

# Inspiring Social Movement Change in Palliative Care: Case Study of Co-Creation with First Nations Communities

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November 17

McMaster University, Hamilton, Ontario, Canada



A serene sunset over a body of water. The sky is filled with soft, colorful clouds in shades of purple, pink, and orange. In the foreground, a small wooden boat with a blue hull is positioned on the water, its reflection visible. In the background, there are fishing nets and structures extending into the water. The overall mood is peaceful and contemplative.

Change is the only constant.

Heraclitus

quote fancy

**Structure:**

Health Policy

Regulation

Accreditation

Performance goals

Compliance

Competition

Programme Management

Restructuring

Incentive systems



Structure





**For those trying to make change in a complex system...**

**Q: What is the secret to scaling and spreading?**



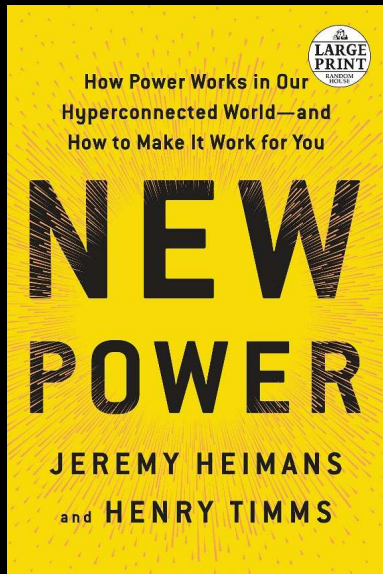


**Q: What is the secret to scaling and spreading?...**

**A: Work in new power ways  
(aka social movement)**

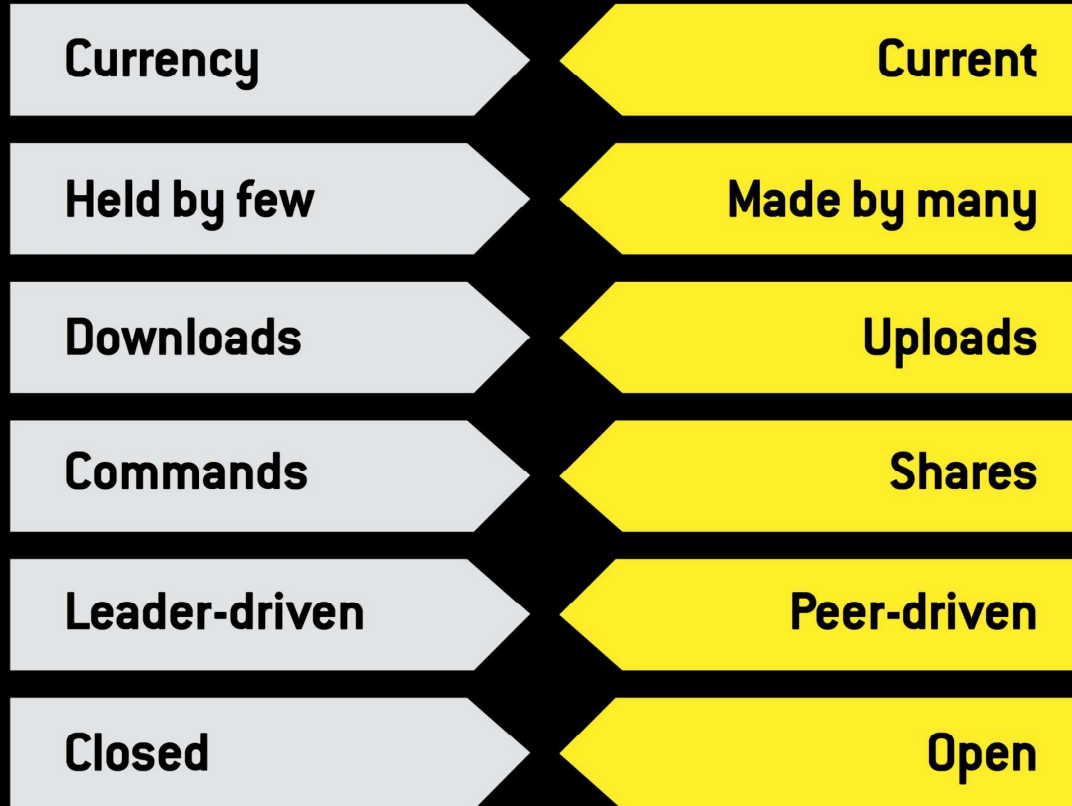






**OLD POWER**

**NEW POWER**



The future belongs to those who can work in “new power” ways

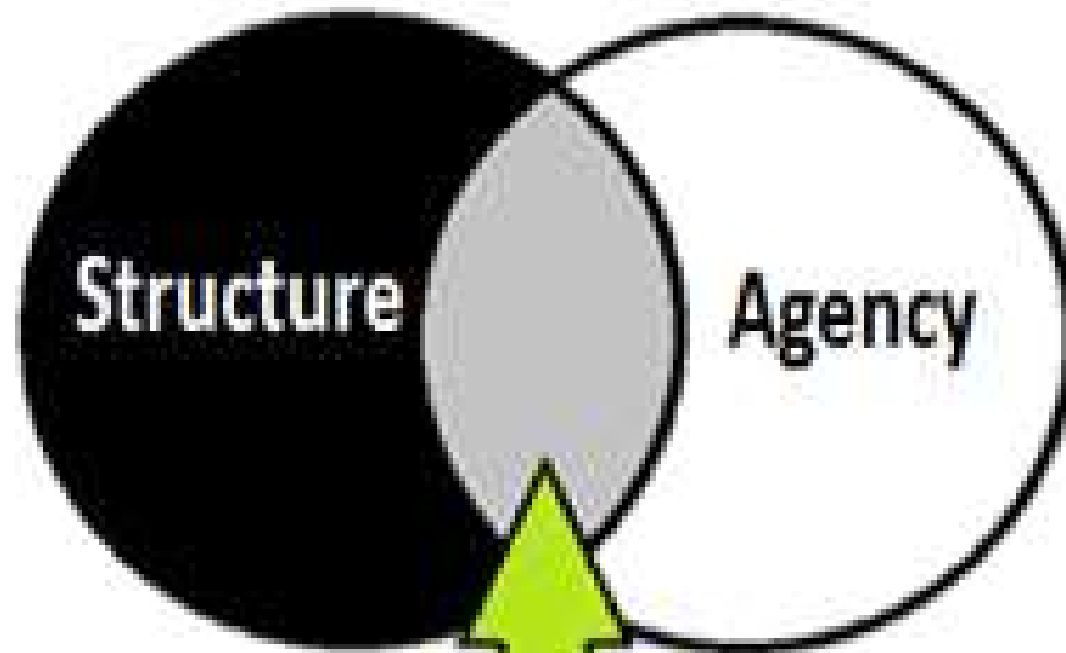
## Old power



## New power



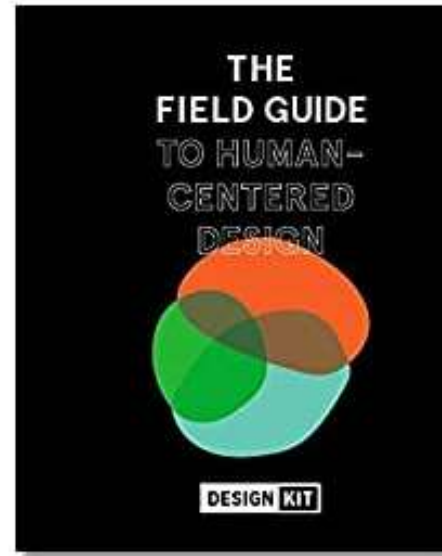




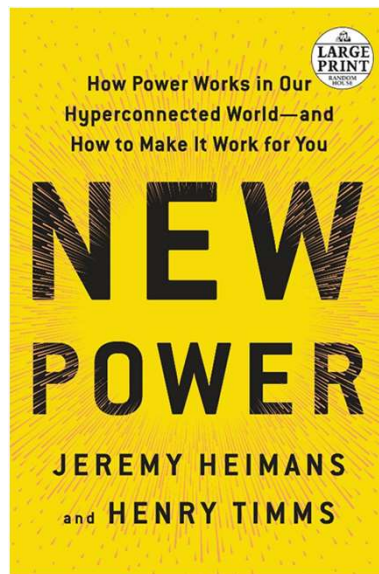
**We need both**

**Agency:**

- Activation
- Ability to make choices
- Capability
- Empowerment
- Quality Improvement\*
- Leaders everywhere
- Social action
- Social movements



## References



## 6 secrets to scale and spread



### **Build your community**

1. Language matters
2. Find the superconnectors
3. Get investment not buy-in



### **Make ideas spread**

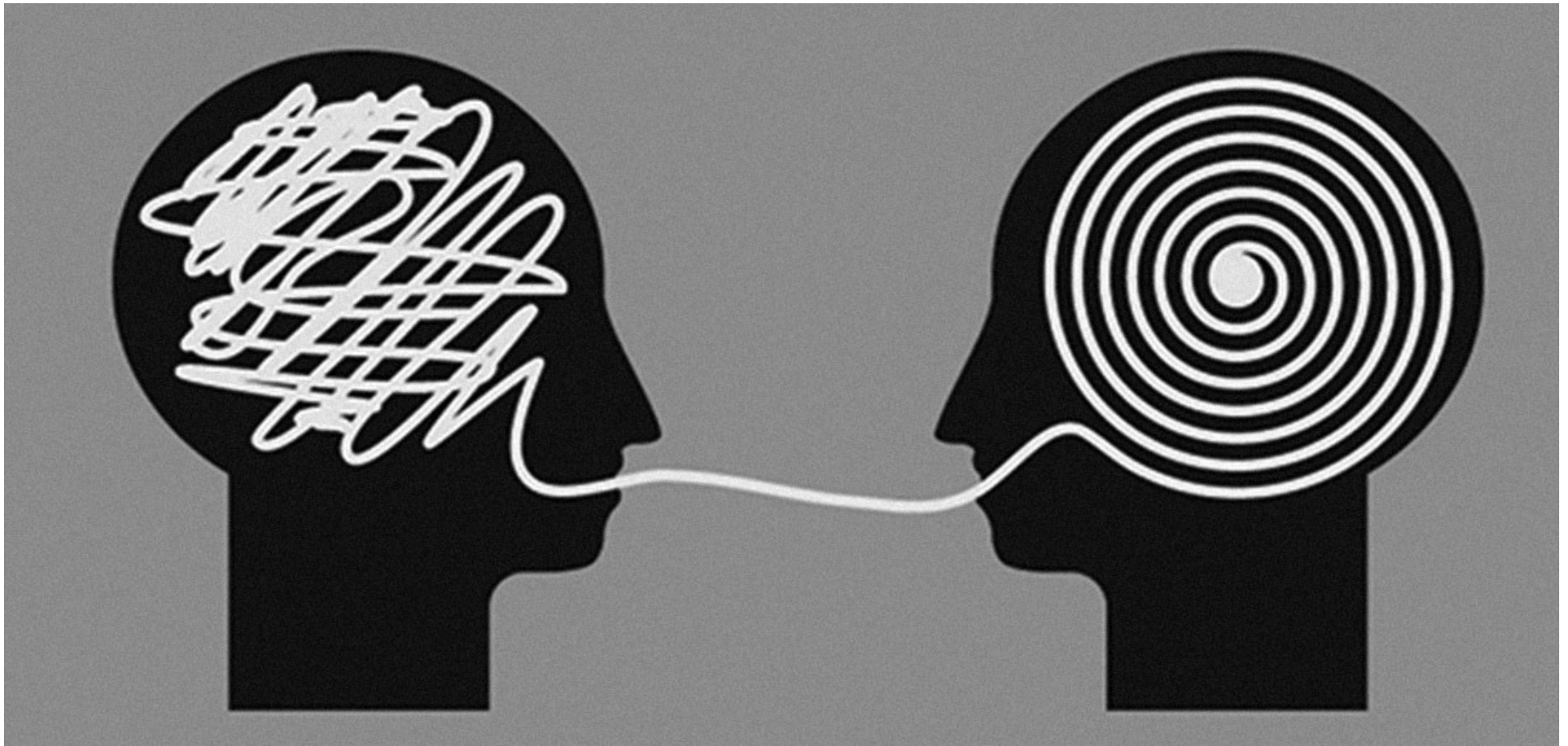
4. A.C.E.
5. Cede Power
6. Rapid prototyping 30-60-90

# Building your community





**Secret # 1: Understand the importance of language:  
labels, framing, narrative**





A silhouette of a person stands in the foreground, pointing towards the Milky Way galaxy in a vast, starry night sky. The galaxy is visible as a bright, hazy band of light stretching across the frame. The background is filled with numerous individual stars of varying colors and brightness. The overall scene is dark and atmospheric, with the person's silhouette providing a sense of scale and contemplation.

I have a dream for patients and families to...  
...get more access to palliative care and earlier

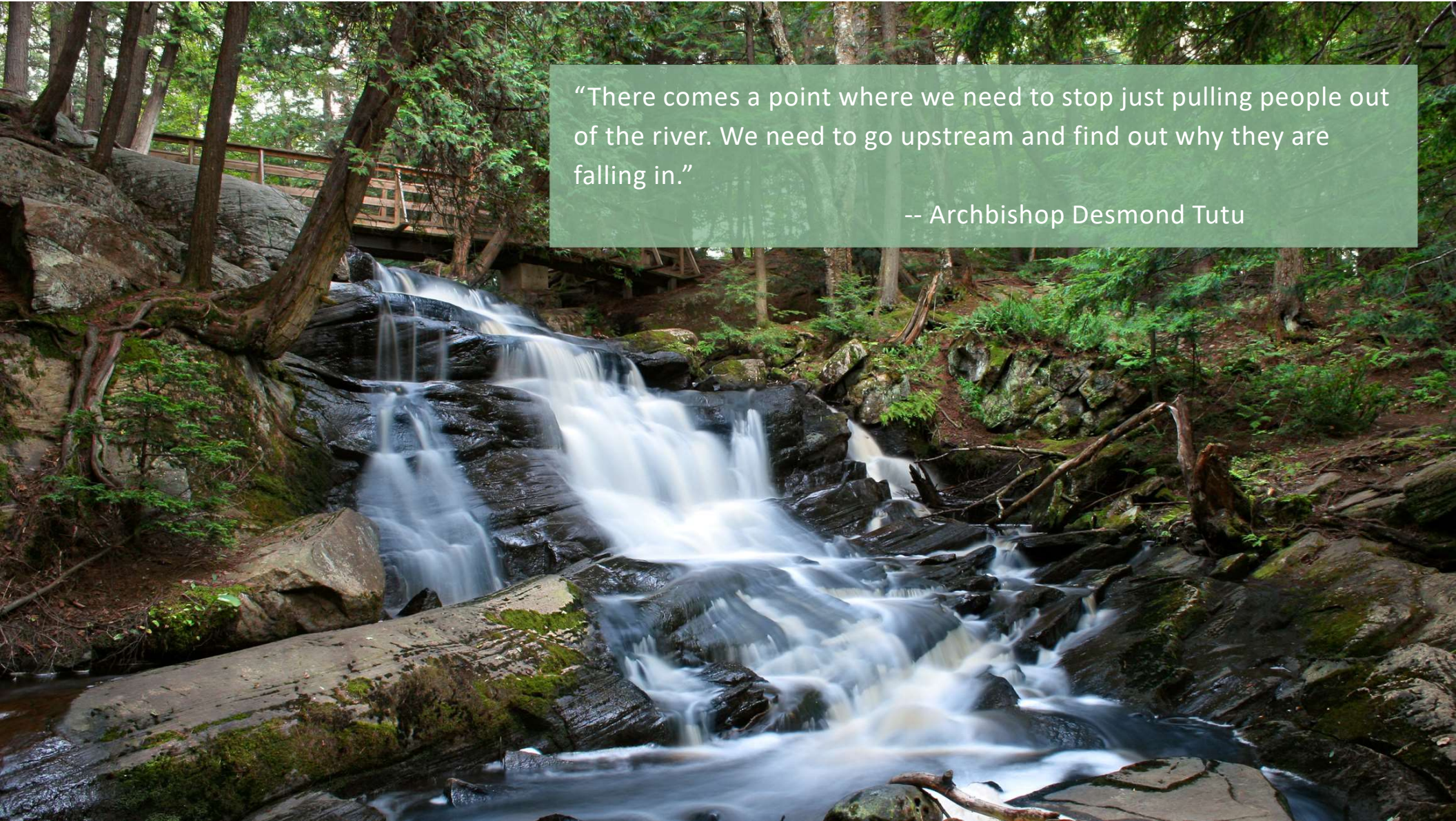


A silhouette of a person stands in the foreground, pointing their right hand towards the bright, glowing band of the Milky Way galaxy that stretches across the night sky. The sky is filled with numerous stars and the dense, dusty structure of the galaxy. The overall scene is dark and atmospheric, with the person's silhouette providing a sense of scale and human connection to the vast universe.

I have a dream for patients and families...

...to have a better experience when facing serious illness.





“There comes a point where we need to stop just pulling people out of the river. We need to go upstream and find out why they are falling in.”

-- Archbishop Desmond Tutu





## The Waiting Room REVOLUTION

is a movement designed  
for patients and families  
to transform the illness  
experience.



Join us!

# Naming the movement

[www.waitingroomrevolution.com](http://www.waitingroomrevolution.com)

# Waiting Room Revolution

## 7 keys to be prepared and hopeful when facing serious illness



### 1. WALK 2 ROADS

Hope for the best and prepare for different outcomes



### 3. KNOW YOUR STYLE

Recognize your strategies for coping and facing challenges



### 5. EXPECT RIPPLE EFFECTS

Prepare for the family's parallel journey



### 7. INVITE YOURSELF

Initiate conversations about what to expect

### 2. ZOOM OUT

Understand the big picture trajectory of your illness



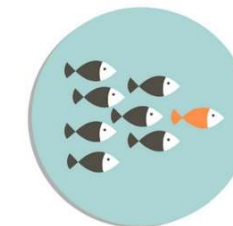
### 4. CUSTOMIZE YOUR ORDER

Tailor the care plan to your preferences



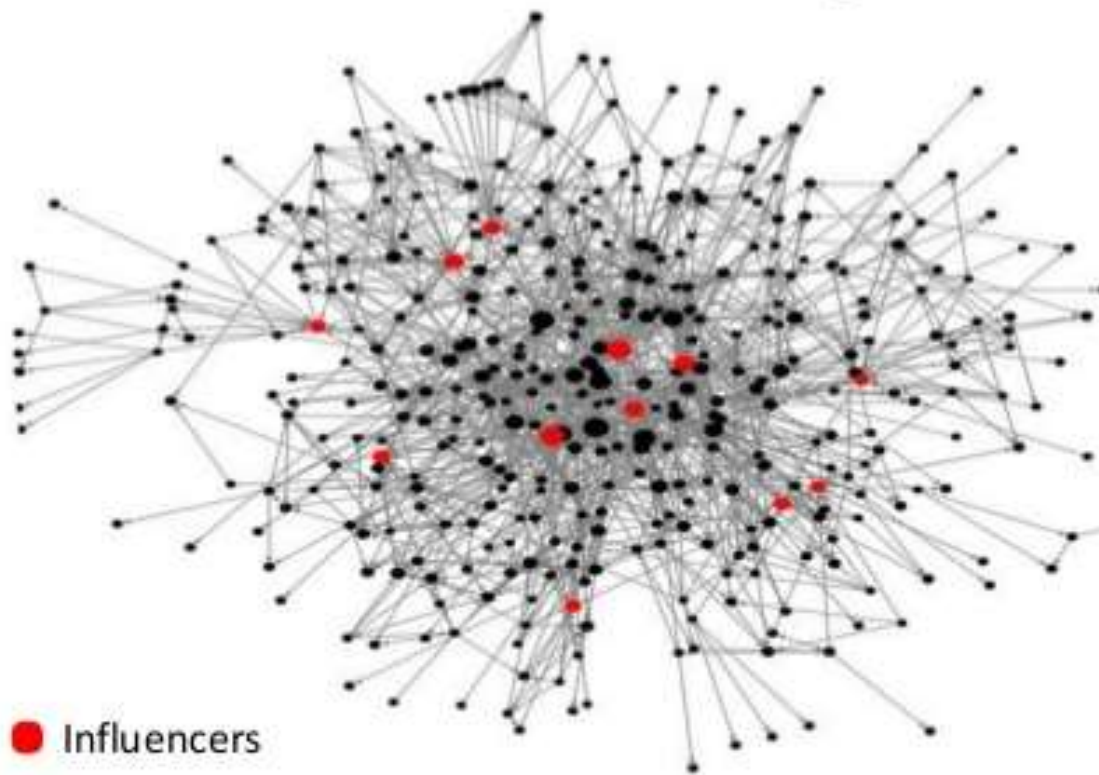
### 6. TAG, YOU'RE IT

Play a central role in connecting the dots



## Secret #2.

# Find the 3% “super-connectors”!



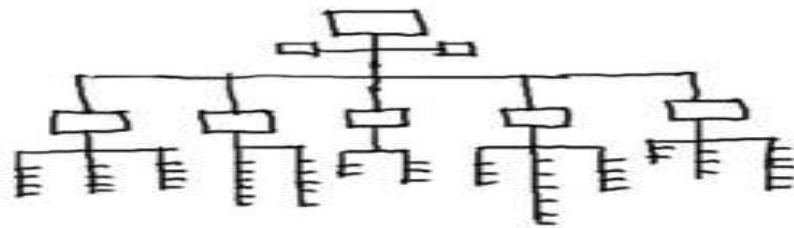
Just 3% of people in the organisation or system typically influence 85% of the other people

Source: Organisational Network Analysis by Innovisor

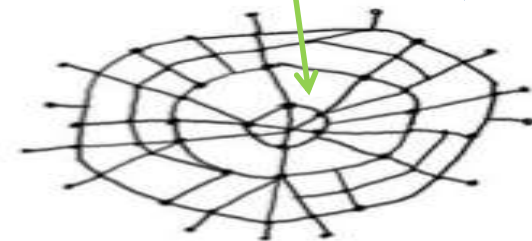
# As senior leaders, we are less influential than we think

If we want to get the same level of influence through top down change as the 3% get, we need **four times** more people

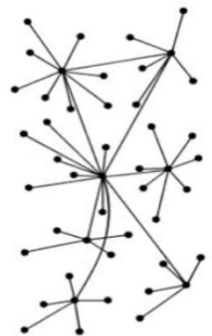
Source : Jeppe Hansgaard



Designed for **DIVISIONS**



Designed for **CONNECTIONS**





## Find the 3%: meet Mandy Carney, Head of Patient Flow at Yeovil Hospital



- “Knows everyone in the hospital”
- “Everyone follows Mandy on Facebook”
- The go-to person for advice
- Mandy makes sense of things and reduces ambiguity for people
- Mandy presents her own monthly award “the Carney cup”

	<b>Catherine Plumber</b> Emergency Department PA at Yeovil District Hospital NHS Foundation Trust
	<b>Helen Lowiss</b> The Sister at National Health Service
	<b>Emy Caines</b> Yeovil, Somerset
	<b>Jacqueline Daley</b> Yeovil, Somerset
	<b>Charlotte Gregory</b> Bristol, United Kingdom
	<b>Geraldine Herd</b>



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.

- [Listen on Apple Podcasts](#)
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- [LISTEN ON STITCHER](#)
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# 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.

Fantastic!

★★★★★

1y ago

famdockerr

Thank you Sammy and Hsien for a fantastic look at this difficult topic. This will prove a great resource for patients... but I think it should be mandatory listening for all healthcare practitioners involved in caring for people with chronic illnesses.

Thanks for simplifying this topic and making it accessible. I will definitely be recommending this to colleagues and patients alike.

Excellent. Practical and useful lesso... 1y ago

★★★★★

Jack477418414147148414

I binged the first season of this in a week. It was so practical and easy to listen to despite the challenging subject matter. I

★★★★★

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!

# The Podcast: s7 out now

- Co-hosts of The Waiting Room Revolution podcast focused on how a better patient family experience.
- >90 000 downloads
- Rated top 1.5% of global podcasts by ListenNotes.com
- Listened to in 82 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

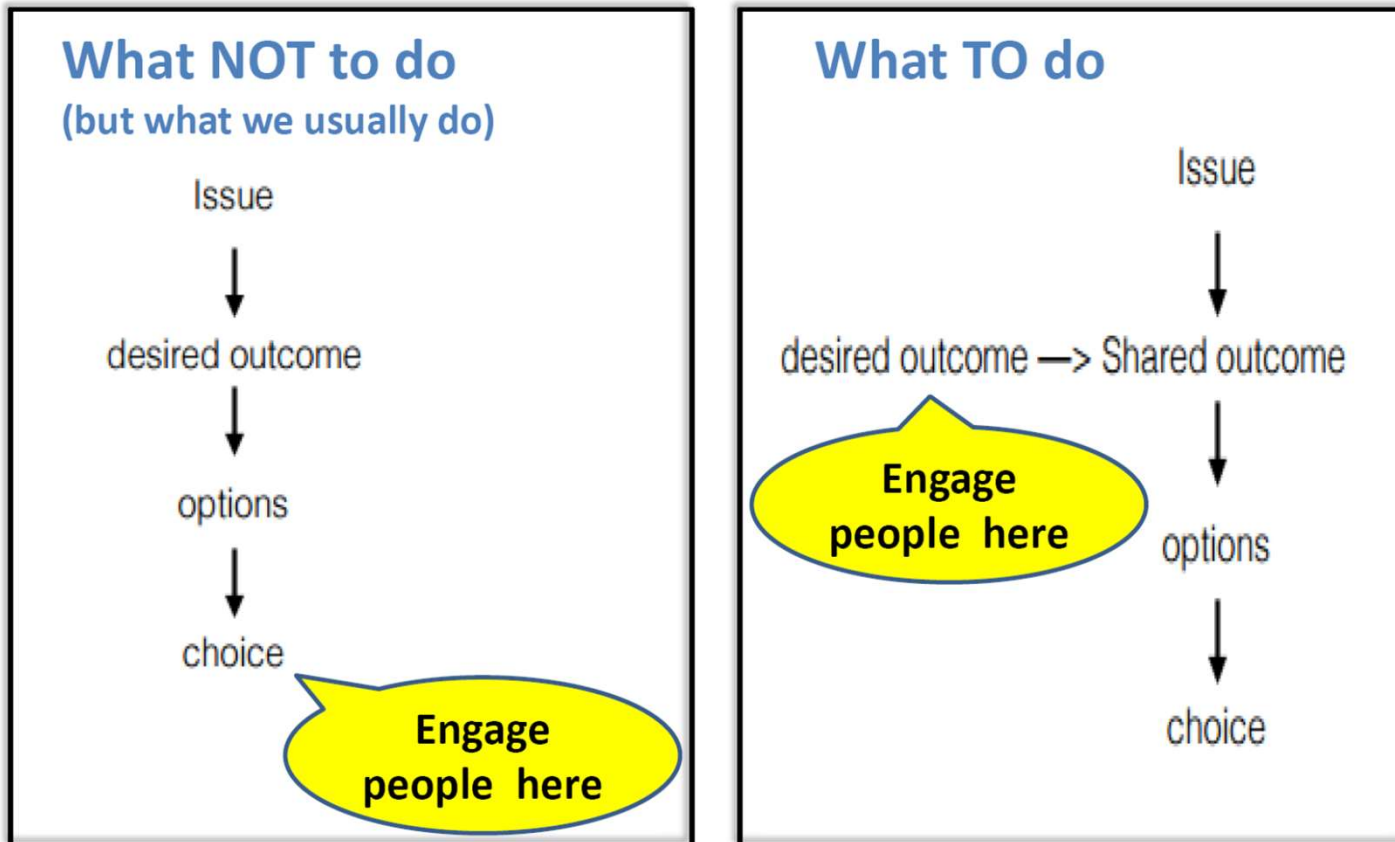




### 3. Get Investors not buy-in



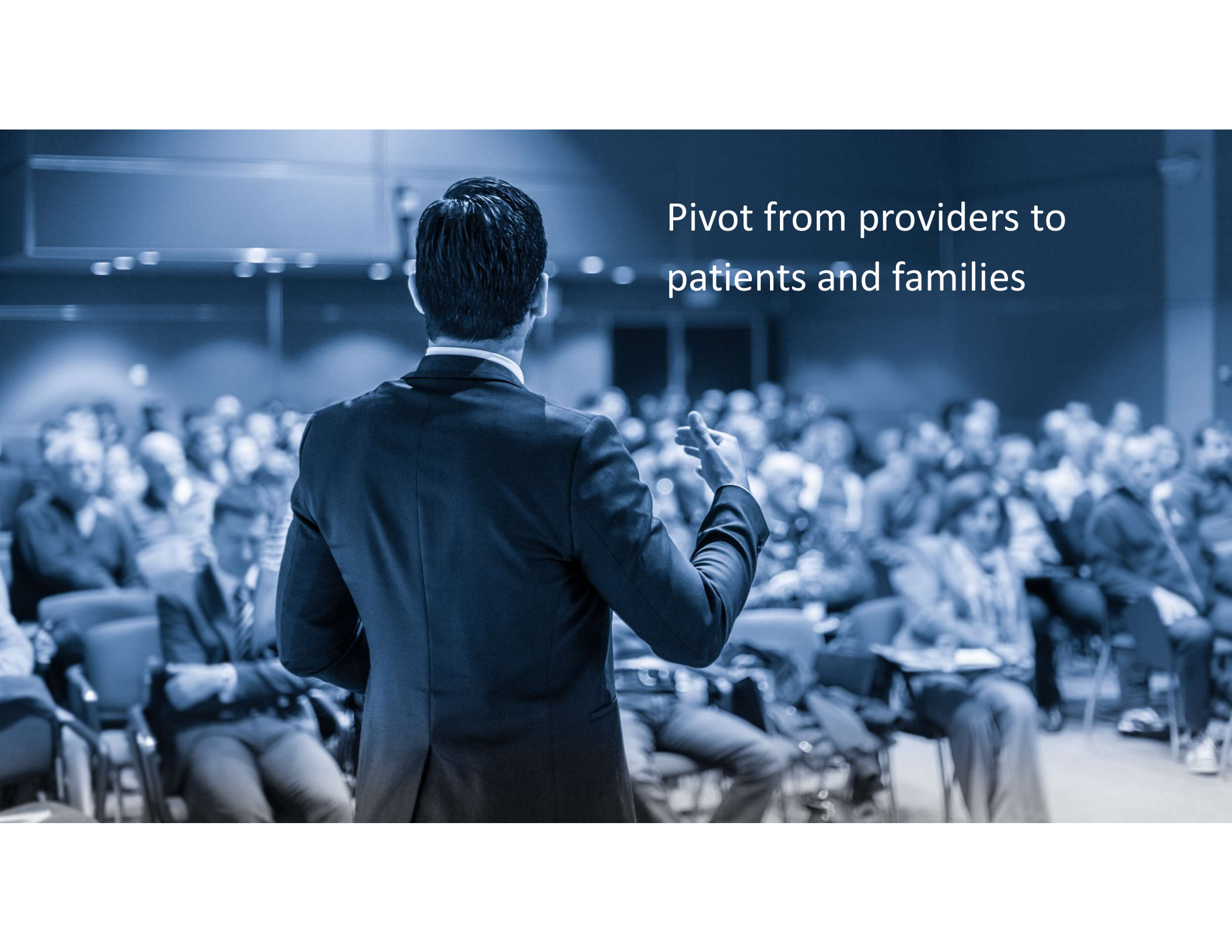
## Mark Jaben on the science behind resistance to change



**We don't need buyers (who "buy-in" to change)**

**We need investors**



A man in a dark suit is seen from behind, standing at the front of a lecture hall. He is gesturing with his right hand towards a large, seated audience. The room is filled with people, and the lighting is dim, creating a professional and focused atmosphere. The text "Pivot from providers to patients and families" is overlaid on the right side of the image.

Pivot from providers to  
patients and families

# Lessons Learned



## Metaphors

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Debate about using the p-word or the d-word, ultimately we didn't shy away from it, but let the patient-family guide us with their comfort level.

## Language matters

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Language, which was easy and sticky, allowed us to make alliances and partnerships easily.

## Provider Reaction

---

Health care provider reaction has been extremely positive; There is an pent up desire to broach this topic not just among palliative care providers.

## Upstream & Hopeful

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Ultimately, these helped remove some of the stigma about palliative care being negative and depressing to positive, upstream, and hopeful.

## Sharing Power

The movement helped to break down the power differential between patients-families and providers. It helped activate them and their voice





**Needed a roadmap – that  
addresses the hidden roadblocks**



Making  
ideas spread





## Secret #4. ACE principle for spreading change in the new era



**ACTIONABLE:** The idea is designed to make you do something. It might start with sharing but it's a call to action

**CONNECTED:** The idea promotes a closer connection with people you care about or share values with. It makes you feel part of a community and the network effect creates further spread

**EXTENSIBLE:** The idea can be easily customised, remixed, reshaped by people taking part. It's structured with a common stem that encourages communities to alter and extend it

Jeremy Heimens, Henry Timms [New Power: How it's changing the 21<sup>st</sup> Century and why you need to know](#) (2018)

# Waiting Room Revolution

## 7 keys to be prepared and hopeful when facing serious illness



### 1. WALK 2 ROADS

Hope for the best and prepare for different outcomes



### 3. KNOW YOUR STYLE

Recognize your strategies for coping and facing challenges



### 5. EXPECT RIPPLE EFFECTS

Prepare for the family's parallel journey



### 7. INVITE YOURSELF

Initiate conversations about what to expect

### 2. ZOOM OUT

Understand the big picture trajectory of your illness



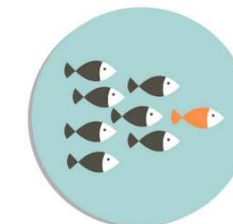
### 4. CUSTOMIZE YOUR ORDER

Tailor the care plan to your preferences



### 6. TAG, YOU'RE IT

Play a central role in connecting the dots





# Follow us #WaitingRoomRev

Instagram

April 2022

- April 5: C. Elizabeth Dougherty
- April 12: Sandra Holdsworth
- April 19: Dr. Fumiko Chino
- April 26: Jennifer Mallmes & Sarah Muxlow

Twitter

Have you listened yet? Check out our new episode with @CEDoughertyMSW, available on all podcast players now! <https://t.co/SqLOH1Wzcy>

"In any role, I think about how we might be able to just hold that silence or that space a little bit longer." <https://t.co/V66LOg2U8F>

Today is Green Shirt Day in Canada in honour of the Logan Boulot Effect to support organ donor awareness and regist... <https://t.co/NQupaPUtd>

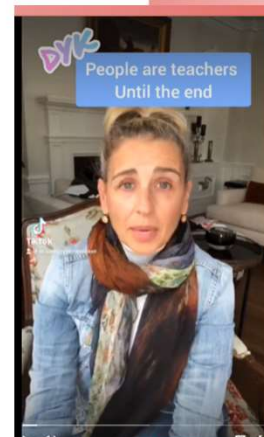
New #waitingroomrev! We chat with social worker @CEDoughertyMSW about the role of social work in #palliativecare... <https://t.co/9hyt2YGvjf>

RT @CarersCanada: On #NationalCaregiverDay, listen to the Prime Minister of Canada, Hon @JustinTrudeau's, remarks on the valuable contribut...

RT @CarersCanada: Learn how to support working caregivers here: <https://t.co/fpeybCJ8Vx>

## Videos

Check out our very own Dr. Sammy on TikTok! [@dr.sammywinemaker](https://www.tiktok.com/@dr.sammywinemaker)

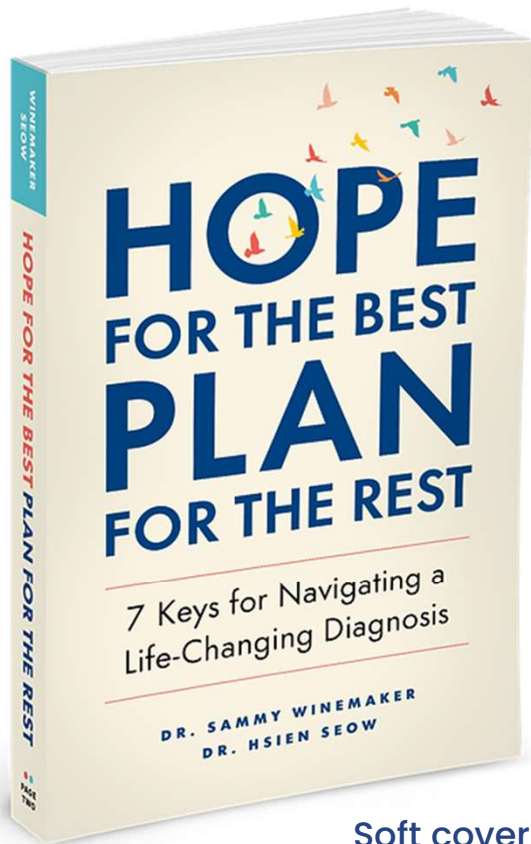


The LTC Chronicles Podcast  
Presented by the PCCA  
The LTC Chronicles Podcast - Dr. Helen Snow, PhD & Dr. Samantha Winemaker - Talk On Palliative Care

Lung Cancer Voices Podcast  
Ep 36 - Lung Cancer Voices Podcast

# Social Media & Presentations

in @HSeowPhD; @SammyWinemaker; @WaitingRoomRev  
 @dr.sammywinemaker  
 @sammy.winemaker  
 Media, Presentations, Other podcasts



Soft cover \$24.95

Also available in ebook & audiobook

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“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.”

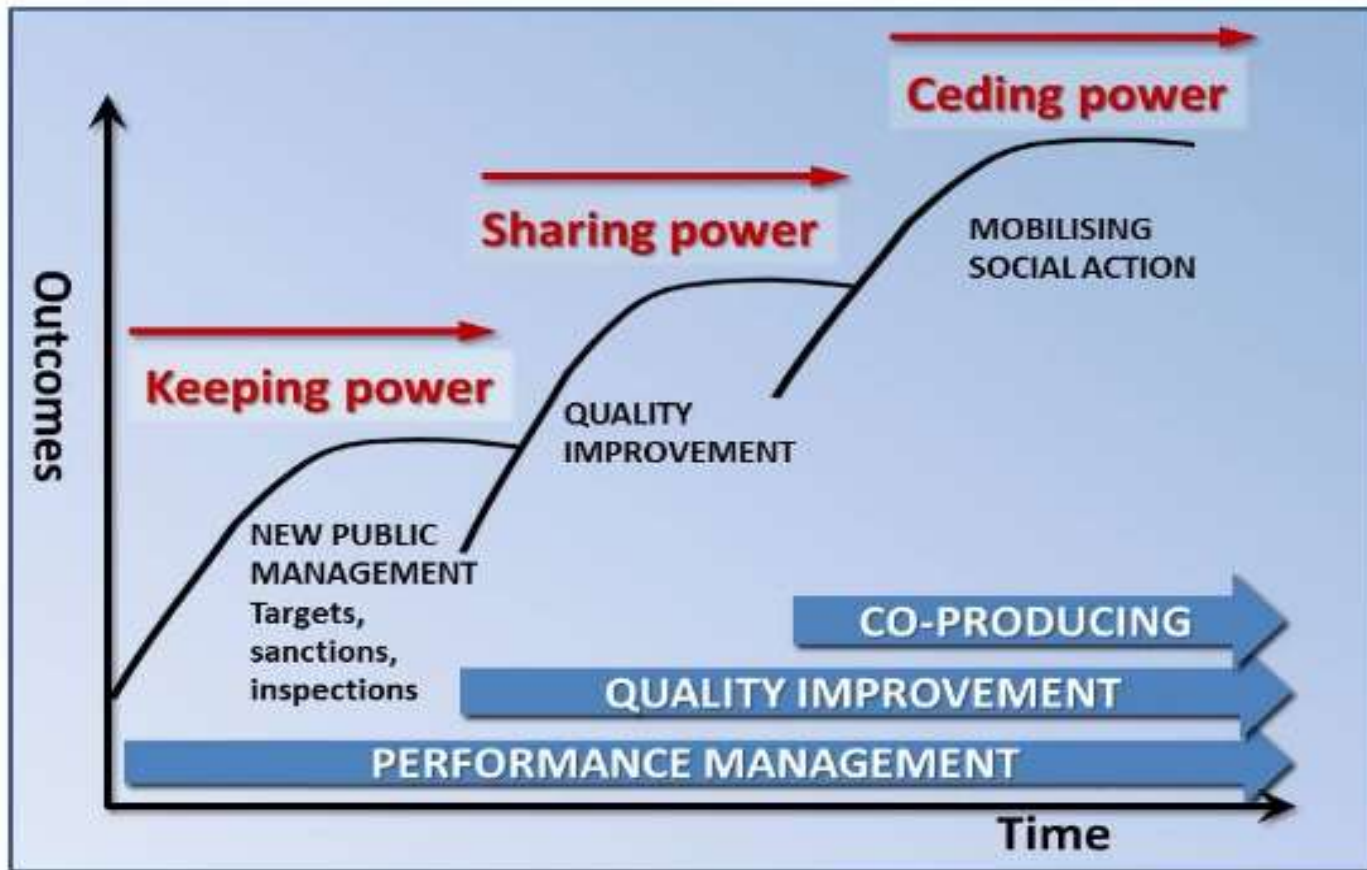
THERESA BROWN, RN, *New York Times*–bestselling author of *Healing*

“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*



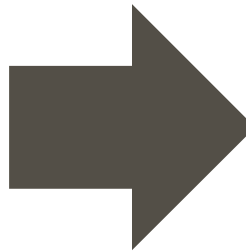
## Secret #5. Getting to the Third Curve





## The Waiting Room REVOLUTION







Unlocking the keys to a better illness experience



**IPEPA** 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?

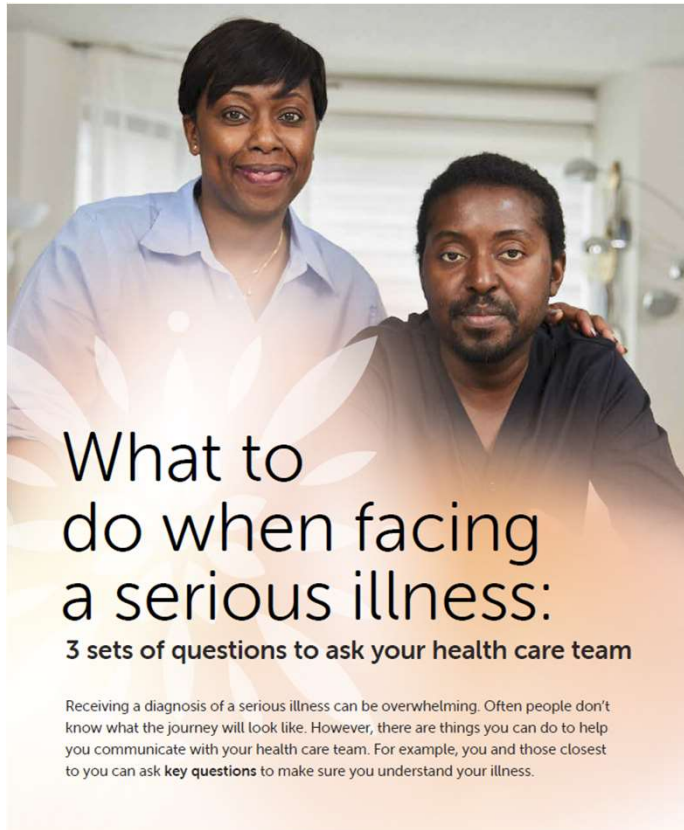
Harmful experience	Changing the experience	Healing experience
REACTIVE	 The ability to swim the river – hoping for the best and being prepared for the different currents - outcomes that may require you to adjust your swimming style. Realise that if you are still swimming, you have hope and this hope changes throughout the illness journey, but it never needs to be lost.	HOPEFUL
UNAWARE	 Understand the typical pattern or storyline of your illness. Knowing what to expect about how the illness will affect your life as things progress.	INFORMED
UNSURE	 Know your usual strategies for coping and facing challenges in life, so that you can better understand how you will cope with this challenge.	CONFIDENT
GENERIC NON-INDIGENOUS APPROACH	 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.	CULTURALLY SAFE AND RESPECTED
OVERWHELMED	 Expect that your illness will have ripple effects on your family and community. Ensure that your family, carers and community are supported so that you and your support system stay strong.	SUPPORTED
FRUSTRATED AND SCARED	 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.	PREPARED

SUBSCRIBE TO THE PODCAST HERE:  
[WAITINGROOMREVOLUTION.COM](http://WAITINGROOMREVOLUTION.COM)

HOSTED BY DR. SAMANTHA  
WINEMAKER AND DR. HSIEN SEOW

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





**1 What does it mean to have this serious illness?**

Not all serious illnesses are the same. Some can be cured while others can't. A person might have the illness their entire life. And some serious illnesses will get worse over time and shorten the person's life. It is important to know the 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 unique. But each serious illness has a general pattern based on the many people who have had it before. Thus, it's possible to learn what the illness looks like in the early, middle and later stages. Having a general sense of this pattern will help you understand where you are at in your illness and what you can expect in each stage.

Ask your health care team:

- Can you explain the big picture and the different stages of the illness?
- Am I currently in the beginning, middle or later stage of my illness?

**3 How can I prepare for what might come next?**

Throughout the illness there will be times when you need to make important decisions about what to do next. Combining information about what to expect, where things are now and what is most important to you will help you work with your health care team. Doing this will help you make decisions about your care that are right for you and those closest to you.

Ask your health care team:

- Can you explain what milestones and decision points are ahead in my illness and how we can plan for them?

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.

**For more information**

Information on serious illness and palliative care in Canada: [canada.ca/palliative-care](http://canada.ca/palliative-care)  
 Waiting Room Revolution – for information and resources to help patients and families who are facing serious illness (English only): [waitingroomrevolution.com](http://waitingroomrevolution.com)

**The Waiting Room REVOLUTION**

978-0-660-4862-7 (PDF)

<https://www.canada.ca/en/health-canada/services/health-services-benefits/palliative-care/awareness-tools.html>

Secret #6. 30-60-90 day cycles; rapid prototyping; collective action

“ We rarely see two, three or four year change projects any more. Now it’s 30-60-90 day change projects

Kinithi Sturtevant, IBM

[13<sup>th</sup> annual Change Management Conference](#) June 2015



 @HelenBevan #womenlead



# Pilots are being replaced by rapid tests and prototypes

Tests		Pilots
RAPID!	Speed to mobilize	SLOW!
WEEKS!	Duration	6-24 wks!
TEENY!	Cost	BIG!
BARELY ANY!	Resources required	LOADS!
PALETABLE!	Data required	EYE WATERING!
LIGHT TOUCH!	Management needed	SPOON FEEDING!
A-OK!	Risk	DANGER HIGH VOLTAGE!

Source: Bromford P (2015), "[What's the difference between a test and a pilot?](#)"

@HelenBevan #womenlead

LinkedIn

← Post

 **Cancer Canuck (Jason Manug...)** · 23h · ...

Congrats to [@SammyWinemaker](#) and [@HSeowPhD](#) on the release of Hope for the Best, Plan for the Rest!

I'm a few chapters in and can already tell this is a must-read for folks unsure how to navigate their illness.

An empowering read.

[#ColonCancer](#) [#StageIV](#) [#PalliativeCare](#)




7 12 85 2,713

I also had a good face-to-face with my **medical oncologist**, talking about return to work and zooming out on my situation to look at the big picture.

Leaving today's appointments with a much better handle on what's likely to happen next, where I am in my life with cancer, and a plan for pain management.

[#palliativecare](#) [#advancecareplanning](#)  
[#cancer](#) [#coloncancer](#) [#StageIV](#) [#mCRC](#)







**CONCLUSION**

## 6 secrets to scale and spread



### **Build your community**

1. Language matters
2. Find the superconnectors
3. Get investment not buy-in



### **Make ideas spread**

4. A.C.E.
5. Cede Power
6. Rapid prototyping 30-60-90

**1** PEOPLE own what they **HELP CREATE**

We create spaces where people with a diversity of views and experiences can come together and co-create the future so we get...

**BETTER, QUICKER, OUTCOMES**

**2** **REAL CHANGE** takes place in **REAL WORK**

We support the frontline staff who do the work to share ideas, experience and operational practise to speed up...

**LEARNING ACTION & CHANGE**

**3** The people who do the work do the **CHANGE**

We help people, staff and patients to build their **POWER** to make a difference

—The—  
**HORIZONS**  
**TEAM**



**4** **CONNECT** the system to **more of itself**

We connect thousands of people to each other, through social networks, virtual communities and social media

Principles taken from Myron Rogers: "Myron's Maxims"



# Directions in Making LARGE SCALE CHANGE HAPPEN

More FOCUS on

- Networks
- Communities
- Informal Power

Less Formal Change Management

More Choreography

More VIRTUAL CONNECTION

Identifying and working through

**SUPER CONNECTORS**

**MORE**  
30, 60, 90  
DAY CHANGE CYCLES

**YOUNG LEADERS**  
at the HEART of CHANGE

Less CHANGE Programmes

More CHANGE Platforms

Less "TOP-DOWN BOTTOM UP"

More "INSIDE-OUT, MIDDLE-LED"

**LESS**  
ONE or TWO YEAR Change Programmes



ILLUSTRATION / DAVE CUTLER

