

#NotJustAVisitor

A Canadian Declaration of Family Caregiver Rights and Responsibilities

Preamble:

Family caregivers are more than just visitors! We define family caregiver as a family member or friend of any age who provides care and support to someone living with disease, disability or frailty due to aging. We, family caregivers, are the person's closest, holistic, and involved care partner. **We deserve to be regarded as critical members of the health care team caring for our loved ones.** Our love, presence and attentiveness are essential elements in the health and wellbeing of those we care for. At the bedside, we perform many small acts of tenderness and are often able to recognize needs that may escape the attention of busy health care workers. We provide counsel to those who are still able to make their own decisions and are the substitute decision makers for those who cannot. We advocate for our loved ones and provide a precious continuity that can be lost in the shuffle of health care workers tending to multitudes of patients. We mop the brow, moisten the lips and check the medications of our loved ones. We notice when they need to be taken for a stroll or to the bathroom or need to be turned in bed. We monitor their symptoms and well-being and tend to their spiritual and emotional needs. What we do is often as important as any service health care professionals provide. There are moments when what we do--even our mere presence--is *more* important. **The aim of this document is 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.**

The Canada Health Act declares that the primary objective of Canadian health care policy is to protect, promote and restore the physical and mental well-being of residents of Canada through a public health care system. Constitutionally, as entrenched in the [Canadian Charter of Rights and Freedoms](#), Canadians have rights to "Life, liberty and security of person." These rights are at stake when the exclusion of essential family caregivers from access to their loved ones threatens the life and security (wellbeing) of patients. As [reported in the media](#), these rights have been violated during COVID-19 as a consequence of restricting family caregivers from vulnerable populations in Canada. The Charter's right to be free from discrimination is also at stake when people who require assistance in order to have access to the same care are excluded from receiving that support. Human Rights legislation of the various provinces and territories also prohibits such discrimination.

We acknowledge and recognize that there are patient rights nested in various pieces of provincial legislation ([summarized here](#)). Some provinces also have laws protecting the rights of residents of long-term care. These laws do not directly address the crucial role of family caregivers in realizing the best health and well-being outcomes of Persons receiving care.¹ Nor

¹ A good example of legislation that codified patient rights and includes rights to caregiver support is in New Zealand: <https://www.hdc.org.nz/your-rights/about-the-code/code-of-health-and-disability-services-consumers-rights/>

does it acknowledge the importance that this contact has to *our* wellbeing. Indeed care giving is a two way street in which the needs of the *carer* and the *cared for* are met.

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.

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 weaknesses in our health care system resulting in egregious and unconscionable harm to Canadian 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. This document is meant to have application to both now and, we hope, in a less exceptional future.

This document is not meant to provide practical solutions but rather a set of guiding principles that should influence decisions-makers. Another example is the "[Principles for Carers](#)" document put forward by the International Alliance of Carer's Organizations. A good illustration of how these guiding principles can influence legislation is a recent [private member's bill](#) to create legislation in Ontario to support the presence of family caregivers in long-term care homes and other congregated settings and the recent [announcement](#) by the Premier of Ontario recognizing that caregivers are essential and that he is introducing policies to accommodate this role.

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The Declaration

We, the undersigned, declare that we have certain rights and responsibilities because of our relationship with people receiving care. We maintain that these rights are reflected in constitutional and human rights and international standards; governments and health care system decision-makers might wrongfully violate them but can never take them away.

We declare that we have a right to advocate for our family members to ensure they receive the best care possible.

We declare that, with the implied or expressed consent of the person receiving care, we have a right to access, be with, support, care for, comfort, and touch and hold our family members in whatever care settings they may find themselves.

We maintain that, with the express consent of the person receiving care, we have the right to timely, consistent, accurate information on our family member's condition and circumstances.

We maintain that we have the right to ensure that our family member receives any religious or spiritual support or ritual, based on their religious and cultural beliefs and their choices or desires, near or at the end of life.

We maintain that in order to secure these rights, health care system leaders have a concomitant duty to provide us with the technology, training, and equipment required for us to exercise our rights. When separated by distance and out of necessity, we call upon health care system decision-makers to utilize current technologies and make available the staff necessary to enable us to stay connected to our family member and receive information from their clinical teams in a timely and efficient manner. In addition, we maintain that the health care system has a responsibility to provide us with the information and support (e.g. personal protective equipment), as necessary, to reduce the risk of transmission of infectious disease to and from our family member and others.²

We maintain that when we are identified as legal substitute decision-makers, we have the right to speak on behalf of a person who has been found to be incapable, to participate in decision-making regarding the level or intensity of health care our family member should receive. We maintain that even when the person is capable, at their request, we should be involved in a supportive role to help our family member decide on the care that is right for them.

We maintain that we have the right to access support and respite, to make and maintain social connections and to look after ourselves physically and mentally. We also have a right to access the information, advocacy and training, appropriate to our stage of the caring journey.

² Similar to what has been done in Alberta to support safety of children in daycares:
<https://www.alberta.ca/release.cfm?xID=732841F013C91-A49B-2604-60224F65F031A32A>

We maintain that we have a right to combine caring with paid employment, be supported by our employers in our caregiving role and have equal opportunities to remain in and return to work.

We recognize that we have the responsibility to minimize the risk of transmission of infectious diseases to and from our family member, members of the health care team, other patients, and the general public. Thus, in the conduct of our duties and responsibilities, we agree to limiting our rights to the physical access to our family member under the following circumstances:

- If we have contracted an infectious disease
- If we have fever or other symptoms of an infectious disease
- If we have travelled to a high-risk zone or come in contact with an infected individual in the recent past
- If we are exhibiting any signs and symptoms of illness as defined by public health

We maintain that governments and health care decision-makers, acting in good faith and in the public's interest may impose restrictions to some of these rights but that these restrictions should not unilaterally be imposed. Rather, we further maintain that we, family caregivers, have a right to be at the 'decision-makers' table when such policies and practices are being discussed that impose on our human rights. Any restrictions should emerge after shared dialogue and a transparent decision-making process. There also needs to be a clear, and fair process outlined for us, as family caregivers to 'appeal' any decisions made by decision-makers that compromise our role as family caregivers.

We understand that there may be a lack of evidentiary basis for many of the restrictions imposed on our ability to execute our human rights and responsibilities of a family caregiver and we further acknowledge the right to participate in research to determine the best practices associated with the fulfilling of our caregiver role and responsibilities.

We have the right to hold health and social care system leaders accountable for their observance of our rights and their support of our responsibilities. We call upon leaders to institute validated measures of compliance, which are publicly reported so that we may judge the adequacy of their efforts.

We call upon responsible citizens, officers of government, and health and social care system decision-makers and providers everywhere to adopt and promote those rights and responsibilities designed to realize, maintain, and strengthen the role of family caregivers as an essential component of a caring and compassionate society. Specifically:

If you are a family caregiver or concerned citizen

1. Please sign the petition supporting this Declaration @ <https://www.caregivers4change.com/>

2. Contact your elected representatives, local, provincial and national, to advocate for the adoption of the rights in the Declaration. Reach out to health care authorities and managers of the institutions in which your family members are being cared for;
3. Share your individual story of caregiving; it can inspire change @ <https://www.caregivers4change.com/>

If you are a Health care Provider or Organization

1. Sign your organization on to support the Declaration.
2. Create a family caregiver policy, separate from a visitor policy, that respects the rights and responsibilities of this [Declaration](#);
3. Become a leader for change in your organization to support the implementation of this family caregiver policy;
4. Make sure family caregivers are involved in providing feedback and direction to the program or organization through councils and other mechanisms.

If you are a Decision Maker or Elected Official

1. Adopt the Declaration in the programs and organizations you lead or fund.
2. Find ways to give voice to family caregivers to ensure they have representation at the decision-making councils.
3. Implement a strategy that allows for grievances to be rapidly assessed and addressed (similar to role of Patient Ombudsman or the like).

Comments, Questions or Suggestions?

Direct to a member of the Executive Committee

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