Carers Advisory Group submission to the ASC Sector COVID-19 Taskforce: How can we prepare and support carers better?

The Carers Advisory Group was set up to provide independent advice to the Adult Social Care Sector COVID-19 Taskforce. With regards to carers, our remit was to provide:

- advice on the Government's COVID-19 Adult Social Care Plan (published 15 April 2020),
- advice on the implementation of the Care Homes Support Package; and
- proposals on the overall advice to Government on what should be in place in the coming months, in time for and throughout winter.

Our evidence (Annex) is drawn from the experience of thousands of unpaid carers, supporting family and friends who are disabled, chronically ill or older. Their challenges, solutions and ways forward are incorporated. We include experience from organisations, local authorities, NHS commissioners, providers of services and researchers. We have evidence from employers and their staff networks on support needed for employers and employees to remain in work.

We recognise the work that many have done to try to support carers, many having gone 'above and beyond'. We are using what we've learned and insight from carers to make a series of recommendations, allowing flexibility should changes occur in the pandemic.

Our proposals on advice, connecting, supporting, capacity and sustainability include:

- Overarching recommendations
- Action that needs to be taken for any local lockdowns or future spikes/waves
- Immediate and urgent actions – to be taken pre-September 2020
- Action required for the first phase of winter – up to October 2020
- Action required for the second phase of winter – up to March 2021

Brief background: During COVID-19, there could be an additional 4.5 million carers, 2.8 million of whom are juggling work and care.[1] Many of the key workers responding to the crisis are also caring for relatives. Without the support of families and friends caring, the response to COVID-19 could have been very different with health and care services quickly being overwhelmed.

This has been an intense period of caring with 70% of carers providing more care[2] and many seeing the needs of the person they care for increase.[3] Some children caring for adults or disabled siblings have taken on more responsibility. There is widespread concern that due to stress and challenges during this time, many carers will not be able to provide the same level of caring throughout winter or in response to a second wave of infection or

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[1] Carers Week Research Report: https://www.carersweek.org

[2] Caring Behind Closed Doors, Carers UK April 2020 https://www.carersuk.org/news-and-campaigns/campaigns/caring-behind-closed-doors

[3] Evidence from Alzheimer's Society research showing 82% of people with dementia had declined during lockdown, losing memory, speech and ability to dress themselves (30 July 2020). There are similar reports from Carers UK, Children's Society, Mencap, Rethink and others, including ADASS recording increased presenting need.

local lockdowns. If this results in carer breakdown from mental and physical health issues, we could see significant increases in demand on social care and NHS and/or individuals going without essential care.

Increased vulnerability/risk: A number of groups of carers need particular consideration because of increased risk/vulnerability. This includes people caring intensively, carers with health conditions, older carers, carers from BAME or other key communities e.g. Gypsy and Traveller, and carers with low incomes. Particular conditions include carers of people with learning disabilities, autistic people, dementia and mental illness. Young carers are a further group. Digital exclusion must also be factored into solutions.

Valuing and Supporting Carers:

Overarching recommendation: Government and leaders should recognise carers early in briefings and communications. The absence of carers when health and care workers were mentioned in news briefings made them feel overlooked, undervalued and confused about what they could access. In addition, the word "carer" was used first to mean health-worker and then care worker by many. **Carers (unpaid carers) should be an early part of leadership messaging whether by Government, advisers, or in local lockdowns, recognising their support and contribution, targeting advice quickly for them.**

Carers need a similar status to key workers in communications and in planning. All the measures in this paper sustain carers' ability to care, improve their health and wellbeing and help to decrease pressure on health and social care.

Actions for national and local lockdowns:

1. **Tailored information and advice: We recommend the Government's carers' guidance is reviewed and updated with learning from the pandemic in the event of a second wave/spike.** Specific guidance for carers in England was produced relatively quickly which was welcomed. We recommend this guidance is reviewed nationally, in collaboration with carers and key stakeholders, in case of the need to reissue quickly. **Locally similar tailored advice must be targeted at carers and in accessible formats, languages and easy-read, consulting key communities and groups.** As well as key public health messages, key areas to focus on include exemptions allowing carers to travel to care, take extra exercise, continue contact for essential care, accompany someone to health appointments. It should also cover testing for carers, PPE rules, masks exemptions, workplace rights, contingency planning, sources of support and volunteer schemes with key messages that they include carers. As well as helping carers, it would help to build trust with key communities e.g. BAME, Gypsy and Traveller communities.

2. **Protecting carers and people they care for: We recommend continued priority testing of carers, access to free PPE for carers and exploring the possibility of developing guidance on early shielding bubbles to provide ongoing support for carers so they are able to have breaks. This also needs to cover people in supported living who often don't have weekend cover, are supported by family or live with family at weekends.**

Supporting carers – We recommend:

3. **Rapid delivery of ID for carers like key workers, with core text/practice from national Government to support appropriate delivery arrangements in local authority areas.** ID has been a key issue for carers i.e. being unable to prove to the police/others of the need to travel to provide care and not being able to prove they are a carer to access priority shopping, both of which were necessary. These have been two major challenges.
4. **Continued clear support for carers from local volunteer schemes, including how this can be used in the future to provide support for carers.**
5. **Guidance to employers from Government on measures to support staff juggling work and care and measures such as access to continued furlough if carers are unable to work because of shielding or lack of day services. Guidance for employers/ees on what happens if it is unsafe for shielding employees to return to work.**
6. **Quick benchmarking tool including key measures to have in place locally for carers in the event of local lockdown.** E.g. action to ensure that carers have access to food, either because of poverty or challenges in shopping for food. These were major issues at the start of lockdown.
7. **Maximising digital and tech opportunities across local government, health and the voluntary sector, reviewing where they work well for carers who want them, where it meets need, positively enhances their lives and delivers more tailored support.**[4] **This might cover systems, processes, information, advice, learning, wellbeing, health, or social activities. All support mechanisms for carers must also factor in digital exclusion and where other options are working better for some carers.**

Immediate and urgent actions before September 2020:

Protecting People – we recommend:

8. **Flu jabs:** carers are already treated as key workers in the list of priorities but need **specific messaging to encourage take-up particularly amongst working carers, those caring at a distance and BAME carers**. CCGs need to look creatively at where and how carers are able to get flu jabs, e.g. GP practices have become less accessible.
8. **Vaccine for COVID-19: That carers are included in the priority list by Government along with other key workers.** This would help to align public messaging with the flu vaccine, improve take-up, value carers, reduce the likelihood of infection, protect the person being cared for and reduce the pressure on health and social care in the event of the carer being ill – one of their biggest concerns.
9. **Test and trace to include a key question to identify whether someone is providing unpaid care** e.g. outside the home or across multiple homes, e.g. to three elderly relatives, and to signpost to tailored guidance. This would help families to plan faster and connect more quickly with appropriate support.
10. **Visiting is a priority for many families and there is strong evidence that this supports the health and wellbeing of the person needing care. We understand the need for infection control. We need regular testing for a single named relative on entry to care homes and supported living. We also need testing for all people discharged from hospital into the community.** This would provide reassurance for

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[4] Building on the CHIP/ADASS Digital Innovations in Social Care work and work of others (see Annex)

families. For those in care homes and supported living, it would improve people's wellbeing and that of their families. For families caring after hospital discharge it would allow them to manage risk and provide safe care.

11. **Access to free PPE for specific unpaid carers in key situations modelled on Scotland scheme. Sufficient free PPE for visitors in care homes, supported living and in hospitals, as well as secure supplies for care workers.**

Supporting carers - we recommend:

12. **Local authorities draw up a 'Back to School' plan for young carers which involves adult social care, reassessing families and ensuring sufficient face-to-face support is put in place to give young carers and their families' confidence that they can return to school.** This return of services includes face-to-face mental health services. To back up existing good practice work with the voluntary sector and join up services, **Government needs to issue guidance to schools to ensure that young carers are clearly identified in order to provide tailored support.**
13. **Address rising need: urgent re-appraisal of baseline need in local authorities and sufficient resource allocation for a) winter and b) the 2021/22 budget for local authorities needing action by MHCLG and DHSC.** Impact and outcome: sufficient funding to shore up essential services, supporting the delivery of Care Act 2014 provisions, prevent carer breakdown, prevent loss of employment through not being able to juggle work and care.
14. **Mental health support for carers**: targeted mental health support for carers, including young carers, is needed to improve health, resilience and to prevent carer breakdown.
15. **Sustainability of the workforce and supporting carers juggling work and care: Government to look quickly at furlough being extended where care services are not yet in place for carers to be able to work. Government guidance for employers clarifying where "return to work" is not possible without day services returning.**
16. **Day services and carers' breaks and opening up/being reinstated: Our evidence demonstrates the need for quick solutions and several stakeholders, including carers, class this as the <u>most urgent issue</u>. Reports of carers at breaking point, the people they care for losing skills and abilities and the lack of key services means that some carers are unable to work.** This is a complex picture and more detail is in the evidence paper. Breaks are delivered in many different forms. Day services and overnight breaks are two types of vital support. Home care services have been used positively where day services have been suspended. The need for breaks has increased. Because of social distancing, it is not possible to provide the same level of capacity for face-to-face support as pre-COVID-19. We have looked at this in some detail. We would recommend:

- Additional investment in day and evening service provision to increase face-to-face support to comply with social distancing and infection control measures – investment by Government to local authorities via Infection Control Fund.
- Sharing good practice such as using additional home care services to provide breaks, providing short term overnight care, waking nights service or live-in care.
- Additional home care services to enable carers to return to work.
- Creative use of direct payments, personal budgets and personal health budgets to give flexibility in breaks provision e.g. agreement on how carers can continue to use their funds in order to secure alternative provision.

- Opening up short term breaks in residential settings e.g. Revitalise breaks or care homes is vital. Both are problematic because of the 14-day quarantining required. Urgent assessment of how this can be managed is needed and additional resource to enable short breaks to be taken, good practice developed and shared with providers.

The evidence is that carers will only trust these services if there is:

- Clear data about the level of risk e.g. low level of transmission among homecare staff
- Openness and transparency about infection control, assurances and delivery of testing of workers, volunteers and carers across settings, including supported living.
- Clear engagement, communication and learning with carers.
- Steady and continuous supply of PPE to workers, but also to carers where necessary.
- Understanding of PPE, when and how it must be used for carers as well as workers. Resources have been developed by local organisations which could be shared.

> *"Day centre twice a week is closed and my brother can no longer take my Dad out one day at the weekend. I am providing three full days more than I used to. 24 hours a day, 7 days a week." Carers UK*

Next 3 months (until October 2020) – winter planning

In preparation for winter or a second wave carers needs should be clearly considered in any NHS winter plan and social care planning incorporating the following:

17. Continuous review of day services/face-to-face services and breaks as above by local authorities, but with national reviews[5] by DHSC and additional funding of breaks and day services/alternatives.

18. Rapid assessment/re-assessment/review by local authorities of carers most at risk, and proactive identification of them, in the event of breakdown or at risk in second wave. This should include contingency planning if the carer is ill, unable to care or the relationship breaks down.

19. Local authorities should encourage early contingency planning by carers who are able to develop their own plan, and focus on those who need more detailed social care support/help developing their plan – this needs to be part of core winter planning.

20. Continued assessments and reviews of those new to caring during COVID-19. Large variation in local authorities undertaking carer's assessments – one has seen carer's assessments nearly double, others are doing very few and few referrals to local services which suggests unmet need building in areas. Complexity has increased.

Supporting carers – NHS doing more:

21. **Rapid upscaling and acceleration of GP identification of carers. This is in the Long Term Plan as good practice, but Government could strengthen and accelerate this with NHSE&I to introduce a basic requirement of all GP practices to have a system in place to identify carers.** This would provide a response for any second spike, or increased demand during winter as well as providing a baseline for prevent e.g. flu jabs/vaccines.

22. **Tackling low income issues that affect many carers – in particular the potential winter effect of being indoors longer.** Working age disabled people do not get the Winter Fuel Allowance, which could be provided to people in receipt of disability and

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carers' benefits. **Carer's Allowance should be increased from its current rate of £67.35.**

Throughout winter (at least to March 2021)

1. Issue guidance that gives priority to carers using non-urgent patient transport (NEPTS) to go with and support the person they care for if this is appropriate e.g. dementia carers
2. Government ongoing monitoring of Care Act 2014 delivery and easements if enacted.
3. NHSE&I needs to set out measures to support carers within the rapid resumption of the full range of healthcare provision that has been missed during the COVID-19 crisis so far. This has to go hand in hand with services for older and disabled people providing replacement social care.
4. Support for carers providing end of life care and bereavement support.
5. DHSC having a national informed view of how far cancelled or reduced services are reinstated to judge where the sector has returned, or not, to previous levels.
6. National review of extent of implementation of reasonable adjustments/disability specific guidance and measures e.g. additional exercise, journeys, accompanying people with dementia, learning disability or autistic people to hospital as standard to see how far these measures are being used/implemented, plugging gaps where necessary. Local authorities could supply proportionate information to DHSC; NHS Trusts and a random selection of GP practices could supply evidence to NHSE&I health inequalities.

Long term

1. Improve data collection on social care and carers including capturing the impact on people from Black, Asian and Minority Ethnic communities.
2. Review NHS responsibilities towards carers, with a view to building on and improving them.
3. Investment in and reform of the social care system.
4. Ensure carers' needs for information, advice and support are fully integrated into future pandemic planning.

Coronavirus made my caring a lot harder' (young carer, Children's Society)

Co-Chairs: Dame Philippa Russell, Carer and Emily Holzhausen, Carers UK
Emily.holzhausen@carersuk.org

7 August 2020

ANNEX

'*Like many other carers, I feel that COVID-19 has turned my previously well-organised life upside down. My son with learning disabilities cannot understand why his formerly active life is shut down and he and I worry about the future. But 50 years of caring has taught me that disasters sometimes create positive change. Carers are resilient and as key partners in fighting the pandemic, I hope that together we can co-produce a safer and healthier future!*' ***Dame Philippa Russell, Co-Chair of Carers Advisory Group and a carer for her son.***

Background evidence: to accompany short paper

Carers Advisory Group submission to the ASC Sector COVID-19 Taskforce: How can we prepare and support carers better?

The **Carers Advisory Group** was set up to provide independent advice to the **Adult Social Care Sector COVID-19 Taskforce**. With regards to carers, our remit was to provide:

- advice on the Government's COVID-19 Adult Social Care Plan (published 15 April 2020)[6],
- advice on the implementation of the Care Homes Support Package; and
- proposals on the overall advice to Government on what should be in place in the coming months, in time for and throughout winter.

Our evidence in this document drawn from the experience of thousands of unpaid carers, supporting family and friends who are disabled, chronically ill or older. Their challenges, solutions and ways forward are incorporated. We include experience from carers as experts with experience, national and local organisations, local authorities, NHS commissioners and providers of service, researchers and academics. We have the insight of employers, and evidence from Centrica, on their experience of the practical support that would make a difference for employers and employees who are caring to remain in work.

We have worked at speed, in a few weeks, at a time when members of the Carers Advisory Group are also running organisations, delivering essential services, supporting carers, caring for their own family members and supporting staff and colleagues.

We recognise the efforts of many people to support carers during the pandemic

We recognise that many people have been working hard, many going above and beyond, to ensure that carers are supported at the start of and during the pandemic in what is an unprecedented situation. This comes through in evidence from organisations where paid care staff have been praised by families for continuing to support and their relatives. We are taking the learning, practice and insight to provide a series of recommendations where further targeted support could make a difference to support carers.

Our proposals on advice, connecting, supporting, capacity and sustainability include:

- Overarching recommendations
- Action that needs to be taken for any local lockdowns or future spikes/waves

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[6] https://www.gov.uk/government/publications/coronavirus-covid-19-adult-social-care-action-plan

- Immediate and urgent actions – to be taken pre-September 2020
- Action required for the first phase of winter – up to October 2020
- Action required for the second phase of winter – up to March 2021

Section 1: Background and context

During COVID-19, there could be an additional 4.5 million carers, 2.8 million of whom are juggling work and care.[7] Many of the key workers responding to the crisis are also caring for relatives.[8] **Without the support of families and friends caring, the response to COVID-19 could have been very different with health and care services becoming quickly overwhelmed.**

This has been an intense period of caring with 70% of carers providing more care[i] and many seeing the needs of the person they care for increase.[9] There are multiple sources of evidence of increased caring including the ONS.[10] Some children caring for adults or disabled siblings have taken on more responsibility.[11] Research in April found that 55% of carers providing substantial care worried they would reach burnout in the coming weeks.[12] Since then, organisations, including local authorities, are findings more carers coming forward with greater levels of stress and need.

There is widespread concern that stress and challenges during this time, many carers will not be able to provide the same level of caring through with winter or in response to a second wave of infection or local lockdowns. If this results in carer breakdown from mental and physical health issues, we could see substantial increases in demand on social care and NHS and/or individuals going without essential care.

Our recommendations are aimed at supporting carers, protecting people, increasing carers' resilience and ability to cope, connecting carers to the right kind of support to be able to care, and ensuring capacity in the sector to be able to support carers. Our objective is for carers to be visible, valued and supported. Many of our recommendations would improve the health and wellbeing of the person/people needing care and support, giving them a better future.

Carers with increased vulnerability/risk who need targeted support:

There are a number of groups of carers who need special consideration because of increased risk/vulnerability. This includes people caring intensively, carers with health conditions themselves, older carers, carers from BAME and key minority communities e.g. Gypsy and Traveller communities, and carers on low incomes. Carers of particular conditions who are either at increased risk themselves or have experienced particular

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[7] Carers Week Research, the rise in the number of carers during the coronavirus outbreak, June 2020

[8] Carers UK estimates this to be at least 1 in 5 public sector workers, based on our work Juggling Work and Care, 2019.

[9] Caring Behind Closed Doors: the impact of the coronavirus outbreak on families, Carers UK, April 2020.

[10] ONS (2020) Coronavirus and the impact on caring, and Caring and COVID series, Sustainable Care,

[11] Carers Trust, Children's Society see young carers section below.

[12] Caring Behind Closed Doors, op cit.

challenges include learning disability and autism, dementia and mental illness.[13] Young carers are at particular risk (see below). We have also factored in digital exclusion or where services are more effective face-to-face.

We have also looked at the situation of working carers, where they are at risk of falling out of work or poorer health and wellbeing, and where employers who are at risk of losing valued colleagues and employees.

Evidence of different groups of carers with increased risk/vulnerability or particular needs:

- Dementia, learning disability and autism, and mental illness
- BAME carers
- Carers from traveller communities
- Carers with conditions themselves and older carers
- Young carers
- Working carers

Dementia, learning disability and autism, and mental illness:

Dementia: Alzheimer's Society provided evidence about carers of relatives and friends with dementia drawn from research, but also insight from 15,000 calls to their helpline, increased contact through their peer to peer support and engagement with carers. There are around 700,000 people who care, unpaid, for someone with dementia.[14] Dementia is the most frequent pre-existing health condition for people dying with Covid-19, and 49.5% of people dying of Covid-19 in care homes have dementia.[15] Like other groups, people caring for people with dementia in the community have seen an increase in the amount and type of care.

Learning disability: Mencap has provided evidence from their local services providing support to family carers and their family members with a learning disability, their helpline and direct contact with carers are reporting increases in need from their services. They have given us evidence around parents of adults, and including parents and siblings with learning disabilities in supported living – which must also be factored into action and solutions.

Autism: There are 700,000 people in the UK with autism and a further 3 million family members and friends. National Autistic Society has provided evidence from their contact with thousands of people with autism and their family and relatives who provide care. This includes their helpline, services and people who have contacted them directly and the work

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[13] As a pan-condition carers charity, Carers UK has highlighted different groups of carers experiencing differing or enhanced challenges which were set out in Caring Behind Closed Doors (op cit). Mencap, Rethink, Alzheimer's Society, National Autistic Society, Carers Trust, Children's Society, the Foundation for People with Learning Disabilities, Friends Families and Travellers and Healthwatch also provided key evidence on behalf of the people they represent.

[14] Lewis et al (2014). Trajectory of Dementia in the UK – Making a Difference.

[15] www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/deathsinvolvingcovid19inthecaresectorenglandandwales/deathsoccurringupto12june2020andregisteredupto20june2020provisional

that they have also done in preparation for the forthcoming Autism Strategy with provided important baseline evidence pre-COVID-19.

Mental illness: Rethink has provided evidence from their contact with carers looking after family members with mental illness, their work with others in the sector, their helpline and their services, and their survey with people experiencing severe mental illness and their carers over April and May. 79% of people experiencing mental illness said that their mental health had become worse or much worse as a result of Covid-19.[16]

BAME Carers: We have heard from BAME carers and reviewed published evidence. There is real concern and fear amongst some communities about the impact of COVID-19 on BAME communities. BAME carers are more likely to be of working age,[17] more likely to be providing care,[18] and less likely to be accessing formal services.[19] It's likely that there are far more BAME carers than the official statistics as 600,000 across England and Wales suggest[20], a number which will have also increased during COVID-19. Not identifying as carers are being less likely to access services are two significant barriers which, combined with the impact of COVID-19, that we urgently need different and tailored efforts to reach BAME carers.

Gypsy and Traveller community: Friends Family and Travellers (FFT) have provided evidence from contact with people in their community. The 2011 ONS census found that Gypsies and Travellers are among the ethnic groups most likely to be providing unpaid care in England and Wales at 11%, and are the ethnic groups most likely to provide more than 50 hours of unpaid care per week, at 4%.[21] They are more likely to be in poor health themselves and therefore more likely to have eligible needs under the Care Act 2014. Many Gypsy and Traveller carers express a reluctance to engage with statutory services for support due to fear of, and practical experiences, of discrimination and express a strong preference for support from within the community. Gypsy and Traveller carers are more likely to be digitally excluded with 1 in 5 not using the internet compared with 1 in 10 of the general population.[22] Throughout lockdown, some individuals have seen their previous support networks disappear, leaving them unable to manage these ADLs. This has left people increasingly isolated and has had associated practical and mental health impacts.

Carers with conditions themselves and older carers: This includes older carers, those carers with health conditions themselves, and mutual carers e.g. people with a learning disability often caring for parents.[23] Mutual carers are often overlooked as a group of carers – and this is where formats such as easy read information are really important, as well as ensuring that they are clearly identified in care planning. Older carers are often physically

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[16] Rethink Mental Illness Covid 19 briefings, Access to NHS mental health services for people living with severe mental illness, June 2020

[17] S Yeandle et al, 2007

[18] NHS Information Centre, 2010, in Facts about Carers 2019

[19] Nan Greenwood, Race Equality Foundation 2018 https://raceequalityfoundation.org.uk/health-care/black-and-minority-ethnic-carers-2/

[20] Census 2011, in Facts About Carers, Carers UK 2019

[21] https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/articles/whatdoesthe2011censustellusaboutthecharacteristicsofgypsyoririshtravellersinenglandandwales/2014-01-21https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/articles/whatdoesthe2011censustellusaboutthecharacteristicsofgypsyoririshtravellersinenglandandwales/2014-01-21

[22] [22] https://www.gypsy-traveller.org/wp-content/uploads/2018/09/Digital-Inclusion-in-Gypsy-and-Traveller-communities-FINAL-1.pdf

[23] Evidence from the Foundation for People with Learning Disabilities on mutual caring.

frailer, Age UK has reported that some have refused services because of worry of infection and many of this group are digitally excluded and are less likely to have access to the internet. There is another advisory group looking at older people and dementia.

Young carers: There are an estimated 800,000[24] young carers across England, under the age of 18, providing care for somebody with a condition, illness, disability, serious injury, mental health condition or addiction. The source of our evidence comes from the Children's Society through their National Young Carers Initiative involving over 75 Young Carers Services and 63 schools backed up by a steering group of young carers and young adult carers about their needs and concerns for the future. Carers Trust recently carried out a survey of young carers and young adult carers to seek their experiences and recommendations for the future, and provided evidence from their network partners.[25] Adult social care commissioners have also raised young carers.

Working carers: Prior to the COVID-19 outbreak there were up to an estimated 5 million people juggling work and care.[26] The outbreak suggests that 2.8 million more are juggling work and care, making nearly 1 in 4 of the working population a working carer.[27] Many working carers have been working from home. For some this has been beneficial, making caring easier to juggle, others have found it more challenging because there are no day services to support them and because they are unable to take a break.[28] We have evidence from Carers UK's Employers for Carers network and Centrica.[29]

Section 2: Overarching recommendation

Valuing and supporting carers – "Think Carer" early in the process

A consistent theme through the pandemic is that carers have felt overlooked and that their needs are not considered until later on. The absence of carers when health and care workers were mentioned in news briefings made them feel overlooked and undervalued. In addition, the word "carer" was used first to mean health-worker and then care worker by many. Although many people don't call themselves "carers", the legislation defines carers differently to workers. Because of the use of the term interchangeably it has become confusing as to who is being talked about.

The value of talking about and thinking carers early is important and has a positive reaction from carers. Carers are keenly aware that if they were unable to care, significant costs would fall on health and social care. When carers were included in the list of key workers who were eligible for testing, their reaction was very positive.

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[24] www.childrenssociety.org.uk/news-and-blogs/our-blog/facts-you-might-not-know-about-young-carers

[25] Carers Trust, My Future, My Feelings, My Family, July 2020 https://carers.org/resources/all-resources/108-my-future-my-feelings-my-family

[26] Juggling Work and Care, op cit

[27] Carers Week Research Report: https://www.carersweek.org/images/CW%202020%20Research%20Report%20WEB.pdf

[28] Evidence from working carers, including through Employers for Carers detailed in Carers UK's Recovery Plan for Carers

[29] Centrica has had a Carer's Policy in the workplace for 16 years, one of the longest in place. It has a thriving carers' network of over 1100 staff. Centrica currently has a 3 year partnership with Carers UK and is a founding member of Employers for Carers.

Our recommendation giving carers a similar status to "key workers" would help to support them in relation to many things below, ID, shopping priority, vaccine priority, visiting to provide support in hospitals or in care homes, supported living, etc.

Our view is that this would be positive, helping to recognise and value carers and provide the necessary support to ensure that they are able to continue caring, look after their own wellbeing and that of the person being cared for.

We have two simple recommendations that would start to change the approach towards millions of people in the UK that would recognise and value their support as well as support prevention.

Overarching recommendation:

1. ***Government and leaders should recognise carers early in briefings and communications. Carers (unpaid carers) should be an early part of leadership messaging whether by Government, advisers, or in local lockdowns, recognising their support and contribution, targeting advice quickly at them.*** *They feel valued and part of the collective effort.*

2. ***Carers need a similar status to key workers in communications and in planning****. In all the measures mentioned below, this sustains their ability to care, improves their health and wellbeing and decreases pressure on health and social care.*

Section 3: Actions for national and local lockdowns

We have gained a huge amount of learning from this pandemic which we can use to prepare for the future, identify where we have gaps and swiftly put in place support for the future.

Tailored information and advice for carers delivered quickly:

Specific guidance for carers in England was produced relatively quickly which was welcomed and useful for people advising carers as well as for carers themselves. Although it did not reach all carers, it was a valuable and necessary exercise providing central direction and clarity on key points. Since then we've developed more learning and insight from carers about the things that they find most important, what they value and how different communities need to have guidance with the right culturally appropriate messages, e.g. BAME communities including Gypsy and Traveller communities.

Getting the right communications disseminated about disability and carer related exemptions has been critical and some of these exemptions have been developed as time went on in response to good evidence that they were needed. We would like simple communications to be developed for Directors of Public Health locally where there are important exemptions e.g. ability to go out more frequently if you have a learning disability/autism for example. These exemptions are valued by carers where they know about them and again, help to improve carers' ability to cope during the crisis and continue caring.

With the lockdowns in the North West of England – some carer exemptions and critical areas have not been carried through into the national Government guidance resulting some confusion for carers. Their key questions include, can I travel to provide care? Can I still provide care? Do social bubbles apply to me, I don't seem to fit in to the categories?[30]

From carers' feedback, the essential exemptions during lockdown have been:

- Travel – to be able to continue to travel to provide essential care – for some, this still needed help e.g. one family would travel 70 miles every two weeks to live in to provide care.[31]
- The ability to continue meet someone/have contact with someone to provide essential care – carers wanted assurance about what constituted essential care and needed more information about proportionate risk. This could be expanded on by Government to support carers making very difficult decisions about whether to continue caring or not and how much risk they would place the person they care for at, versus risk of the person not receiving care. This would provide reassurance. They also need PPE to reduce any risk to the person being cared for whilst caring at a distance.
- Exemptions for people caring for people with conditions that are very active e.g. learning disability/autism, dementia, etc. to be able to go out more than once during restrictions has been vital. If restrictive measures have to be put in place again, this is an essential exemption. As well as communicating this clearly to carers, making the rest of the population aware of this is important so that carers are not criticised in their neighbourhood.
- The ability to accompany someone with communication difficulties to appointments has been vital for some and for others unable to do this will have prevented the person being cared for from getting the right treatment. This must be built in as an essential.[32]
- The ability to visit someone in hospital with a learning disability or dementia – the possibility of exemptions again is seen as a critical issue because the lack of familiar faces, which carers have described as a terrifying experience for some people with dementia and around challenges to communicate. Carers are recommending that the "good practice" status of the guidance is reviewed to make this mandatory.
- Contingency planning has been one of carers' greatest concerns – what happens if I cannot care? Links to the right pathways for information has been critical. We address contingency planning later in this evidence.

There is an opportunity to build on the guidance that has already been published, using learning that we've all developed nationally and locally, working with carers, including particular communities e.g. BAME and Gypsy and Traveller communities

3a. We recommend that the national carers' guidance is reviewed and updated with learning from the pandemic in the event of a second wave/spike. *If this is done now, it can be quickly reissued.*

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[30] Contact with Carers UK's helpline after the Government guidance was published on 4 July 2020
[31] Carers UK carer evidence
[32] Evidence from Alzheimer's Society:

3b. We recommend that every local area develops similar guidance for carers, including local links, support, and processes e.g. urgent need for social care.

Protecting people:

Testing carers: The inclusion of carers within the list of key workers who could receive a test was very welcome. We do not have any data on take from carers of those tests, but would recommend that this continues.

PPE supplies are essential for carers to trust using services: We have evidence from all groups that carers have withdrawn from services through lack of PPE of workers. Keeping a flow of PPE for key services is essential for maintaining carers' trust in services and protecting the people they care for.

PPE is needed for specific groups of carers: Carers have not had access to PPE themselves even though the guidance for anyone providing care, living outside of the household should be wearing it. There are a number of challenges for carers not being able to access PPE: those on low incomes who cannot afford it e.g. a carer paying £5 on PPE for gloves from her Carer's Allowance of £67.35 per week. Carers have found it difficult to obtain on the open market and many are caring at a distance without PPE themselves putting the person they care for at risk. Scotland have introduced a system of PPE for carers which is run by local authorities, working in partnership with local carers' organisations to provide PPE for those most at risk. This system was developed with stakeholders. This has worked well with reasonable demand. Some local authorities have implemented a similar system. However, we do not believe this to be widespread, although no systematic work has been undertaken on this.

When lockdown allowed bubbles for single parents to provide them with support, carers - often with sons and daughters with learning disabilities - contacted our organisations to say that they needed this too. This included single parents with sons and daughters aged 30, 40, 50 + caring full time at home, for others it was caring for both parents. This might also work for older carers needing a son or daughter to provide a break, but have been very concerned about doing this and risk of infection. Since breaks and respite care is a strong theme across all our evidence, we would recommend that Government looks at the concept of "shielding bubbles" along with the Association of Directors of Public Health and Public Health England for families caring for someone with complex disabilities to be able to get breaks.

We recommend continued priority testing of carers, access to free PPE for carers and exploring whether the possibility of developing guidance on early shielding bubbles to provide ongoing support for carers so they are able to have breaks. This also needs to cover people in supported living who often don't have weekend cover, are supported by family or normally live with family at weekends.

Carer ID – benefits and why it matters

A key issue raised with all the organisations working with carers was the issue of Carer ID. With travel restrictions in place, they felt they could not "prove" they were carers and some were stopped by the police. They felt they could not always prove that they were carers. Some had to provide shielding letters, some didn't have these to show, or a Carer's Allowance letter. Early on during the pandemic, the co-chair of the Carers Advisory Group, Dame Philippa Russell, was stopped by the police locally when she was out with her son, Simon, who has learning disabilities and describes this as a very uncomfortable experience. Simon cannot go out safely on his own and Philippa has been his sole carer during lockdown. The police did not seem aware of the exemptions, but were understanding once the situation had been explained to them. Since then, many carers have talked to Philippa and other organisations talking about the fear of being stopped and fined prevented them from going out or made journeys more stressful.

The other key issue faced by carers was challenges around shopping and access to food. Shopping was challenging because of increased queuing time because they could either not take the person they cared for as they could not have coped with social distancing measures or they could not leave the person they cared for alone for long enough. A specific briefing on food and has published examples of local practice in the response to the rapid need for carers to have ID.[33] The value of this ID, when it operates well, has brought peace of mind and reduced stress, improved access to food and improved carer wellbeing.[34]

Any successful ID scheme is based on:

- Good lists to identify carers
- Recognition by the police what it is for when there are travel restrictions.
- Good understanding by retailers and priority shopping for carers.

A rapid review of local schemes needs to take place with a view to how practice might be enhanced including core text from national Government. For any future lockdowns we recommend:

Rapid delivery of ID for carers like key workers, with core text/practice from national Government to support appropriate delivery arrangements in local authority areas.

Local volunteer schemes – making sure carers are clearly supported

Early on the crisis, a number of different volunteer schemes developed locally and nationally with the NHS Responder service. It was not always clear that carers could be part of volunteer support, and whilst carers were added as eligible for the NHS Responder service which was welcome, they were not included in main communications as an eligible group.

Feedback from carers showed that they were not always aware they would be entitled to support and, in the early days of the crisis, some were turned away from support.

For any local or national lockdown, clear messaging for carers needs to be in place.

When building future services, these new volunteer support networks could offer additional support to carers. We recommend:

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[33] Carers, Food and ID and Recovery Plan for Carers, both Carers UK, July 2020.

[34] Recovery Plan for carers, July 2020 https://www.carersuk.org/for-professionals/policy/policy-library/a-recovery-plan-for-carers

Continued clear support for carers from local volunteer schemes, including how this can be used in the future to provide support for carers.

Support for working carers and employers to support staff

With a national shift to predominantly working from home, and some families losing key care services as well as dealing with the challenges of lockdown restrictions and work, both employees and employers have had to adjust quickly and have gained a great deal of learning in the process. Furlough has been a critical measure supporting business, but also carers where they have been unable to care because of supporting someone who is shielding. This clarification has been welcomed. Because caring is less well understood, employers may not always have applied this provision. Employment related queries to Carers UK's helpline often focussed on understanding this provision with carers unaware of it being in place. Carers Trust and their Network Partners heard from local NHS staff had raised that they were not eligible for furlough. This has also also been raised with other organisations e.g. Carers UK.[35]

We received evidence from Centrica detailing their support for staff in response to the pandemic. They have an active and longstanding staff carers' network and a well-defined support offer for carers – e.g. working carers' passport and carer's leave provisions which has helped carers. Centrica's carers network grew by 9% in the period following the COVID-19 lockdown at the end of March. A number of other employers that Carers UK has been working with have introduced Carer's Leave and other measures to support working carers.

We have heard from working carers that the lack of day services has placed additional pressure on them, and Centrica has feedback from the experience of its staff about the vital role that care plays in their lives. Carers within the Centrica staff carers network who responded to a survey said that half had seen an interruption in their usual care and support services. Carers UK has evidence that amongst carers with significant caring responsibilities there is concern about returning to work. The evidence from Centrica's staff network is corroborated by Carers UK's contact with carers including; worry about infection risk to the person being cared for, a lack of day services making return to work extremely difficult or impossible and the lack of day activities increasing the loneliness and isolation of the person needing care. For some, it includes the loss of flexibility of working from home. Others want to return to the workplace as a place for a break. We recommend:

Guidance for employers from Government on measures to support staff juggling work and care and measures such as access to continued furlough if carers are unable to work because of shielding or lack of day services. Guidance for employers/ees on what happens if it is unsafe for shielding employees to return to work.

Benchmark tool for actions to cover for carers locally in any lockdown plan

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[35] Furlough was possible for public sector workers, but only in exceptional circumstances where they could not be redeloyed.

From the experience of those making up the Carers Advisory Group, we would recommend gathering together a very short tick box benchmark tool for local authorities for carers to check the essentials have been put in place, including specific measures for groups we've identified as most vulnerable and at risk. This should be a quick internal assurance tool for authorities, based on experience and learning across England. This would build on the guidance already developed by the Local Government Association, Association of Directors of Public Health and Public Health England.[36] We recommend:

Quick short benchmarking tool including key measures to have in place locally for carers in the event of local lockdown.

Maximising digital and tech opportunities across local government, health and the voluntary sector.

During this crisis, we have seen an acceleration of digital solutions to support carers and the people for whom they care. This has resulted in a number of different innovations such as Mencap's support services for people with learning disabilities e.g. online disco, Carers UK's Care for a Cuppa, virtual activities during Carers Week, online activities for people with dementia, local authorities using texting to contact carers quickly, remote GP consultations, Carers Trust set up an Innovation Fund for its Network Partners to help support digital innovation, local authorities used personal budgets to support digital inclusion for carers including teaching carers how to use tech, and local authorities have used Carers UK's Digital Resources for Carers providing carers and employees with support.

We recognise that there needs to be a range of services with face-to-face services, e.g. GP consultations for some older people and including mental health services which some people find better than online services. These valuable services must continue.

However, we want to build on the gains that many have made in digital and tech and we recommend:

Maximising digital and tech opportunities across local government, health and the voluntary sector, reviewing where they work well for carers who want them, where it meets need, positively enhances their lives and delivers more tailored support.[37] This might cover systems, processes, information, advice, learning, wellbeing, health, or social activities. All support mechanisms for carers must also factor in digital exclusion and where other options are working better for some carers.

Section 4: Immediate and urgent actions before September 2020:

Protecting People

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[36] https://www.local.gov.uk/sites/default/files/documents/COVID-19%20Suggestions%20for%20mitigating%20the%20impact%20on%20health%20inequalities%20at%20a%20local%20level%20%282%29.pdf

[37] Building on the CHIP/ADASS Digital Innovations in Social Care work and work of others (see Annex)

Flu jabs: public health messaging targeted at carers and specific groups of carers

Carers are already treated as key workers in the list of priorities on the basis that they are caring for someone who would be at risk of flu or at risk if they were unable to care for them. The evidence is that the take-up rate amongst carers providing substantial care drops significantly for working carers, those caring at a distance.[38] Many carers are unaware of their right to receive a flu jab, of all ages.[39]There is also very little information on BAME carers take up of the flu jab which we see as a priority. Last year's flu season materials did not have specific message for carers. They had marketing materials for care workers, but not carers.

With many health settings more difficult to access, and flu being a CCGs need to look creatively at where and how carers are able to get flu jabs, e.g. GP practices have become less accessible.

We recommend:

Flu vaccination communications need specific messaging to encourage take-up amongst carers, particularly working carers, those caring at a distance and BAME carers. CCGs need to look creatively at where and how carers are able to get flu jabs, e.g. GP practices have become less accessible.

Vaccine for COVID-19

The fact that people with dementia are included in the priority list by the Joint Committee on Vaccination and Immunisation is welcome.[40] Given that carers are considered to be a priority for flu we consider there are good grounds for including carers in this this as well alongside other key workers.

This would help to align public messaging with the flu vaccine, improve take-up, value carers, reduce the likelihood of infection, protect the person being cared for and reduce the pressure on health and social care in the event of the carer being ill – addressing one of carers' biggest concerns. We recommend:

That carers are included in the priority list for the COVID-19 vaccine by Government along with other key workers.

Test and trace – protecting people and connecting carers to support

The experience of carers during the crisis around isolation is how to put in place measures to care to continue to support the person they care for, decisions about whether they can continue caring, how to ensure the support network for medication, shopping, food, etc. with one in four of the population potentially providing care,[41] if they are told to isolate, then they need to put in place plans to ensure support for the person they care for. This might be a situation where someone cares outside the home, across multiple homes e.g. to three elderly relatives. Ideally, test and trace would ask a question about whether someone cared for someone, and would signpost them to the national guidance for carers, which includes continency planning – much of which they may be able to put in themselves. We would like

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[38] Further analysis of State of Caring Survey, 2019, Carers UK

[39] As above and evidence from Carers Trust.

[40] Insert reference

[41] Carers Week Research report, op cit

to explore whether it is possible to place a flag on their record in case any follow-up is needed. We feel this measure would help families to plan quicker and be connected with support quicker. We recommend:

Test and trace should include a key question to identify whether someone is providing unpaid care e.g. outside the home or across multiple homes, e.g. to three elderly relatives, and to signpost to tailored guidance.

Visiting supported living and care homes including regular testing for relatives on entry to care homes

Given the experiences of families with relatives in care homes, we are keen to see visiting made possible for everyone and for supported living. We understand very keenly the need for infection control. We believe that care homes and supported living settings need additional support to do so. 79% of care home managers told us that the health and wellbeing of their residents is deteriorating because of a lack of contact with loved ones.[42] There strong evidence on the therapeutic benefit for people with dementia and learning disabilities as well as benefits for family members many of whom have been very distressed at not seeing their relative for a long time.[43]

Mencap has suggested a number of different innovations to improve visiting, including winter-proof solutions for visiting and “virtual visiting”. We are also mindful that whilst this digital has been positive, there are still carers and relatives who do not have digital solutions at home. This would help to reduce the anxiety and worry of relatives as well as improve the quality of care – with families providing insight.

Alzheimer’s Society has provided good evidence that testing a single relative consistently on entry to the care home would be beneficial, providing positive outcomes for staff, relatives and residents improving their wellbeing, cognitive function and reducing agitation. The recommendation would be to test on a similar basis to a key worker under Pillar 2. The Alzheimer’s Society estimates that if each of the 410,000 residents were to nominate one relative then roughly around 50% additional capacity would be required to deliver this.

Visiting is a priority for many families and there is strong evidence that this supports the health and wellbeing of the person needing care. We understand the need for infection control. We need regular testing for a single named relative on entry to care homes and supported living.

Regular testing for people discharged from hospital into the community

When the Social Care Action Plan was produced, it did not include testing for everyone leaving hospital from being an in-patient to the community. We understand that this has been undertaken on a case by case basis. However, for families providing care at home or at a distance, this is a more important issue. They may be being discharged back into a family where there is a vulnerable person. We recommend:

Regular testing for people discharged from hospital into the community to provide reassurance for families and quick tracing.

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[42] Alzheimer’s Society survey of 100 care homes April 2020

[43] Alzheimer’s Society, Mencap and National Autistic Society

Continued supplies of PPE are critical for services and free PPE for carers

We have evidence from different organisations that access to PPE, in terms of supply and cost is critical for safe services, but also opening them up further. Providers of services have told us about increased costs e.g. Mencap, Carers Trust, and the National Autistic Society. A lack of PPE and infection risk was also cited as a reason why carers of people with dementia or a learning disability could not visit them in hospitals, supported living or in care homes.[44]

Carers themselves have found it very challenging to get PPE in a variety of different scenarios[45]. Scotland offers similar scheme of free PPE for carers and the people they are for who are most at risk. We recommend:

Access to free PPE for specific unpaid carers in key situations modelled on Scotland scheme. Sufficient free PPE for visitors in care homes, supported living and in hospitals, as well as secure supplies for care workers.

Supporting carers:

Supporting young carers and their education

A key feature of the pandemic, along with all other groups is the increased role of caring that is undertaken, including by young carers under the age of 18. Carers Trust's survey My Future, My Feelings, My Family, found that 58% of young carers and 64% of young adult carers felt that the **amount of time they spend caring** had increased since Coronavirus. For some this went up to caring around the clock.[46]

Children's Society told us, "Across all regions it has been noted that significant numbers of families have been impacted by reduced or cancelled 'Care Packages'[47]. Either families themselves have cancelled their schedule of care provided by a local agency as they fear the spread of the virus through agency workers. This includes care for adults with acute mental health needs in places only being supported over the phone. An outcome of the reduction of care packages is that many young carers are experiencing an increase in inappropriate caring responsibilities; including giving personal care, using hoists, lifting and giving and managing medication, giving emotional and mental health support, managing challenging or changeable behaviours of loved ones; among other additional and increased caring activities.

"A direct impact of this has been that many young carers have disengaged completely from education during lockdown for a variety of reasons including digital poverty, low parental capacity or lack of parental engagement; increased caring responsibilities, loss of motivation, desire to focus on caring duties. School staff have shared the impact of the sudden closure as triggering low mood and worse, suicidal thinking amongst pupils who are young carers. Desperation and loneliness further intensified by seeing their peer group non-carer friends return to school and social activities whilst young carers are still shielding and providing

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[44] Evidence from Alzheimer's Society and Mencap

[45] https://www.carersuk.org/for-professionals/policy/policy-library/a-recovery-plan-for-carers
And evidence from Carers Trust, Mencap and National Autistic Society regarding direct payments users.

[46] My Future, My Feelings, My Family, Carers Trust, July 2020

[47] www.socialcareservices.co.uk/care-package

ongoing and additional care. Unless support services are reinstated for families, young carers will not be able to return to education in September or to normality."

'Coronavirus made my caring a lot harder' (young carer)

'No, I can't go to school because my mum might have a flare up and they'd be no-one checking in on her'. (young carer)

Carers Trust also reported an increase in the complexity and need for support from young carers during the crisis through their Network Partners, placing additional demand on young carers' services.[48]

In terms of their education, 56% of young carers and 39% of young adult carers said their **education** is suffering. 44% of young carers and 30% of young adult carers would like more support with their education. 41% of young carers said they didn't have enough time to spend on schoolwork.[49]

Local authorities have a responsibility to young carers under the Care Act 2014 which focusses on ensuring sufficient support is provided to an adult with care and support needs to prevent any excessive caring for any children within the family. The duty of co-operation under the Care Act 2014 requires a Whole Family Approach.

There is real time deadline in September to ensure that young carers are able to return to school. There is also a need for support throughout winter with specific measures targeted at young carers.

Carers Trust and the Children's Society are developing guidance for schools to help support young carers' return to schools and this will be published shortly. We would like any winter planning to highlight this work.

We recommend: Local authorities to draw up a 'Back to School' plan for young carers which involves adult social care, reassessing families and ensuring sufficient face-to-face support is put in place to give young carers and their families confidence they can return to school. This return of services includes face-to-face mental health services.

To back up the good practice work of the voluntary sector and to join up services, Government needs to issue guidance to schools to ensure that young carers are clearly identified in order to provide tailored support.

Addressing rising need

Prior to the crisis, several reputable sources were documenting rising unmet need as funding for social care was not keeping pace with need and that Directors of Adults Services were increasingly concerned they would not be able to meet their statutory duties.[50]

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[49] Carers Trust, evidence
[50] ADASS Budget Survey 2019

During this crisis, we heard evidence from every group that the needs of the person being cared for have often increased.[51]

As well as the needs of the person being cared for, we are seeing increased need of carers – particularly in terms of their mental wellbeing. This is across all groups of carers, but more acute in the carers we have looked at being more vulnerable. Work by the Universities of Birmingham and Sheffield provide evidence from large data sets.[52] Carers say that this is due to the effects and impact of lockdown and the reduction in services. Services run by Rethink, local carers organisations, including Network Partners of Carers Trust, local Mencap services, Alzheimer's Society services, advice services run by Carers UK, local National Autistic Society services, Age UK, have seen an increase in support needed. As an example, Rethink Mental Illness Service in Oxfordshire, since the outbreak of Covid-19 there has been an increase in the number of carers being referred to the service and an 'influx' of people who have used the service in the past returning to seek further support.

The Association of Directors of Adults Services (ADASS) said in their budget survey, "Overall, the onset of the pandemic has led to an increase in the number of people presenting adult social care needs to local authorities and unmet need."[53] ADASS and the Local Government Association suggested that providers and other care costs would rise to £6.6 billion by the end of September.[54]

Sufficient funding is needed to continue essential services providing capacity and sustainability of the care and charity sector, provide sufficient breaks for carers - prevent carer breakdown of all ages, including young carers; improve carers' resilience, improve disabled and older people's health and wellbeing and prevent loss of employment for carers needing to juggle work and care.

We consider this a key priority.

Address rising need, capacity building and sustaining key care services and support: urgent re-appraisal of baseline need in local authorities and sufficient resource allocation for a) winter and b) the 2021/22 budget for local authorities needing action by MHCLG and DHSC

Mental health support for carers:

We have addressed this here specifically because of the increased mental health challenges faced by carers that is documented by many.[55] Around 50 charities have called for a Mental Health Renewal Plan, which would help to deal with the immediate and future needs of the caring population which should be examined.[56]

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[51] We have heard this through Mencap, Alzheimer's Society – 82% of people with dementia seeing a decline in speech, memory or skills, Carers UK, Children's Society, National Autistic Society, Rethink Mental Illness, Carers Trust, Local Government Association, Association of Directors of Social Services

[52] Caring and Covid series: http://circle.group.shef.ac.uk/2020/06/17/caring-covid19-report/

[53] ADASS Budget Survey June 2020: https://www.adass.org.uk/media/7967/adass-coronavirus-survey-report-2020-no-embargo.pdf

[54] https://www.adass.org.uk/social-care-providers-face-more-than-6bn-in-extra-covid-19-costs - June 2020

[55] Caring Behind Closed Doors, op cit, Rethink Mental Illness, Caring and Covid series http://circle.group.shef.ac.uk/2020/06/17/caring-covid19-report/

[56] https://www.rethink.org/news-and-stories/news/2020/06/prime-minister-urged-to-create-new-mental-health-renewal-plan-for-england/

Mental health support must be specifically targeted at carers, along with good information and advice and the reinstatement of day services, breaks and community-based support services as soon as possible.

For carers of people with mental illness, they need the same information, contact, face-to-face support for the people they care for, as well as the same testing for in-patient and secure accommodation. The same issues also apply as we raise elsewhere for carer's assessments.

Carers returning to work

Shielding paused/ended in areas not in full lockdown on 1 August 2020 and it is the Government's ambition for as many people to return to work or their place of work where it is safe to do so. As many care services are not at the same capacity rate as they were pre-crisis across health and social care, this poses a considerable problem for carers who have to return to work but cannot until care services are in place. We have this evidence from carers who are asking about their rights and from a variety of different sources, e.g. employers feeding back experiences of staff.

There is also evidence that the impact of day services affects carers wellbeing, something that is important to employers.[57]

As already detailed, clear guidance is needed to employers about asking to come back to the workplace and clear statements about the reinstatement of day services.

We recommend:

Government considers extending furlough where usual care services are not yet in place for carers to be able to work. Guidance for employers must be provided where carers have caring responsibilities for someone who needs care and support and returning to work.

Carers' breaks and day services opening up/being reinstated

Our evidence demonstrates the need for quick solutions and we class this as urgent. Reports of carers at breaking point without breaks, the people they care for are losing skills without their usual services and contact, young carers may not feel confident to return to school and the lack of key services means that some carers are unable to work:

Where face-to-face services have continued, carers have welcomed and praised the commitment and dedication of care workers and care services and shows the value that families place on good quality services.

The picture of services is complex and does not cover not just traditional care services, but a whole range of services and support run in community, voluntary and faith settings which provide families with support and breaks and the person they care for with important activities. Many valued services are volunteer-led.

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[57] Employers for Carers, Carers Health and Wellbeing report
https://www.employersforcarers.org/news/item/1514-new-report-on-health-and-wellbeing-in-the-workplace

Mencap highlighted the fragility of care, support and breaks arrangements that are often informal to meet a range of caring responsibilities. They raised the issue of additional pressure of home-schooling and caring across different settings.

SCIE has published good practice guidance on opening up day services. Breaks are delivered in many different forms but day services and overnight breaks are two types of vital support. Home care services have been used positively where day services have not run and could be used more. But they are not the solution for everyone. The general consensus is that the need for breaks has increased. Because of social distancing, providers have told us that it is not possible to provide the same level of capacity for face-to-face support as pre-COVID-19.[58] We have looked at this in some detail and across different groups including young carers.[59]

Having overnight stays in different types of accommodation giving carers a break is vital and, whilst sleep-in services might be available these types of breaks, away from home, can be essential. Revitalise runs a longer breaks service for people with complex disabilities and it is highly valued by people who use it and their families get a real break. Because of their specialist services and knowledge, they have very positive outcomes for all concerned.

Revitalise has highlighted an additional challenge for overnight residential care. Where a person needing care does NOT move permanently into residential care, the 14-day quarantining period required in residential settings creates a real issue for short term overnight breaks. In order to comply with the 14-day quarantining direction, they have had to devise a system whereby the person isolates at home for a week, is tested and then goes into isolation in their breaks facility. For those with two weeks break they would have a full week of activities. This approach has been cleared with their insurer as well.

This is problematic since many breaks are only for a week. This will not be appropriate for all guests using their services – since some will not be able to cope with isolation in the facility for a week. We need an urgent conversation about how residential based respite care, or breaks as we prefer to call them, can be opened up within the 14-day quarantining period. We have included this within the recommendations.

All evidence has pointed towards the urgent need to reinstate support back to previous COVID-19 levels.

We would recommend:

- Urgent review of breaks provision by Government to delve deeper into solutions for carers and providing sufficient capacity for the sector.
- Additional investment for day and evening service providers to increase face-to-face support to comply with social distancing and infection control measures. Investment in this could come from Government to local authorities via Infection Control Fund.
- Sharing of good practice such as using additional home care services to provide breaks, providing short term overnight care, waking nights service or live-in care as an alternative.

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[58] Evidence from Mencap, National Autistic Society, Carers Trust from their local Network Partners
[59] Evidence from Children's Society and Carers Trust

- Additional home care services to allow someone to return to work to be built into planning.
- Creative use of carers personal budgets and personal health budgets to give flexibility in breaks provision e.g that they can continue to use their funds for.
- Opening up short term breaks in a residential setting e.g. Revitalise or care homes is vital. Both face challenges because of the 14-day quarantining required. Urgent assessment of how this can be managed is needed and additional resource to enable short breaks to be taken, good practice developed and shared with providers.

The evidence is that carers will only trust these services if there is:

- Clear data about the level of risk e.g. low level of transmission of homecare staff
- Openness and transparency about infection control, assurances and delivery of testing of workers, volunteers and carers to settings, including supported living.
- Clear engagement, communication and learning with carers.
- Steady and continuous supply of PPE to workers, but also carers where necessary.
- Understanding of PPE, when it must be used and how for carers as well as workers. Resources have been developed by local organisations which could be shared.

Next 3 months (until October 2020) – winter planning

In preparation for winter or a second wave we hope that family carers are considered properly in the any NHS winter plan and social care planning by incorporating some of these measures. We recommend:

Continuous review of breaks as above by local authorities, but with national review by DHSC and additional financing of breaks and day services/alternatives.

Assessments and contingency planning:

Given the situation with carers, all those providing evidence have made strong calls for rapid re-assessment of carers and the people they care for with appropriate care plans. There is a mixed picture with carers' assessments with one area nearly seeing a doubling of assessments, however in many areas, referrals for assessments are significantly down as carers have less contact with GPs, social workers and key referral routes.

Contingency planning with carers is a vital part of this. This is one of the key issues raised by carers very early on with carers' organisations locally and nationally. Many carers will be able to build their own contingency plan with tools to help and use the support of the voluntary sector to do so. However, some carers need input from social care, with a robust plan should the carer not be able to care. This has been one of carers' greatest worries – what happens if I cannot care? It is particularly acute for older carers caring for each other, older carers looking after sons and daughters with learning disabilities/autism where the impact of not having contingency plan in place can be significant for health and care services, but particularly distressing for the person needing care. Carers UK has created a new digital tool to help carers think about contingency planning, but for some this will still require the input of social care e.g. with assessments.[60] With a number of different good practice resources, contingency planning must be built in to routine practice and any urgent reviews and reassessments.

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[60] MyBackUp – Carers UK's digital contingency planning tool - https://carersdigital.org/mybackup/

A number of different organisations have also raised the issue of those new to caring during COVID-19 either due to the long-term effects of the virus, or because of another condition. Continued efforts to identify those new to caring need to be made and continued during the winter.

Of real concern are those carers who are digitally excluded and cannot access any type of support, apart from keeping in touch/wellbeing calls. These are welcome and important, but some carers need more support.

Rethink raised the issue of continued strong focus on carer's assessments and a need for confidence in the process. There is pre-COVID-19 evidence that carers of people with mental illness are less likely to receive assessments.[61]

Some carers of real concern are those who have refused services because of worry about infection risks and are now reaching breaking point. Research has found that 22% of carers had refused services.[62] We are concerned that there will still be carers who will be too worried about using services even though they need a break. This includes people caring for adults with complex disabilities and health conditions and older carers.

- ***Rapid re-assessment of carers most at risk in event of breakdown or at risk in second wave by local authorities. This should include contingency planning if the carer is ill, unable to care or the relationship breaks down.***
- ***A focus on those who have refused services because of fear of risk of infection.***
- ***Local authorities should encourage early contingency planning by carers who are able to develop their own, and focus on those who need more detailed social care support – this needs to be part of core winter planning.***
- ***Continued assessments of those new to caring during COVID-19. Large variation local authorities undertaking carer's assessments – one has seen nearly double the number of carer's assessments, others are doing very few and there are few referrals to local services which suggests unmet need building in areas.***

Hospital discharge and support for carers

Much of the work around hospital discharge has rightly focussed on discharge into care homes. However, very little work has been done on the impact and outcomes for people discharged back into the community. Carers Trust told us that rapid discharge from hospital mean that many carers did not have the discharge arrangements that support them and the person they care for or were forced to accept placements that would not ordinarily have been acceptable.

With carers not being in hospital with the person they care for, as they would be normally, they are in less of a position to observe how their relative is managing and their condition.[63] Carers have a right to be involved in the process of hospital discharge under the Care Act 2014, to be given information and advice and to potentially have a carer's assessment.

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[61] Rethink evidence referring to State of Caring 2019 survey.
[62] Caring Behind Closed Doors op cit
[63] Evidence from Alzheimer's Society, Carers Trust and Carers UK

Healthwatch is currently conducting a survey into patient and carer experiences of hospital discharge. We recommend:

The results of the Healthwatch survey on hospital discharge for carers are considered in winter planning.

Supporting carers – an enhanced role of the NHS

The GP practice has been at the heart of the pandemic response for many by identifying people who need to shield and are extremely clinically vulnerable, those who are clinically vulnerable. Good proactive GP practices e.g. in Surrey are important referral routes into local carers' support, however, this is not standard practice. The identification of carers through a GP Quality Marker Scheme is good practice identified in the Long Term Plan with the aim of greater uptake. Identification of carers in GP practices helps with a number of prevention response measures for COVID-19 - to flu, any COVID-19 vaccination programme, advice for carers managing conditions at home more with fewer health visits, risk stratification, prioritisation of any treatment. Identification of carers is not widespread in GP practices, and we believe it would be beneficial to the COVID-19 winter response if this were accelerated. We therefore recommend:

Rapid upscaling and acceleration of GP identification of carers. This is in the Long Term Plan as good practice, but Government could strengthen and accelerate this with NHSE&I to introduce a basic requirement of all GP practices to have a system in place to identify carers.

Support for end of life care and bereavement services

This is an important area for carers where social care needs to work with health and the voluntary sector to look at end of life care and bereavement services. There are examples of good practice for carers, but we do not know how widespread this is.[64]

Low incomes and the effect of winter

During the pandemic, a feature remarked on by carers is the rise in costs of food, goods, but also heating. Since the crisis has been over summer, this is less than it might have been. Carers and others on low incomes needs to be considered during the winter. Working age disabled people do not receive the Winter Fuel Allowance, nor to carers, but this could be vital over winter.

Carer's Allowance, the main carers' benefit, and other legacy benefits have not increased during COVID-19. Carer's Allowance is the lowest benefit of its kind at £67.35 per week. The evidence shows that the increased costs of caring during COVID are impacting on carers and their families.[65]

We recommend:

Tackling low income issues that affect carers – in particular the winter effects of being indoors longer and a rise to Carer's Allowance.

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[64] Recovery Plan for Carers, op cit.

[65] Further detail can be found here for more background detail as well as the specific solutions being proposed: https://www.carersuk.org/news-and-campaigns/campaigns/fairer-for-carers

Section 6: Throughout winter (at least to March 2021)

We have evidence from a number of different sources that the following are needed and we recommend:

Issue guidance that gives priority to carers using non-urgent patient transport (NEPTS) to go with the person they care for if this is appropriate.

NHSE&I needs to build carers' needs into take-up of healthcare that has been missed during the crisis. This has to go hand in hand with services for elderly and disabled people's services opening up and replacement social care.

The reinstatement of more face-to-face health visits for people who find communication more difficult. Continued contact with GP practices and consultants by telephone or video/online where this is working.

Capacity building families and workers - awareness of COVID-19 amongst key conditions/disabilities e.g. dementia and how it may present or where someone has communication issues. This could be delivered through Skills for Care working with key stakeholder groups for staff and also for families.

Reassurance around rights and the Care Act 2014 and a quick review of practice of carers' assessments during COVID-19 to assure processes.

We received evidence directly from carers and leading advocates within the carers community that there is widespread concern about the easements with the Care Act 2014. Although the easements are not currently operating in any areas, the changes to assessments, very few face-to-face, services reductions because of social distancing etc. and community-based support not operating that were featured in people's care plans, carers are worried about their rights in the future. We strongly recommend reassurances that services will be reinstated and to check that the delivery of assessments and care planning are done as close as possible to the Care Act 2014.

Assessors have been telling us that although telephone assessments are taking place and some face to face, many of the assessments are far more complex because of lockdown and the fact that so many community services and care support is not available. Good practice needs to be swiftly gathered together, working through bodies such as the Association of Directors of Social Services and stakeholders.

DHSC having an informed national view on whether level the cancelled services and whether reinstated to judge where the sector has returned, or not, to previous levels. DHSC taking a clear view on the level, quantity and content of carer's assessments.

Section 7: Data collection and longer term

We consider that there are a number of different implications for data collection and analysis. The first is that the insight provided by key data sets such as Understanding Society are brought into planning and directly into practice. We recommend:

Improve the data collection on social care and carers including capturing the impact on people from Black, Asian and Minority Ethnic communities

Review the NHS responsibilities towards carers, with a view to building on and improving them.

Investment and reform of the social care and welfare benefits system

Ensure that carers' needs for information, advice and support are fully integrated into future pandemic planning.

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