

Our Recovery Plan for Unpaid Carers

1. Introduction and overview

As the impact of the coronavirus pandemic continues and lockdown is easing, Carers UK is calling for a Recovery Plan for Unpaid Carers. This needs action from Government, health services, local government, employers, business, supermarkets and local shops, local communities and the general public. We have set out what we think this should look like based on carers' experiences and would welcome comment and input to build on it further.

The purpose of this Recovery Plan is to ensure that there is a clear vision looking at how the needs of carers and the people they care for are fully considered in any recovery plans – whether they are by Government, the NHS, local authorities, organisations providing services to carers, businesses or employers.

What timescale are we talking about?

This Recovery Plan for Unpaid Carers focusses on the following:

- Sustaining and rebuilding health and wellbeing for unpaid carers
- Any period of restriction including those who were shielding or seen as “vulnerable”.
- Easement of lockdown restrictions through to the end of lockdown
- Continued periods of social distancing and the impact on carers and people needing care and support
- Any future localised outbreaks or future waves
- A move to a better post-COVID society in the medium term

Any second wave, mass waves or localised outbreaks would rely on the measures that we are also setting out below in key areas e.g. carers' identification letters or cards, identification of carers on patient records, testing categories, flexible working, etc. In any non-COVID time we would consider these measures to be good practice. COVID-19 has shown us that these measures have moved beyond good practice into essential mechanisms.

What does it not include?

Carers UK has a longer-term vision for carers, including long term sustainable funding for social care and support from the NHS. This paper does not focus on this longer term, but it is essential if we are to move to a brighter and stronger future for carers and the people they care for.

What geographical area does this cover?

This is predominantly written for England and for any matters that are reserved for either Great Britain or the UK. We have drawn on the good practice in Wales, Scotland and Northern Ireland to inform our plan going forward.

Why is this necessary?

Pre-COVID-19 there were up to 8.8 million unpaid carers across the UK providing everything from a few hours a week support to intensive and complex round the clock care.¹ The people they are caring for have disabilities, mental illness, long term conditions or are older and need support, support valued at £132 billion per year.²

The pandemic has resulted in millions of new carers – 4.5 million new to caring since the start of the pandemic, 2.8 million of whom are juggling work and care.³

Carers have been hit particularly hard as a result of the COVID-19 outbreak. Many have had to make extremely difficult decisions about work and family. Anxiety levels over risk and how to manage have increased. 70% of carers say they were providing more care. 35% said they were providing more care because services had closed or were not available because of lack of PPE, care staff self-isolating or having caring responsibilities themselves. 22% of carers said that they had cancelled services because of worry about passing on the virus. This included a range of services from health services, to care services, cleaning and support to go out and about.⁴

Worryingly 55% said they were finding it hard to manage and were concerned they were going to burn out in the coming months⁵. With many breaks services not available or closed, there is a really urgent need to ensure that the most vulnerable carers are supported now, through any easing of lockdown and back into the community in the future. SCIE has produced guidance on opening up day services, but many services will be operating at lower capacity and we do not have a timetable for when some services will open again.⁶

There is also a group of carers who say that their lives are not any different, that they were already isolated and poorly supported. Some have found that life is easier to manage e.g. working from home, having more family around, volunteer support delivering medication, etc. This group are likely to find it hard when lockdown eases – when wider family has to go back to work, if volunteer support is not sustained and a greater gulf opens between a freer and a more restricted society again.

As lockdown loosens, we are starting to see a two-tier society develop – those who have additional freedoms, but those who feel the need to continue to shield or are vulnerable and for whom services have not restarted and do not have sufficient

¹ Carers Week Research Report: rise in the number of unpaid carers during the coronavirus (COVID-19) outbreak (June 2020), Carers UK <https://www.carersweek.org/media-and-updates/item/493439-covid-19-pandemic-4-5-million-become-unpaid-carers-in-a-matter-of-weeks>

² Buckner L and Yeandle S, Valuing Carers: calculating the value of carers' support, University of Leeds and Sheffield, 2015, Carers UK

³ Carers Week Research Report, *op cit*

⁴ Caring Behind Closed Doors: Forgotten Families in the Coronavirus Outbreak, April 2020, Carers UK <https://www.carersuk.org/news-and-campaigns/campaigns/caring-behind-closed-doors>

⁵ *ibid*

⁶ <https://www.scie.org.uk/care-providers/coronavirus-covid-19/day-care/safe-delivery>

support. This places additional risks for carers of negative health and wellbeing, poverty and a reduced ability to be in paid work. Evidence suggests that this is likely to hit particular groups harder such as women⁷ and BAME communities.⁸

Where does our evidence from come?

Our evidence is drawn from our research with thousands of carers, our interaction with carers over social media and online, engagement events with thousands of carers across the UK, support mechanisms that we deliver, our feedback from our volunteers and our information and advice services. We have also worked with voluntary and statutory sector colleagues gaining their insight and experience. We have partnered with academics, particularly the Universities of Birmingham and Sheffield and used published data from Public Health England, the Care Quality Commission and the Office for National Statistics.

We have engaged with Government throughout this whole process commenting on and supporting guidance, looking for solutions, and implementing our own support for carers where we can. We have also worked with our colleagues in other countries sharing experiences.

Carers voices and experiences at the heart of recovery

Throughout the pandemic, carers have told us in different ways about their experiences and what they want to see changed and prioritised. Their voices and experiences must be at the heart of building future recovery, locally and nationally.

What we're aiming for e.g. prevention, rehabilitation and recovery:

Carers UK has identified a number of key areas where we need to tackle the issues that carers are facing to ensure:

- a) Prevention of challenges from developing or progressing further
- b) Rehabilitation
- c) Reintroduction
- d) Recovery
- e) Resilience and preparation for any future outbreaks

⁷ Women's Budget Group: <https://wbg.org.uk/media/crises-collide-women-and-covid-19-2/>

⁸ Understanding the impact of COVID-19 on BAME communities
<https://www.gov.uk/government/publications/covid-19-understanding-the-impact-on-bame-communities>

2. Recommendations and Actions

Our Recovery Plan for Unpaid Carers recommends the following actions.

These are based on the following principles that:

- Carers have a voice and are involved in decision-making
- Carers are valued, in terms of their contribution and their expertise
- They have a choice about caring
- Their health and wellbeing is protected
- They are able to continue to juggle work and care
- They do not face poverty or financial hardship
- They are able to have a break and time off
- They are able to learn new skills and pursue their own leisure interests
- Young carers have a right to a childhood and to education
- Carers are treated equally and are not discriminated against
- That they do not face loneliness and isolation, but are able to maintain friendships and relationships
- That they live in and care for friends and relatives in suitable accommodation

Recognition of carers, equality and diversity

- Quick and clear messages addressed to unpaid carers from future Government if there are local lockdowns and future waves. Government must recognise carers during COVID-19 in an ongoing way and they must be backed up by concrete actions.
- Opportunity to build on increased awareness of carers and caring to signpost to support and to plan ahead, for Government, the NHS and social care.
- Any future relevant Government guidance must have clear and specific measures for unpaid carers contained within it.
- Clear stand-alone guidance for unpaid carers for local lockdowns or with any second wave has value and needs to be widely promoted.
- Introduction of carers' identification for any future lockdown/second wave and introduction of Carers Passports/Cards locally to prepare.
- Key services must ensure there are clear data markers for people with caring responsibilities to allow for prompt action and tailored support.
- Key groups of carers who are vulnerable must be identified early and support put in place quickly.
- A focus on equality and diversity, including BAME carers, women and other groups.
- Carers' voices and experiences must be at the heart of any recovery.

Carers and their finances

- Increase in Carer's Allowance and associated premia to match the increases in Universal Credit.⁹
- Continued flexibility in the conditions for claiming Carer's Allowance.
- A longer-term increase in Carer's Allowance.
- A rise in the earnings limit for Carer's Allowance to allow carers to continue to juggle work and care – helping carers to remain in the workplace.
- Writing off of overpayments where the carer has made a mistake.

Health, wellbeing and prevention

- Investment in carers' mental wellbeing locally and a delivery by national Government of a new Social Contract for Mental Health¹⁰.
- Robust and systematic reviews and planning to ensure that those most at risk of poor wellbeing and burnout are supported.
- Sufficient PPE for unpaid carers, adopting the Scotland model
- Test and trace identifying carers, providing information and back-up care
- Promotion of contingency planning for carers, including where social care and/or health intervention is needed – and to become part of standard operations.
- Prioritisation of carers with cancelled planned medical treatment.
- Preventative public health services – flu jabs and other health services targeting carers.
- Inclusion of carers in any vaccine priority list – effectively mirroring the flu jabs priority list and ensuring specific data capture recording whether the person is a carer or not.
- Specific targeting of flu campaigns at carers.
- For any future lockdown or second wave: clarity of definitions for carers e.g. essential care defining how and when carers and provide care, or whether family can provide breaks.
- Supporting carers through bereavement and loss, including investment in these services.
- Targeted help for those carers at risk of loneliness, or as lockdown eases, loneliness potentially increases.
- Physical activity – targeted promotion and support for carers.

Carer identification

- Carer awareness learning as standard for all health and care staff, and in key services.
- Key flags on records, etc. to be able to identify carers quickly
- Delivery of a Carer ID mechanism in every local authority with plans on how to do this in a localised lockdown or second wave.
- Support to tackle everyday stressful activities by utilising Carer ID such as shopping.

⁹ Carers UK's Fairer for Carers work:

¹⁰ <https://www.mentalhealth.org.uk/new-social-contract>

Carers assessments as a prevention tool

- Every local authority to have an online carer's assessment.
- Creative ways of delivering face-to-face assessments.
- Re-assessments for those most in need.

Services, care support and the NHS

- Reintroduction of carers' breaks and social care support
- Proactive community and primary health services supporting carers
- Systematic carer identification within hospitals and upon discharge
- Creative use of personal budgets and carers' personal budgets.
- Visiting guidance for care homes to be implemented quickly and urgent publication of supported living guidance needed.
- Stronger guidance around relatives supporting hospital visits or visiting especially for people with dementia or learning disability/autism.
- A review by the Care Quality Commission about its consumer facing resources since COVID-19 to reflect carers' new questions.
- A focus on supporting young carers, by adult social care and robust identification systems.
- A focus on care and support for parents of disabled children.
- Rehabilitation and recovery of lost skills, health and wellbeing to be made a priority for investment by Government, the NHS and locally.
- Rapid reassessment of the level of need, pre-winter and for 2020/21 Autumn Statement.

Food and hunger

- Improving access to food with supermarkets and local stores
- Ensuring continued help from foodbanks

Investment in digital and tech

- Digital and tech strategies locally to support carers
- Accelerating assisted living support
- Local authorities and health bodies increasing access to services, information and advice online, including online carer's assessments.
- Increased use of Carers UK's digital resources for carers.
- Mainstream delivery of carer support groups, e.g. Care for a Cuppa chats with carers.
- Investment in digital learning and development for carers e.g. Learning for Living.

Work

- Clarity around carers' status within furlough and furlough extension.
- Boosted flexible working
- Encouragement of introduction of carer friendly work practices including Carer's Leave

- Promotion of good practice around carer friendly employers – through Employers for Carers, now reaching over 3.5 million workers.
- Specific and focussed work to support paid work and employment – enabling carers to juggle work and care and supporting employers.

Medium term

- Government to accelerate its plan to introduce a right to Carer's Leave within the workplace.
- A new approach from the NHS towards unpaid carers including new legislation ensuring health services identify carers and promote their health and wellbeing
- Continued focus on supporting paid work and employment – enabling carers to juggle work and care and supporting employers. Ensuring that this is built into local strategies to support carers.
- Using the Social Value Act to positively encourage suppliers to be carer friendly employers by national as well as local government.
- Housing strategies that support ageing and disability better, reducing the level of health harming caring needed and increasing people's independence.
- Sufficient funding for social care locally.
- Ongoing work on carers and equalities
- Developing a new programme of support following the Carers Action Plan which ended in June 2020.

3. Background to recommendations and actions

3.1 Recognition of carers, equality and diversity

Public awareness of unpaid carers and caring

Public awareness of unpaid carers is higher than it has ever been, with 48% of the public saying they are more aware of unpaid carers.¹¹ We need a nationwide effort to ensure that this continues through the next phase and beyond so that communities continue to support carers to reduce loneliness and isolation and to provide practice support. This is also necessary to help carers remain valued and connected. Improved awareness needs to go hand in hand with positive disability awareness and age positive behaviours.

Carers, on the other hand, do not feel valued and this has been a stronger and more consistent message during this time.

There are a number of lessons learned that we would recommend adopting going forward:

- Quick and clear messages addressed to unpaid carers in any future briefings if there is a lockdown and post-COVID-19 recognition of carers' contribution.
- Opportunity to build on increased awareness of carers and caring to signpost to support and to plan ahead.
- Any future relevant guidance must have clear and specific measures for unpaid carers contained within it.
- Clear stand-alone guidance for unpaid carers for local lockdowns or with any second wave has value and needs to be widely promoted.
- Introduction of carers' identification for any future lockdown/second wave and introduction of Carers Passports/Cards locally to prepare.
- Ensuring that there are clear data markers for people with caring responsibilities within key services across health, social care and essential community services.
- Ensuring that key groups of carers who are vulnerable are identified early and support put in place quickly.
- Opportunity to build on increased awareness of carers and caring to signpost to support and to plan ahead.

3.2 Carers and their finances

81% of unpaid carers have seen an increase in the amount they have to spend as a result of COVID-19 on additional equipment, more costly food including food delivery, more heating, increased costs of PPE.¹² Many are struggling on low

¹¹ Carers Week Research 2020, op cit

¹² Caring Behind Closed Doors, op cit

incomes.¹³ Whilst Universal Credit recipients have seen the equivalent of £20 increase per week, those in receipt of Carer's Allowance or who receive a premium as a result of entitlement, and people in receipt of 'legacy' disability benefits have not seen an increase. Carers have also told us that costs are mounting up over time. It is essential that they receive parity of esteem.

The Scottish Government already provides carers with more income than the UK Government, with the Carer's Allowance Supplement paid every six months which effectively raises the level above the level of Jobseeker's Allowance. They have also doubled the six-month Carer's Allowance Supplement payment providing much needed additional income. Carers in Wales, Northern Ireland and England are being left behind.

There are clear links between poverty, ill health and resilience. Financial hardship in these circumstances is even harder. It is essential that carers receive an increase in Carer's Allowance which takes them through to recovery and beyond with lasting improvements to the benefit. More information can be found through Carers UK's [Fairer for Carers](#) campaign.

Recommendations:

- An equivalent payment to UC to those in receipt of Carer's Allowance or receive a premium due to underlying entitlement. This would also help older carers who are on low incomes.
- Continued flexibility in the claiming conditions for Carer's Allowance.
- Longer term rise in the level of Carer's Allowance and associated premia.
- A rise in the earnings limit that is pegged to the National Living Wage.
- Write off any overpayments debts for carers that have may have occurred during this time where the carer has made a mistake.

3.3 Health, wellbeing and prevention

Investment in carers' mental wellbeing locally and delivery by national Government of the new Social Contract for Mental Health

It is essential that there is strong and sustained investment in carers' mental health, wellbeing and ability to care, ensuring that they also have a life outside of caring. The research shows that carers have faced worse mental health during the pandemic.¹⁴ Supporting carers' mental health is as much about positive wellbeing support, as it is about concrete and practical support for people needing care and carers. Nationally, we need Government to invest in a [New Social Contract for Mental Health](#).

¹³

¹⁴ Caring Behind Closed Doors, op cit and Sustainable Care Caring and COVID series; <http://circle.group.shef.ac.uk/2020/06/17/caring-covid19-report/>

Investment in outreach services by local authorities and health bodies must ensure that the right responses can be planned particularly mental health and wellbeing services for carers.

This needs:

- Investment in IAPT¹⁵ services targeted at carers.
- Counselling – related to traumatic or difficult situations experienced, e.g. caring without any support in very challenging circumstances and any PTSD.
Counselling for death and bereavement.
- Coaching – pro-active support that focus on changed behaviours and coping mechanisms.

Many carers have had to care with very little support and many are seeing the health, wellbeing and mobility of the person they care for deteriorate and feel powerless to be able to be able to change this. This is also having an impact on carers' mental health and wellbeing, but also their physical health. This includes all groups of carers - those caring at home, those caring at a distance and people with relatives in care homes where they regularly provide support and have been unable to do so. The need for services to support carers and the person they are caring for is getting increasingly urgent.

Some carers have seen the positive benefit of increased support from family, friends and community. The question is whether this positive mental health and wellbeing can continue to be sustained when people's living arrangements change (people have temporarily moved out/in), when people providing broader unpaid support have to return to work, or simply have broader interests and less time. This is true of all ages of carers, including young carers.

Local organisations' welfare checks/Keeping In touch calls are providing some levels of support. Carers UK's volunteers are contacting harder to reach members, for example. Locally and nationally organisations are utilising more online mechanisms for support, e.g. Carers UK's regular Care for a Cuppa. Carers Week (June 2020) saw a proliferation of online activities aimed at carers wellbeing. However, targeted mental health support is also needed.

Carers UK has signed up to and supports the new Social Contract for Mental Health and believes that this could significantly help carers.

Robust systematic reviews and planning to ensure that those most at risk of poor wellbeing and burn out, are supported.

Many local authorities and local carers' support services are conducting welfare checks and some have risk stratification. However, some carers are also reporting that they have not been contacted by anyone.

As lockdown continues to ease, these welfare checks should continue to ensure that carers most at risk are not left behind, that vital services and support continue to

¹⁵ Improving Access to Psychological Therapies

reach these carers. Many local organisations and local authorities see these welfare checks continuing into the future. For any future localised outbreak and lockdown or second wave, we would want to see welfare checks immediately put in place.

Sufficient PPE for specific unpaid carers

Public Health England guidance stipulated that care workers coming into the home should have PPE. However, despite unpaid carers doing exactly the same role, they have not been able to get PPE. Some forward thinking local authorities have limited supplies for unpaid carers in vulnerable situations, however this is not widespread. Scotland has developed a system for providing PPE to unpaid carers that is working well and this should be extended to England.

PPE will continue to be critical in opening up services for people who need care and to provide breaks and support for carers.

As well as preventing against COVID-19, PPE is also essential for some carers providing personal care. Normal stocks are hard to come by and some have taken over care, without any PPE at all. This will continue to be a matter of concern as we go forward. One carer said she was paying £5 for gloves from her Carer's Allowance – her only income – at £67.25 per week.

Some local authorities and one ICS has provided advice and guidance for carers on donning (putting on) and doffing (taking off) PPE. We recommend that all local authorities and CCGs ensure that carers have access to this information along with paid workers.

Our recommendation is that our Government adopts the model introduced by Scotland on PPE, ensuring that through local authorities working directly with local carers support organisations, a targeted group of carers needing PPE are able to get it.

Test and Trace – identifying carers, guidance and care support

Including carers within the list of key workers to allow them to be tested was welcome. Carers feel that this could have been introduced sooner.

The NHS Test and Trace system needs to be able to identify carers and deliver appropriate isolating advice as this has different implications for carers compared with others. They will often have to make different arrangements to ensure that the person they care for is still supported.

With the NHS Test and Trace system, if a carer has to self-isolate, a robust social care response may be needed. This will also be dependent on carers' willingness to accept support as well as the availability of appropriate care.

Promotion of contingency planning for carers, including where social care and/or health intervention is needed

Contingency planning has been consistently high on carers' agenda since the start of the outbreak. Planning for emergencies has always been a concern for carers, but contingency planning is broader. We would strongly recommend continued

proactive communications with carers to encourage contingency planning, and for those who need the intervention of social care or NHS support, that those discussions and plans are put in place quickly.

Prioritisation of carers with cancelled planned medical treatment

With high numbers of patients having cancelled planned treatment, we are concerned that carers are not left behind as a result. Pre-COVID, Carers UK had robust evidence that carers often put off treatment because they were unable to get the time off or the care they needed to have the treatment or recover. It is essential that in the Restore and Rebuild within the NHS that there is good joint working between health and social care to identify carers and ensure that care and support is provided free of charge to enable the carer to receive treatment.

Preventative public health services – flu jabs and other health services targeting carers

Traditional public health services have always been more of a challenge for carers to access, e.g. screening, because they are unable to get alternative care or an appointment when they have got care. These types of services will need to be more flexible.

With the planning for the flu season already underway, the vaccination programme in 2020 will need to be even more tailored to carers' needs and the people for whom they care.

Some local authorities actively promote back-up care to enable carers to attend health appointments.

As a priority, we would recommend:

- Systematic and proactive promotion of flu jabs for carers.
- Particular focus on flu jabs for carers juggling work and care, based on Carers UK evidence¹⁶.
- Ensuring back-up social care and accessibility measures to allow carers to attend public health screening.
- Diversity checks to ensure that key groups of carers are not missing out e.g. BAME carers

Inclusion of carers in any vaccine priority list – mirroring the flu jabs priority list.

The current JCVI guidance does not include carers as a priority group for any COVID-19 vaccination. If carers have an equivalent “key worker” status for flu jabs vaccination, they should have a similar status for the vaccination. It would not only recognise carers, but make the streamlining of messages much easier.

¹⁶ Carers access and attitudes to flu jabs, aged 50-64, Carers UK, additional analysis carried out in 2019

For any future localised lockdowns or second wave: clarity of definitions for carers e.g. essential care defining how and when carers and provide care.

It has been clear throughout the pandemic that many carers who have continued to provide essential care have felt they are “breaking the rules” by continuing to do this. Other carers have stopped providing care for fear of transmitting infection.

With any future guidance, there must be clear definitions of “essential care” that are communicated very clearly to carers, so that essential care continues to be provided.

For any future lockdown, allowing families and individuals with chronic illness/disability to have “protective bubbles” early to allow breaks and to continue support.

With the drop in external support for carers, and with guidance setting out bubbles, many carers were left out until guidance was broadened. Given the negative impact of providing care and the high pressure on carers, without breaks, Carers UK is recommending early “protective bubbles” including staying overnight. This would suit a number of different caring situations – an older couple where one has dementia who might get help from their son, a young disabled child who might get help from an auntie, a person with mental illness who gets help from a close friend, parents of an adult with a learning disability who get help from their sons/daughters. Of course, this must be set against risk, and families helped to understand making these judgements, and to be supported to do so with Government guidance.

Supporting carers through bereavement and loss

At this time, bereavement and loss has been especially difficult. Carers have provided more support at end of life when caring at home and others have been separated when loved ones have been in hospital or care homes.

Our Caring Behind Closed Doors report¹⁷, which also included a section on bereavement and loss recommended that bereavement services are able to keep pace with demand along with counselling where carers want to receive it. Professionals also need to be trained in how to deal with bereavement and loss.

Local authorities use a range of different services to support this, with some reporting that online resources from Hospice UK and CRUSE are proving useful.

Targeted help for those carers at risk of loneliness, or as lockdown eases, loneliness potentially increases

Pre-COVID-19, there was significant evidence that carers were more likely to face loneliness than non-carers. Since the outbreak, some carers have experienced better support than ever before from the local community, neighbours and friends. Others, however, have become increasingly lonely and as lockdown starts to lift, they are worried about the increasing gap that will widen as others return to a more normal life, but they are left behind.

¹⁷ Caring Behind Closed doors op cit

- Continuing with Keeping In Touch mechanisms such as Carers in Herts, using phone calls and other methods
- Continued online engagement.
- Opening up of face-to-face support services. Organisations like Care for the Carers East Sussex have been seeking carers views on what they wish to do and what would be most valuable in order to open up services.

Physical activity – targeted promotion and support for carers

Carers UK's research pre-COVID-19 found carers aged 55+ who are providing substantial care are much less likely to be reaching the Chief Medical Officers' recommended activity levels compared with all adults aged 55+¹⁸. This is often because of an inability to find time or motivation to take part in activity due to their caring role. This means carers are experiencing profound health inequalities as they do not get the mental and physical health benefits of taking part in activity and the protection from future conditions that keeping fit offers. Recent research by Sport England shows that the coronavirus crisis has exacerbated the differences in physical activity that were already happening before the crisis and that inequalities need to be tackled. Disabled and older people and carers need specific targeting and support by local physical activity teams so that there is some element of rehabilitation.

- Include carers as a group at risk of inactivity when working strategically on public health, health inequalities, or ensuring equal access to sport and physical activity.
- Targeted programmes for carers involving physical activity, particularly the shielded groups. Investment in technology to enable this to happen e.g. wifi and Zoom/Teams/Skype/GoogleMeet.
- Mainstreaming physical activity programmes into commissioned support for carers and other services for carers.
- Use of local authority budgets for walking and cycling to promote accessible opportunities for carers and their families for physical activity.

3.4 Carer identification

Support to tackle everyday stressful activities and carer ID

Simple things like making sure there is enough medication, enough caring supplies such as incontinence pads, or getting food has been highly stressful during the pandemic. Carers have been challenged by the police and by neighbours for doing what Government is highly supportive of – caring for relatives unpaid. This has caused a great deal of anxiety as well as anger.

This demonstrates the value of identification of carers that is robustly recognised – in the short term, the delivery of identification letters for carers that are also recognised

¹⁸ Carers and physical activity policy briefing, Carers UK, Jan 2020

<https://www.carersuk.org/for-professionals/policy/policy-library/carers-and-physical-activity-policy-briefing-jan2020>

by the police, have improved this where they have been issued locally. Local authorities and local carers organisations have been putting in their own measures, but a national guidance would have been better.

In the future and over time, we would like to see the Carer Passport more widely adopted – a brand and a system that is already developed and could be incorporated into local systems and local branding. This would improve carers' identification including when they were out of area, across county boundaries, in different hospitals, etc.

Recommendations:

- Unpaid carer awareness training for all frontline health and social care staff.
- Key frontline services systematically identifying carers and cross refer to support, information and advice.
- Good data markers identifying carers as standard.
- Continued support for medication delivery and mechanisms need to be in place for any future localised outbreaks.
- Local systems ensuring that there is a Carer ID system in place, that the local police are also aware of during any localised lockdowns or second wave.
- Broader adoption and introduction of Carer Passports – with a greater reach and more sustained outcomes.

3.5 Carer's assessments as a prevention tool

There is a mixed picture for carer's assessments, but several local authorities reporting a drop in assessments and several local carer's organisations reporting a drop in referrals.

Carer's assessments have continued, but over the telephone. Those authorities with online carer's assessments, had a ready-made accessible route for carers to be able to still access their rights. Most carer's assessments have been conducted over the telephone. When able to, one carer's organisation offered socially distanced carer's assessments in people's own gardens.

Whilst some carers have reported an improvement in the person's condition because of the lack of stress of going into the community, the majority of carers have reported a decrease in skills and abilities of the person they care for.

- Online carer's assessments should be developed as standard to allow a mechanism for carers to be able to access their rights at any time.
- Creative ways of delivering face-to-face assessments.
- Rapid reassessment of carers to review needs in the light of rising need.

3.6 Services, care support and the NHS

Reintroduction of breaks services and social care support

Some people continue to receive care services into the home as self-funded services, through Continuing Healthcare services or through council funded services delivered through private, public or voluntary sector providers. Some people employ their own personal assistants through personal budgets, or employ people directly. These services need to be rebuilt where services have been reduced or withdrawn. The guidance produced by SCIE will be a useful tool.¹⁹ As these start to rebuild, these are the most important areas to focus on. These are all practices that have been implemented by different commissioning authorities and organisations across England:

- Trust and assurance mechanisms for carers who accept services with very clear communications.
- If day care services are not possible swapping to home-based breaks with care assistants or volunteers in the home.
- Targeted rebuilding and expansion of day care services.
- Using personal assistant type support for activities to give carers a break instead of group activities.
- Online activities with the person being cared for to give the carer a break – anything from playing chess which may have been played in person to playing a game online, to dance, music, physical activity and other interests.
- Creative use of personal budgets to pay family members to provide care, also being mindful of the impact it can have on any benefits of the family member being paid.
- Creative use of personal budgets to provide other things that support a “break” e.g. through the provision of laptops, paying for wifi, etc. making other activities accessible when other breaks may not be possible.

Residential breaks are often taken in specialist centres or in care homes. Revitalise, for example, runs critical breaks services for carers who often provide support around the clock. Government, CQC and PHE need to look at ensuring that carers are able to make the best use of these types of overnight services.

Carers UK has called for a boost to the breaks fund provided by Government in the past and is calling for overall increases to local authority funding. This needs to be a specific focus so that local government has the funds it needs to sustain carers breaks into the future as we do not know how long this will be.

Government also needs to review how many services are at risk as a result of the loss of charitable income that funds other services that are vital for carers. This includes some day centres, lunch clubs for older people, dementia cafes, young carers trips and support – the list is considerable and often these services are vital for breaks and carers’ wellbeing.

¹⁹ SCIE guidance op cit

Government also needs to consider holiday schemes and after-school provision, most of which have not been in place for disabled children.²⁰

Risk stratification for carers is essential. From carers' stories the following groups are most in need of breaks:

- People caring significantly for people with dementia.
- People caring for people with complex physical needs and learning disabilities.
- Complex physical disabilities and/or health conditions.
- Parents of disabled children with significant needs, particularly at transition.
- Severe anxiety and mental illness.
- Older carers in particular, and those in poor health or with significant disabilities.
- Families needing adult social care and including children in the family.

In order for carers to trust the quality of these services the following is needed:

- Robust PPE mechanisms that inspire trust and confidence
- Clear training and advice around PPE
- Clear and proper explanation of risk
- Social distancing rules are clearly explained in advance for the setting/activity
- Rules which are clearly adhered to in the setting
- Strong, responsive and reliable testing regimes
- Well trained and reliable workers

We would strongly recommend that these services are provided free at the point of delivery under s. 2 of the Care Act 2014 prevention duties that have remained unamended in all local authorities in England.

Some carers rely on overnight breaks where the person they care for spends a short period of time in a care home or another specialised overnight setting. This may be more difficult to re-establish but is an essential form of care. Many carers will be concerned about safety and risk in these settings following the infection rates being published. Waking night services may provide some support for carers, but may not be the complete break they need.

Easing of lockdown may make it easier for some families to provide some breaks, but only if they are convinced that they will not be putting the person needing care at risk. It's likely that this process will be gradual and will be highly specific to different families. Early guidance on forming a social bubble included lone parents, but failed to consider a parent caring for someone with a disability or chronic illness who could have benefited from social contact. In the future, any guidance needs to consider an exception bubble or clarification around essential care, so that carers are able to work as families to provide breaks.

For those who are at higher risk, families may need to have PPE to reduce risk.

²⁰ Left in Lockdown, Disabled Children's Partnership,
<https://disabledchildrenspartnership.org.uk/left-in-lockdown/>

Proactive community and primary health services

Carers UK has heard a mixed picture from carers about community health services. Some GPs have proactively contacted carers looking after someone with complex needs to check how they are doing. This has been warmly welcomed. Other carers have told us that community nursing services have been withdrawn. Some community nursing services have continued.

In the short term, it is essential that GP practices start to identify carers most at risk and continue to proactively contact them. Areas of concern include:

- Those most at risk of mental ill-health because of complex caring
- Those most of risk through very physically demanding regimes
- Those known to have withdrawn from most services
- Those who should be having medical treatment, but where it has been cancelled/postponed.

Carers UK has strong evidence that carers postpone and delay their own medical treatment because they are unable to get care for the person for whom they care if they cannot care themselves²¹. This normal effect in everyday caring in the UK will be amplified and extended if there is a shortage of care, and shielding groups have to continue to remain under more restricted conditions. We are concerned that both physical and mental health issues are being stored up for the longer term.

In terms of lessons learned, we would recommend the following:

- Proactive and systematic identification of carers through GP practices, that this should be ramped as a matter of urgency.
- Online patient records should be encouraged as a matter of urgency to increase the ability of patients and their families (with permission) to manage healthcare online.
- Risk stratification with GP practices.
- Improved staff awareness of unpaid carers – and a move to make this mandatory learning.
- More online and telephone consultations where this has been asked for by patients and unpaid carers where it has proven benefits e.g. challenges of leaving the house with someone with dementia, or with a severely autistic child.

Systematic carer identification within hospitals and upon discharge and allowing carers to support relatives in hospital e.g. people with dementia or learning disability/autism.

Hospital discharge is a point at which life can change significantly for carers, particularly if insufficient support is put in.

- Every family should receive a leaflet targeted at unpaid carers and where to get support, at the point where their relative is discharged from hospital.

²¹ Insert reference

- When building back services, more targeted in-Trust support, with a carers lead professional preferably with a clinical background within the Trust with authority to work across wards, clinics and functions. This has been shown to transform the level of support within a hospital. The NHS Plan's target to introduce a Carers Passport into secondary care is a positive one that builds on this and as hospitals open up again, must be part of any rebuild package. There is good practice to build on and hospitals will need the support of families to be able to manage well.
- A Carer Passport in every hospital for carers visiting, with clear and definable benefits.
- During any future wave or lockdown, stronger guidance around families being able to accompany to hospital/appointments or support in hospital with particular conditions e.g. learning disability/autism or dementia.

Systematic support for health the health and social care workforce juggling work and their own caring responsibilities.

- The NHS People Plan should have clear targeted support aimed at working carers.
- A Working Carers Passport²² for every relevant unpaid carer staff member in NHS Trusts, CCGs and GP practices. West Yorkshire and Harrogate Partnership has been successful in delivering this. Similar mechanisms could be introduced in local authorities and across the employers within the voluntary sector.

Creative use of personal budgets and carers' personal budgets

Caring Behind Closed Doors²³ showed that carers were experiencing increased costs associated with caring, such as having to purchase activities or equipment to engage the person they cared for. Many others were experiencing technology for the first time, or have limited or poor access to technology. Investment in computers, wifi, technology, online learning, equipment and activities for people being cared for and the carer are being deployed through personal budgets by some local authorities as a means of sustaining their wellbeing and ensuring they can engage in society. One local authority has supported a parent carer with equipment in their garden so that their disabled child is able to have physical activity whilst their day centre is closed.

Reliable and quality services

During the pandemic, care homes and support living have been closed to relatives and friends and all services have been under extreme pressure. This has always been one of several ways of maintaining and improving the quality of services based on their feedback.

For any carers wishing to use services for the first time or find new service providers, it is vital for carers and the people they care for to understand the quality of services

²² <https://www.carerpassport.uk/>

²³ Caring Behind Closed Doors op cit

that they may wish to use. Carers UK's evidence shows that carers find the Care Quality Commission's ratings useful and use them in making decisions about care.²⁴ As we move forward, they are also likely to have different and additional questions about care providers. In order for carers to be able to rebuild their relationship and trust with services, the following are essential:

- We have welcomed the visitors guidance published by the National Care Forum, and now the guidance from Government, which must be implemented quickly, with the right support in place.
- The guidance on supported living must be published by Government.
- Feedback from carers must be encouraged and Carers UK will play its part in this.
- The Care Quality Commission needs to work with providers to look at common questions that people wishing to use services will have now. This is essential to both help providers, but also to help carers make an informed choice about using services.

A focus on supporting young carers, by adult social care and robust identification systems

Some young carers have found the pandemic a better experience, having parents working from home, more support. Others have found it harder than they would normally. The Children's Society²⁵ and Carers Trust²⁶ have separately published different research documenting young carers' experiences. Their key recommendations are:

- The crucial role of care services to enable the young carer to be able to go to school.
- Identification at school of young carers.
- Ensuring that their experiences are part built into support and solutions.
- A focus on care and support for parents of disabled children.

Rehabilitation and recovery of lost skills, health and wellbeing to be made a priority for investment by Government, the NHS and locally.

Good quality care, mental health support and community connections are vital for disabled and older people. Many people have told us that the condition of they are caring for has got worse, with loss of mobility, loss of cognitive function, heightened anxiety and poorer mental health. This is increasing the pressure on unpaid carers in

²⁴ <https://www.carersuk.org/for-professionals/policy/policy-library/measuring-up-cqc-2018>

²⁵ Empty shelves and endless information: <https://www.childrenssociety.org.uk/news-and-blogs/our-blog/new-challenges-for-young-carers-during-covid-19>

²⁶ My Future, My Feelings, My Family: <https://carers.org/what-we-do/our-survey-on-the-impact-of-coronavirus-on-young-carers-and-young-adult-carers-00001>

terms of the quantity and complexity of care as well as sadness seeing the loss of skill and ability of the person they are caring for.

In addition, physiotherapy, occupational therapy and psychiatric services are vital to prevent any conditions from deteriorating and maximising independence.

This needs urgent and specific investment. Families and people needing care are already experiencing a decreased quality of life as well as increased needs. Additional pressure will be placed on core services, including social care services at a time when local government income has fallen and the NHS is concerned about winter pressures and any further waves of the virus.

Rapid reassessment and re-appraisal of the level of need for social care

Given the levels of reported increased need from people with disabilities, chronic illness and carers, we need a rapid reassessment and re-appraisal of the level of need for social care and housing. This needs to go into preparation for winter and then for the Autumn Budget.

3.7 Food, hunger and access to food

One of the greatest concerns very early on from carers, were the challenges faced in getting food. Carers are twice as likely to have used a foodbank during the pandemic compared with non-carers.²⁷ Carers UK has set out the evidence for this – including difficulties shopping. Our recommendations apply for any localised outbreaks or for a second wave. More detail can be read here:

www.carersuk.org/for-professionals/policy/policy-library/policy-and-practice-briefing-improving-carers-access-to-food-and-carer-id

- Local food strategies must continue to support carers and their families. Evaluation is also needed to look at how many have caring responsibilities that are using services. Data must include unpaid caring as an identifier.
- Clear support from supermarkets and local convenience stores with strong messages about supporting unpaid carers nationally, fed down locally.
- Key guidance from DEFRA about food security continues to include and support carers. This includes support for any localised outbreaks in the future.
- All local authorities should join the Supermarket Referral Scheme to ensure they are able to refer carers and people who are vulnerable for priority delivery slots.
- Tackling food poverty of unpaid carers and their families on an ongoing basis and clarity about those with caring responsibilities for disabled and older people who are using foodbanks.
- Carers who have seen increased costs and are struggling to access and afford food should be a priority group for local authorities when distributing the local authority Emergency Assistance Grant for Food and Essential Supplies.

3.8 Investment in digital and tech

²⁷ Caring and COVID references

Continued and augmented digital and online support for carers and a focus on tech enabled care

Those local authorities, businesses, community organisations and carers who have digital and online support have been the ones who have been most ready to adapt. Carers organisations and others have found digital engagement to be very effective for some carers. Some carers have found it better, more flexible and more inclusive. Carers Week 2020 which Carers UK recommended was virtual – is a good example of how creativity from the sector served a varied programme and different support.

Whilst COVID-19 has placed a pause on some tech-enabled care which required a home visit, Carers UK believes that this needs to be a specific and augmented focus – increasing independence, building in resilience for any future waves.

We would strongly recommend:

- A strong focus on digital strategies within local government across all areas of their work – specifically targeting carers and people needing care.
- Rapid local reviews of assisted living technologies improving local support.

Maximising “population level” use of digital resources and support that has been specifically created for carers e.g. Learning for Living – online learning for carers developed by Carers UK, with support from DHSC, which helps carers to identify some of the soft skills gained whilst caring and set personal goals. Digitally badged to provide recognition of learning, it is also free to use.²⁸ Courses like this, developed with carers insight, are not part of routine support for carers in some areas, but could be.

Locally, many local carers’ organisations have trialled online support in a different way, and all those that have, say they are keeping those methods of support in the future. Many have attracted new carers, some carers have found it more convenient and have made new links.

New efforts must be made to ensure those that are digitally excluded are either included, or if they don’t wish to be or cannot that alternative support is provided.

Overall, we recommend:

- Digital and tech strategies locally to support carers
- Using communications methods such as mass texting to contact carers with key public messages linking to support – some local authorities have utilised this.
- Accelerating assisted living support
- Local authorities and health bodies increasing access to services, information and advice online, including online carer’s assessments.
- Increased use of Carers UK’s digital resources for carers.
- Mainstreamed delivered of carer support groups, e.g. Care for a Cuppa chats with carers.

²⁸ <https://www.carersuk.org/search/learning-for-living>

- Promotion of digital learning and development for carers e.g. Learning for Living and online wellbeing resources

3.9 Work – juggling work and unpaid care

Returning to work – furlough extensions and exemptions needed for unpaid carers

The most immediate issue facing working carers in the near future is the return to work or workplace. With many social care services and support not at the same capacity and concerns over infection risks, many carers will be unable to return to work. Carers UK has urged the Government to extend furlough and take on board the fact that some carers, who have been able to work from home, may not be able to return to the office.

Until social care services, holiday play schemes and specialist services are fully restored to their former levels, many carers will be unable to return to an office or workplace. Carers who are caring for someone who is shielding, whose workplace is not Covid-19 safe. Furlough needs to be extended, and exemptions introduced for carers newly unable to return to work. It should be funded at the same level of support as when first introduced (80 per cent of income on a monthly salary of up to £2,500).

Paid work and employment – enabling carers to juggle work and care and supporting employers

The world of work has changed forever, with employers trying new flexible ways of working, breaking new boundaries and finding new solutions to support workers. There are some jobs that simply cannot be delivered at home, from the kitchen table. For others, home and family situations prevent working from home effectively.

In rebuilding work, Government, alongside employers and local authorities and others need to encourage:

- Flexibility – seeing this as the norm, not the exception.
- Continued flexibility for furlough where social care services have not reopened sufficiently to allow a carer to return to work.
- Ability to use job protection mechanisms if there are localised lockdowns.
- Occupational health and workplace wellbeing programmes that clearly incorporate and explicitly mention caring for disabled, older and ill relatives and friends as a core part of delivery.²⁹
- 63% of employers in our Employers for Carers insight survey said that better clearer public information about support and the same percentage said care services were needed to help employees juggle work and care.³⁰

²⁹ <https://www.employersforcarers.org/news/item/1514-new-report-on-health-and-wellbeing-in-the-workplace>

³⁰ Ibid

- Increased spread of [Carer Confident](#) benchmark for employers – ensuring that this is mainstreamed and championed by Government. This was developed with support from DHSC as part of the Carers Action Plan.
- Rapid awareness raising of unpaid carers juggling work and care, using examples of good practice, such as Centrica. Awareness raising of carers juggling work and care should be promoted through Government messaging and support.
- Carers UK will continue to promote good practice through Employers for Carers now reaching over 3.5 million employees.
- Key public bodies could be using their procurement powers under the Social Value Act to require carer friendly policies from any contractors for their employees to help spread the adoption of good practice.
- With increasing numbers of unpaid carers, and existing carers doing more, recognition by employers that more of their staff will be juggling work and unpaid care.

4. Background to medium term recommendations, learning from others and what next

4.1 Medium term

The following are our recommendations for how to move forward beyond the next 12 months:

Ensuring that carers are able to continue to juggle work and caring by Government accelerating its plan to introduce a right to Carer's Leave within the workplace.

Carers UK has welcomed the Government's plans and Carer's UK's views, response and evidence can be found here.³¹

A new approach from the NHS towards unpaid carers – setting a new foundation for the future

Many of our recommendations and good practice demonstrates that the NHS needs to step up its approach to unpaid carers. We are recommending a number of areas that are "good practice" become part of core essential standards. This will also be vital to prepare for any future waves of the pandemic outbreak, but to improve the resilience of the NHS and families providing care on a longer-term basis.

We also believe that this will improve the NHS' efficiency and effectiveness – vital at a time when public funding is likely to be stretched.

Government needs to give the NHS clear responsibilities towards carers i.e. duties that even up the balance between health and social care. Whilst social care has clear parity of esteem between people needing care and people providing unpaid care, the NHS references are scattered and could be consolidated into a clear objective. As well as simplifying and streamlining, this would also help to underpin common objectives to help integrate health and social care.

A continued focus across Government on supporting carers to continue juggling work and care

We would also encourage local strategies to be developed to encourage this. Government needs to build in the voice of employers into its plans to reform social care.

Government could encourage all public bodies to use the Social Value Act to positively be carer friendly employers.

³¹ <https://www.carersuk.org/news-and-campaigns/campaigns/right-to-carers-leave>

Government's housing strategy needs to support ageing and disability better. The housing strategy needs to have affordable housing at its heart, but also promote housing which increases and maximises people's independence.

Sufficient funding for social care and longer term reform with sustainable funding of social care

There must be sufficient funding of social care in the short and medium term. Longer term reform of social care and a sustainable funding model must not be put on the back-burner but taken forward quickly.

This must also put good quality services and personalised services at the heart of the future. This has proven positive benefits not just for the person needing care, but also the carer.³²

Workforce plan for social care equal to that of the NHS

The crisis has further highlighted the gaps that we already have in the social care workforce. With an estimated 1 in 5 workers pre-COVID juggling work and unpaid care, up to 280,000 people working in social care could also be carers.³³

The workplace plan needs equal status and proportionate investment with the NHS People Plan.

Any future relevant guidance must have clear references to carers contained within them.

The Government must ensure that any future guidance for people who are shielding or vulnerable and carers is clear and appreciate their concerns and worries. Some guidance around shielding has caused confusion and the worry that the public generally are not following social distancing rules causes great anxiety to those most at risk and will continue to do so as restrictions are relaxed.

Carers' own skills, learning and development

During lockdown, carers have had to cope with more things than ever before. They will also have gained new knowledge and insight which could be recognised and counted. Evidence continues to point to carers wanting more online learning information so that they feel more confident.

- Structured proactive programme by local government to support existing online learning activities, mixed with face-to-face activities when they can resume to help boost carers' knowledge.
- Systematic roll-out of skills recognition packages such as Carers UK's Learning for Living programme – designed to support carers' own recognition of skills and includes digital badging.

³² <https://www.carersuk.org/for-professionals/policy/policy-library/care-quality-working-with-families-to-improve-the-quality-of-care>

³³ Based on 1.49 million workers in social care, Skills for Care workforce report, September 2019. Calculated doing further analysis of Juggling Work and Care, Carers UK, February 2019.

- Consistent access to learning programmes that suit different carers' needs – starting with online as the mass offer, but tailoring with face to face learning when that is possible. Some understanding of how learning is currently offered and promoted is necessary to ensure that this is part of personalised care – every carer who is willing to use online and digital technology should be offered the opportunity to learn about the condition, how to care, etc. This is not a replacement for good quality care, but a mechanism that provides some assurance for carers themselves. They place a high priority on this themselves.
- Learning and development needs to hardwire in digital skills for all and to continue to cut through to support others.

Equalities and Unpaid Carers

Throughout this pandemic, unpaid carers have felt largely invisible, not being mentioned in the daily briefings by the UK Government. They have been mentioned more frequently in Wales and in Scotland the First Minister dedicated part of a briefing to unpaid carers as they increased the Carer's Allowance Supplement which they doubled for six months to help with extra coronavirus costs.

COVID-19 has opened up and increased gaps between different groups of carers and made some challenges harder not easier. We need greater and more information on BAME carers, whom we already know have poorer health outcomes from the GP patient survey.

We need:

- Particular focus on equalities issues
- Targets to close not open up gaps in healthy life expectancy, ability to work, etc.
- A focus to raise awareness of caring in the workplace.
- Consideration over time to moving towards making unpaid caring a protected characteristic.

4.2 Working with and learning from others Wales, Scotland and Northern Ireland

Carers UK recognises that many of our recommendations involve England only on devolved matters. Our colleagues Carers Scotland, Carers Wales and Northern Ireland have also set out what they need to see going forward. They can be found here: Carers Scotland: National Carers Organisations: Life Leaving Lockdown.³⁴

Carers Wales which chairs the Wales Carers Alliance: set out it's early thoughts to the Welsh Assembly Government.³⁵

³⁴ https://www.carersuk.org/scotland/policy/policy-library?search=list_policy_sco&task=search

³⁵ <https://www.carersuk.org/wales/news-campaigns/news/wales-carers-alliance-thoughts-regarding-welsh-government-recovery-roadmap>

Carers Northern Ireland worked with their Assembly to help deliver a Carers ID system that was delivered by every Trust in Northern Ireland.

4.3 What next?

We need the Government, the NHS, employers, voluntary organisations to take on board our recommendations for carers.

We need Government to consider our Recovery Plan for Unpaid Carers going forward within its forward planning for the short and medium term. Carers must be part of their recovery plans.

We recommend that Government looks at the need for a second Carers Action Plan to provide tangible and deliverable outcomes for carers and invests significantly in support for carers. This would fit with and support the strategic direction for a future funding settlement for social care.

Carers UK will be updating our work constantly to ensure that it is relevant and responsive to carers' needs as the situation evolves and as evidence presents itself. We may publish updates to this Plan as we go forward.

We will continue to work in partnership with others to deliver practical support to carers and ensure that their voices are heard.

We will ensure that carers' voices continue to be a part of the future.

Date: July 2020

Contact: policy@carersuk.org

Keep up to date with our campaigns and research:

Web: carersuk.org Facebook: facebook.com/CarersUK Twitter: twitter.com/CarersUK

Carers UK is a charity led by carers, for carers – our mission is to make life better for carers.

- We give expert advice, information and support
- We connect carers so no-one has to care alone
- We campaign together for lasting change
- We innovate to find new ways to reach and support carers

20 Great Dover Street, London, SE1 4LX

T: 0207 378 4999

E: info@carersuk.org

Carers UK is a charity registered in England and Wales (246329) and in Scotland (SC039307) and a company limited by guarantee registered in England and Wales (864097). Registered office 20 Great Dover Street, London, SE1 4LX.

