

Vancouver, British Columbia

Oct 4, 2024

How we can achieve a Palliative Care Revolution:

A social movement of patients, families and clinicians

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Innovation

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[@HSeowPhD](https://www.facebook.com/HSeowPhD); [@SammyWinemaker](https://www.facebook.com/SammyWinemaker); [@WaitingRoomRev](https://www.facebook.com/WaitingRoomRev) 





In the Dark

Unprepared

Reactive

Unaware

Unsure

Generic

Overwhelmed

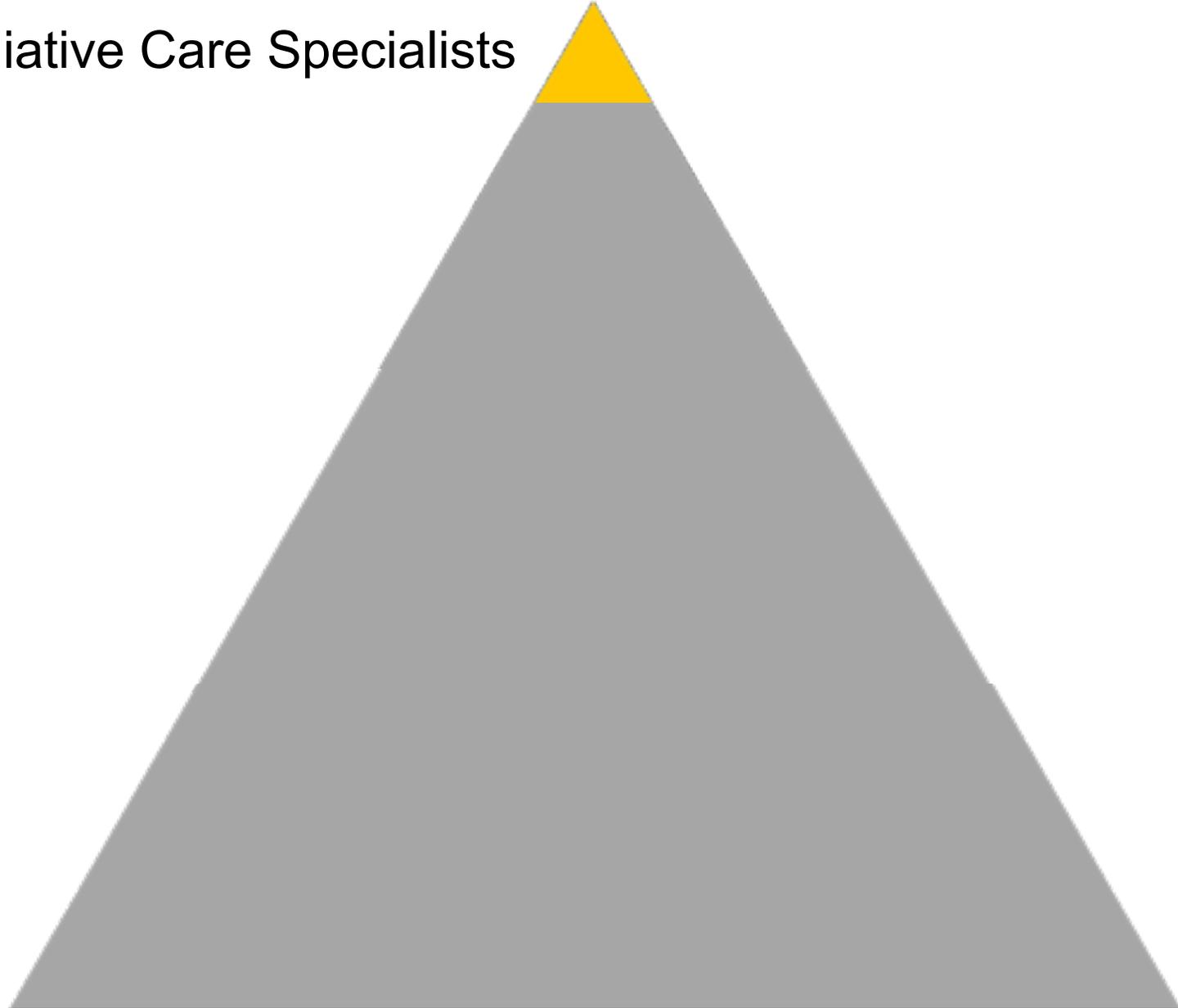
Frustrated

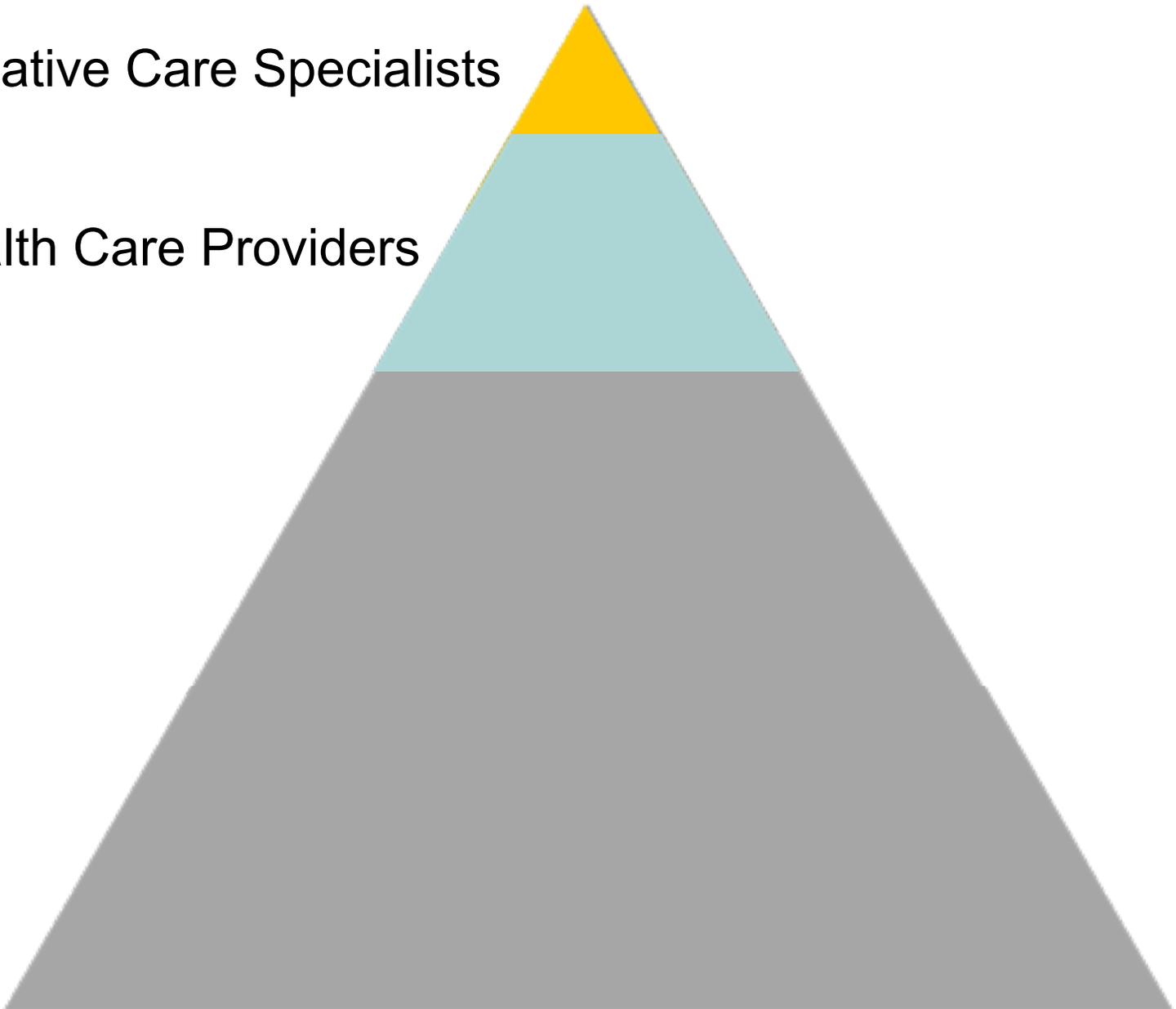
Scared





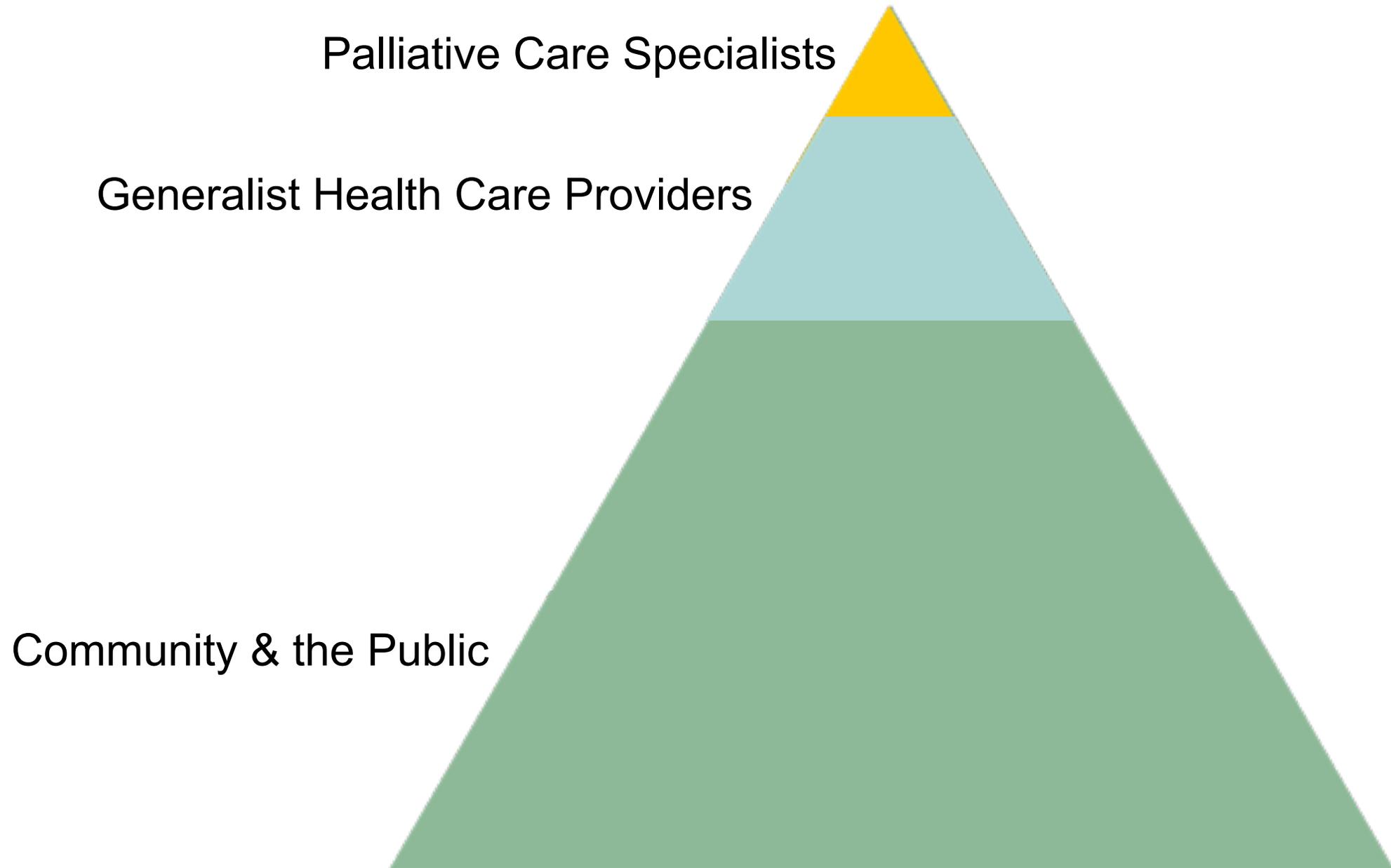
Palliative Care Specialists





Palliative Care Specialists

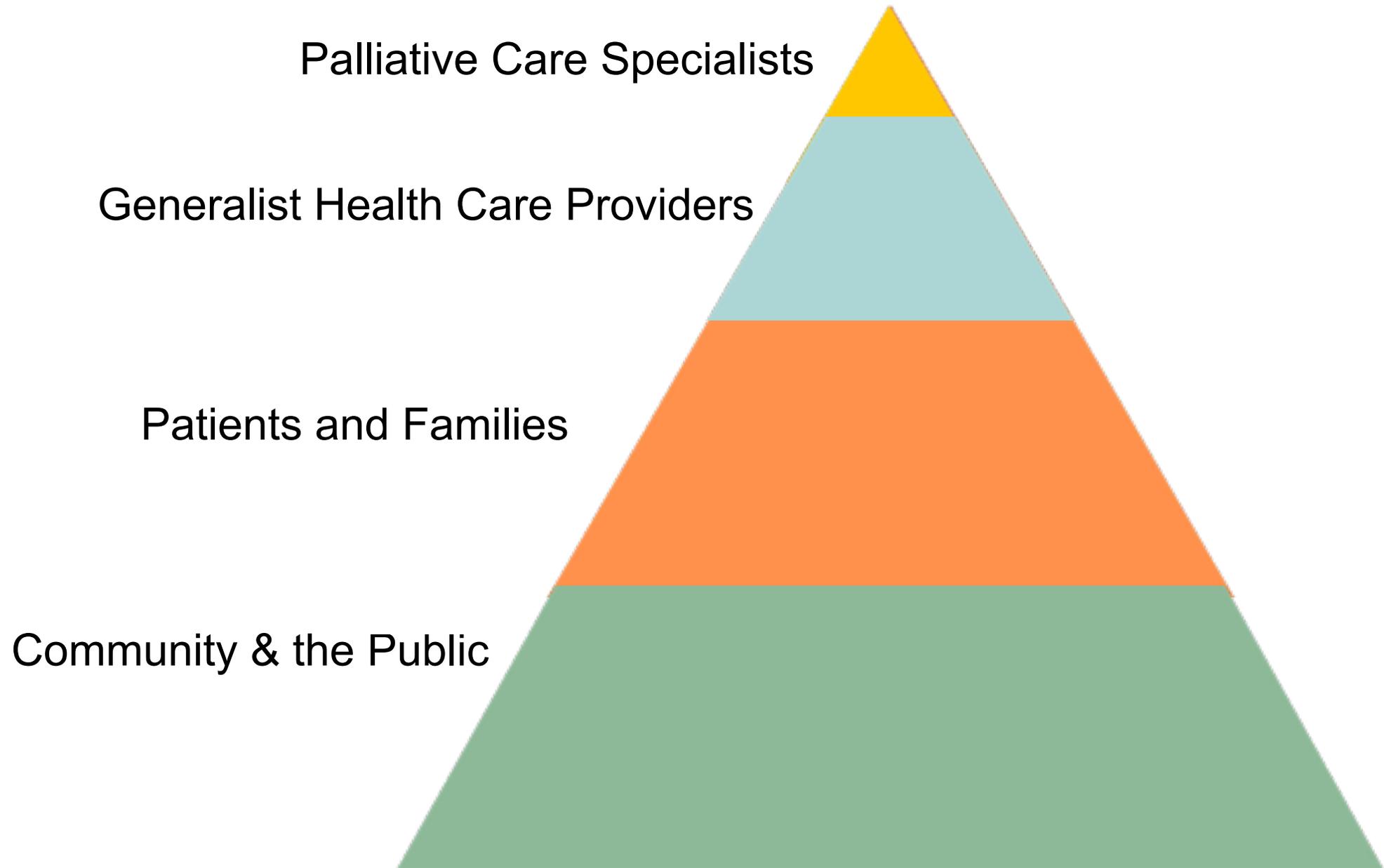
Generalist Health Care Providers



Palliative Care Specialists

Generalist Health Care Providers

Community & the Public



Community & the Public

Patients and Families

Generalist Health Care Providers

Palliative Care Specialists



1

**Going Upstream and
Public Facing**



**They didn't want what we
were selling**



~Menu~

Palliative care

Palliative approach

Palliative patient

Palliative diagnosis

Palliative team

Palliative unit

Palliative service

Palliative focus

Palliative specialist

Palliative stage



**Deconstructed elements of
palliative care approach**

7 keys for navigating a life-changing illness



WALK TWO ROADS

Hope for the best and plan for the rest



ZOOM OUT

Understand the big picture of your illness



KNOW YOUR STYLE

Reflect on how you cope and face challenges



CUSTOMIZE YOUR ORDER

Tailor the care plan to your values and preferences



EXPECT RIPPLE EFFECTS

Prepare for the family's parallel journey



CONNECT THE DOTS

Play a central role in navigating the system



INVITE YOURSELF

Initiate conversations about what to expect

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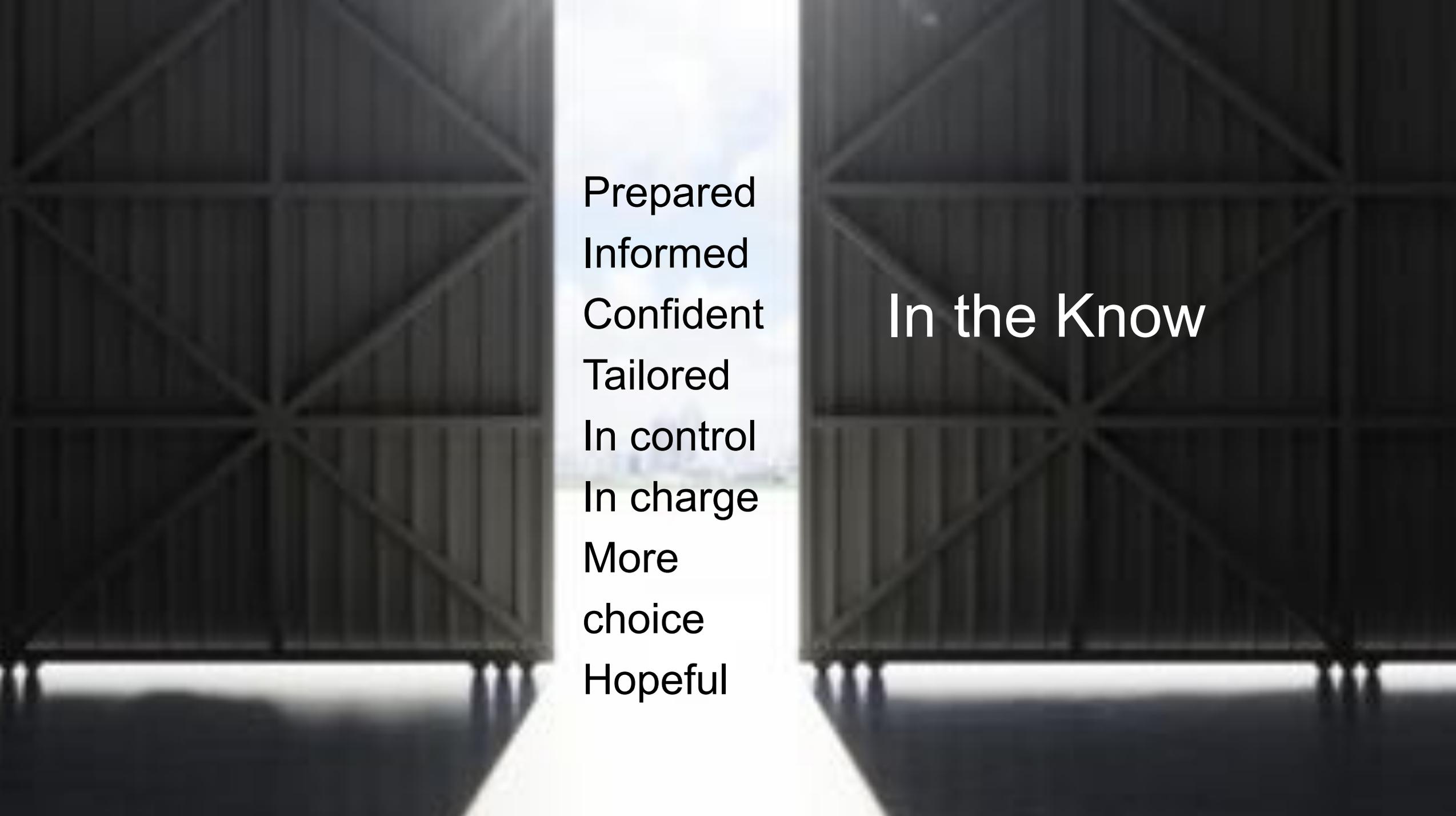
Frustrated

Scared

In the Dark



In the Know



Prepared
Informed
Confident
Tailored
In control
In charge
More
choice
Hopeful

In the Know

Our goal is to improve
the patient and family
illness experience



The Waiting Room REVOLUTION

Our goal is to improve
the patient and family
illness experience

www.waitingroomrevolution.com

Join our newsletter!



2

Spreading the Message



Listen to Season 1 now:

- EP 1: THE ORIGIN OF THE REVOLUTION [Listen](#)
- EP 2: WALK 2 ROADS [Listen](#)
- EP 3: ZOOM OUT [Listen](#)
- EP 4: KNOW YOUR STYLE [Listen](#)
- EP 5: CUSTOMIZE YOUR ORDER [Listen](#)
- EP 6: ANTICIPATE RIPPLE EFFECTS [Listen](#)
- EP 7: TAG, YOU'RE IT [Listen](#)
- EP 8: INVITE YOURSELF [Listen](#)
- EP 9: WHEN TIME IS RUNNING OUT [Listen](#)
- EP 10: PUTTING IT ALL TOGETHER [Listen](#)



The Podcast

A podcast about unlocking the secrets to a better illness experience.



Podcast: Season 1

We started the podcast to get the message out quickly.

We focused on the 7 Keys in Season 1. We were blown away by the enthusiastic response from listeners.

The Podcast: s9 out next week

- Co-hosts of The Waiting Room Revolution podcast focused on how a better patient family experience.
- >125 000 downloads
- Rated top 1.5% of global podcasts by ListenNotes.com
- Listened to in 100+ countries
- 5 star ratings on Apple Podcast



” What a resource for those in need.. to know that there can be control, hope and bittersweet joy in the journey, both for patients and their families.”

Apple Podcast Listener

Dr. Naheed
Dosani



Bif Naked



Theresa Brown

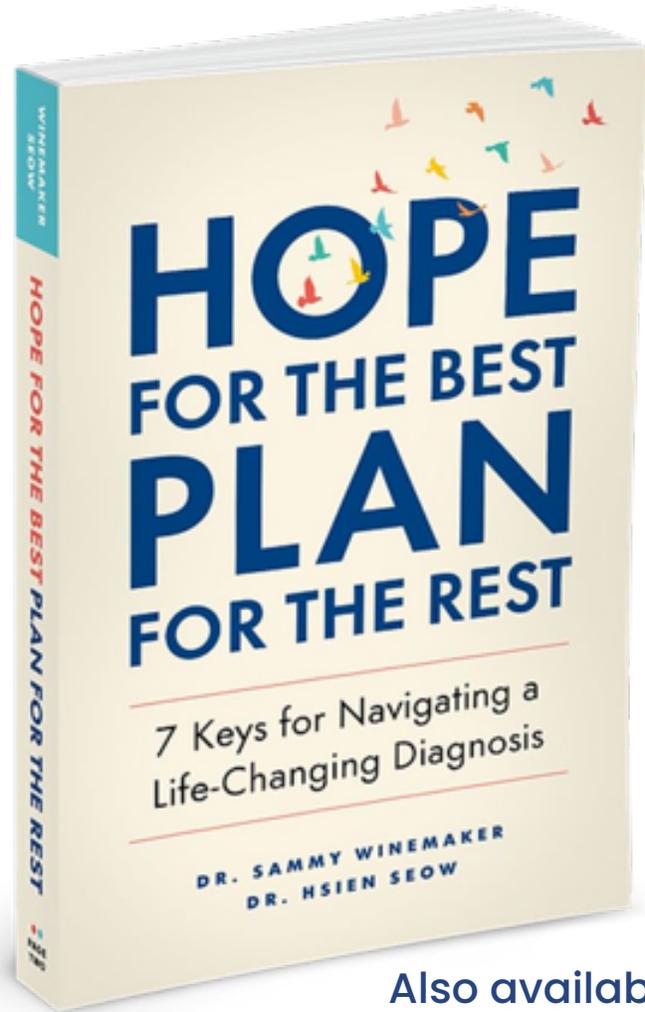


Hospice Nurse
Julie



Dr. Kathryn
Mannix





Also available in
ebook & audiobook

“Kind, clear, and system-changing:
a clarion call for a patient-led revolution in health care.”
KATHRYN MANNIX, MD, *Sunday Times*–bestselling author of
With the End in Mind

“A lightning bolt of hope! A palliative care tour de force and essential
reading for all who feel overwhelmed and alone in the health care system.”
THERESA BROWN, RN, *New York Times*–bestselling author of *Healing*

“Succinct, practical tips for getting the best care
and living well through the course of your illness.”
IRA BYOCK, MD, bestselling author of *The Four Things That Matter Most*



Kathryn Mannix @drkathrynmannix · May 10, 2021

This is a wonderful resource, reaching out to patients to give them the keys to navigate serious illness their own way.

We are at our patients' service, & this is a way to give them back their power.

@WaitingRoomRev



Angus Pratt 🇨🇦 @anguspratt · Apr 28

Replying to @jillfeldman4

@WaitingRoomRev has been showing me the importance of a palliative approach throughout medicine. Clinicians aren't listening so patients need to take it into their own hands. Hence the revolution.



Meg Trehwitt

I asked this question today for the first time. It was really powerful.

3d Reply



DrRadar1

Your posts empower both the aged and their families in asking effective questions of practitioners.



KaytheRay

This podcast is essential listening for anyone living with a serious illness and their family members. Sammy and Hsien's message is that if you are brave enough to seek- even demand- information, you can take some control back in a situation where you might feel completely out of control. So much wisdom here.

A must listen!



1y ago

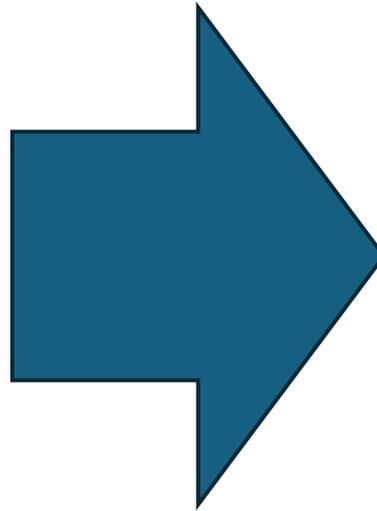
CarlyBrie

This podcast is a must listen for med students, family doctors and anyone involved in end of life and life limiting illness care! It totally changed my perspective and approach to patients with life limiting illnesses & I think it's also an amazing resource for patients as well!



Benefits for Providers

Transactional

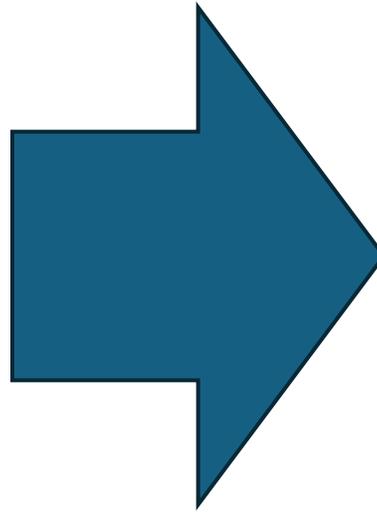


Relational

Benefits for Providers

Transactional

- Weary
- Detached
- Reactive
- Helpless
- Hopeless
- Frustrated
- Conflicted
- Burnout



Relational

- Caring
- Engaged
- Proactive
- Helpful
- Hopeful
- Meaningful
- Satisfied
- Resilient

Our goal is to put the
human back at the
center of care



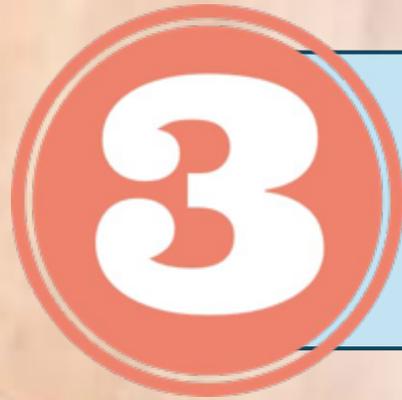
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The Waiting Room REVOLUTION

Our goal is to put the
human back at the center
of care





Act Together

Work as an individual



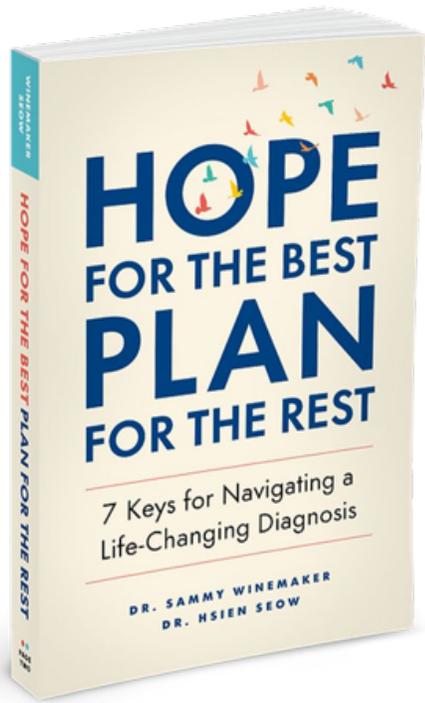
The Morning News Revolution Podcast

Podcast description text, including a title and several lines of introductory text.



Work as an individual

1. Podcast



Work as an individual

1. Podcast
2. Book & book club

HOPE FOR THE BEST PLAN FOR THE REST

DISCUSSION GUIDE

- 1 How did your opinion of the book change as you read it?

- 2 Which key was your favorite and why?

- 3 Which key did you find most challenging and why?

- 4 What was the most valuable piece of advice and why?

- 5 What surprised you most about the book?

- 6 Did you try out any of the keys or exercises? How did it go?

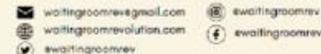
- 7 Did you re-read any chapters? If so, which ones?

- 8 Who would you recommend this book to and why?

- 9 Are there lingering questions from the book you're still thinking about?



Want to tell us how it went? Reach out:



7 KEYS

for navigating a life-changing diagnosis



1. Walk Two Roads

Balance staying positive while also seeking honest, accurate information. This helps you stay hopeful and grounded to reality.

ACTION

Ask yourself what you are hoping for and what you need to plan for just in case?

2. Zoom Out

Every illness has a known pattern to it. Understanding this storyline gives you a bird's-eye view of where you are at in your illness and the long view.

Ask your provider: "What will my illness look like over time? What can't I expect along the way?"

ACTION



3. Know Your Style

Your unique way of being will have as much impact on your illness experience as the illness itself. Harness information about your style to gain more control.

ACTION

Reflect on your tendencies when facing stressful situations and how those might apply in your illness.

4. Customize Your Order

At times you may want to tailor your care to match your values. Use your values and preferences to guide your decisions throughout your illness.

Ask yourself: what do you value most?

ACTION



5. Anticipate Ripple Effects

Your inner crew (e.g. family and caregivers) will have a parallel illness journey. Their lives will be affected in multiple ways.

ACTION

Consider what support you need from your inner crew. Encourage them to get information and support too.

6. Connect the Dots

You and your inner crew need to play a central role in coordinating information. This enhances continuity and safety, especially at transition points.

Ask yourself: who will be the manager of your journey?

ACTION



7. Invite Yourself

Initiate conversations with your healthcare team. Don't assume no news is good news. Positive, polite patients are encouraged to be respectfully assertive.

ACTION

Ask questions and seek the information you need so you can make informed decisions.

Adapted from the book "Hope for the Best, Plan for the Rest"

For more info:

waitingroomrevolution.com

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Work as an individual

1. Podcast
2. Book & book club
3. Invite patients to know more by using the keys

Work with organizations

Work with organizations

1. Health Canada



What to do when facing a serious illness:

3 sets of questions to ask your health care team

Receiving a diagnosis of a serious illness can be overwhelming. Often people don't know what the journey will look like. However, there are things you can do to help you communicate with your health care team. For example, you and those closest to you can ask **key questions** to make sure you understand your illness.

1 What does it mean to have this serious illness?

Not all serious illnesses are the same. A person might have the illness for a long time and it might get worse over time and nature of the illness.

Ask your health care team:

- Is the illness curable?
- Will it get worse over time?
- Will it shorten my life?

2 What can I expect now and in the future?

Every person's experience is different. Based on the information you learn, you can learn what the illness for general sense of the patient's illness and what you can expect.

Ask your health care team:

- Can you explain the illness to me?
- Am I currently in the best place for me?

3 How can I prepare for what might come next?

Throughout the illness, you will have decisions about what to do next. It's important to think about what you want to do now and what you want to do later.

Ask your health care team:

- Can you explain why the illness is happening and how we can manage it?

Ask yourself:

- What's most important to you and those closest to you?
- Share this information with your health care team.

Speaking your mind and asking questions can be intimidating but can help you and those closest to you understand your illness journey. These 3 sets of questions will help you be more informed, have more choice and control, and be more hopeful and prepared.

3 Questions to ask yourself that make difficult conversations about serious illness easier

Talking with your patients about their serious illness is not easy. We all have had that uncomfortable feeling of not knowing what to say or when to say it. Regardless of your role, ask yourself these three questions.

Where do I start?
What do I say?



1 Is a treatment or care decision needed?

The answer directs you to the purpose and outcomes of the conversation.

If yes, then you are supporting **decision-making**. Make sure illness is understood and decisions align with a person's values and goals.

If no, then you are helping with **preparing**. Prepare a patient and substitute decision maker (SDM) for progressing illness and future decision-making.

2 What do they know?

Up to **70%** of people do not understand that their serious illness cannot be cured and will progress over time. Exploring what the person understands about their illness helps you to know how much and what kind of information to offer.

3 What matters to the person?

There is clear evidence that values and goals guide **as few as 10%** of clinician recommendations. Helping your patient express their values and goals will keep the person at the centre of the decision.

Benefits – When a seriously ill patient and their substitute decision maker (SDM) are prepared, outcomes are better, distress is less and clinicians have greater professional satisfaction.

For more information
Information on serious illness and palliative care in Canada: canada.ca/palliative-care
Walking Room Revolution – for information and resources to help patients and families who are facing serious illness (English only): walkingroomrevolution.com



Work with organizations

1. Health Canada

2. Roadmaps

COPD ROADMAP

Understand Where You Are in the Illness

WHAT IS THIS FOR

Understanding common signs and stages of how COPD evolves is key to getting the right types of support, feeling prepared, and having more choice and control.

This tool allows for open conversations between patient, family / caregivers, and health care teams to talk about where things are at now and what to expect later. Revisit this roadmap over time.

HOW DO I USE THIS

The general pattern of COPD is typically a gradual decline with intermittent episodes of sudden flare ups.

Use the space below to discuss with your team

1. Your c
2. What
3. What qual

BEGINNING STAGE SIGNS

- Breathless with activity, e.g. climbing stairs
- Intermittent wheezing
- Chronic lingering cough
- Coughing up mucus
- Tightness in the chest with activity

MIDDLE STAGE SIGNS

- Breathless when walking at own pace
- Decreased exercise tolerance
- Frequent wheezing
- Increased chronic cough and sputum
- Periodic flare ups may require new medications or ER visits
- Disruption to sleep, fatigue

LATE STAGE SIGNS

- Breathless after minimal exertion
- Spend more time sitting
- More frequent flare ups, may require hospitalization
- Decreased appetite
- Persistent fatigue

END STAGE SIGNS

- Breathless at rest
- Spend more time in bed
- Weight and muscle loss
- May require oxygen therapy

Financial contribution:  Health Canada |  Santé Canada | The above information is not intended to replace the advice of your health care provider.

Scan QR to [waitingroomrevolution.com](#)

COPD PLANNING ROADMAP

Prepare for Key Life Changes

How to Use: Review this table to understand what key life changes to expect and things to do in each stage.

	Key Life Changes	Things to Do
BEGINNING STAGE	Learn ways to slow progression & lessen symptoms	Prioritize lung health by: <ul style="list-style-type: none"> - Consider quitting smoking and getting updated on pneumonia and flu shots - Take medications as prescribed - Limit exposure to triggers (e.g. pet dander, dust, respiratory illnesses) - Integrate good nutrition, regular physical exercise, and social engagement - Make time for medical visits and pulmonary rehab programs
MIDDLE STAGE	Manage increased flare ups & symptoms Address personal affairs early	Use self-management strategies: <ul style="list-style-type: none"> - Continue with healthy lifestyle changes as mentioned above - Learn techniques for effective coughing, breathing, and clearing phlegm Designate person(s) for healthcare support, including future healthcare oversight: <ul style="list-style-type: none"> - Companion for appointments - Advance Care Plan discussions - Substitute Decision Maker / Power of Attorney for health care - Point person(s) for coordination, communication and documentation of care
LATE STAGE	Arrange supports to manage personal care as illness progresses	Assess needs and get support to maintain daily routines: <ul style="list-style-type: none"> - Cleaning, groceries, meal preparation, banking, home affairs - Medication management - Exercise, social interaction and companionship - Transportation - Emotional support - Support for family caregivers to prevent burnout Use techniques for maximizing energy and independence: <ul style="list-style-type: none"> - Make home modifications to enable mobility (e.g. walker, wheelchair, stair lift) - Enhanced home care supports (e.g. public home care, private care, community) - Consider living arrangements (e.g. one floor living, retirement home)
END STAGE	Plan for major changes in physical function & independence Prepare for End of Life	Assess ability to provide care at home: <ul style="list-style-type: none"> - Add home care supports for feeding, bathing, hygiene, dressing, toileting - Ensure action plan is in place for symptom flare ups - Ongoing support for family caregivers to prevent burnout Make care decisions with a focus on quality of life: <ul style="list-style-type: none"> - Review which medications are no longer needed - Discuss preferences for Do-Not-Resuscitate or Allow-Natural-Death Manage additional personal affairs: <ul style="list-style-type: none"> - Share critical account access, passwords, important contacts - Complete Will & Estate Planning - Talk about funeral and burial plans, legacy leaving - Discuss preferred location of care (e.g. hospice support)

Financial contribution:  Health Canada |  Santé Canada

The above information is not intended to replace the advice of your health care provider.

Scan QR for more resources [waitingroomrevolution.com](#) 

Work with organizations

1. Health Canada
2. Roadmaps
3. Adapt the keys

PEPA Indigenous Program of Experience in the Palliative Approach

WHAT DO PEOPLE WITH SERIOUS ILLNESS NEED?

How do we support our people to change a harmful experience of serious illness to a healing experience, that is grounded in sovereignty, dignity and self-determination?

Harmful experience	Changing the experience	Healing experience
REACTIVE	 <p>The ability to swim the river – hoping for the best and being prepared for the different currents - outcomes that may require you to adjust your swimming style. Realize that if you are still swimming, you have hope and this hope changes throughout the illness journey, but it never needs to be lost.</p>	HOPEFUL
UNAWARE	 <p>Understand the typical pattern or storyline of your illness. Knowing what to expect about how the illness will affect your life as things progress.</p>	INFORMED
UNSURE	 <p>Know your usual strategies for coping and facing challenges in life, so that you can better understand how you will cope with this challenge.</p>	CONFIDENT
GENERIC NON-INDIGENOUS APPROACH	 <p>Be aware that you don't have to accept the care and treatment options that are offered as standard care. You can customise a holistic plan that meets your own needs, beliefs and preferences.</p>	CULTURALLY SAFE AND RESPECTED
OVERWHELMED	 <p>Expect that your illness will have ripple effects on your family and community. Ensure that your family, care and community are supported so that you and your support system stay strong.</p>	SUPPORTED
FRUSTRATED AND SCARED	 <p>Start conversations with healthcare staff about what to expect, rather than waiting for them to tell you. You have a right to know about anything that involves you.</p>	PREPARED

Adapted from: Seow H & Whelan T (2021) The Waiting Room Revolution: Unlocking the keys to a better illness experience, <https://www.waitingroomrevolution.com/season-1-one-page/> Used with permission.

Work Together

The Map Project

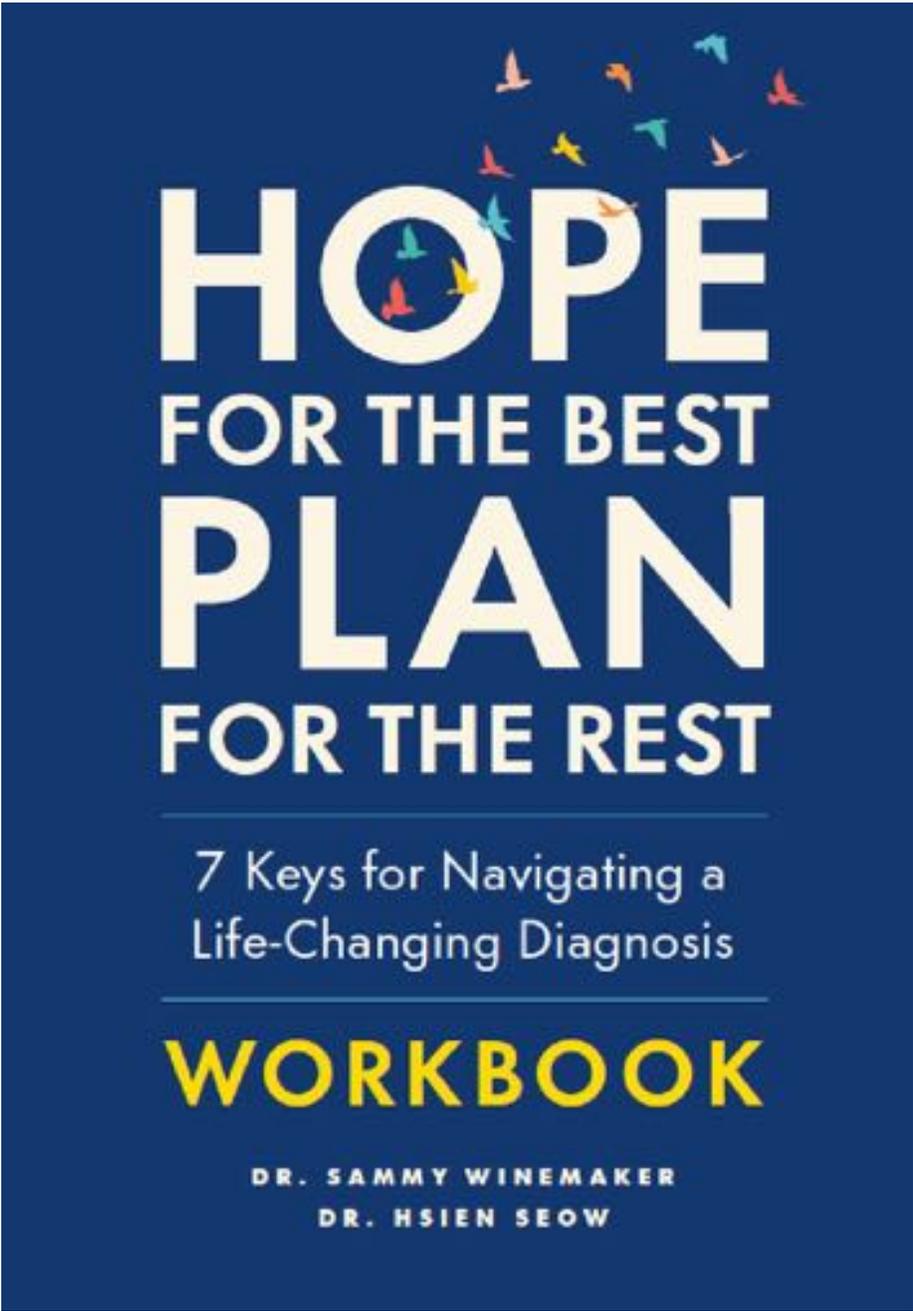
The Map Project is a collaborative effort to create a comprehensive world map that includes information about various countries, including their names, capital cities, and major cities. The project is designed to be a useful resource for students and teachers alike.



The project is designed to be a useful resource for students and teachers alike. It includes a list of countries and their capital cities, as well as a list of major cities for each country. The project is designed to be a collaborative effort, with students working together to create the map. The project is designed to be a useful resource for students and teachers alike.

Work Together

1. Map project



HOPE FOR THE BEST PLAN FOR THE REST

7 Keys for Navigating a
Life-Changing Diagnosis

WORKBOOK

DR. SAMMY WINEMAKER
DR. HSIEN SEOW

Work Together

1. Map project
2. Workbook coming up



Work Together

1. Map project
2. Workbook coming up
3. Public Health Palliative Care
– Compassionate communities



CONCLUSION

Revolutionize your work

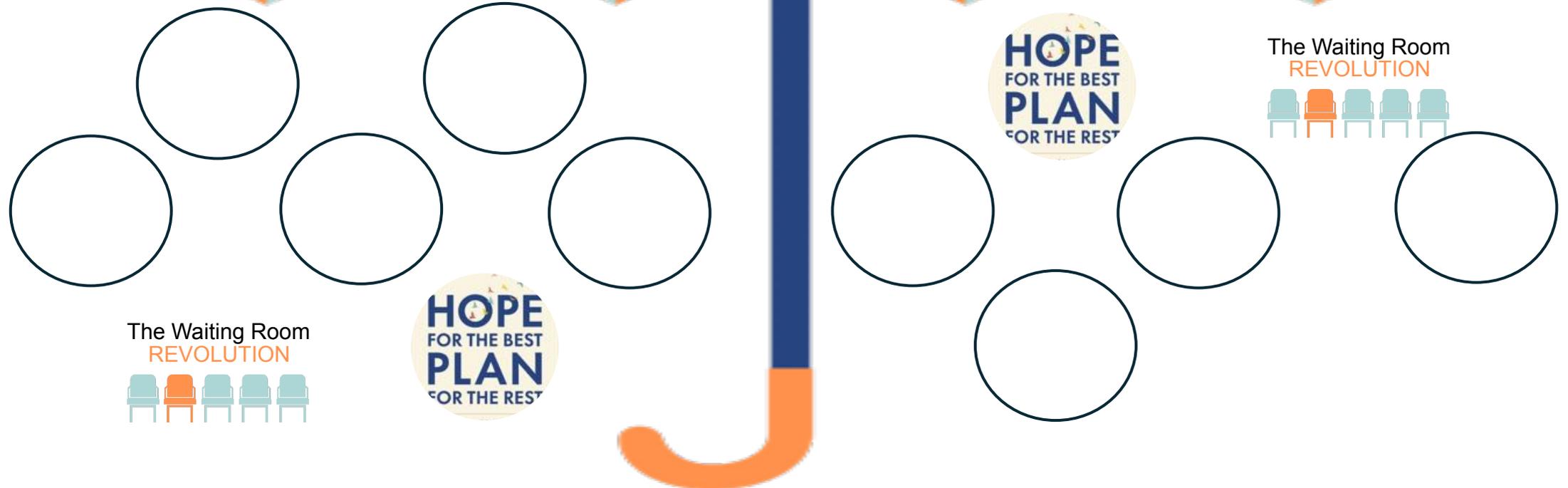
Accessible

Actionable

Upstream



Everyone is invited to be part of the Revolution!



The Waiting Room
REVOLUTION

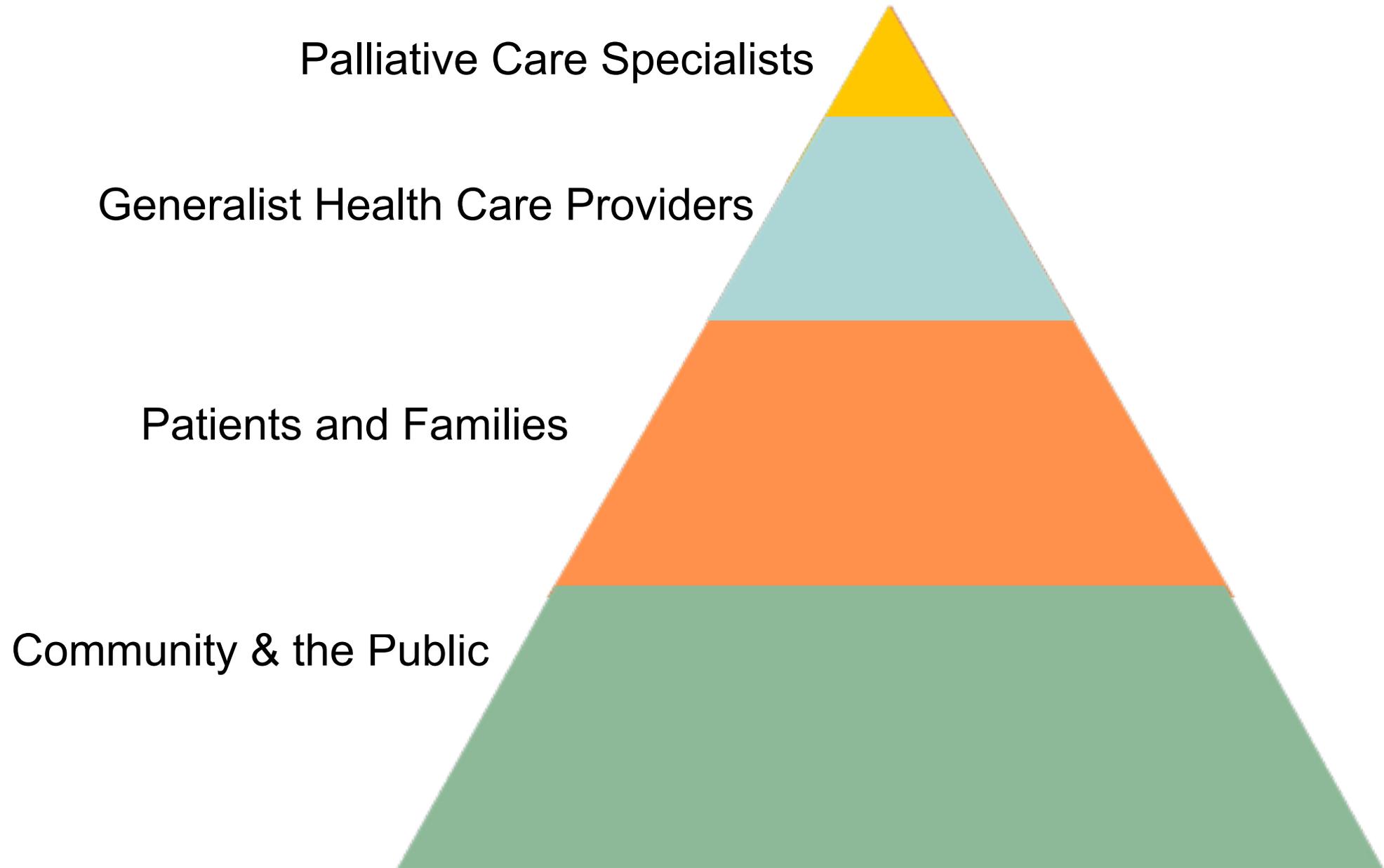


HOPE
FOR THE BEST
PLAN
FOR THE REST

HOPE
FOR THE BEST
PLAN
FOR THE REST

The Waiting Room
REVOLUTION





Community & the Public

Patients and Families

Generalist Health Care Providers

Palliative Care Specialists



Finding [the book] changed the way we lived this past year and how we prepared for the future. [Before] he was scared to ask questions and didn't know what to expect of his cancer journey. As a caregiver, [the book] helped me realize that I needed to ask the important questions while I still had the time... so that I could help navigate, advocate and honour the way he wanted to live and die.

- Deborah, wife of Stephen who died of lung cancer in 2023

Vancouver, British Columbia

Oct 4, 2024

How we can achieve a Palliative Care Revolution:

A social movement of patients, families and clinicians

Hsien Seow, PhD

Canada Research Chair Palliative Care and Health System

Innovation

Professor, Dept of Oncology, McMaster University, Canada

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