

JOINT STATEMENT: CARERS UK and CARERS TRUST COVID-19 (coronavirus)

Carers UK and Carers Trust are making this joint statement regarding the coronavirus – or COVID-19. This covers an overview of the current advice for people who are providing unpaid care. We also set out what we believe services should be planning and preparing, making sure that everyone from Government, to the NHS, to social care understand the role that unpaid carers play in society; how they should be adequately accounted for in planning and supported. Whilst we can advise carers, they are also concerned with the ‘what if?’. We raise their questions in this document.

The 2011 Census tells us that there are 6.5 million carers¹. Carers UK’s polling research suggests that this could be far higher with 8.8 million over the age of 16². In addition, there are many young carers. Carers Trust quotes research which suggests there could be as many as 800,000³ young carers.

Advising carers

Carers UK has developed [information and advice](#) for carers based on questions carers are asking us, which Carers Trust and Carers UK are both promoting. The advice being provided to unpaid carers follows the latest UK and Nation Governments public health advice, is regularly reviewed and updated when necessary.

The core of this advice is to:

- follow core public health advice
- ensure carers, people with care and support needs and people coming into the home of a person with care needs should follow hygiene and infection control guidelines
- plan for contingencies and check with the local authority what the emergency plan is, or your local health organisation if your families’ or friends’ care is health funded
- make the most of networks now, family, friends and neighbours, and your local community organisations to plan for ‘what if’
- make sure you have key information to hand about the person you care for
- make the most of technology that can keep you in touch with the person for whom you care, or keep them in touch with others.

1 Census 2011

2 Carers UK, Juggling Work and Care, 2019 and Carers Week, 2019

3 University of Nottingham (2018)

<https://www.nottingham.ac.uk/news/pressreleases/2018/september/children-england-care-sick-family.aspx>

Our overall message to systems planners in terms of carers

- Planning must be carer sighted ie understanding of the role that carers play in each of the nations across the UK. Carers in the UK provide unpaid care to the value of £132 billion a year – equivalent to the NHS. The majority are invisible to health systems in particular, but many are also outside of formal social services, and even wider social care systems and community organisations.

Employers need to ensure that their staff members can juggle work and care

- All employers consider what might happen for their staff if they need to provide unpaid care for someone because there is no alternative available and they are at risk. Whilst many carers will try to work flexibly, this may be impossible for some. Our message to employers, including in the health or social care sector, is that they will need to consider this very urgently and make new or extra leave and work provisions to ensure that workers do not lose their job or extensive amounts of pay.

Services must be in place for the following situations

- If carers become ill themselves with COVID-19, they may not be able to provide care.
- If the carer lives with the person being cared for, robust plans to support the person with care needs must be developed. It is essential that services are not withdrawn without clear risk planning. This equally applies to a clear process for providing emergency support for those carers who provide care with no support from formal social care.
- Carers may not always live with the person being cared for. 76% of those providing less than 20 hours of care per week do not live with the person they care for⁴.
- In the event that carers are not able to support the person needing care eg travel or are looking after children unable to attend school, then it is essential that the local health and care services have a clear picture of the person needing support.
- Carers may have long term conditions or disabilities themselves that increase their vulnerability, which must be factored into planning.

Who needs care in a local area?

- When health and social care are developing their plans for who is most in need or at risk in the community, this needs to take on board the fact that many will be unknown to health, care and even community services.
- This is often because they are being cared for by family or close friends. It is essential that national planning takes this on board, and locally health, social care, GPs and community organisations must work together to get the best possible picture of this.
- Data and intelligence pooling could be a real asset to ensure that we get the best picture possible of those most in need. Carer identification needs to be a core part of this.
- Information systems, like 111 should start collecting data on whether someone is a carer and ask this question to anyone who either reports symptoms or has to self-isolate ie if they provide an important level of care to someone who might be vulnerable in the community. This should then lead to an appropriate response from the authorities.

Allaying carers' concerns

- Continuity of key medical supplies ie key medication, or equipment such as peg feeding or oxygen tanks, etc. This also includes products carers often buy themselves such as incontinence products and items now in short supply such as wipes and disinfectant. Carers need assurance that key processes will ensure that these vital services will continue.
- Carers will need assurance for individuals who have high personal care needs that only a highly skilled care worker or nurse can provide, will continue to have these needs met.
- How will they manage if care is withdrawn or stopped? What happens if the care worker does not turn up, or if care is removed? Who do they contact? What is the response?
- Will the care service be protected in the future? If care has to be stopped for some reason, and the family is able to manage in the very short term, will there be guarantees that this would resume in the future?

Food and nutrition for the person needing care

- There is a worry that if the carer is not able to cook/shop, or where the person living alone is not able to do so, who will do the shopping and cooking. Our advice to carers is to strengthen personal networks now, but this may also need a community response coordinated by health and social care bodies.
- Care and health workers and others coming in to the home eg cleaners should follow strict hygiene procedures. Carers have asked how they will know if they are following these procedures and what employers are doing to enforce these.

Waiving charging and eligibility rules for emergency social care

- We believe that current, often slow assessment of care processes and rigid eligibility criteria must be waived during this period. It is vital that support is provided where and when it is needed, as quickly as possible. Current reablement processes on discharge from hospital may be a good template for delivery of this type of model.
- Where there are charges for social care, we believe it is vital that charging rules are waived for emergency social care during this period. It does not make economic or practical sense for a system that is trying to cope with an emergency to apply means-testing and a financial assessment at the point of need. Nor should any bill be sent after the event.
- We need to be reassured that if people need social care in an emergency, that it will be free at the point of delivery and Governments need to fund local authorities to be able to do so.

The role of mental health services

- We are also aware through carers, that the focus and messages have been primarily around health services, rather than care services. Mental health services are also a key element particularly for those with extreme and severe anxiety disorders which may be triggered or exacerbated by the current and developing situation.
- Carers are also concerned that inpatient, crisis or emergency psychiatric liaison services may become difficult to access if the person they care for becomes unwell.

Young carers

- Young carers, under the age of 18 are in a particularly difficult situation and this may be disproportionately worrying for those who are caring for a parent in a single parent household. It is vital that services understand the situation and do things that strike a balance between supporting children who have caring responsibilities and not placing inappropriate responsibility on a young carer.
- Support provided by local carers services and schools can be crucial in helping young carers to balance their needs with those of the person needing care and support. Should this be unavailable, young carers' needs may need to be swiftly re-assessed, and more support put in place, so they are not providing inappropriate or excessive care. Young carers are children and young people, so developmentally they may need more support in terms of managing dynamic and changing situations, especially if their usual solutions are not available (eg their local supermarket or pharmacist does not have supplies).
- It is important that if schools close, that they understand who within their schools are identified as young carers. We would strongly urge schools to nominate a lead person to make regular contact with young carers during this time as it may only be the school or teacher who knows that one of their pupils is looking after someone at home.

Additional stress on carers and break services

Caring for someone can be difficult and has a negative impact on carers' health and wellbeing. The stress on carers should also be factored into planning. In the coming weeks, carers under great stress may not be able to access their normal breaks or time off to recharge their batteries. This must be recognised by all support agencies. Carers should be kept updated and contacted, making sure that there are clear plans to reintroduce care and breaks as soon as possible. As a matter of principle, it is important that carers are informed of decisions that affect them.

Loneliness and isolation

There is increasing concern about people becoming more isolated, especially older and disabled people living alone, when the advice is to reduce contact. It is critical that advice addresses this within its response.

Carers already experience loneliness and isolation, particularly if providing substantial care. 81% of carers in this group have experienced loneliness as a result of caring⁵ and carers are up to seven times more likely to be lonely than the general population⁶.

5 Carers UK, State of Caring 2019

6 Carers Week 2019

Accelerating actions to support carers and those they care for

This situation is demonstrating the complex and valuable support that families and close friends provide. It also shows the high value of robust systems and structures to identify carers, understand the whole care situation of the person needing care, and any unpaid care being provided. Not all parts of the health and social care system have these in place. This now turns what has been considered 'good practice' into 'essential practice'.

There are several actions that could be accelerated locally in order to help plan for a much potentially more serious situation with COVID-19.

- The need for all GPs to identify carers of the person needing care, particularly if they are not themselves part of the GP practice. GPs identifying their own patients who are carers is also critical. GPs should also be asked to ensure that they are aware of any young carers in their practice.
- Having systems to plan for emergencies and contingencies should be part of everyday business for the NHS, local authorities and partnerships to work with families, but in a future situation, could be critical.
- The NHS must have a better awareness of carers overall, including the role of young carers. This will be critical if increasing numbers of people are hospitalised with COVID-19 alongside people who are in hospital with other 'normal' infections, accidents and illnesses. There must be clear joint processes for discharge in all circumstances to ensure that those individuals are provided with the support they need, ready on their discharge. Individuals should not be left unsupported because of a need to free up bed capacity to deal with COVID-19.
- The ability for carers and others to engage with the NHS digitally and remotely is also essential.

The indicators in the NHS Plan for England, for example, could be accelerated by this action.

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