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Project ECHO®

Palliative Care - Canada

WELCOME

7 Keys to Delivering Palliative Care Upstream: What we learned from 1,000 patients and families

Host and Moderator: Dr. José Pereira

Presenters: Dr. Samantha Winemaker and Dr. Hsien Seow

The Palliative Care ECHO Project – An Overview

- The Palliative Care ECHO Project is a national initiative to deliver technology-enabled interprofessional education and cultivate a community of practice and continuous professional development among health care professionals and members of our community who care for patients with life-limiting illness.

Stay connected

www.echopalliative.com

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Thank You

- The Palliative Care ECHO Project is supported by a financial contribution from Health Canada.

- Production of this document has been made possible through a financial contribution from Health Canada. The views expressed herein do not necessarily represent the views of Health Canada.

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Housekeeping

- Your microphones are muted. Use the raise hand feature and if time permits we will be able to unmute you.
- Use the Q&A function at the bottom of your screen to submit questions. Please do not use the chat function for questions.
- This session is being recorded and will be emailed to webinar registrants within the next few days.

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Conflict of Interest

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- Non-profit
- Partially funded through a contribution by Health Canada.
- Generates funds to support operations and R&D from course registration fees and sales of the Pallium Pocketbook

Presenters

- Dr. José Pereira – Paid by Pallium Canada as Scientific Officer
- Dr. Samantha Winemaker - None
- Dr. Hsien Seow - None

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Presenters

Host and Moderator

Dr. José Pereira MBChB, CFPC(PC), MSc, FCFP
Professor and Director, Division of Palliative Care, Department of Family Medicine, McMaster University, Hamilton, Canada
Scientific Officer, Pallium Canada

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Presenters

Samantha Winemaker MD, CCFP(PC)
Palliative care physician
Associate Clinical Professor, Dept of Family Medicine, Division of Palliative Care, McMaster University

Hsien Seow, PhD
Associate Professor, Dept of Oncology, McMaster University
Canada Research Chair in Palliative Care and Health System Innovation

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Learning objectives

- Describe a podcast project that aimed to implement a palliative care approach earlier
- Share 7 keys that were common to a better illness experience
- Have a discussion about concrete ways clinicians could incorporate these keys into practice

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Diagnosis –
5 years ago

Doctors: “This is a chronic illness. But don’t worry. We have an amazing respirology team here at this hospital, one of the best in the country. Let’s get you started on treatment.”

Family: “You have to think positively. Don’t lose hope. Hopefully the medication with cure the disease.”

Regular appts
with specialist

Stable-ish
Less appts with FP

Providers: “You are looking great today, Gerry! Keep it up.” Things are worsening slowly but Gerry is still able to function as he was.

Busy with appointments. He thinks his specialist is his new MRP. He assumes that the specialist and family practice are communicating about his illness.

Stamina is
decreasing

Period of decline
↑ breathlessness
↑ oxygen/month

The 15 min appt focused on his worsening O2 saturations. His home O2 increases…again. They change his medication. They run out of time to talk about decline in physical function and SOB.

Daughter: “His oxygen level keeps getting increased. What does that mean? I’m wondering how much time we have?”
Doctor: “I don’t have a crystal ball. Let’s cross that bridge when we get there.”

3 years into dx

Team tells him he needs a transplant

They discuss the steps in the process of getting a transplant.

Wife asks: “what would you do, doctor?”

He says: “Your options are transplant or death. Your best bet is to get stronger to qualify for the transplant.”

Regular appts
with respirology
and transplant
team

His physical condition ↓

He is getting worried. Wife says: Look no news is good news. They’ll tell us if there’s something we need to know.
She sees he isn’t eating well but they were told he must get stronger for the transplant. She calls the respirologist… she says, “Keep up the effort. You must fight. You have to eat well. We will arrange for a dietician.”
Also she says that he may qualify for a clinical trial which will allow them to access even newer treatment options. They will discuss it at the next visit.

1 year ago

He goes to ED 3x for his SOB.
↑ ↑ anxiety/fear re: suffocation

He is given more O2 in the ER. They do a chest xray and tell him he doesn’t have any chest infection or clot and that he can go home. They send him home on steroids. This same pattern happens each time.

Present
Day

Told no transplant. He requests MAID

You are too weak to qualify for a transplant. I’m sorry. There’s nothing more we can do for you here. Let me refer you to palliative care.

It is here, where he asked for MAID.

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

- Desmond Tutu

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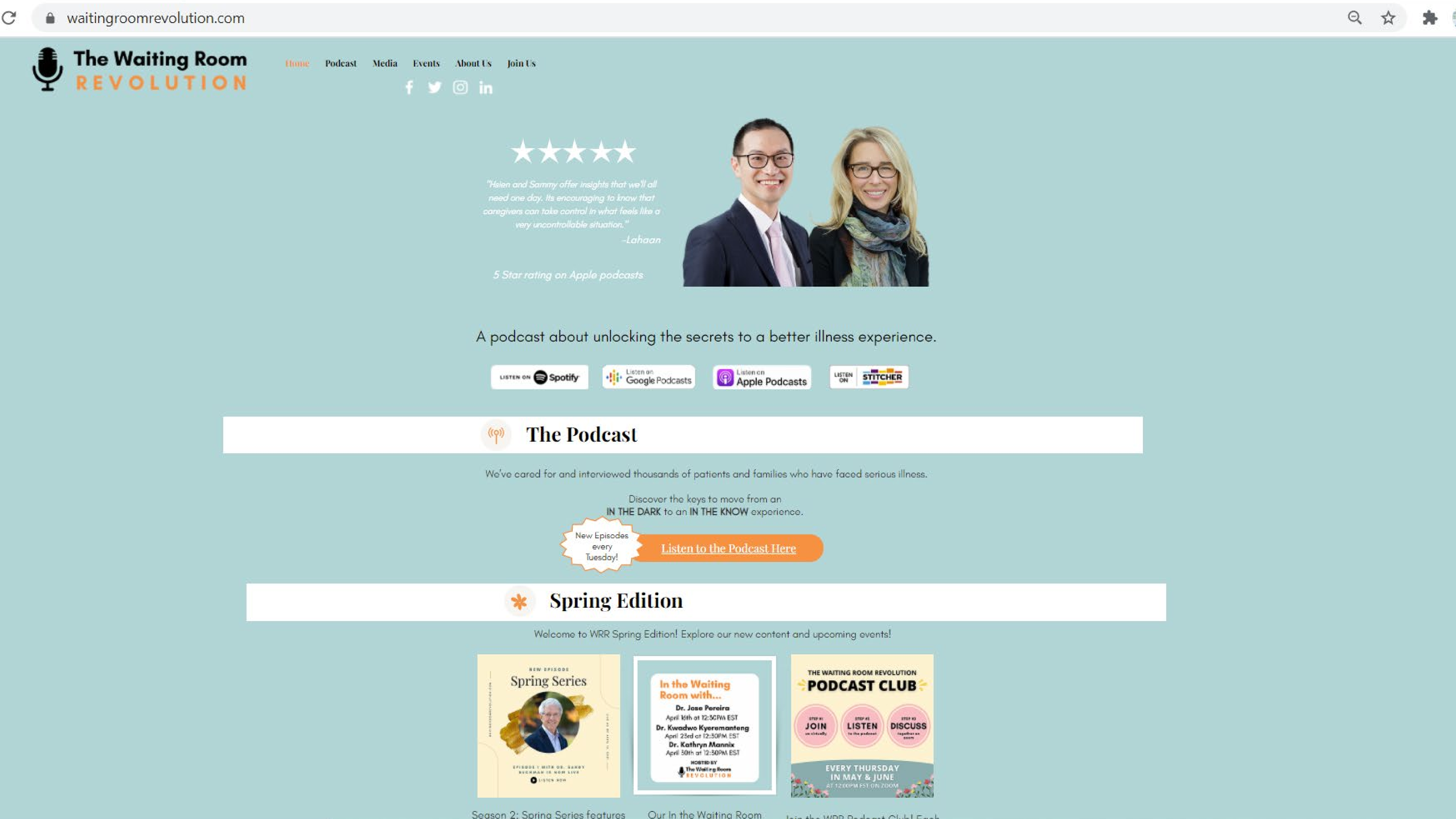
The Waiting Room REVOLUTION

A podcast to unlock the keys to a better illness experience

Dr. Hsien Seow & Dr. Samantha Winemaker



The Waiting Room
REVOLUTION

★★★★★

"Hsien and Sammy offer insights that we'll all need one day. Its encouraging to know that caregivers can take control in what feels like a very uncontrollable situation."
-Lahaan

5 Star rating on Apple podcasts

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

The Podcast

We've cared for and interviewed thousands of patients and families who have faced serious illness.

Discover the keys to move from an
IN THE DARK to an **IN THE KNOW** experience.

New Episodes every Tuesday!

Listen to the Podcast Here

Spring Edition

Welcome to WRR Spring Edition! Explore our new content and upcoming events!

NEW EPISODE
Spring Series
EPISODE 1 WITH DR. SANDY BUCHMAN IS NOW LIVE
LISTEN NOW

In the Waiting Room with...
Dr. Jose Pereira
April 16th at 12:30PM EST
Dr. Kwadwo Kyeremanteng
April 23rd at 12:30PM EST
Dr. Kathryn Mannix
April 30th at 12:30PM EST
HOSTED BY
The Waiting Room REVOLUTION

THE WAITING ROOM REVOLUTION
PODCAST CLUB
STEP #1 JOIN us virtually
STEP #2 LISTEN to the podcast
STEP #3 DISCUSS together on zoom
EVERY THURSDAY IN MAY & JUNE
AT 12:00PM EST ON ZOOM

Season 2: Spring Series features

Our In the Waiting Room

Join the WRR Podcast Club! Each

The Waiting Room REVOLUTION

Unlocking the keys to a better illness experience

REACTIVE	**WALK TWO ROADS** Hope for the best and prepare for different outcomes	**PREPARED**
UNAWARE	**ZOOM OUT** Understand the big picture trajectory of your illness	**INFORMED**
UNSURE	**KNOW YOUR STYLE** Recognize your strategies for coping and facing challenges	**CONFIDENT**
GENERIC	**CUSTOMIZE YOUR ORDER** Tailor the care plan to your preferences	**TAILORED**
OVERWHELMED	**EXPECT RIPPLE EFFECTS** Prepare for the family's parallel journey	**IN CONTROL**
FRUSTRATED	**TAG, YOU'RE IT** Play a central role in connecting the dots	**IN CHARGE**
SCARED	**INVITE YOURSELF** Initiate conversations about what to expect	**HOPEFUL**

SUBSCRIBE TO THE PODCAST HERE:
WAITINGROOMREVOLUTION.COM

HOSTED BY **DR. SAMANTHA WINEMAKER AND DR. HSIEN SEOW**

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↑ breathlessness
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3 years into dx

Team tells him he
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Regular appts with
respirology and
transplant team

His physical
condition ↓.
He is worried

1 year ago

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Day

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Doctors: “This is a chronic illness. But don’t worry. We have an amazing respirology team here at this hospital, one of the best in the country. Let’s get you started on treatment.”

Family: “You have to think positively. Don’t lose hope. Hopefully the medication with cure the disease.”

This is a condition that is non-curable and changes over time. My team and I are committed to trying to help you have the highest quality of life. No two patient journeys are the same. There is lots of uncertainty. I am here to help you **walk two roads**: to hope for the best, and to plan for the what if’s along the way.

The medication you are starting on is to help try to slow this illness as much as possible but it won’t get rid of it.

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Providers: “You are looking great today, Gerry! Keep it up.” Things are worsening slowly but Gerry is still able to function as he was.

Busy with appointments. He thinks his specialist is his new MRP. He assumes that the specialist and family practice are communicating about his illness.

(**Invite them**). I want you to know that I am here to help. Help you understand your illness better, help manage symptoms, and plan ahead for the future

I’ve cared for many people with this exact illness so I can describe the illness in general terms. You may also be curious about the average timeline of the illness and where you fall on the illness storyline. (**zoom out**)

Many people worry about suffocating to death.

Can you give me an idea about how much you want to be ‘in the know’ about your illness? To what level of detail? Straight up or sugar coated? (**know your style**)

Stay in contact with your family practice.

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Daughter: “His oxygen level keeps getting increased. What does that mean? I’m wondering how much time we have?”
Doctor: “I don’t have a crystal ball. Let’s cross that bridge when we get there.”

Shall we review what this illness journey looks like again? Are you curious where you are at in this journey? Does your mind ever wander into the future and wonder what’s next? (**Zoom out**)

Let’s talk about your symptoms. Self management strategies. If we are struggling with symptom management, the palliative care team can be very helpful in managing symptoms and maintaining the best quality of life.

BTW: Daughter, you have a critical role in your dad’s well-being. And if you or your mom have questions or need support, you should talk with your family doctor or me—because you are important in all this. Keeping track of what’s happening is going to be a key role, especially with home care and the oxygen, that you or someone may want to take on. who should I be liaising with in the family? **(Ripple effects and Tag you’re it)**

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Walk two roads again. Hope for the best. Here are other what ifs.

While you are exploring the option of lung transplant, we will continue to focus on your quality of life. Pulmonary rehabilitation is your best chance to maintain your function and meet the criteria for transplant, but ultimately your body will tell us if we can get you to maintain your strength. As you know, over time, it is normal to continue to lose stamina… (**zoom out**)

If you don’t get a transplant, this doesn’t mean that you will suffer until death. We will continue to focus on quality of life and symptom management as the illness changes. There are lots of supports out there for you and your family. (**Ripple effects/Tag you’re it**)

They discuss the steps in the process of getting a transplant.

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This is another chance for **zoom out**… which leads to **customize your order.**

"Have you noticed any changes in yourself? And if so, what do you think is going on?" Explore what their fears are, and how this illness might be interfering with their function, and the things that they enjoy in life, and understand what is important to them. So that their choices can reflect their values/goals of care.

Would it be helpful to have a dietitian come to the home to give you some tips? However, there is only so much you can do. We have to listen to his body…

He is getting worried. Wife says: Look no news is good news. They'll tell us if there's something we need to know.

She sees he isn't eating well but they were told he must get stronger for the transplant. She calls the respirologist… she says, "Keep up the effort. You must fight. You have to eat well. We will arrange for a dietician."

Also she says that he may qualify for a clinical trial which will allow them to access even newer treatment options. They will discuss it at the next visit.

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More of the same: **zoom out**…make meaning of the ER visits and decline.

Offer a home visit or virtual visit

Discuss their experience that triggered the ER visit, their experience in the hospital.

Ask about what is important to them.

Offer context, normalize the decline, discuss 'action plans in the home'.

Discuss what this next chapter is going to look like at home. Discuss the changing demands of caregiving, the supports, who to call etc.

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Day**

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Zoom out, tag you’re it, anticipate ripple effects. e.g. Explain resources. Who to call. Role of a back up plan.

Renew your vows.

Gerry sees that he can remain reasonably comfortable with good symptom control. He feels ‘in the know about his illness journey’.

He feels supported and that he has been treated as a person. No regrets about any of their decisions. They knew this decline was going to come at some point and they have been preparing for the possibility of no transplant.

They are award of MAiD….but this option is only a comfort and is on the back burner.

You are too weak to qualify for a transplant. I’m sorry. There’s nothing more we can do for you here. Let me refer you to palliative care.

It is here, where he asked for MAID.

Q&A

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THANK YOU

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