

Quality Hospice Palliative Care Coalition of Ontario

Patients and Caregivers Declaration of Rights at End of Life

OVERVIEW

Background:¹

Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership and Commitment to Action was released in December 2011. It is through this document and in this context that the partners of the Declaration have come together to set forth a new vision and a new plan for palliative care in Ontario. Through this plan, we can provide better care for Ontarians at end of life while we better manage our health care resources over time.

The Declaration of Partnership sets out individual and collective commitments, common priorities, and appropriate actions to optimize palliative care in Ontario. Our goal is to improve the experience of the individual and caregiver, the quality of care and the value the system delivers. The Declaration identifies the next steps to provide equitable access to safe, comprehensive, and high-quality palliative care and support for individuals and their families across the province. We are committed to implementing the recommended actions – both short and long-term.

Declaration of Partnership Recommendations:²

In the Declaration Report under Shared Priorities and the Key Issue related to Strengthen Caregiver Supports there are several recommendations to empower clients and caregivers, including:

- Develop a “caregiver declaration of rights” and embed it in Health Service Provider service plans to clarify expectations and accountability for all partners to support informal caregiving.
- Develop a “client declaration of rights” to embed in HSP service plans and build on existing legislative rights.
- Include the individual and their family and designates in developing the goals of care and an overall care plan, as well as organizing the team to the extent the person wishes.
- Encourage the use of client and family care conferences with the inter-professional care team to discuss or update goals of care, disease prognosis and advance care planning, as well as provide overall information and support.
- Adopt self-management as a core philosophy where appropriate, respecting individual choices and independence.
- Build definition of palliative care into existing caregiver education programs, university and college programs, and patient and family education materials. The goal is to improve understanding of individuals, families, care providers and society that palliative care is not only for end of life. This will lead to earlier willingness for people to be identified as benefiting from palliative supports.

¹ *Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership and Commitment to Action* was released in December 2011

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Specific action commitments were then directed to the Quality Hospice Palliative Care Coalition of Ontario (QHPCCO), including:

- QHPCCO will develop a caregiver declaration of rights”. Work will include a review of existing “care” or “caregiver” bills (legislation) or declarations (policy) of rights within Ontario as well as nationally and across other jurisdictions.
- QHPCCO will develop a “client declaration of rights” that builds on existing legislative rights. Work will include a review of the Canadian Hospice Palliative Care Association (CHPCA) Patient ‘Client Bill of Rights and feedback from LHINs through their Regional Networks/Programs.
- Following completion, QHPCCO will work with its members and LHINs will work with their HSPs to embed the declaration of rights into their service plans. Sector/HSPs will include the individual and their family and designates in developing the goals of care and overall care plan and organizing the team to the extent the person wishes.

Process Description and Outcome:

The following steps describe the actions taken by the QHPCCO to address this recommendation:

- Established a Coalition working group in January 2018 tasked with the action commitment. An update of progress, and feedback from the membership, was provided at each Coalition meeting.
- Conducted a literature review of existing “patient/client” and “caregiver” and bills (legislation) or declarations (policy) of rights within Ontario as well as nationally and across other jurisdictions
- Identified themes and draft statements capture the themes.
- Incorporated the Health Quality Ontario Palliative Care Quality Standards and Patient Reference Guide
- Finalized a Draft of Patient and Caregiver Declaration of Rights at End of Life – September 5, 2018
- Conducted a Caregiver focus group pretest October 2, 2018
- Prepared an electronic survey and broadly circulated it for Public Consultation: October 23, 2018 - December 17, 2018. Received 385 responses (*See Appendix B for feedback summary*)
- Engaged a French Language Consultation - November 15, 2018 - December 17, 2018
- Engaged a First Nations Inuit Metis Consultation – December 1, 2018 - January 11, 2019
- Revised the Final Draft of Patient and Caregiver Declaration of Rights at End of Life
- QHPCCO members reviewed, endorsed, adopted the final draft committing to work with its members to embed the declaration of rights into their service plans – February 8, 2019
- QHPCCO members presented the Patient and Caregiver Declaration of Rights at End of Life to their Board of Directors for formal endorsement and adoption – May 10, 2019

Next Steps

Next steps as proposed in the Declaration of Partnership Recommendations, included that:

- LHINs will work with their HSPs to embed the declaration of rights into their service plans.
- Sector/HSPs will include the individual and their family and designates in developing the goals of care and overall care plan and organizing the team to the extent the person wishes.

However, given the Ontario Health Care system restructuring from the LHINs to Ontario Health, fulfilling this action became challenging to achieve. Therefore, the Coalition working group reconvened in December 2020 and joined with the national group *Caregivers4Change* working on A Declaration of Family Caregiver Rights and Responsibilities Affirms the Role of Family Caregivers as an Essential Component of Care (October 7, 2020) with a specific focus on caregivers.

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. 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, released 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.

Caregivers4Change was also 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.

Given the similar goals, the Coalition and the *Caregivers4Change* working groups joined forces to develop a communication and advocacy strategy to promote the tools. New representatives brought to the table also included the Ontario Caregiver Organization.

Strategies achieved to date include:

- Creation of a communication strategy – September 2021
- Development of an infographics for the Rights document - October 2021
- Workshop at HPCO Fall Symposium: Supporting the Caregiver – November 25, 2021
- Exploring engagement opportunities on National Caregiver Day – February 18, 2022
- Poster submission at the HPCO 2022 Annual Hospice Palliative Care Conference – April 24-26, 2022
- Working with McMaster University on a Caregiver Summit Fall 2022

APPENDIX A: Quality Hospice Palliative Care Coalition of Ontario

PATIENT DECLARATION OF RIGHTS FOR HOSPICE PALLIATIVE AND END OF LIFE CARE

The following are the **Patient** Commitments and Commitment Statements for
Hospice Palliative and End of Life Care

Commitment	Commitment Statement
Informed Consent	You have the right to have all the information and the time you need to make an informed decision i.e., to give or refuse consent to any treatment, care or services. You have the right to have others included in receiving information (e.g., your substitute decision maker).
Respect	You should always be treated with respect (e.g., being heard, treated with value, kindness, courtesy, regard etc.,)
Safety	You should receive care in a safe environment free from all forms of abuse, neglect, or mistreatment.
Honesty	You should be provided clear information about your disease, condition and prognosis when desired in words you can understand and participate in conversations with the care team* to understand options and ask questions.
Care	You should be cared for by compassionate, sensitive and appropriately trained providers who will work to understand your needs and meet them to the best of their ability.
Holistic Care	You should be able to: <ul style="list-style-type: none"> • Participate fully in your plan of care; • Create a plan of care that is reflective of your diverse wants and needs; • Have your decisions and choices respected and followed, even though they may be contrary to the wishes of others.
Information	You should be provided timely information about palliative care services, resources, supports and options that are available in your area (e.g., counselling, hospice volunteers, wellness programs, spiritual care, support groups, alternative care etc.)
Coordination	You should have your information shared in a timely and effective manner among providers that are part of your care team* to ensure continuity of care. You should be informed of what plans are available, if any, for after-hours care if needed.
Individuality	You should have your individuality and dignity honoured without prejudice or judgement.
Privacy	You should expect full consideration of your privacy and confidentiality in the care you receive.
Emotions	You should be able to appropriately express your feelings and emotions about your end-of-life experience in your own way.
Independence	You should receive care which maximizes your independence to the greatest extent possible in keeping with your wishes.
Advocacy	You can ask and advocate for care and services reflective of your diverse wants and needs.
Services	You should be accommodated if accessible and culturally appropriate services are required.
Hope	You should be cared for by those who can maintain a sense of hopefulness for the best possible quality of life throughout your experience.

*Care Team is defined as anyone the patient chooses to have included in their circle of care, including both formal and informal care providers.
(February 2019)

Quality Hospice Palliative Care Coalition of Ontario

CAREGIVER DECLARATION OF RIGHTS FOR HOSPICE PALLIATIVE AND END OF LIFE CARE

The following are the **Caregiver** Commitments and Commitment Statements
for Hospice Palliative and End of Life Care.

Commitment	Commitment Statement
Respect	You should be respected and included as a valuable member of the care team*.
Honesty	With the permission of the person you are caring for, you should be provided clear information about the individual's disease, condition and prognosis in words you can understand, and participate in conversations with the care team* to understand options and ask questions.
Self-Care	You should be able to seek help from others and be supported to take care of yourself which includes accessing any available respite and support you need to take a break. This is not an act of selfishness. It will enable you to take better care of your loved one.
Communication	You have the right to express your thoughts and emotions, whatever they may be, in a way that is respectful of others, as well as be validated for your feelings.
Advocacy	You should be provided the opportunity to have a voice, provide meaningful feedback, and express that ongoing efforts be made in Ontario to find resources to support caregivers like yourself.
Honour	Your role as a caregiver is important and you should expect to be valued and honoured in this role by others.
Services	You should receive services and information that is aligned with your cultural preferences and accessibility needs to support your caregiving.
Hope	You should be supported in maintaining hope and a positive outlook, however changing its' focus may be.
Individuality	You should be recognized as person beyond and including your caregiver role and be supported in maintaining a life for yourself as you choose.

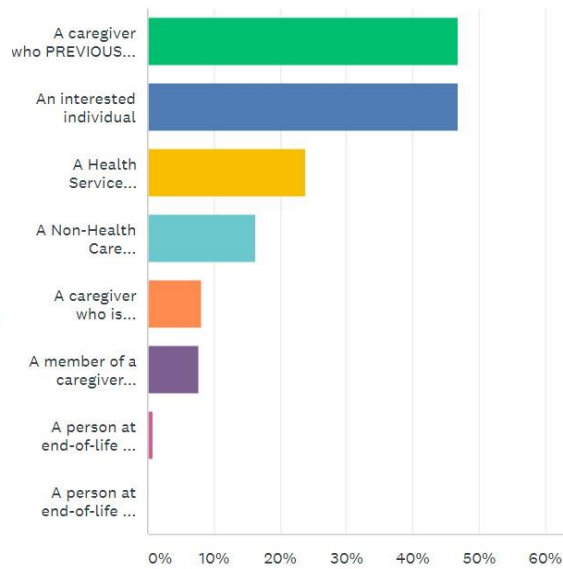
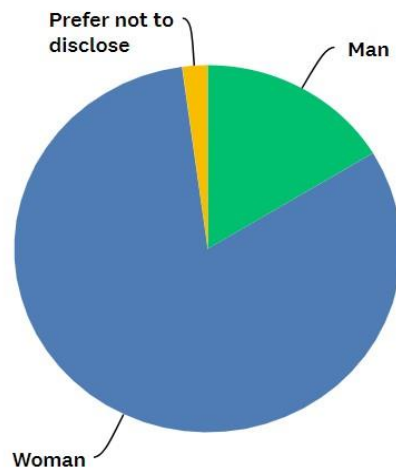
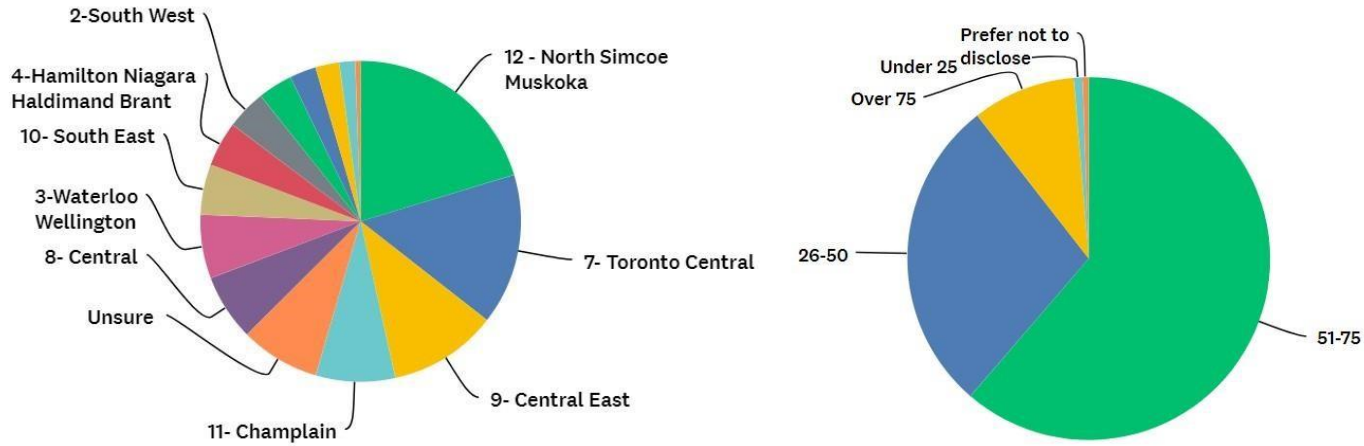
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(February 2019)

Endorsed by the Provincial Associations and Academic Institutions comprising the Quality Hospice Palliative Care Coalition of Ontario

APPENDIX B: Quality Hospice Palliative Care Coalition of Ontario Patient and Caregiver Declaration of Rights – Survey Summary

Total Responses: 385



Patient Statements	Approval	Importance	Suggested Changes
Respect	92%	94%	➤ Lack of definition for “respect”
Holistic Care	87%	82%	➤ Holistic care is not defined
Informed Consent	91%	95%	<ul style="list-style-type: none"> ➤ pts should not be rushed to make a decision ➤ change to have “ALL” the information you need (patient should be made of aware of all options available) ➤ statement should be reversed – receive all the information first, and then provide or withhold consent ➤ where does age come into play? I.e. Minors with parents making decisions for them
Care	91%	85%	<ul style="list-style-type: none"> ➤ Don’t appreciate “try to meet them” maybe alternative is “to the best of our ability” or “ensure to meet them” ➤ Add “trained”
Information	90%	79%	<ul style="list-style-type: none"> ➤ Information should be provided earlier – at the beginning of any life limiting illness diagnosis ➤ Should also share information with the pts caregiver/family ➤ Provide info on alternative care
Honesty	94%	88%	<ul style="list-style-type: none"> ➤ Info should be offered, then delivered if desired, (pts may miss out on info that they didn’t think to ask) ➤ Ask/confirm how much pts want to know about condition/prognosis, options to refuse details (speak to an advocate on their behalf instead)
Emotions	90%	71%	➤ “appropriately” express, provided others aren’t endangered, should not infringe upon the rights of others (ex. anger – yelling at staff or physically destructive behavior)
Hope	81%	55%	<ul style="list-style-type: none"> ➤ “However, changing its’ focus might be.” Doesn’t make sense, instead of changing should it be challenging? ➤ Encouraging false hope? Clarify what hope means – to hope for better quality of life, EOL, etc.
Services	86%	61%	<ul style="list-style-type: none"> ➤ Issue of funding, how would you do accomplish this? ➤ Difficult to promote in remote, small towns, that don’t have large or diverse staff/volunteers
Advocacy	87%	63%	➤ Redundancy with services statement
Individuality	93%	75%	<ul style="list-style-type: none"> ➤ Redundancy with respect statement ➤ not too comfortable with use of word “pride”
Safety	94%	91%	N/A
Privacy	94%	75%	N/A

Independence	92%	66%	<ul style="list-style-type: none"> ➤ Redundancy with respect statement ➤ Do all patients want maximum independence? Independence is a choice, maybe not all want it at the greatest extent possible
Coordination	89%	75%	<ul style="list-style-type: none"> ➤ Change timely way to timely manner ➤ Define timely? ➤ On a need to know basis
Security	87%	66%	<ul style="list-style-type: none"> ➤ Confusion on how the title of the statement and actual statement are related – how does security match after hours of care, maybe re-word the title

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Caregiver Statements	Approval	Importance	Suggested Changes
Respect	98%	88%	N/A
Care	95%	83%	<ul style="list-style-type: none"> ➤ Lack of services/access makes this difficult to accomplish
Services	90%	62%	<ul style="list-style-type: none"> ➤ Receive spelt incorrectly ➤ Concerns about how every culture can be accommodated, maybe change to “whenever possible” or “reasonable”
Hope	86%	57%	<ul style="list-style-type: none"> ➤ Be wary of encouraging false hope – hope should be based on medical reality, define hope (hope for good health? Hope to get through? Hope to be free of pain? Hope for better quality of life?)
Honour	90%	65%	<ul style="list-style-type: none"> ➤ Don’t appreciate se of word “pride” – patronising ➤ Redundancy with the respect commitment
Communication	95%	72%	<ul style="list-style-type: none"> ➤ Appreciate the wording in this statement more, compared to the coinciding patient commitment on emotions
Individuality	89%	57%	N/A
Honesty	96%	86%	N/A
Advocacy	93%	65%	N/A

