

# Guiding Conversations with Patients and Caregivers: Using Emotional Intelligence Skills

## Presenters:

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Host and Moderator: Jennifer Campagnolo, CHCA

Date: February 24, 2022



Canadian  
Home Care  
Association

# Land Acknowledgement



We recognize with humility and gratitude that Canada is located in the traditional, historical and ceded and unceded Lands of First Nation, Inuit and Metis Peoples. On behalf of us all, we acknowledge and pay respect to the Indigenous peoples past, present and future who continue to work, educate and contribute to the strength of this country.

# Introductions

## Presenters:



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Caregiver Declaration of Rights  
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# Caregiver Declaration of Rights for Hospice Palliative Care

Palliative Care ECHO Webinar Presentation February 24, 2022

Quality Hospice Palliative Care Coalition of Ontario

Sharon Baxter & Julie Darnay

Coalition Caregiver Working Group

# Objectives

- Review the development and final Ontario Caregiver Declaration of Rights for HPCO and EOL prepared by the Quality Hospice Palliative Care Coalition of Ontario,
- Discover the resources available to support the Caregiver Declaration of Rights
- Explore how it can be used by a wide variety of care settings to support caregivers during this challenging time.
- Discuss how this can be promoted in a broad supportive implementation strategy

# Quality Hospice Palliative Care Coalition of Ontario (QHPCCO)

- ▶ Since 2011 the Coalition has been working collaboratively with Ministry of Health and Long-Term Care and the Local Health Integration Networks (now Ontario Health) to review how hospice palliative care is provided in Ontario and identify priorities to achieve quality hospice palliative care for all Ontarians.
- ▶ The Coalition's primary mandate is to act as an advocate for quality hospice palliative care for all Ontarians.

# Quality Hospice Palliative Care Coalition of Ontario (QHPCCO)

Membership is open to any provincial organization or academic centre with an interest or role in the planning or delivery of quality hospice palliative care for all Ontarians.

- AdvantAge Ontario
- Association of Family Health Teams of Ontario (AFHTO)
- ALS Canada, Ontario Division
- Alzheimer's Society Ontario
- Bereavement Ontario Network (BON)
- Canadian Cancer Society, Ontario Division (CCS)
- Catholic Health Association of Ontario (CHAO)
- Heart & Stroke Foundation of Ontario
- Hospice Palliative Care Ontario (HPCO)
- Home Care Ontario (HCO)
- Lakehead University
- McMaster University
- Nurse Practitioner Association of Ontario (NPAO)
- Ontario Association of Paramedic Chiefs
- Ontario Association of Social Workers (OASW)
- Ontario Caregiver Coalition (OCC)
- Ontario College of Family Physicians (OCFP)
- Ontario Community Support Association (OCSA)
- Ontario Long Term Care Association (OLTCA)
- Ontario Medical Association (OMA)
- Palliative Care Consultants Network (PCCN)
- Pregnancy and Infant Loss Network (PAIL)
- Registered Practical Nurses Association of Ontario (RPNAO)
- Registered Nursing Association of Ontario (RNAO)
- University of Toronto



# Quality Hospice Palliative Care Coalition of Ontario (QHPPCCO)

- ▶ The work of the Coalition resulted in a [Declaration of Partnership](#), a road map for HPC in Ontario which lays out six priority areas and over 70 recommendations.
- ▶ Within each priority area Coalition partners, LHINs/OH, and MOH agreed to dozens of action commitments deemed necessary to improve hospice palliative care.
- ▶ MOH, LHINs/OH, and Coalition partners actively work to carry out the action commitments from policy, planning, and service delivery perspectives.



# Empower Clients and Caregivers

- ▶ Within the key issue of Strengthening Caregiver Supports, the Declaration of Partnership recommended the development of patient/client and caregiver bills of rights
  - ▶ Develop a “caregiver declaration of rights” and embed it in HSP service plans to clarify expectations and accountability for all partners to support informal caregiving.

# Phases of development

- ▶ Coalition working group established to develop client and caregiver bills of rights (Jan 2018)
- ▶ Conducted a literature review of existing “patient/client” and “caregiver” bills or declarations of rights within Ontario as well as national and across other jurisdictions
- ▶ Incorporated the Health Quality Ontario Palliative Care Quality Standards and Patient Reference Guide
- ▶ Conducted a Caregiver focus group pretest (Oct 2018)
- ▶ Prepared and broadly circulated an electronic survey for Public Consultation (Dec 17- 23, 2018): 385 responses
- ▶ Engaged a French Language Consultation (Nov 15 - Dec 17, 2018)
- ▶ Engaged a First Nations Inuit Métis Consultation (Dec 1, 2018 - Jan 11, 2019)
- ▶ QHPCCO members reviewed, endorsed, and adopted the final draft (Feb 8, 2019) and committed to working with members to embed it into their service plans
- ▶ QHPCCO members presented the final version to their Board of Directors for formal endorsement and adoption (May 10, 2019)

# CAREGIVER DECLARATION OF RIGHTS



For Hospice Palliative and End Life Care. (2019)

## 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 those **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

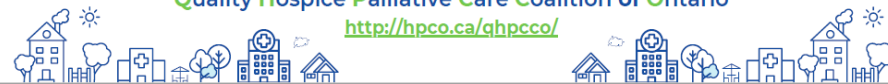


You should be recognized as a **person beyond** and including your **caregiver role** and be supported in maintaining a **life for yourself** as you choose.

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

Quality Hospice Palliative Care Coalition of Ontario

<http://hpco.ca/ghpcco/>



# Empower Clients and Caregivers

- ▶ Following the completion of the development of patient/client and caregiver bills of rights, the Declaration of Partnership further recommended:
  - ▶ QHPCCO will work with its members to apply and embed the bills of rights into their operations
  - ▶ LHINs will work with health service providers (HSPs) to embed the bills of rights into their service plans
  - ▶ Sectors/HSPs will include the individual and their family and designates in developing goals of care and the care plan

# Strategies Achieved to Date

- ▶ Creation of a communication strategy (Sept 2021)
- ▶ Development of an infographics for the Rights document (Oct 2021)
- ▶ Aligned with Compassionate Care Act (Nov 2021)
- ▶ Promotion on National Caregiver Day (Feb 18, 2022)
- ▶ Presentation with PC ECHO (Feb 24, 2022)
- ▶ Promotion on National Family Caregiver Day (April 5, 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)
- ▶ Working with InterRai to align with their new Caregiver Self Assessment Tool
- ▶ Working with Ontario Caregiver Organization (OCO) to align with their supports
- ▶ Working to support the Hospice Palliative Care Ontario (HPCO) Caregiver on-line Education



# interRAI Carer Needs Assessment

## What is the Carer Needs Assessment?

- Informal caregivers provide unpaid care for their family members or friends with impaired health.
- While the care provided by informal caregivers has been recognized as a crucial contribution to the sustainability of the health system, limited attention has been paid to how best to support caregivers.
- interRAI has recently developed a comprehensive assessment to identify strengths and needs of informal caregivers providing care to individuals living in the community. This instrument provides key information for decision and policy-makers to better understand and attend the unique needs of informal caregivers.

## Study Recruitment

- The study population will consist of adult informal caregivers (can be family or non-relative). It will involve a single “primary caregiver” for each care recipient.
- Each participating site must enroll a minimum of 50 carers with an ultimate goal of 100 carers.
- If a site provides services to fewer than 50 carers then it is expected that all carers will be enrolled.

## Participating Countries

- There are currently 5 countries participating in this multinational study:
  - Belgium
  - Canada
  - Iceland
  - Ireland
  - United States
- An additional 9 countries have expressed interest in enrolling including Australia, Brazil, Hong Kong, and Singapore.

## Study Outcomes

- The outcomes from this study will allow the refinement of the caregiver assessment and assist future participating organizations to design care plans that considers the unique challenges, strengths and needs of informal caregivers.
- interRAI will provide a summary report to all participating organizations once all data have been collected and analyzed

**For more information or to enroll your organization please contact  
Melissa Ziraldo via email**

[mziraldo@uwaterloo.ca](mailto:mziraldo@uwaterloo.ca)  
[www.interrail.org](http://www.interrail.org)  
[www.interraicanada.uwaterloo.ca](http://www.interraicanada.uwaterloo.ca)

# Ontario Caregiver Organization (OCO)



<https://ontariocaregiver.ca/>



**24/7 Caregiver  
Helpline &  
Weekday  
Live Chat**



**SCALE  
Program**  
Webinars and  
group/individual  
coaching  
(8 week series)



**Peer 1:1  
Mentoring  
Program**



**Online  
support  
Groups**



**Educational  
Webinars**



## Caregiver Support and Learning



- ▶ Offered free of charge
- ▶ Available in English, French and for First Nation, Inuit and Metis Peoples
- ▶ <https://caregiversupport.hpcoco.ca/>

# Application of the Caregiver Declaration of Rights

- ▶ Usefulness in a Variety of Care Settings
  - ▶ Focuses on values core to caregivers – applicable in most, if not all settings, while still being implementable. Supporting caregiver programs should use these core values.
- ▶ Relevant to the Specific Context presented during COVID-19
  - ▶ Statements in Bill of Rights mirror issues which came to the forefront for caregivers during COVID-19
- ▶ Equity/Rurality
  - ▶ Bill of Rights remains relevant even in settings with fewer or no hospice palliative care specific services. These setting could include acute care, Long term care, home care, hospice residences and other community care settings.

# Call to Action

- ▶ Identify target populations to promote awareness and encourage adoption:
  - Patients and Caregivers – amplify their voices
  - Health care providers those working in HPC and other areas
  - Health care programs and organizations
- ▶ Use of Resources to promote at campaigns events:
  - Infographic of the Bill of Rights document to promote values
  - Link promotion to National Caregiver Day – April 5<sup>th</sup>, 2022
  - Website
  - Newsletter articles
  - Build an advocacy and awareness campaign to bring voice to the role of caregivers

# Contact Information

- ▶ Julie Darnay, Consultant

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- ▶ Quality Hospice Palliative Care Coalition of Ontario

<http://www.hospice.on.ca/qhpcco/the-quality-hospice-palliative-care-coalition-of-ontario/>

# The Caregiver Declaration of Rights

Putting it into your Practice  
through Listening



## The Caregivers



**Lester**  
**Caregiver for his wife**  
**27 Years**  
**Wife passed March 2021 – cancer**



**Daniel**  
**Caregiver(with his mother) for his father**  
**27 weeks**  
**Father passed Feb 2021 – chronic illness**

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

**RESPECT** - You should be respected and included as a valuable member of the care team.

**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.

**HONOUR** - Your role as a caregiver is important and you should expect to be valued and honoured in this role by others.





## Main reasons we may find it hard to listen:

Lost in your thoughts

Not actively paying attention to the other person

Distracted by something or someone else

Held back by preconceived judgements on the person or conversation topic

Lack of comprehensive understanding (context or language used)



	Never	Rarely	Sometimes	Often
1) I check my phone or computer screen during conversations	4	3	2	1
2) When people make confusing comments I feel annoyed.	4	3	2	1
3) I get easily distracted during conversations.	4	3	2	1
4) Making eye contact with people who talk to me can be uncomfortable for me.	4	3	2	1
5) I communicate more through text messages/emails than face to face.	4	3	2	1
6) While others talk, I'm thinking of what I want to say next.	4	3	2	1
7) I say what I think without filtering my comments.	4	3	2	1
8) I unintentionally offend others.	4	3	2	1
9. I think a person's body language is unimportant to what they are feeling.	4	3	2	1
10) People complain that I don't understand them.	4	3	2	1
11) I get into arguments with others.	4	3	2	1



# Benefits of Mindful Listening

Able to make better decisions

Able to see hidden messages or agenda behind what the person is saying

Better, deeper, more connected relationships with people

More substantial, fulfilling conversations

Become a more compassionate, empathetic person





# Validating the caregiver

Validation means that we are acknowledging another person's emotions, thoughts, experiences, values.

Some validating statements:

- Thank you for ....
- Tell me more about ....
- How are you feeling today?
- I want to hear about your day/night/week
- It makes sense that you feel....
- I've noticed that you....
- What do you need from me right now?
- How can I help?
- What you are thinking/feeling is normal.
- Your emotions make sense.

“ They may forget what you said, but they will never forget how you made them feel”





## Cognitive Empathy in Listening

- It helps us to understand how the caregiver has formed their perspective
- It reduces the possibility of us misunderstanding caregiver.
- It enables us to determine what information is important to share with them, and how best to frame that information so that they understand where we're coming from.
- It enables us to navigate to a place of common understanding.

# Tips for developing Cognitive Empathy

- Imagine that you *are* the speaker in *their* situation.
- Just listen mindfully. Don't talk or interrupt except to ask questions.
- Listen for their feelings and emotions as well as their actual words spoken.
- Keep an open mind - to listen with empathy we must listen without judgement.
- Encourage them to elaborate further with back-channel signals (“mmhmm”, “aha”, “go on”, etc) and with questions
  - “What might that look like in your situation?”
  - “What has \_\_\_\_\_ been like for you?”
- Reflect any feelings that you observe, followed by a question to further explore their message and feelings:
  - “You sound concerned about the care plan. What’s concerning you?”



By mindfully putting these listening skills in your practice, you give life to the Caregiver Declaration of rights.

**RESPECT** - You should be respected and included as a valuable member of the care team.

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**HONOUR** - Your role as a caregiver is important and you should expect to be valued and honoured in this role by others.

Thank you for LISTENING  
And Putting it into Your Practice



# Questions & Discussion



# Next Series:

Coming in April, June, September and November 2022

## 'B' Prepared for Palliative Emergencies in the Home

- **B**leeding
- **B**reathing
- **B**alance
- **B**rain

[www.cdnhomecare.ca/palliative-care-echo-hub](http://www.cdnhomecare.ca/palliative-care-echo-hub)





# CHCA ECHO Hub Community

[www.echo.cdnhomecare.ca](http://www.echo.cdnhomecare.ca)

- Microlearning **NEW!**
- Recordings
- Presentations
- Evidence-Based Resources

### Join the CHCA ECHO Hub Community

Complete the participant information section. Once you receive your log in and password, you can access the valuable resources in the CHCA ECHO Hub.

As a CHCA Palliative Care ECHO Hub member I agree to:

- Participate in the ECHO learning sessions, join the discussion, and give feedback
- Share my expertise and issues to help shape the content of the CHCA Palliative Care ECHO Hub
- Participate in program evaluation to help us better understand our impact and how we can support teams across the country

Register:

First Name:\*  Last Name:\*

I agree to the statement of participation, to becoming part of the CHCA ECHO Hub community and receiving regular notifications from the CHCA. By completing the registration for the CHCA Palliative Care ECHO Hub, you consent to the collection, use and disclosure of your personal information for the purposes of program planning, evaluation and research. \*

Username:\*








Email:\*

Password:\*

Password Confirmation:\*

13 + 5 equal\*

### Course Content Expand All

	<input checked="" type="checkbox"/> About WPCR 1 Topic	<input checked="" type="checkbox"/> Expand
	<input checked="" type="checkbox"/> Practice Change: Enhancing the Circle of Care 2 Topics	<input checked="" type="checkbox"/> Expand
	<input checked="" type="checkbox"/> Practice Change: Facilitate a WPCR 3 Topics	<input checked="" type="checkbox"/> Expand
	<input checked="" type="checkbox"/> Practice Change: Get Referrals to WPCR 2 Topics	<input checked="" type="checkbox"/> Expand
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	<input checked="" type="checkbox"/> Practice Change: Implement Actionable Recommendations from the Rounds 1 Topic	<input checked="" type="checkbox"/> Expand
	<input checked="" type="checkbox"/> Implementing WPCR: Five Practice Changes 3 Topics	<input checked="" type="checkbox"/> Expand