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## CONFERENCE ABSTRACT

# COVID19 as the Impetus for a Social Movement for Healthcare Transformation: Caregivers as Advocates

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### ***Introduction***

COVID19 has resulted in meaningful insights gained by many caregiver advocates about gaps in the current systems and the potential to close those gaps across the continuum of care. The pandemic has highlighted that, like many sectors in healthcare, caregiver advocacy is also siloed. Caregiver partners are usually associated with a specific organization, sector, disease or geography. Caregivers are not represented in an integrated way across the continuum of care. For community caregiver advocates, not affiliated with an organization or sector, this affiliation dependency has hindered the ability to influence care and to promote integrated care at the policy level.

### ***Aims Objectives Theory or Methods***

As active caregiver advocates, we decided early in the pandemic to combine our networks, knowledge and experience to help bridge those gaps between siloed experiences in healthcare that were exacerbated by the pandemic. We examined our own lived experience, determining that the largest gap in care provision was integrated care. It stands to reason then that during a time of crisis such as a pandemic, attention paid to integrated care would be lacking. By proactively connecting with caregiver advocates, not affiliated with any specific organization, we created a network of support for individuals and a body of shared lived experience.

### ***Highlights or Results or Key Findings***

Early in the pandemic, it became clear that the role of caregivers in supporting families and patients, was misunderstood and often undervalued. Individual caregivers began to identify others in similar circumstances and began to bridge various sectors of care and various ministries responsible for delivering care. This organic network of caregiver advocates grew consistently throughout the pandemic to the point where previously isolated voices were brought together, providing a collective of voices. This collective has led to the provision of individual support, reduced isolation, a robust system of knowledge exchange and opportunities to influence healthcare and social policy. It has led to grassroots efforts to organize across sectors; a specific example is in the case of caregivers and parents of those living in congregate settings other than long term care. A collective, Ontario

Families Of Group Home Residents, @ONfghr has been formed by caregivers who came together during the pandemic.

### ***Conclusions***

While the pandemic has been a challenge for everyone, caregivers in various sectors felt isolated and unable to influence policy relating to those they cared for. Caregivers are isolated at the best of times; COVID19 heightened that isolation. A social movement grew as individual caregivers sought information and needed support.

### ***Implications for applicability/transferability sustainability and limitations***

The collective voice that has been brought to the forefront by caregivers during COVID19 has been a life-line to many. We have started a social movement that is shared by many, and that will provide much needed peer support now and in the future. This movement is not going away.