



[Caregivers4Change](#)
For caregivers, by caregivers

A Declaration of Family Caregiver Rights and Responsibilities Affirms the Role of Family Caregivers as an Essential Component of Care

OTTAWA, October 6, 2020 - In response to inconsistent and in some cases extreme restrictions on end-of-life visitations across Canada during the COVID-19 pandemic, *Caregivers4Change* in collaboration with [Plan Well Guide](#) and numerous provincial and national organizations, to release a [Declaration](#) of Family Caregiver Rights and Responsibilities affirming that family caregivers are more than just visitors. The Declaration calls upon all Canadians to adopt and promote caregivers' rights and responsibilities designed to realize, maintain, and strengthen the role of family caregivers as an essential component of a caring and compassionate society.

1 in 4 Canadians are caregivers who provide care and support to those living with disease, disability or frailty due to aging. 75% of care is provided by family members who are often the care recipient's closest, holistic, and involved care partner; family caregivers deserve to be regarded as critical members of the health care team. Daren Heyland, critical care physician and creator of the [Plan Well Guide](#) and lead author of the Declaration, says "In no way do we suggest or imagine that the rights of the family caregiver supersede those of a patient. Family caregiver rights are consistent with the needs and desires of the people they care for and should complement, not conflict with patient rights".

There have been too many stories of family caregivers who were unable to perform their caregiver's duties due to extreme restrictions on end-of-life visitations. The [Declaration](#) affirms certain caregivers' rights and responsibilities and maintains that these rights are reflected in constitutional and human rights and international standards. "We aim to influence policy and practice so that family caregivers are never excluded from their essential role as part of the health care team except at the behest of a competent care-recipient" says Hsien Seow, Associate Professor from McMaster University and lead of the Caregivers4Change network.

[Caregivers4Change](#) is urging decision makers and elected officials to deliver on the following key asks:

- Adopt the Declaration in the programs and organizations, they lead or fund;
- Find ways to give voice to family caregivers to ensure they have representation at the decision-making councils;
- Implement a strategy that allows for grievances to be rapidly assessed and addressed.

Sharon Baxter, Executive Director [Canadian Hospice Palliative Care Association](#), says "We acknowledge that previous work has attempted to formulate a "rights-based" approach for family caregivers. However, these efforts were pre-COVID-19 and this pandemic has exposed new challenges resulting in unconscionable harm to patients by restricting and often excluding family caregivers from the bedside where they could fully participate in care. These are not new problems, but they have been intensified and made more obvious during this pandemic. The Declaration is meant to have application to both now and, we hope, in a less exceptional future".

Health care providers and organizations are encouraged to become leaders for change in their organization by signing on this declaration and supporting the implementation of a family caregiver policy, separate from a visitor policy, that respects the rights and responsibilities outlined in the Declaration.



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Caregivers4Change invites Canadians to sign [this petition](#) supporting the Declaration and use the hashtag **#NotJustAVisitor** on social media to advocate for the adoption of the rights in the Declaration. For more information, please visit www.caregivers4change.com

Read the full Declaration of Family Caregiver Rights and Responsibilities [here](#)

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Caregiver4Change is a growing network of people passionate about improving the lives of caregivers. This includes caregivers, researchers, clinicians, and organizational partners across Canada. The movement aims to inspire individuals and communities to support family caregivers.

Plan Well Guide is an online tool, created by Dr. Daren Heyland. The goal behind the Plan Well Guide is to help prepare people to make decisions with doctors when seriously ill by helping them learn about medical treatments and by helping communicate important values and preferences.

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