**The impact of COVID-19 on carers in Northern Ireland**

**A statement by the Coalition of Carers Organisations NI**

**Introduction**

Established in 2016, the **Coalition of Carers Organisations (CoCo)** is an alliance of community and voluntary organisations collaborating to advance the rights of unpaid carers in Northern Ireland. Before the outbreak of COVID-19, the unpaid carers we represent already experienced difficulties in accessing enough practical support and short breaks / respite, juggling work and care and accessing financial support. These challenges have been further compounded by the pandemic, with many coping with additional caring responsibilities and limited or no external support.

A recent survey of carers in Northern Ireland[[1]](#footnote-1) shows that:

* **78%** are providing more care during COVID-19
* **87%** are worried about their loved one getting ill
* **77%** are spending more money (highest expenditure on food)
* **64%** are feeling overwhelmed and worried that they are going to burn out in the coming weeks.

**Key impacts of COVID-19**

**Visibility:** Provided in people’s homes behind closed doors, the role of unpaid carers is largely unrecognised. The lockdown and ongoing pandemic have made them even more invisible.

* **Carers cannot be expected to ‘carry on’ quietly and in crisis for an unspecified period:** When we

think of essential workers, little acknowledgement is given to the essential work that is being done outside health settings by unpaid carers in keeping vulnerable people safe at home. They are providing high levels of care and support 24-7 for family members or friends affected by poor health, a disability or mental illness, many with multiple conditions and complex needs. The role of unpaid carers must be explicitly acknowledged and considered in the government response to the pandemic.

* **Carers voice and lived experience needs to be heard:** Never more than in the current crisis has this

‘silenced’ community required advocacy[[2]](#footnote-2) to ensure they are appropriately supported in decision-making about care and treatment, and for the issues they face to be communicated. With unclear timeframes around the restoration of support, carers must also be part of service planning discussions/decision-making.

**Isolation:** Almost three quarters of carers (74%) feel isolated or lonely because of their caring role.[[3]](#footnote-3) The need for shielding and social distancing during the pandemic has made this even more acute.

* **While a degree of normality will return to communities as lockdown lifts, many carers will remain in**

**isolation.** Although lockdown measures are being eased, without a vaccine, the continued presence of the virus creates uncertainty for vulnerable people with complex health conditions, and their carers. There is a real risk that they will get left behind as COVID community responses are stepped down.

* **Prolonged isolation over the course of the pandemic may have serious health implications for carers.**

The negative effects of loneliness and isolation on our physical and mental well-being are well documented. Without access to appropriate emotional support, carers will be at greater risk of experiencing chronic stress, anxiety, or depression.

**Access:** Access to support services and employment are vital for the safety and well-being of carers and who they care for; however, this is significantly impacted by the pandemic.

* **Care, treatment, and support services have been withdrawn or limited across key sectors:** Many carers and family experiences are not consistent with the messages that services remain accessible. The removal or reduction of key supports such as family support, domiciliary care, day opportunities, short breaks, appropriate care packages after hospital discharge and the closure of Special schools has placed increasing pressures on carers to provide round the clock emotional, personal, and therapeutic care and support. Without these essential services carers are at risk of mental and physical exhaustion, with some already at crisis point. Carers are also concerned about the lack of access to carers assessments, and the absence of any contingency planning should they themselves become ill.
* **Employment and financial implications:** 53% of carers in NI are in paid work[[4]](#footnote-4).To fit around their caring responsibilities, many carers are in low paid, part time work or are self-employed. Already at particular risk of poverty, they are experiencing increased food, utilities and other costs during lockdown. Many who were working have had a drop in salary due to furlough or had to take unpaid/sick leave without childcare or alternative home care support. Until services return, some will be unable to return to work and may face redundancy.

**Grief and loss:** Carers are experiencing increased feelings of grief and loss throughout this crisis.

* **Fear and anticipation of loss is a feature for many carers throughout their caring experience.** The fear of losing someone they have been caring for is constant and will be especially heightened in this pandemic.
* **Loss of contact and support from family and friends as well as relevant services,** has left many feeling isolated. The loss of contact and connection with those in residential care as well as the loss of control over how this care is delivered is of real concern.
* **Grief and bereavement:** COVID-19 has left many of us unable to spend end-of-life time with loved ones, or to grieve and mourn in familiar ways leaving some unable to process their grief.

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| **The Coalition of Carers Organisations is calling on the NI Executive to take action to:*** **Ensure that carers rights are maintained and enhanced, and the vital role of unpaid carers in supporting the health and social care system is clearly recognised in the rebuilding, and delivery, of health and social care going forward.**
* **Co-produce an action plan with carers to restore essential services and support carers to transition back to some sort of normality as lockdown eases and while COVID-19 remains present.**
* **Ensure key work continues in exploring the long-term needs of carers and strategic planning to meet those needs in partnership with carers**
* **Increase financial support for carers through increasing Carers Allowance or introduce some form of supplementary payment for carers**
* **Work with employers to ensure those juggling work and care are supported to return to work**
* **Identify carers as a priority group requiring emotional support services; and develop an agreed pathway for them to access interventions such as psychological talking therapies.**
* **Work in partnership with third sector organisations providing advocacy and other key support services to carers.**
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**For further information, please contact: Clare-Anne Magee, Chair** **clareanne.magee@carersni.org**      ****  ****

1. Carers UK (2020) Caring behind closed doors [↑](#footnote-ref-1)
2. This includes self-advocacy; individual advocacy; community/representative advocacy and systems advocacy. [↑](#footnote-ref-2)
3. Carers NI, NI State of caring (2019) [↑](#footnote-ref-3)
4. Carers Week report (2020) [↑](#footnote-ref-4)