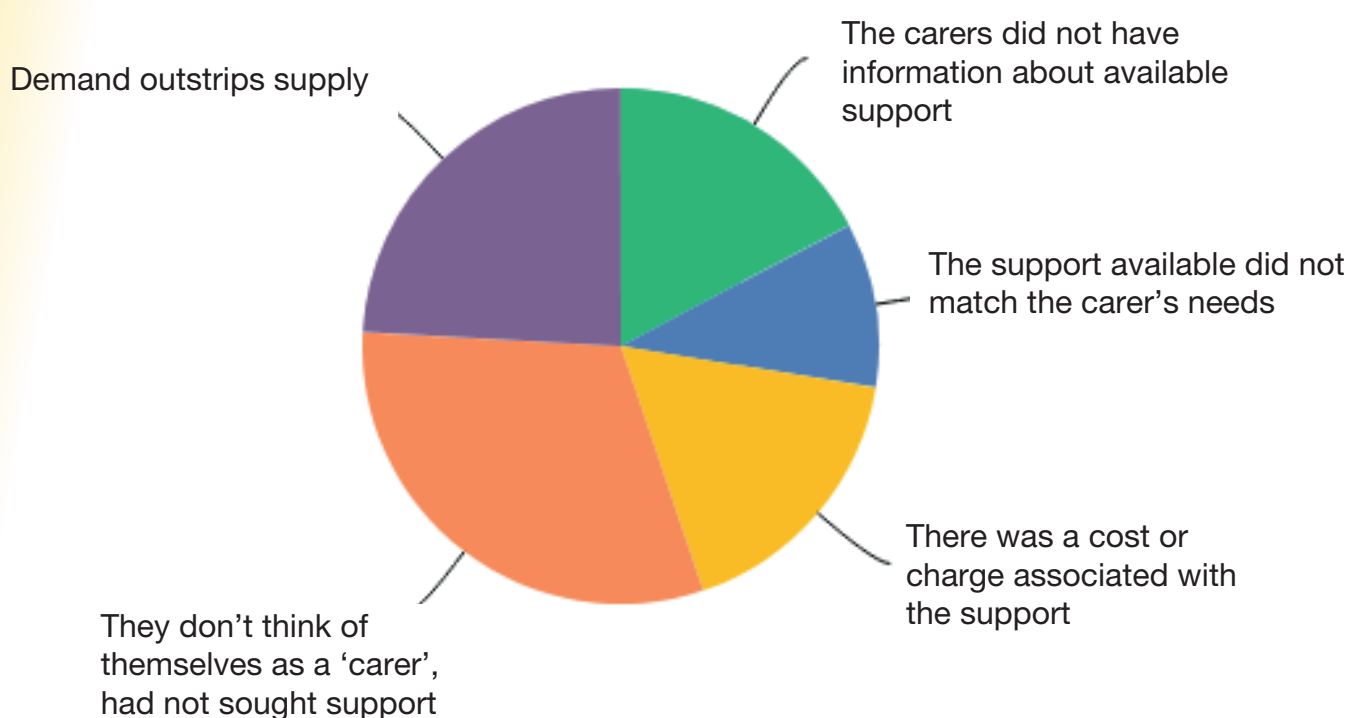
Why don't unpaid carers access support? The barriers they face

Even prior to the pandemic, many unpaid carers did not always access support that could help them.

Carers' Resource staff and volunteers were asked to consider why services and support for unpaid carers might not be easily accessible – what were the potential barriers? They ranked a list of possible barriers, shown in Chart 2.

All interviewees - staff, volunteers and unpaid carers – were asked to reflect on the barriers to access, and describe their own experiences.

Chart 2: Barriers that prevent carers accessing support & services (staff/volunteer views)



Barrier: Identifying as an unpaid carer

The biggest barrier to people seeking support appears to be that they do not identify as a carer. The care they provide is simply part of home life. It's just what they do. The unpaid carer accepts the situation and often doesn't recognise the level of support they are providing.

Some respondents don't like to label themselves as a carer, and prefer to think of themselves in terms of their familial or friendship relationship to the person that they care for. This can be particularly true for partners and spouses, and for parent carers. There is often a strong sense that family ought to look after the person who needs care. There can be a generational dimension to this view, as well as community and cultural differences.

Why don't unpaid carers access support? The barriers they face

Some carers have a fear of drawing the attention of statutory social services to their home life, or wish to maintain a sense of privacy and dignity.

The term “carer” is also still misunderstood, by many unpaid carers, professionals, and members of the public – it is often thought of as meaning a paid-for worker, for example someone who works in the NHS or a care home.

Barrier: Supply and demand

“Demand outstrips supply” was ranked by Carers’ Resource staff/volunteers as the second biggest barrier to access. Some carers also gave examples of demand failing to meet needs.

This supply-demand relationship is a complicated one: the support requirements of each unpaid carer are as different as their circumstances. Many carers and cared-for people need more than one care provider.

Where people live makes a difference. Locality and logistics make the lack of support services even more acute. Some issues are specific to rural areas while others, such as lack of appropriate transport, are also applicable to towns and cities. Support might be available - just not where it is needed.

Barrier: Cost

Any services which are paid-for are by definition more difficult to access for many carers. Even before the pandemic, a survey in 2019 showed that 70% of carers identified money worries as a source of stress, and 32% of carers had struggled on at least one occasion to pay an essential bill.

Barrier: Information about support and services

Low awareness about the support that might be on offer, or insufficient information about how to access services, was ranked as the fourth largest barrier by members of Carers’ Resource staff and volunteers. Digital exclusion can magnify this barrier.

Unpaid carers will often carry on as they are until they reach a crisis. At that point, they will need to deal with whatever the crisis is, before they can begin to think about the information they’ve been given regarding possible support and services.



Covid-19 pandemic & unpaid carers' experiences

Having established a general picture of support for unpaid carers, the study set out to understand how these were affected by the Covid-19 pandemic.

This research was carried out in the spring of 2022; there had been several stages of the pandemic, with different policies and regulations in place at different times. As the survey took place, the country was in another transition, towards complete relaxation of Covid-19 restrictions.

The survey questions were designed to help participants to reflect on their experiences as the country moved through these phases, asking three sets of questions: about the very early stages of the pandemic in spring 2020; the easing of restrictions in late 2021; and whether life was returning to normal for them in March-May 2022.

Participants were asked to cast their thoughts back to March 2020, at the outbreak of Coronavirus in the UK and the introduction of a national lockdown to try to control its spread.

Participants were presented with the list of support and services again, and were asked to describe their experiences of how these services changed at the start of the pandemic.

For most participants, day care, respite care, sitting services and support groups more or less stopped completely in spring 2020.

Around half of respondents thought that the statutory services they had been in receipt of – including social services, primary and secondary health care – decreased significantly in the first waves of the pandemic.

Carers' experiences differed widely

It is evident that the experiences of the pandemic were not universal amongst unpaid carers. People had widely differing experiences of the same service, and individuals had wide-ranging experiences of different services.

New carers were particularly badly affected

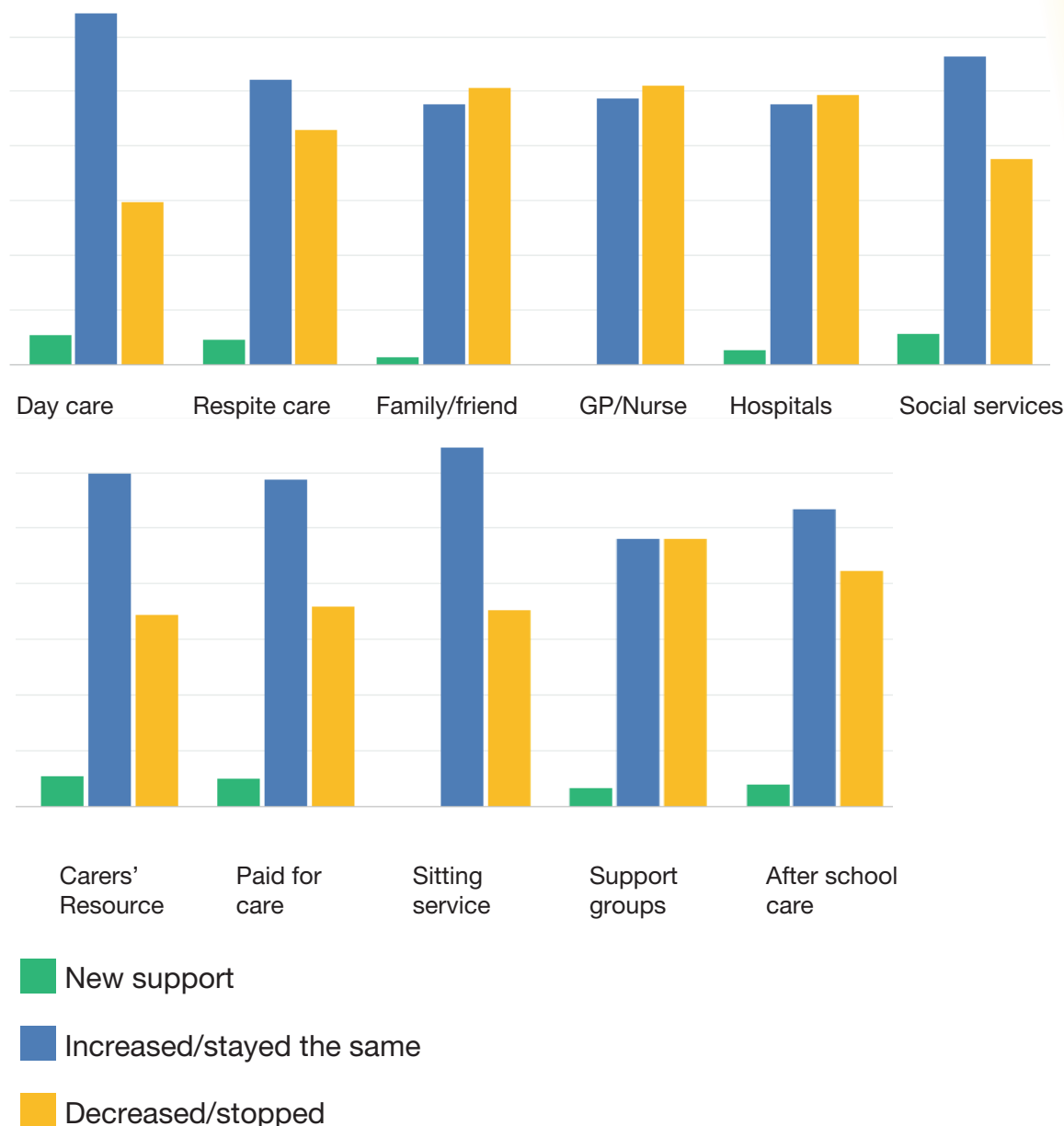
One factor that appeared to make a difference was where carers were in relation to a care pathway. If there was already a social worker, domiciliary or paid-for care allocated, the carer probably still had some support. Where it was a new requirement, access was harder. The feeling was that high risk cases were prioritised, out of necessity, and the eligibility bar was raised.

Some carers saw little or no change

For some participants, life carried on as usual, although it must be noted that many who said there was no change had not accessed support before the pandemic.

Covid-19 pandemic & unpaid carers' experiences

Chart 3: Thinking now about the level of support you received during the pandemic, has there been a change? Please indicate what support you have accessed to help you as a carer, and whether this has stayed the same, increased, decreased, or stopped completely.



Lockdown closed much support

For many respondents, there was a significant change in the support they received, a major shift in their routines, and a closing down of their normal lives.

Many support services began to trial the use of Zoom, Microsoft Teams, video calls through WhatsApp, and telephone contact with their clients.

Local voluntary organisations in particular tried to be as creative as possible in finding ways to reaching out to carers to plug the gap left by face-to-face offerings closing down.

Covid-19 pandemic & unpaid carers' experiences

The pandemic disproportionately impacted unpaid carers

Respondents felt unpaid carers were already often overlooked, in terms of health and social care policy, funding, and in the design of service delivery. The sense of being 'at the back of the queue' intensified during the pandemic.

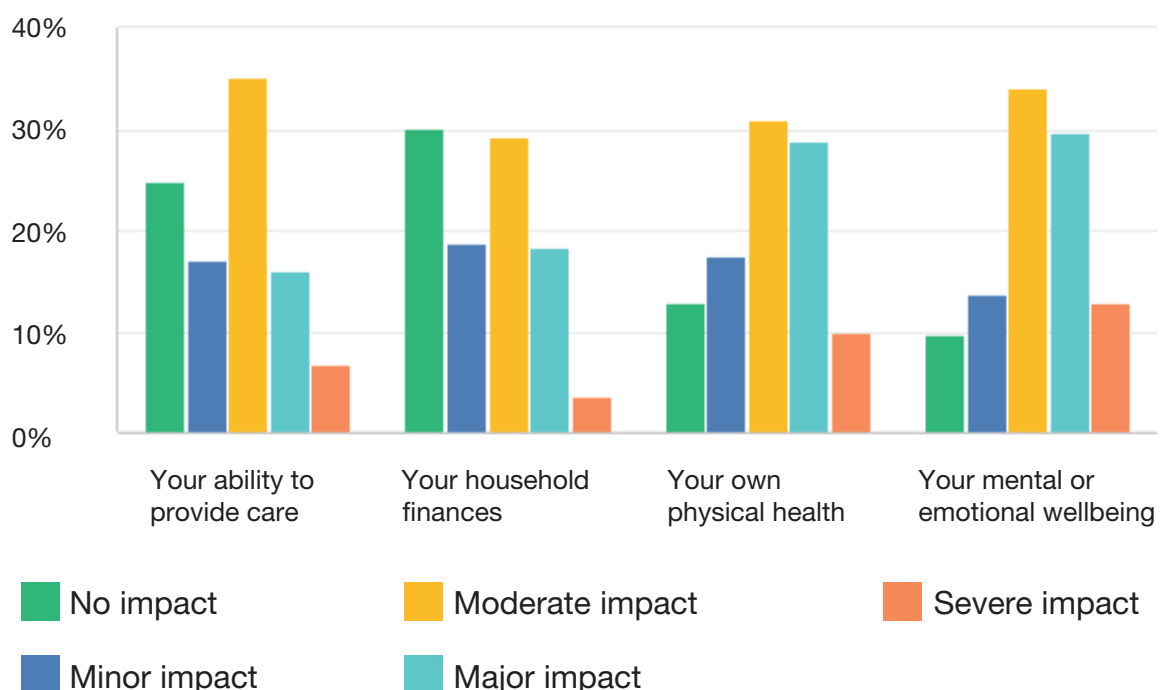
It is evident that the Covid-19 pandemic and the restrictions to control it disproportionately impacted on unpaid carers. In the early months in particular, the regulations were strict and were applied rigidly for most people.

The specific needs of unpaid carers were not considered in the development of the national regulations. With restrictions on households mixing, and support such as day care or sitting services largely unavailable, everyday tasks became even more of a logistical challenge for carers and the people they care for.

Many respondents talked about experiencing emotional stress and tensions over the Covid-19 restrictions, and their ability to stick to the rules. The regulations and messaging about them were confused and confusing. This left space for different family members to interpret guidance differently, or perhaps to disregard some rules as just being too difficult for their family circumstances.

Many survey participants talked about the higher levels of stress experienced, as the individual(s) cared for could become much more seriously ill if they were to get Covid-19. The unpaid carer was also often the only point of contact and support for the cared-for person, with a lot of responsibility on one set of shoulders.

Chart 4: Did the changes in the support you receive to help you as a carer have an effect on any of the following:



Covid-19 pandemic & unpaid carers' experiences

Lack of information and advice on caring for someone during the pandemic

Just over half of the online respondents had received some information about being a carer during the pandemic. Around two-thirds of those who received information thought that it was helpful.

68% either did not receive any information or advice about caring for someone during the pandemic, or they thought the information was not useful.



As the pandemic rolled on, the guidance changed and the rules were clarified to reflect a greater understanding of the needs of unpaid carers and the people they care for. There was greater awareness that, for some people, being able to form 'a bubble' was more than being able to have social contact with another household. It was vital peer support that helped someone manage in their care role.

There was also a realisation by policy-makers that young carers being unable to attend school or college affected more than their educational and developmental progress. School or college can be their only respite from the heavy burden of their caring role.

The effect of the pandemic on cared-for people was significant

Participants were asked what the impact had been on the cared-for individual due to changes in support or services received.

40% of online respondents said that the cared-for needs had shown a moderate increase, and 35% said the change in services had had a major impact on the needs of the cared-for.

Carers, and Carers' Resource staff, described people with dementia appearing to decline much more rapidly. They said lack of stimulation, loss of routine and absence of social interaction with their loved ones were major contributing factors.

Covid-19 pandemic & unpaid carers' experiences

People with autism were particularly hard hit by the withdrawal of support and the lack of structure and routine the cared for person typically requires. Those with depression or other mental health conditions report becoming far more troubled mentally.

Levels of anxiety have risen amongst many cared-for individuals, and their self-confidence has plummeted. People described the cared-for individual being too nervous to go out, even when the rules allowed.

Respondents said their cared-for people's fitness and general health levels had deteriorated. Older people have become more frail and lacking in stamina. And many carers said they are finding it difficult to help them return to pre-pandemic fitness levels. For many, the cared-for individual is often just so much more reliant on the unpaid carer now.

Unpaid carers had to do more

Carers were asked whether there had been any change in the support they need to give to their cared-for individuals. 37% of online respondents said there had been a moderate increase in the care they give, while 34% said there had been a major increase.

Even among those respondents who said there had been no change in the needs of their cared-for person, almost half said that the care they needed to give changed during the pandemic.

Carers were asked about the general impacts of the pandemic and how it affected home life and household budgets. They were also asked about the effect on their physical, mental and emotional health and wellbeing, and whether this affected their ability to provide care in any way.

National research by Carers UK shows that unpaid carers had poorer health outcomes than the general population even before the pandemic. The impacts over the past two years have simply compounded this.

31% of online respondents said there had been a moderate impact on their own physical health, while 29% said the impact had been major.

34% of online respondents said there had been a moderate impact on their emotional and mental wellbeing, while 30% said this was a major impact. Mental health concerns, stress and emotional exhaustion were common themes raised during qualitative interviews with unpaid carers and Carers' Resource staff and volunteers.

Household finances were often affected

For many respondents, there were very significant negative impacts on their finances. As with the general population, carers have lost jobs, been on furlough, had children at home who would have been receiving free school meals, or had to run equipment and heating that would not have been necessary with the previous support in place.

Covid-19 pandemic & unpaid carers' experiences

Some carers found there were positive effects

Some respondents talked about positive experiences during the pandemic, such as being able to work from home and not having to worry about the person they care for, who might otherwise be on their own. Working from home also felt safe for some people. Other respondents said that eliminating travel saved commuting costs, and saved them time each day, giving them a much better balance between work and their caring responsibilities. Some carers found they were better off financially during the pandemic.

The pandemic often reduced carers' capacity to care

Many respondents worried that the pandemic, and all of the changes it brought in its wake, has had a significant and potentially lasting impact on their ability to provide care. Of the online respondents, 35% said this was a moderate impact, while 23% said it was a major or severe impact.

For many carers, the Covid-19 pandemic had multiple impacts, across many aspects of their lives, and this has had cumulative effects. Some carers were living in situations that were fraught or even unsafe.

Many unpaid carers found the nature of their relationship with the cared for individual shifted, often permanently. Some carers view their interactions with support and services less favourably than before the pandemic.

It is clear that, during the Covid-19 pandemic, unpaid carers did not receive the practical support they need; their cared-for individual(s) did not receive the services that helped the carer to carry out their caring role; and that this had – and is still having – a growing and cumulative effect.

The full extent of the pandemic's impacts on unpaid carers' lives has still to unfold.



Experiences of primary and secondary health care

Respondents were asked about their experiences of health care in the community and in hospital settings, during the pandemic. Many wanted to convey how grateful they were to the NHS, health and care workers for their service during the pandemic, and the roll-out of the vaccine programme.

Experiences varied widely

Participants in the online survey were asked to rank their experiences of GP and community health services, and hospital services, on a five-point ranking scale from poor to excellent. However, many commented that they found this difficult as they had very mixed experiences, which varied over time. Interview participants also wanted to give a nuanced response, and to draw a distinction between treatment for Covid and other critical care, and elective or routine care, or treatment that might not be time critical.

Hospital care experiences were more positive – but still problematic

Interview participants reported more positive experiences with hospital treatment, compared to their opinions of GP services. Even when people had experienced disruption to routine care or elective procedures, they tended to hold more positive opinions of hospital care.

There were, however, examples of failures in care, in appointments being cancelled last minute and people getting sicker because of it. Respondents also found PPE, visiting restrictions, and difficulty in getting information about their cared-for individual added to what was already a worrying and frustrating episode.

GP services were badly affected

Generally, people thought hospital services coped better with the pandemic than GP and community care. 20% of online respondents held the opinion that GP/community services should be rated as 'poor', compared to 11% who rated hospital services as poor.

Respondents generally said access to GPs during the most severe restrictions was extremely limited, and that surgeries have been very slow, overall, to return to what people consider normal access. Carers gave examples of appointments being cancelled last minute, and of appointments for assessment or referral being really hard to get.

The pandemic altered health service provision for many people in the UK. However, the additional factors in unpaid carers' lives meant the impact of these changes were often more extensive, have deeper consequences and are longer lasting.

Experiences of primary and secondary health care

Covid-19 vaccine roll-out experiences

94% of online respondents said they had received their vaccine and boosters.

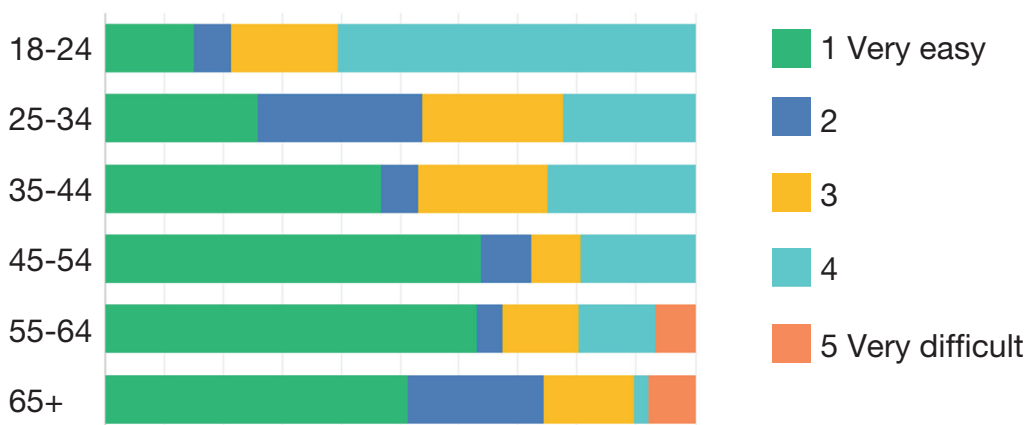
The roll out of the vaccine for carers was confusing and fraught with challenges for unpaid carers. In the first instance this emanated from national government who, after lobbying, included unpaid carers in cohort 6 of the roll out but failed to communicate this effectively to local areas.

Carers' Resource urged all unpaid carers to ensure they were registered as a carer with their GP, so they could be contacted by them for the vaccine and this revealed a second issue. There was a lack of clear definition of an unpaid carer, which led to some carers being told they weren't eligible as they were not in receipt of Carers Allowance.

When carers were asked to rank how easy it was to get their vaccine, the younger cohorts were more likely to say that it was difficult, and particularly for their first jab.



Chart 5: rate how easy it was to get the vaccine (unpaid carers' views)

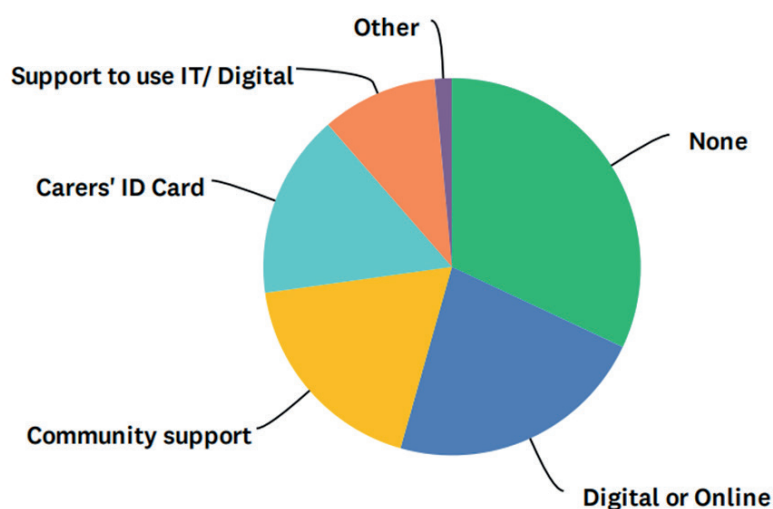


When the vaccine programme began, it was initially targeted at vulnerable people. Unpaid carers were not recognised as a key group, and therefore found they could not be vaccinated at the same time. Respondents felt it would have made better sense to be vaccinated together, because the carer is in close contact and possibly providing personal care.

Many people reported difficulty getting an appointment. There were numerous examples of long and tricky journeys, and the stresses of having to organise the logistics of multiple trips. Some decided to delay getting their jabs until a more accessible location was offered.

Innovation, new access routes and technology

Chart 4: What new or innovative support and services did you use during the pandemic?



Innovative uses of technology were developed through necessity while Covid-19 restrictions prevented people being together in person. Some carers used remote monitoring for the first time, and were more accepting of it as an alternative to being able to see a health professional in person.

Some described using digital media with the support of a care worker, for example during a home visit, using their work phone so that they could WhatsApp their family members for the carer. For some, they said it was their first contact with the outside world.

As might be anticipated, younger carers were more likely to be comfortable with screen time, and this allowed youth support groups to get really creative with online sessions and a type of blended delivery.

Digital exclusion remains an issue

Some carers remain digitally excluded. Some said they do not like to use any form of IT, that they find it too invasive and impersonal, and others said they simply cannot afford it. There are also localities that continue to have poor broadband services, particularly in the North Yorkshire villages.

Many charities, local groups and people in the community made huge efforts to distribute physical kit to people who needed help to get online. Some grants were made available, for example for young adult carers to purchase a laptop.

There was also support available in some areas to help people to set up their equipment and develop the skills and confidence to use it.

Innovation, new access routes and technology

Carers also said that digital services are not always the right solution in every circumstance, and have limitations. Some called for policy makers and service designers to ensure that they did not rush to digital as the default provision.

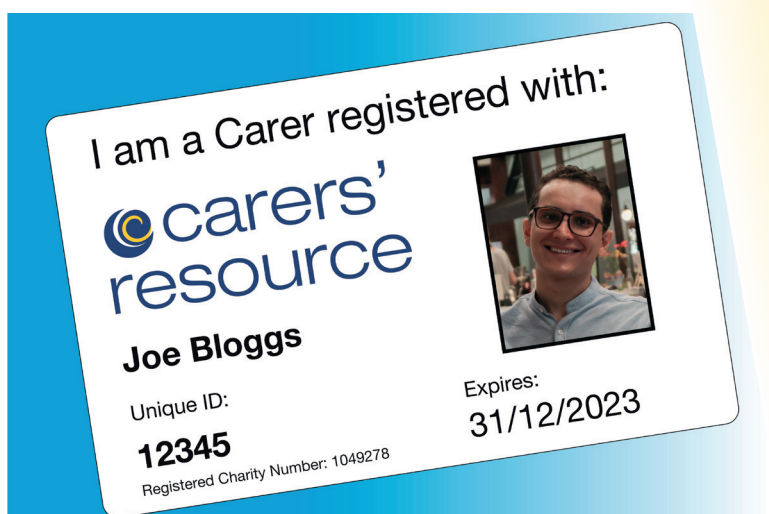
Local groups stepped up to provide support

Not all of the new approaches that were tried or accelerated during the pandemic related to new technology and digital media. Participants were very keen to say how much they were helped by the support they received from their local communities. Many of the support groups and local connections have continued as Covid-19 restrictions have eased. And for some respondents, the loss of their routine and 'life infrastructure' that helped their care role was the first time that they became aware of support organisations such as Carers' Resource.

Carer's ID card proved valuable

One simple innovation, identified by several respondents, was the Carer's ID Card, provided by Carers' Resource. People found the ID Card really useful during hospital appointments, at GP surgeries, and even to inform hotel staff that a spouse has dementia, and to alert the bearer of the card if the cared-for is seen on their own.

Some respondents also talked about a 'vaccination letter', devised by Carers' Resource in conjunction with other local voluntary organisations, which had been helpful in explaining their carer status to vaccine centres, and get through the bottleneck caused by strict eligibility criteria.



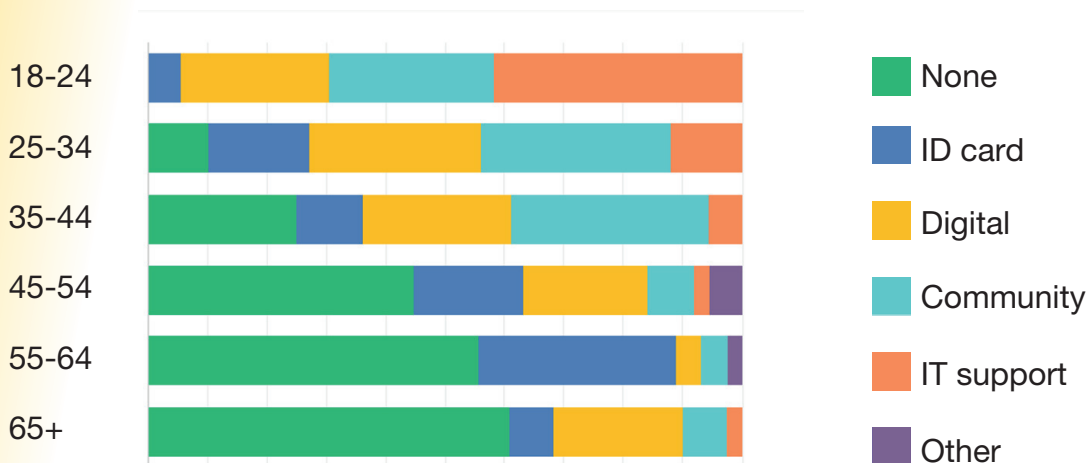
Innovation, new access routes and technology

Many carers accessed no new support at all

The majority of online respondents had tried some form of new or innovative support or means to access services. Most interview participants said they would be happy if the most convenient or useful features remained as options in the future.

But 32% of those carers who answered the questionnaire online had not used any of the examples listed, nor did they identify any others that they had experienced.

Chart 5: New or innovative support and services accessed by age



The youngest cohort, aged 18-24, had all experienced some innovative or new aspects of services, particularly digital access and support with IT/online resources. Only 10% of those aged 25-34 said they had tried nothing innovative, but this rose to 61% of those aged 65+.



Life in spring 2022

In February 2022, the UK Government announced it was easing, and subsequently removing, Covid-19 restrictions, and began talking about life returning to normal.

As the research was carried out during March-May 2022, respondents noted that, on the whole, the support and services that help unpaid carers were moving towards re-opening.

The legacy of Covid remains

Many respondents said social services and community services were continuing with hybrid working, and so access remained difficult. People were finding that face to face appointments with GPs were still hard to get, and day care services had only just begun to return in March and April 2022.

Carers reported that the pandemic continued to affect day care, home care, domiciliary care and paid-for services, generally due to staff illness, stress and staff shortages. Respondents thought waiting times for local authority services were longer than they used to be; people were still getting held up in hospital because there were no staff available for discharge services; and high staff turnover continued to have detrimental effects on home care.

Some respondents found that they needed more paid for care, once they returned to work or stopped working from home, than they did before the pandemic. This might be because the person they care for has deteriorated in that time, or they have become used to having someone at home with them more frequently and are simply less independent now.

The effect on young carers is ongoing



Some young carers report experiencing anxiety and stress as the expectation of going back to normal seems overwhelming. Many have fallen behind with their education or lack confidence. Most young people now see digital services as completely natural, to the extent that they may struggle to communicate face to face.

Fears and anxiety over the lifting of restrictions

Many carers said they, and the person they care for, were becoming more confident and happy to re-join support groups and social activities in community settings.

There were, however, people who were even more concerned and anxious, noting that, as restrictions were being fully lifted and people were circulating more, the news was reporting an increase in Covid-19 cases.

Life in spring 2022

Continuing impact on all aspects of life

Support workers and volunteers reported that cared-for people who might previously have had several more years living independently in their own home, are needing to go into full time residential care more quickly.

Carers who were bereaved during Covid reported they did not feel that they had gone through the usual process of grieving. They couldn't just be with family to grieve together. They couldn't, in the normal course of normal interactions and conversations with colleagues, acknowledge their loss and receive support.

Many participants stressed that society is still dealing with the pandemic, despite the removal of any restrictions. People spoke of friends and family who have caught coronavirus more recently, some of whom were quite poorly.

Many carers were struggling financially, some more so in the spring of 2022 than in the earlier phases of the pandemic. More people are asking for financial advice and support in seeking funding and benefits.

Growing number of carers with more complex needs

This research suggests there will be more people new to the unpaid caring role emerging as a result of Covid-19. People's physical and mental health has deteriorated at a faster rate than it would have, and carers have stepped into the gap left by services closing or reducing. There will have been many missed and misdiagnoses. Early signs of illnesses or conditions were not picked up by medical professionals, because consultations were not done face to face.

Many people continue to struggle to access statutory services, with long waiting times for social services assessments, delays in referrals from GPs to specialist care, and respite or day care often prioritised for those in acute need. Many respondents were concerned that support and services are now only able to operate on a reactive, rather than preventative, basis and that this will result in higher levels of specialist support over the medium to long term.



Inside an organisation that supports unpaid carers

This research has benefited from the input of members of Carers' Resource staff and volunteers, from background information that helped scope the study, to testing the design of the questionnaires, and advocating for the unpaid carers that they supported over the last two years.

They also shared their experiences about the way the pandemic impacted on professional life. The nature of frontline work was thought to have changed, particularly in the first year of the pandemic as carers needed much more support for their mental wellbeing.

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Demand is still increasing

Members of staff felt that demand for support services had increased as the pandemic wore on, as some carers did come to recognise the just how much care they were providing. And some felt that demand was still yet to peak.

Others considered first how the transition to online and digital access, and then the development of hybrid working, was affecting both demand and the capacity of staff to meet it.

Referral pathways and networks need to be rebuilt

One theme that emerged repeatedly from staff was how much the referral pathways between services were disrupted by the pandemic. The organisations that would normally refer people to Carers' Resource, or other sources of help, were no longer doing so. Hospital Discharge Support Services, regular clinics, even delaying routine hospital treatment, all meant that unpaid carers were not getting referred as they previously did. It was also more difficult for Carers' Resource staff to refer people into other services.

The Covid-19 pandemic exposed how much the support for unpaid carers and cared-for people relies on individual employees making and maintaining relationships with people in other organisations. There is a lot of effort and work required to keep networks and knowledge about service provision up to date.

Efforts have been made to try to fill the gap left by the loss of face-to-face connections, for example the Treacle app covering services in Bradford District, and particularly social prescribing. While an interesting and useful innovation, the app was still in development, covered a limited geography, and perhaps lacked the granularity for up-to-minute information about actual service availability.

Inside an organisation that supports unpaid carers

The impact on employee wellbeing

Staff and volunteers from Carers' Resource agreed that society has underestimated the impact that Covid has had on carers. They also thought that society underestimated the impact on people who work or volunteer to support carers.

Staff did speak positively about the support that has been put in place to try to ameliorate these stresses, including referrals to counselling.

Positive lessons for future developments

Some Carers' Resource staff and volunteers described how the organisation rapidly adapted, and was positioned so it could respond creatively. This was a source of professional pride for some. Another was the leap in technical skills, opening up new ways of working.

In some cases, professional networks were improved and services worked together more effectively. The benefits of healthy working practices were also brought to the fore.



Conclusions & Recommendations

The role of unpaid carer is not recognised enough by society as a whole, by health and care professionals, or by carers themselves.

Many unpaid carers do not identify themselves as carers, which is one of the major barriers to accessing support and services.

Health and social care professionals are often unaware of or do not place enough importance on the caring role, and do not recognise the needs of carers as distinctive from the wider population.

Carers are often excluded from assessments and clinical appointments with the cared-for person on the grounds of confidentiality, when in fact the carer will be instrumental in delivering the intervention, care package or treatment under discussion.

The pandemic has had a serious impact on the physical and mental health and wellbeing of carers, which is under severe strain and is not improving significantly.

Many carers are struggling with the level of care that they continue to give, and are suffering physical, mental and emotional distress. Without taking action, carers may be unable to care safely for their cared-for individual, and more pressure will result on statutory health and social care services.

Recommendation 1: Recognition that there needs to be a sustained campaign to encourage unpaid carers to recognise their role, and that asking for support as a carer is an acceptable thing to do

More research with unpaid carers is needed to understand how they and future carers might better recognise their role. Many underestimate how much care they give, and how much time they spend doing so. Nationally, including in formal education settings, there needs to be a sustained campaign to raise awareness of the unpaid care role, and highlight the types of support that are available to help carers.

Recommendation 2: An increased focus on the need for a break from caring, and funding to support it.

Increased funding packages for respite care are crucial; this would help give carers a break before they reach breaking point. In November 2020, Carers UK estimated that unpaid carers were saving the UK £530 million per day. If respite care and other support services for carers are not funded sufficiently, carers are more likely to break down and the cost to society will be far greater.

Recommendation 3: Greater recognition of the role and needs of, unpaid carers in any future public health campaigns

Unpaid carers must be recognised as a specific group with a specific set of needs when developing any measures to deal with public health issues in the future.

Conclusions & Recommendations

Recommendation 4: At a local level there needs to be a greater recognition of the carer's role in health and care settings

The NHS and social care should engage with organisations that support unpaid carers to develop and deliver awareness training in health and care settings. Training for health care professionals should include the vital support the carer provides in keeping 'their patient' as healthy as possible, treating the carer as a partner in the provision of care, and as an individual with their own social and care needs.

Recommendation 5: Work needs to be undertaken in primary care settings to embed the Quality Markers for carers to ensure that all carers, including young carers, are registered with their GP

Medical records of the unpaid carer, and their cared-for, should be tagged to show that there is a caring relationship as well as a familial or guardianship one. GP records, hospital admission and discharge notes all should identify the carer as such. This will enable information, advice and support to be targeted at carers. It will also facilitate the 'partner in care' approach. The NHS can build on lessons from COVID-19 vaccination programme to identify carers, and push towards more data sharing with permissions.

Recommendation 6: Agencies and organisations need to be creative in enabling carers to be consulted, and to engage in the co-design of services

Carers' voices must be heard and their particular needs recognised and met. Designing services must be an inclusive process, ensuring accessibility for neurodivergent groups and translation and interpretation facilities for those who need them, and recognising and tackle any cultural barriers to reaching carers. Carers should also be invited and supported as experts by experience to attend strategic health and care meetings, share their experiences and co-design services.





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