

## **Care Alliance Ireland – Position Paper on Vaccine Prioritisation for Ireland's Family Carers**

**March 2021**

### **Introduction**

The purpose of this Position Paper is to outline the Care Alliance Ireland position on vaccine prioritisation for family carers in Ireland, with specific reference to the concepts of 'rationale' and 'ethical principles' which accompany the Government's vaccination priority guidelines.

### **Background**

There are 500,000 family carers in Ireland<sup>1</sup> – friends, family members and neighbours providing varying levels of care, support and practical assistance to people with disabilities, mental and physical health issues, concerns arising from ageing, and both chronic and acute health conditions. For many people who receive care, this is what enables them to remain living in their communities. From the economic perspective, it is estimated that family carers contribute €20 billion worth of care to the Irish economy every year.<sup>2</sup>

We are about to experience the first anniversary of the initial Covid-19 lockdown. While it feels to some extent as though we never left that first lockdown, many of us were able to experience some kind of normality in the summer of 2020, and over Christmas, when numbers of cases dropped enough for restrictions to be eased. Many were able to see family and friends, go shopping, perhaps even take a short break or holiday.

This has not been the case for family carers. They have remained in a perpetual lockdown for a year, with access to practically none of the supports normally

<sup>1</sup> Central Statistics Office, 'Irish Health Survey 2019 - Carers and Social Supports' (Dublin: Central Statistics Office, 2020), <https://www.cso.ie/en/releasesandpublications/ep/p-ihsc/irishhealthsurvey2019-carersandsocialsupports/carers/>.

<sup>2</sup> Estimated by Family Carers Ireland: <https://familycarers.ie/news-press-releases/2020/december/over-half-a-million-family-carers-in-ireland-according-to-irish-health-survey>

available. Respite, schools, day services, support groups, information sessions and other supports have been obliterated. Some supports have moved online, but this has left many carers behind, since not everybody has the skills or desire to take part in Zoom calls or Microsoft Teams support groups.

Family carers are often referred to as the ‘backbone’ of the health system in Ireland. The *National Carers Strategy* identifies them as ‘key care partners’.<sup>3</sup> Carers have spent the last 12 months keeping some of the most vulnerable members of Irish society safe and well. Arguably, the reason that people being cared for at home have not appeared in the statistics for Covid deaths is that they have been protected by the work and sacrifice of their family carers. In this regard carers have admirably fulfilled their role as key care partners.

### **Family carers and the vaccination rollout**

The main hope for returning to normal is now pinned on population-wide access to vaccines, and the current vaccination rollout is welcome. Part of that rollout is the creation of a vaccination priority list in order to protect those most in danger from the worst effects of Covid-19, protect healthcare capacity and enable social and economic activity.

Family carers, who provide vital health and social care support, are not on the vaccine rollout plan as a distinct group. Under current conditions, carers will receive the vaccine only on the basis of other priority factors. So, for example, even as the sole carer for an ageing mother, a 35-year-old family carer with no diagnosed health conditions will be among the last to receive the vaccine. We believe there are strong arguments for prioritising fulltime family carers for vaccination, and through this achieving protection of both carers and vulnerable people, as well as cost savings in both the short and long term.

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<sup>3</sup> Department of Health, ‘The National Carers’ Strategy’ (Department of Health, 2012).

## The arguments for priority vaccination of fulltime family carers

There are both practical and policy reasons why family carers and the organisations who support them are now calling for fulltime family carers to be deemed a priority group.

To be clear, family carers are not asking to be prioritised **above** those with medical conditions on their own merit. Of all people, carers have no wish to put the health and life of medically vulnerable people at risk. Fulltime family carers simply request recognition as a priority group, with the option to receive the vaccine at the same time as the person they care for. The following aspects specific to the family caring situation illustrate the arguments for prioritising fulltime family carers.

### Family carers and those they care for are a unit

In caring, family carers and those they care for must be seen as a unit. What adversely affects one adversely affects the other. This linkage is a recognised aspect of the caring situation. In the UK, the Chair of the Standing Commission on Carers has stated: ‘Historically there has often been too much of a divide between the user and the carer, whereas the physical and emotional well-being of both are inextricably linked.’<sup>4</sup>

### Risk of hospital or residential care admission

We know our health system is stretched. If a family carer contracts Covid-19, there is a danger that they will become completely unable to care for their relative. What happens then? The answer is that many of those currently being supported to live at home will not be able to stay at home. This creates the risk of costly hospital or long-term residential care admissions, a situation which would be directly at odds with stated health policy.

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<sup>4</sup> Russell, P. (2010) ‘Introduction’, Carers and Personalisation: Improving Outcomes.

### Risk of regression and 'downstreaming' of healthcare costs

The risk of regression in the condition and physical health of people being cared for arising from admittance to residential or hospital care is significant, heightening complications and the need for significant interventions down the road. Research undertaken during the pandemic as services began to close and adapt<sup>5</sup> has already evidenced such regression.

### Carer vaccination as protection for the person receiving care

Some care recipients, for a variety of reasons, are unable to receive a vaccine because of the risk of additional complications. Carer vaccination acts as a protective barrier for such people.

### Carer vaccination as alleviation of mental health risks to carers

All of us have been affected by the unprecedented challenges presented by Covid-19. Many struggle to remain motivated and positive. Some who experience mental health difficulties have seen these exacerbated by the uncertainty caused by the pandemic, along with experiencing heightened anxiety about close relatives. Evidence has been emerging that family carers have been disproportionately affected in this regard. Research published by Family Carers Ireland highlights that 84% of family carers report being worried about getting the virus and being unable to care for their relative.<sup>6</sup> The fear for many family carers is not for their own health, but for the people they care for, and what would happen if they were no longer available to provide care:

*I am terrified that I will get Covid-19. There is no one else to fill my role. What happens then? Not knowing keeps me awake at night. When I do sleep, it gives me nightmares. The uncertainty fills me with fear.<sup>7</sup>*

<sup>5</sup> Carers UK, 'Caring behind Closed Doors: Forgotten Families in the Coronavirus Outbreak' (Carers UK, 2020); Family Carers Ireland, 'Caring Through COVID: Life in Lockdown' (Family Carers Ireland, 2020); Alzheimer Society of Ireland, 'Caring and Coping with Dementia During Covid-19' (Alzheimer Society of Ireland, 2020).

<sup>6</sup> Family Carers Ireland, 'Caring Through COVID: Life in Lockdown'.

<sup>7</sup> Family Carers Ireland, 'Caring Through COVID: Life in Lockdown', p. 9.

Other research from the University of Limerick and Northumbria University (UK) suggests that family carers are at greater risk of depression as a result of the Covid-19 pandemic than the general population.<sup>8</sup>

### The approach of other jurisdictions

Many jurisdictions around the world have included family carers as a priority group within vaccination rollout plans. Our nearest neighbours in Northern Ireland, England, Scotland and Wales have all done so. Various US states have also taken this approach.<sup>9</sup> While our national practice is of course independent of international practice, it is prudent to take into account the decisions of other jurisdictions, all of whom have given careful consideration to vaccine prioritisation.

### **Summary**

All of these elements combine to create a robust argument for including fulltime family carers as a priority group within the vaccine rollout plan. In considering family carers and the vaccination programme, in addition to assessing prioritisation based on current and past infection levels as a measure of risk, a holistic understanding of the nature of family caring must be included.

The arguments presented here map to *the rationale and the ethical standpoints* of the existing government prioritisation guidelines.

Prioritisation of this group will reduce the risk of hospital/care admission of the medically vulnerable, alleviate mental health effects in carers and in some cases directly protect those receiving care (where they cannot be vaccinated themselves).

The ethical principle of minimising harm is realised through prioritising family carers, as benefit will accrue to family carers and those they care for, producing a

<sup>8</sup> Stephen Gallagher and Mark Wetherell, ‘Risk of Depression in Family Caregivers: Unintended Consequence of COVID-19’, preprint (*Psychiatry and Clinical Psychology*, 17 June 2020), <https://doi.org/10.1101/2020.06.15.20131532>.

<sup>9</sup> Meghan C. Halley and Christina Mangurian, ‘Caring for the Caregivers — Covid-19 Vaccination for Essential Members of the Health Care Team’, *New England Journal of Medicine* 384, no. 9 (4 March 2021): e33, <https://doi.org/10.1056/NEJMp2101339>.

multiplier effect. Society also has a reciprocity-based duty to protect those who bear additional risks to safeguard the welfare of others.<sup>10</sup>

Prioritising fulltime family carers is not just the ‘right’ thing to do in terms of recognition of the significant sacrifices made in the past 12 months to keep their vulnerable relatives safe – it also makes compelling practical sense for the reasons shown.

### **Note on implementation**

We understand that there will be debate as to how to identify family carers for the purposes of this proposed change to the vaccination rollout plan. Care Alliance Ireland does not endorse a particular method; however, we outline a number of possible options below. We are happy to discuss these with relevant officials as necessary.

#### **a) Through GP contact**

Many (if not all) of those in receipt of family care will be known to their GP or through hospital contact. Therefore, their carers can be identified through these channels.

#### **b) Through receipt of the Carer Support Grant**

Some of this group will already be on the priority list by virtue of their age or health condition. The likely number would be less than 100,000. This approach, however, will not take into account the full spectrum of care being provided, as only a certain cohort of family carers are in receipt of this grant.

#### **c) Through self-identification**

Similar to registration for healthcare workers, it may be possible for family carers to opt-in to receive updates and register for inclusion in the vaccine rollout.

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<sup>10</sup> The wording here is adapted from the current iteration of the Government Vaccine Rollout Plan for Frontline Health Workers.