

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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In the Dark

Unprepared

Reactive

Unaware

Unsure

Generic

Overwhelmed

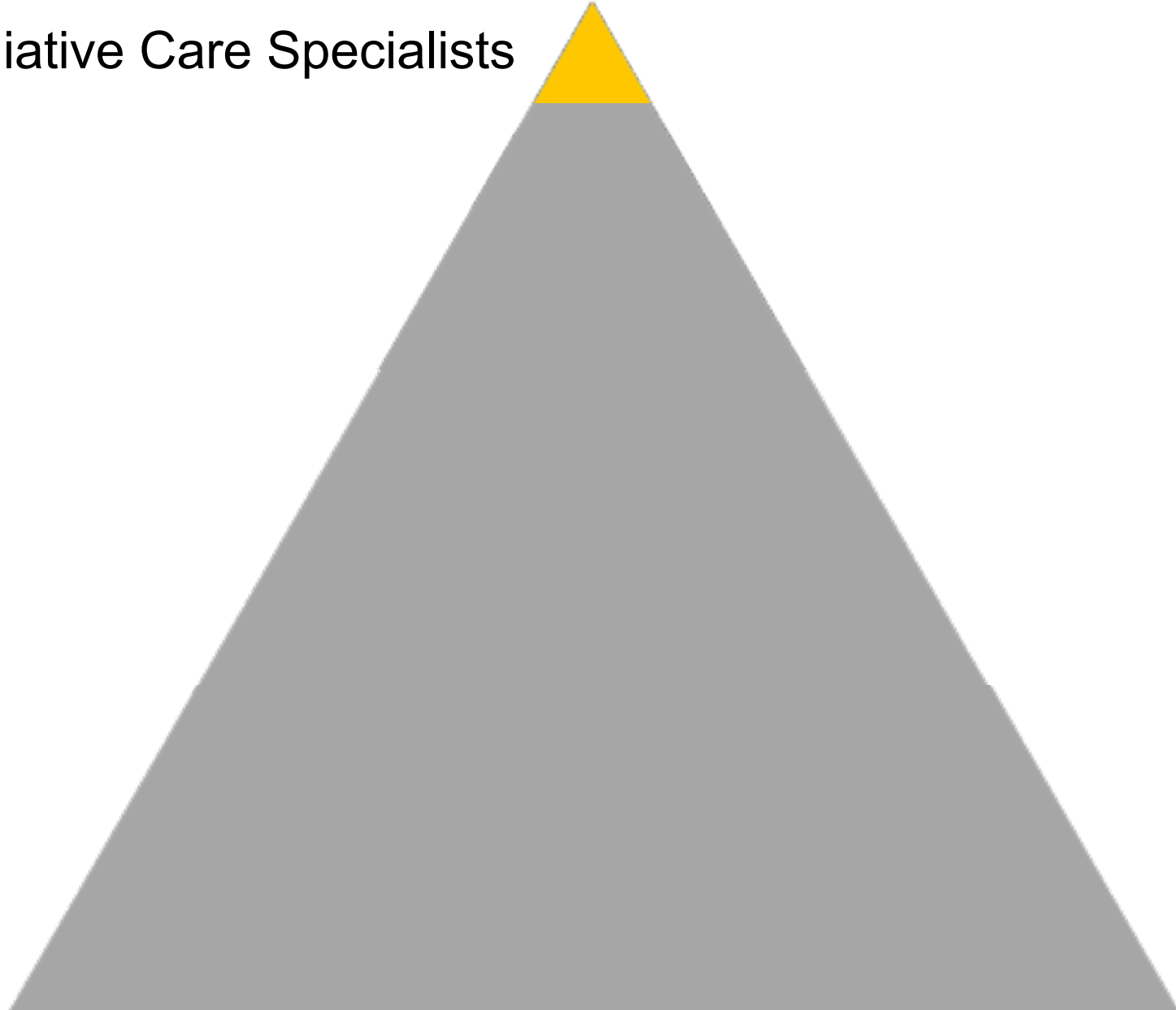
Frustrated

Scared





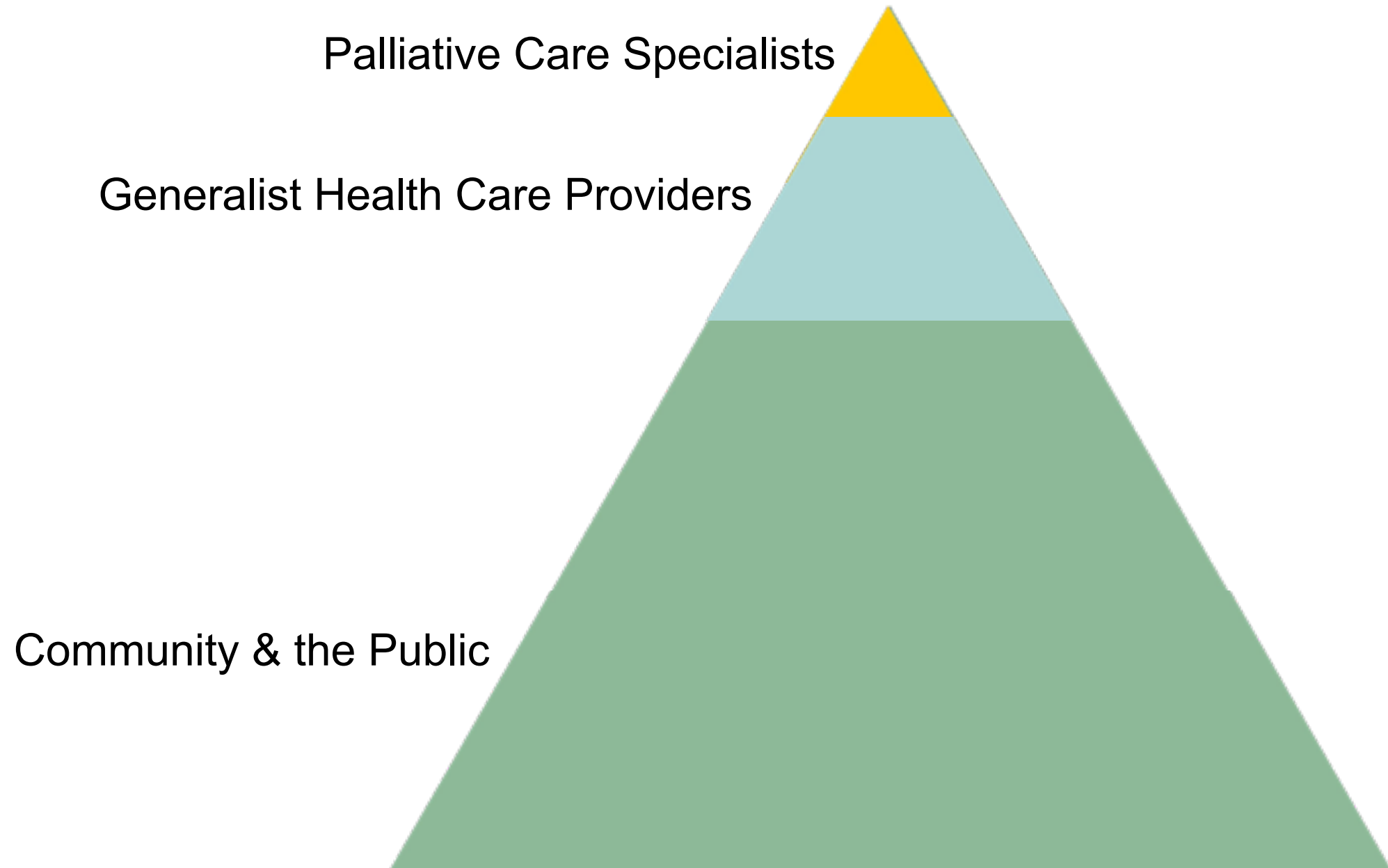
Palliative Care Specialists

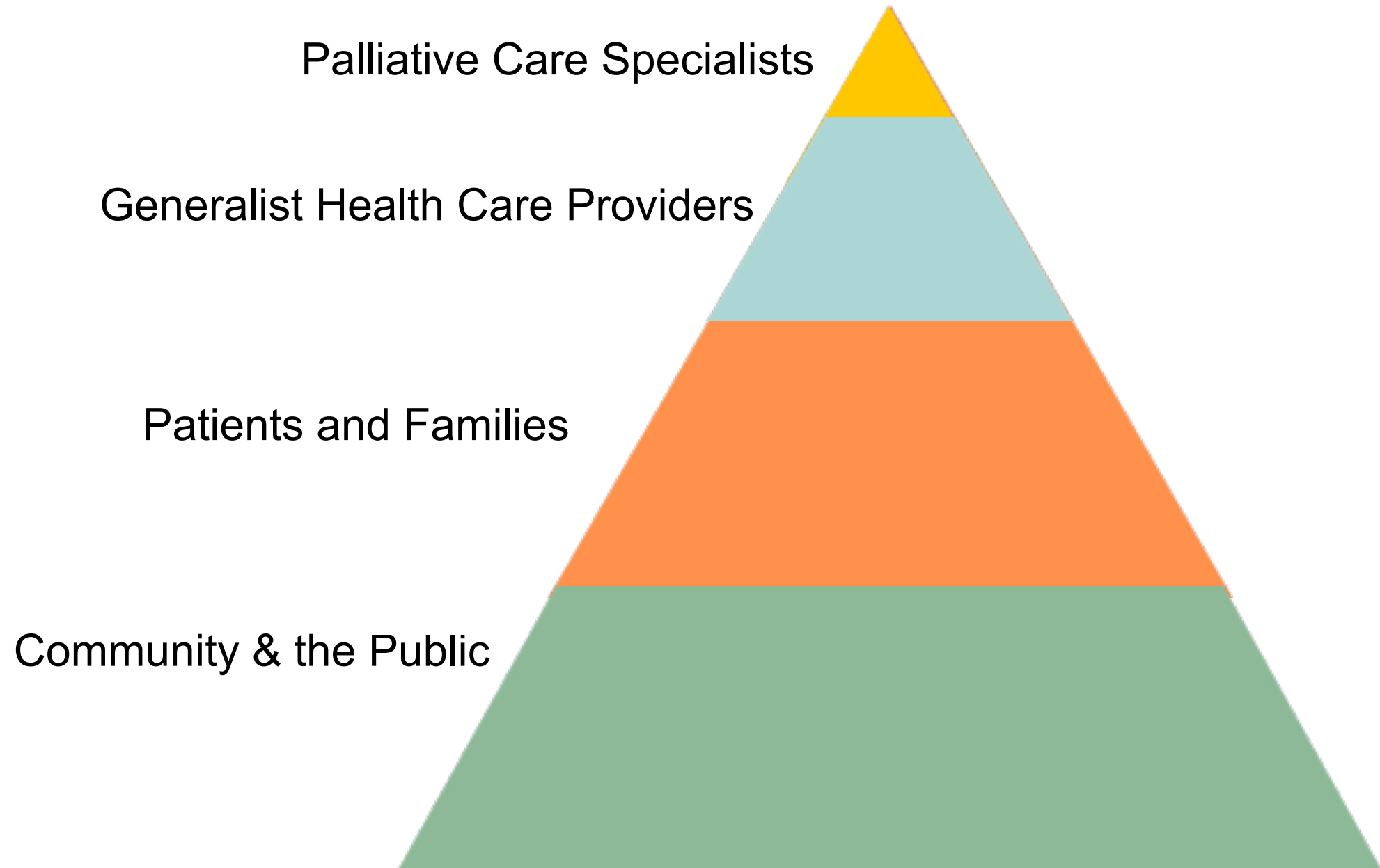




Palliative Care Specialists

Generalist Health Care Providers



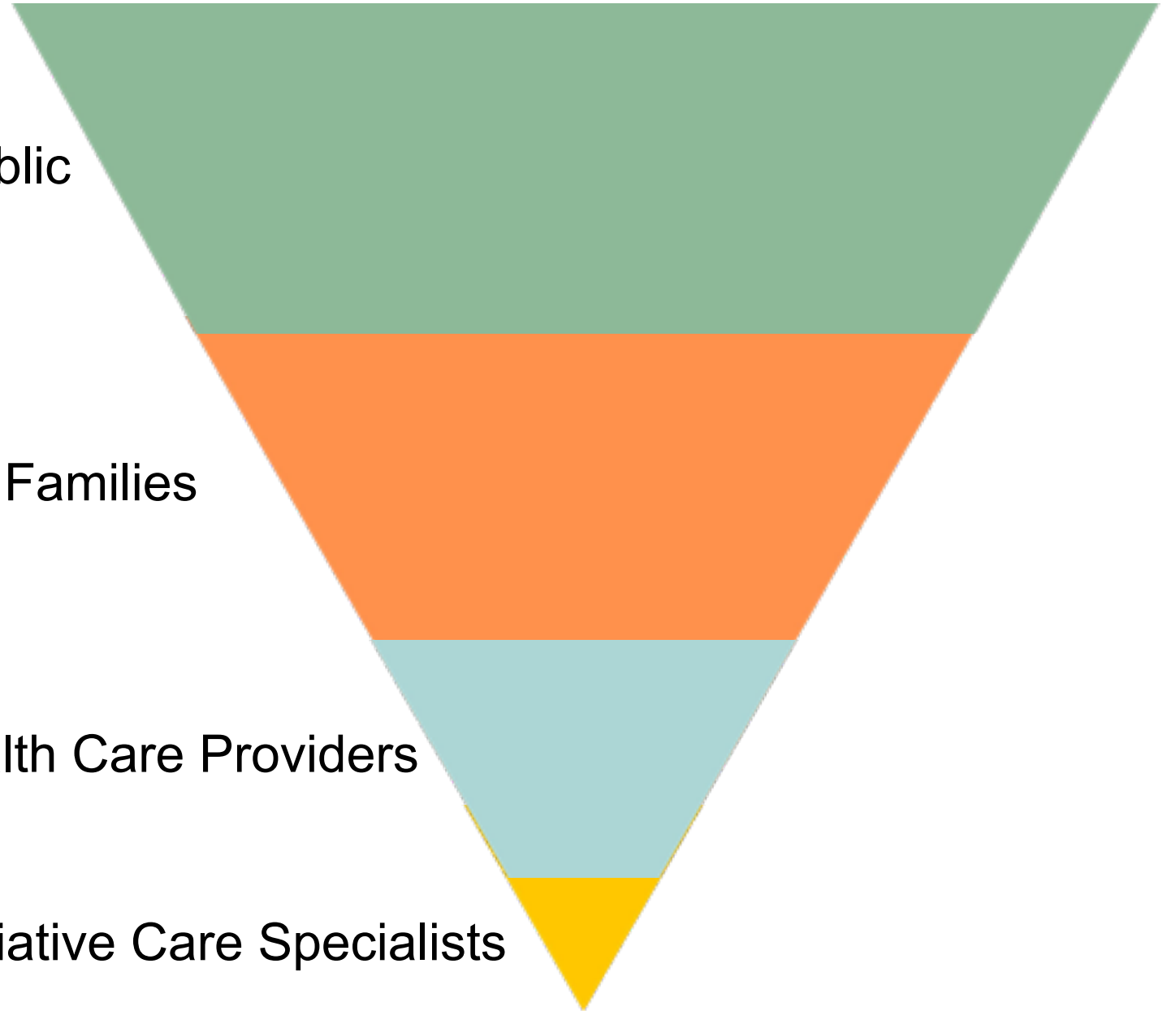


Community & the Public

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

In the Dark

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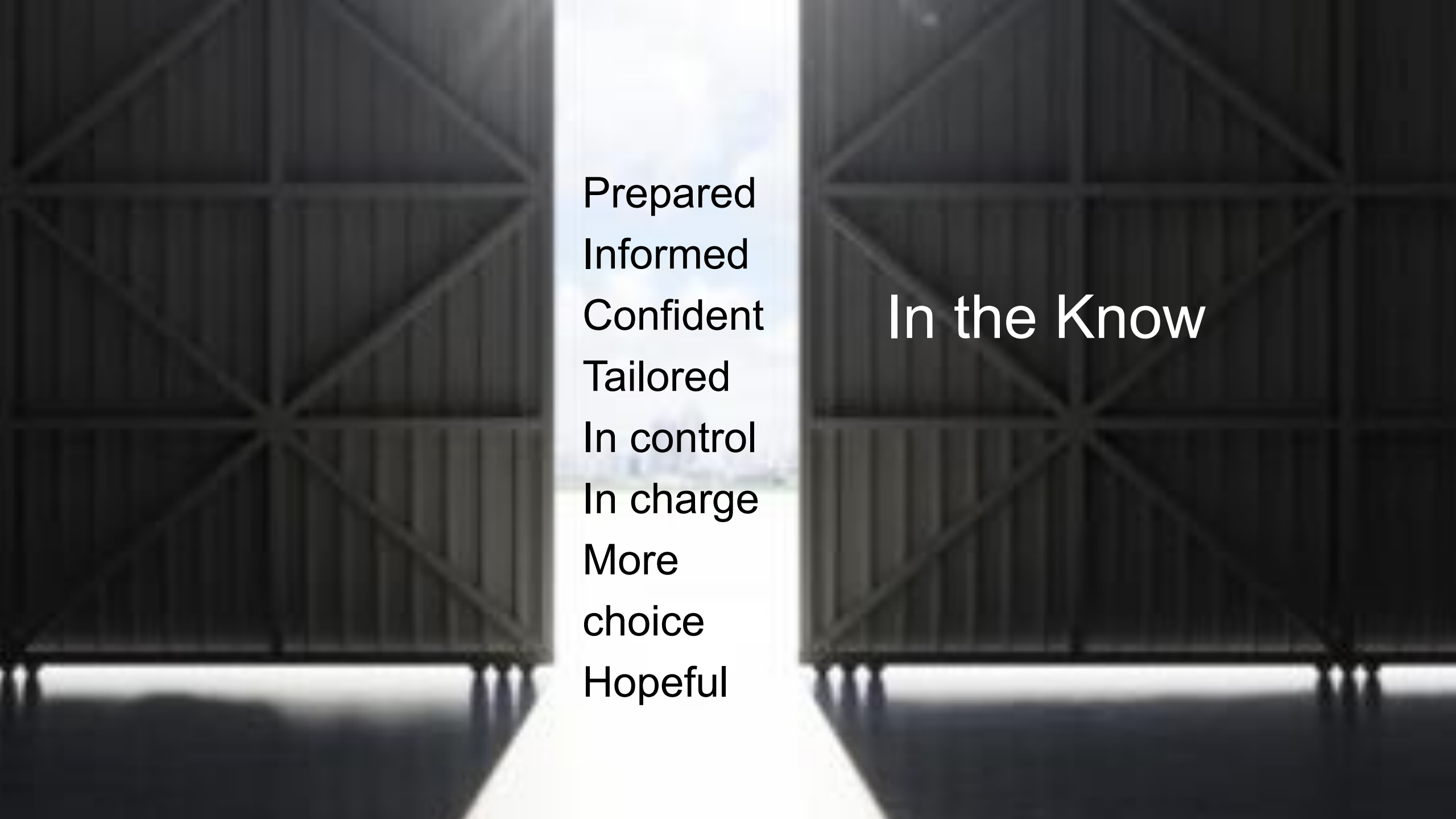
Frustrated

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



www.waitingroomrevolution.com

Join our newsletter!

The Waiting Room REVOLUTION

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the patient and family
illness experience



2

Spreading the Message





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

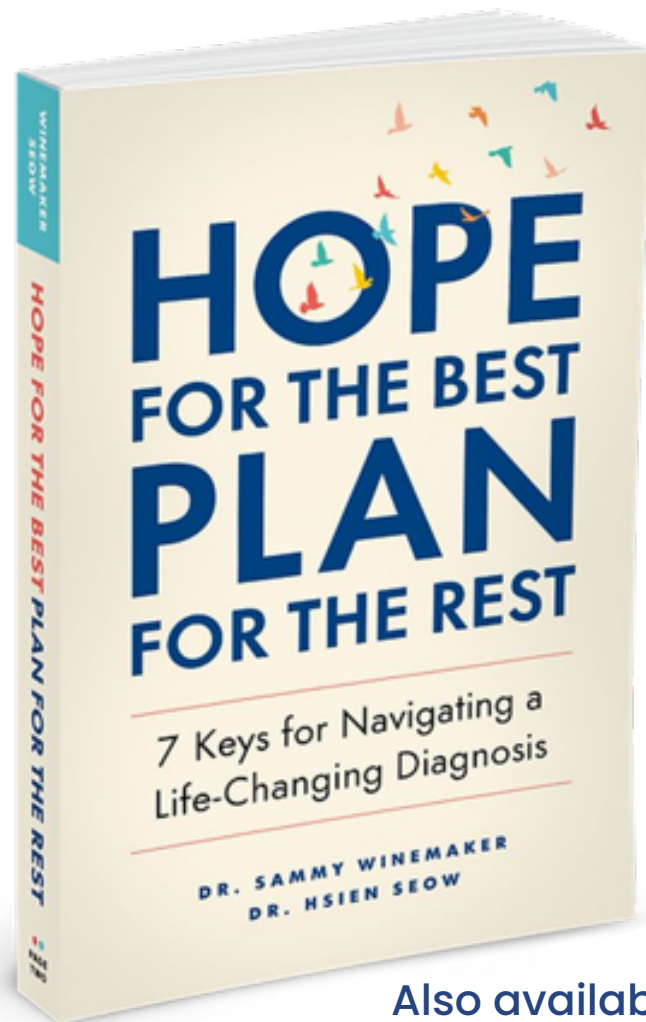


Hospice Nurse
Julie



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

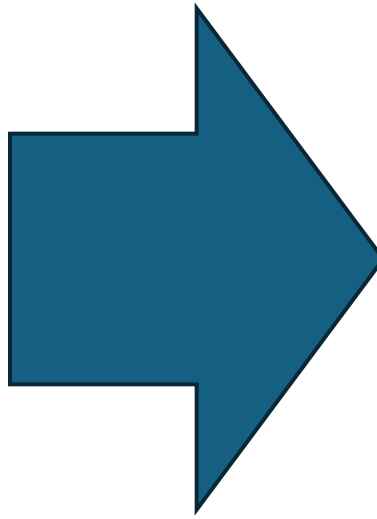
CarlyBrie

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

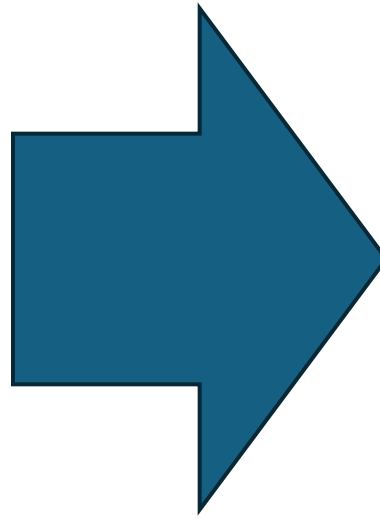


Relational

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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3

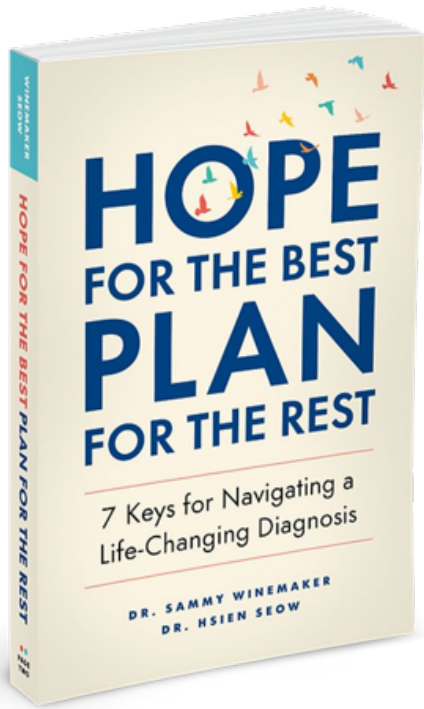
Act Together

Work as an individual



Work as an individual

1. Podcast



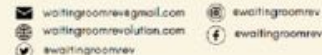
HOPE FOR THE BEST PLAN FOR THE REST

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?

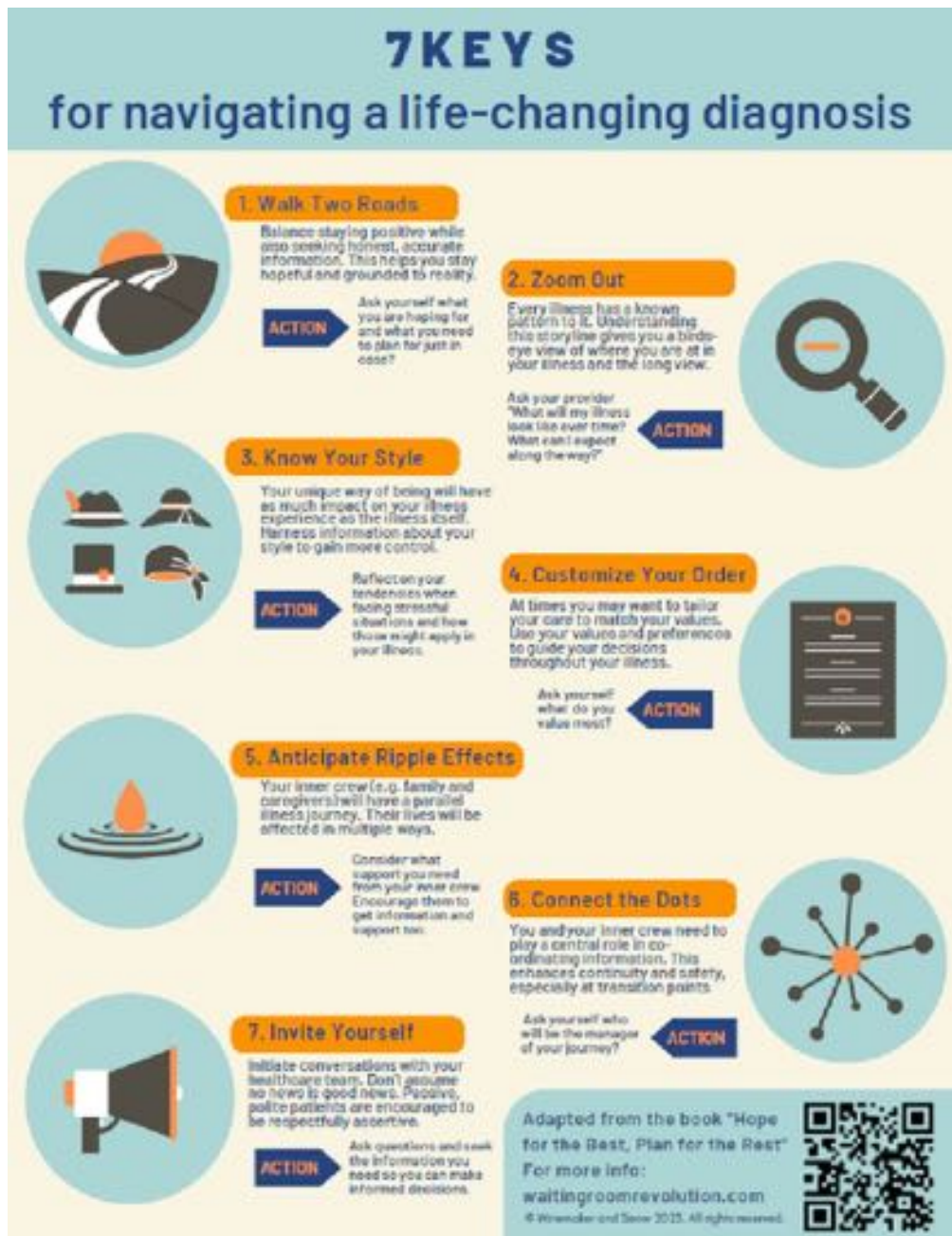


Want to tell us how it went? Reach out:



Work as an individual

1. Podcast
2. Book & book club



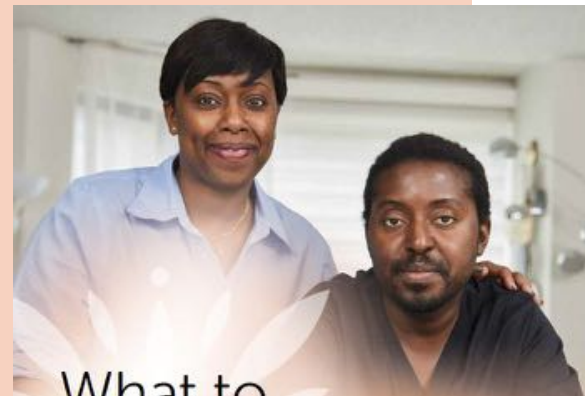
Work as an individual

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 medical history, the person can learn what the illness looks like for general sense of this person's illness and what you can expect.

Ask your health care team:

- Can you explain the illness and how we can manage it?
- Am I currently in the best place for this illness?

3 How can I prepare for what might come next?

Throughout the illness, it's important to think about what you want to happen when things are not going well. Where things are now and where things might be in the future are important to you and those closest to you.

Ask your health care team:

- Can you explain why things are happening and how we can manage them?
- What's most important to you and those closest to you?
- Share this information with your health care team.

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

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.


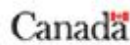
2 What do they know?

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.

The Walking Room REVOLUTION



Work with organizations

1. Health Canada

2. Roadmaps

ALZHEIMER'S ROADMAP

Understand Where You Are in the Illness

WHAT IS THIS FOR

Understanding common signs and stages of how Alzheimer's 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 TO USE THIS

The general pattern of Alzheimer's is typically a slow, gradual and long decline.

Use the space below to discuss with your team and take notes on:

1. Your current stage
2. What's unique to your experience
3. What can be done to maximize quality of life at any stage

| BEGINNING STAGE SIGNS | NOTES ON MANAGING EACH |
|---|------------------------|
| <ul style="list-style-type: none">• Repetition of questions/stories• Difficulty processing complex information• Confuse times/places• Forget recent events & conversations• Gets lost easily• Mild personality changes• Social withdrawal | |
| <h3>MIDDLE STAGE SIGNS</h3> <ul style="list-style-type: none">• Forget information, meals, medication• Wandering• For some, resistance to personal care• For some, agitation, anxiety, delusions, aggression, hallucinations | |
| <h3>LATE STAGE SIGNS</h3> <ul style="list-style-type: none">• Can't recognize familiar people• Loss of expression & emotion• Changes in mobility• Loss of bladder/bowel control• Difficulty communicating | |
| <h3>END STAGE SIGNS</h3> <ul style="list-style-type: none">• Loss of interest in food• Difficulty swallowing• Weight loss• Fatigue, long periods of sleep, unresponsive | |

Alzheimer's contributors: Health Canada, Santé Canada | This document is for informational purposes only and does not represent the views of Health Canada. | Scan QR for more resources: waitingroomrevolution.com

ALZHEIMER'S 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 Think About |
|------------------|--|---|
| BEGINNING STAGE | Decline in ability to live independently | Assess needs and get support to maintain daily routines: <ul style="list-style-type: none">• Cleaning, groceries, meal preparation, home affairs• Medication management• Managing personal finances• Exercise, social interaction and companionship• Transportation |
| | Decline in memory and cognitive function | Designate person(s) for future healthcare oversight before patient is unable to express consent and needs: <ul style="list-style-type: none">• Substitute Decision Maker / Power of Attorney for health care• Point person(s) for communication and coordination of care• Companion for appointments and tracking of medical information Settle personal affairs proactively while patient can still express preferences: <ul style="list-style-type: none">• Critical account access, passwords, contacts (e.g. banks, life insurance)• Will & Estate Planning• Advance Care Plan discussions• End of Life Wishes (e.g. legacy leaving & funeral planning) |
| MIDDLE STAGE | Increase in care needs | Assess ability to provide care at home and consider professional services to: <ul style="list-style-type: none">• Assist feeding, bathing, hygiene care, dressing, toileting• Prevent wandering or getting lost• Prevent falls (walker, cane, wheelchair) Assess home environment to ensure safety: <ul style="list-style-type: none">• Modify home to prevent risk of injury and/or wandering• Explore alternative living arrangements (e.g. enhanced home support)• Consider need for and transition to institutional care |
| | Require full-time supervision | Prevent Loneliness & Isolation: <ul style="list-style-type: none">• Explore ways for social interaction/companionship Identify and support family caregivers: <ul style="list-style-type: none">• Find resources and strategies to prevent burnout |
| LATE & END STAGE | Major changes in function and significant overall decline | Discuss and make decisions with a focus on quality-of-life such as: <ul style="list-style-type: none">• Recall advance care planning discussions to inform decision-making• Discuss Do-Not-Resuscitate / Allow-Natural-Death designation• Discuss pros and cons of antibiotics for infections• Seek resources for grief support Prepare for end-of-life care: <ul style="list-style-type: none">• Discuss stopping unnecessary medications• Understand the burdens of artificial nutrition and hydration• Prepare for bedridden care• Understand what natural dying looks like with Alzheimer's• Explore resources for bereavement support after death |

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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
2. What
3. What

quality

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

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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 shotsTake medications as prescribedLimit exposure to triggers (e.g. pet dander, dust, respiratory illnesses)Integrate good nutrition, regular physical exercise, and social engagementMake 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 aboveLearn 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 appointmentsAdvance Care Plan discussionsSubstitute Decision Maker / Power of Attorney for health carePoint 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 affairsMedication managementExercise, social interaction and companionshipTransportationEmotional supportSupport 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, toiletingEnsure action plan is in place for symptom flare upsOngoing 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 neededDiscuss 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 contactsComplete Will & Estate PlanningTalk about funeral and burial plans, legacy leavingDiscuss preferred location of care (e.g. hospice support) |

Financial contribution:

Health Canada Santé Canada

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Scan QR to waitingroomrevolution.com

Work with organizations

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



Work Together

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!

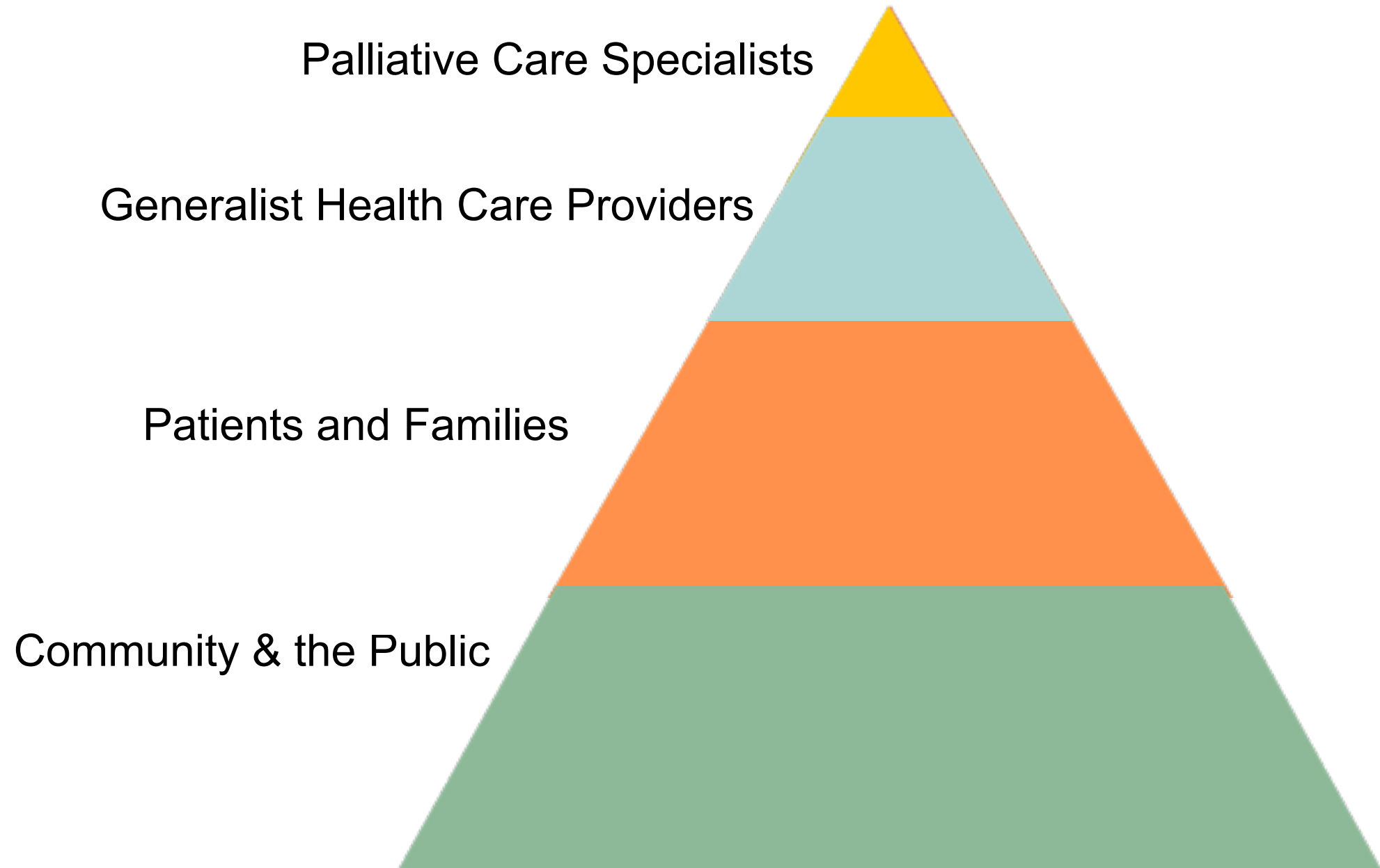


The Waiting Room
REVOLUTION



The Waiting Room
REVOLUTION



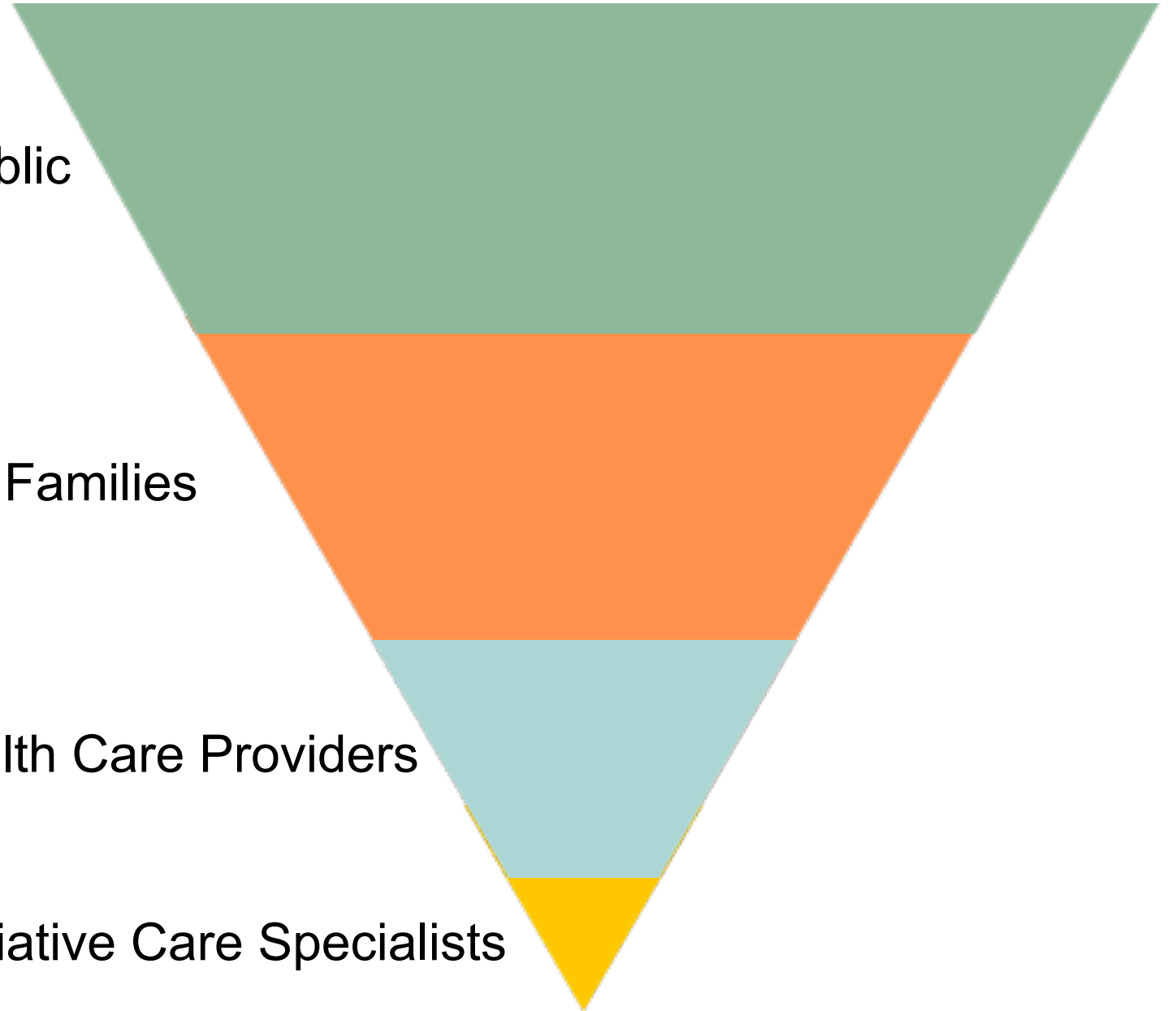


Community & the Public

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

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