

# What's New in Palliative Care?

An Update for Primary Care Clinicians

Dr. Robin McClure, MD, CCFP (PC)

Physician, WRHA Adult & Pediatric Palliative Care Program

Lecturer, Department of Family Medicine

Member, Section of Pediatric Palliative Care, Department of Child Health

Max Rady College of Medicine

Rady Faculty of Health Sciences

University of Manitoba



# Faculty/Presenter Disclosure

- **Faculty:** Robin McClure, MD, CCFP(PC)
- **Relationships with financial sponsors:**
  - **Any direct financial relationships including receipt of honoraria:** 2022 Research Grant Received from Riverview Health Centre Foundation
  - **Memberships on advisory boards or speakers' bureau:** None
  - **Patents for drugs or devices:** None
  - **Other: (financial relationships/investments)** Contracted Consulting Physician for the WRHA Adult and Pediatric Palliative Care Program



# Mitigating Potential Bias

- No relationship between today's presentation and Riverview Health Centre Foundation or the research they funded
- Although currently contracted exclusively to provide services for the WRHA Palliative Care Program, previous general family practice experience mitigates some of the bias arising from working in a specialized practice for the past 15 years
- This presentation was reviewed by my fellow presenters, all of whom practice in primary care settings in addition to their work in specialized palliative care



# Copyright

- This copy is provided exclusively for research purposes and private study. Any use of the copy for a purpose other than research or private study may require the authorization of the copyright owner of the work in question. Responsibility regarding questions of copyright that may arise in the use of this copy is assumed by the recipient.



# Learning Objectives

At the completion of this presentation, participants will be able to:

- i. Describe the expanding reach of the palliative care approach using the bowtie model and the impacts on care provision
- ii. List recent developments in palliative care and consider their applicability to patients in your practice
- iii. Integrate the serious illness conversation guide and other evolving palliative care communication tools into routine clinical practice
- iv. Reflect upon and celebrate the unique contributions family physicians make in supporting patients and their families experiencing the challenges of serious and progressive terminal illness



## Traditional Territories Acknowledgement

The University of Manitoba campuses are located on original lands of Anishinaabeg, Cree, Ojibwe-Cree, Dakota, and Dene peoples, and on the National Homeland of the Red River Métis.

We respect the Treaties that were made on these territories, we acknowledge the harms and mistakes of the past, and we dedicate ourselves to move forward in partnership with Indigenous communities in a spirit of reconciliation and collaboration.



Turtle Island, by Patrick Hunter





A little about me...



# Palliative Care

“Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.”

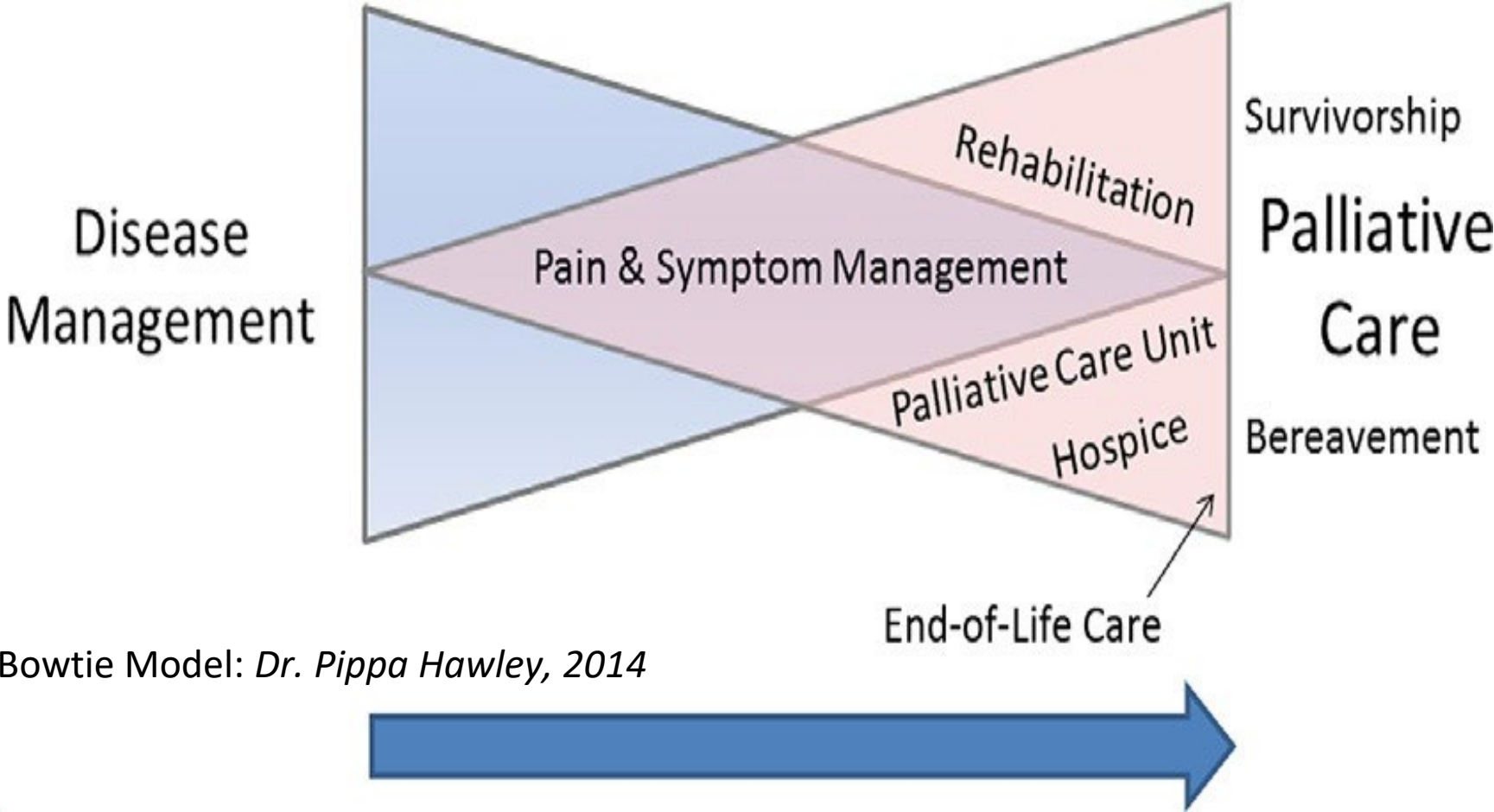
- *World Health Organization (2020)*

<https://www.who.int/teams/integrated-health-services/clinical-services-and-systems/palliative-care#:~:text=Palliative care aims to prevent,psychological, social and spiritual suffering.>





# Models of Palliative Care



Bowtie Model: *Dr. Pippa Hawley, 2014*



# Family Medicine

*“The specialty of family medicine is centered on lasting, caring relationships with patients and their families. Family physicians integrate the biological, clinical and behavioral sciences to provide continuing and comprehensive health care. The scope of family medicine encompasses all ages, sexes, each organ system and every disease entity.”*

- American Academy of Family Physicians



# Recent Developments

- ✓ Pharmacologic: methadone, buprenorphine, cannabinoids, psychedelics, pharmaco-vigilance
- ✓ Populations served: expanding demand from patients with non-malignant chronic disease, also neonatal, pediatric and young adult patients
- ✓ Use of prognostic tools and needs assessments in palliative care/hospice program enrollment process (SPICT, Gold Standards)
- ✓ Development of collaborative models of care: early Palliative Care referral stream at CancerCare Manitoba, similar initiatives in advanced chronic disease
- ✓ Expanded on-line education and support for patients/families/professionals: Canadian Virtual Hospice, Project ECHO, Pallium LEAP Courses, Mygrief.ca
- ✓ Development of standardized communication education and tools with adaptations for vulnerable/marginalized populations: Serious Illness Conversation Guide, VitalTalk



The SPICt™ is used to help identify people whose health is deteriorating. Assess them for unmet supportive and palliative care needs. Plan care.

Look for any general indicators of poor or deteriorating health.

- Unplanned hospital admission(s).
- Performance status is poor or deteriorating, with limited reversibility. (eg. The person stays in bed or in a chair for more than half the day.)
- Depends on others for care due to increasing physical and/or mental health problems. The person's carer needs more help and support.
- Progressive weight loss; remains underweight; low muscle mass.
- Persistent symptoms despite optimal treatment of underlying condition(s).
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Look for clinical indicators of one or multiple life-limiting conditions.

### Cancer

Functional ability deteriorating due to progressive cancer.  
Too frail for cancer treatment or treatment is for symptom control.

### Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; difficulty with swallowing.

Urinary and faecal incontinence.

Not able to communicate by speaking; little social interaction.

Frequent falls; fractured femur.  
Recurrent febrile episodes or infections; aspiration pneumonia.

### Neurological disease

Progressive deterioration in physical and/or cognitive function despite optimal therapy.

Speech problems with increasing difficulty communicating and/or progressive difficulty with swallowing.

Recurrent aspiration pneumonia; breathless or respiratory failure.

Persistent paralysis after stroke with significant loss of function and ongoing disability.

### Heart/vascular disease

Heart failure or extensive, untreatable coronary artery disease; with breathlessness or chest pain at rest or on minimal effort.

Severe, inoperable peripheral vascular disease.

### Respiratory disease

Severe, chronic lung disease; with breathlessness at rest or on minimal effort between exacerbations.

Persistent hypoxia needing long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

### Other conditions

Deteriorating from other conditions, multiple conditions and complications that are not reversible; best available treatment has a poor outcome.

### Kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.

Kidney failure complicating other life limiting conditions or treatments.

Stopping or not starting dialysis.

### Liver disease

Cirrhosis with one or more complications in the past year:

- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is not possible.

Review current care and care planning.

- Review current treatment and medication to make sure the person receives optimal care; minimise polypharmacy.
- Consider referral for specialist assessment if symptoms or problems are complex and difficult to manage.
- Agree a current and future care plan with the person and their family/people close to them. Support carers.
- Plan ahead early if loss of decision-making capacity is likely.
- Record, share, and review care plans.







# Serious Illness Conversations



[https://youtu.be/45b2QZxDd\\_o](https://youtu.be/45b2QZxDd_o)





# Serious Illness Conversation Guide

## CONVERSATION FLOW

### 1. Set up the conversation

- Introduce purpose
- Prepare for future decisions
- Ask permission

### 2. Assess understanding and preferences

### 3. Share prognosis

- Share prognosis
- Frame as a “wish...worry”, “hope...worry” statement
- Allow silence, explore emotion

### 4. Explore key topics

- Goals
- Fears and worries
- Sources of strength
- Critical abilities
- Tradeoffs
- Family

### 5. Close the conversation

- Summarize
- Make a recommendation
- Check in with patient
- Affirm commitment

### 6. Document your conversation

### 7. Communicate with key clinicians

# Serious Illness Conversation Guide

## PATIENT-TESTED LANGUAGE

**SET UP** “I’d like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — **is this okay?**”

**ASSESS** “What is **your understanding** now of where you are with your illness?”  
“How much **information** about what is likely to be ahead with your illness would you like from me?”

**SHARE** “I want to share with you **my understanding** of where things are with your illness...”  
*Uncertain:* “It can be difficult to predict what will happen with your illness. I **hope** you will continue to live well for a long time but I’m **worried** that you could get sick quickly, and I think it is important to prepare for that possibility.”  
OR  
*Time:* “I **wish** we were not in this situation, but I am **worried** that time may be as short as \_\_\_ (*express as a range, e.g. days to weeks, weeks to months, months to a year*).”  
OR  
*Function:* “I **hope** that this is not the case, but I’m **worried** that this may be as strong as you will feel, and things are likely to get more difficult.”

**EXPLORE** “What are your most important **goals** if your health situation worsens?”  
“What are your biggest **fears and worries** about the future with your health?”  
“What gives you **strength** as you think about the future with your illness?”  
“What **abilities** are so critical to your life that you can’t imagine living without them?”  
“If you become sicker, **how much are you willing to go through** for the possibility of gaining more time?”  
“How much does your **family** know about your priorities and wishes?”

**CLOSE** “I’ve heard you say that \_\_\_ is really important to you. Keeping that in mind, and what we know about your illness, I **recommend** that we \_\_\_. This will help us make sure that your treatment plans reflect what’s important to you.”  
“How does this plan seem to you?”  
“I will do everything I can to help you through this.”



© 2015-2017 Ariadne Labs: A Joint Center for Health Systems Innovation (www.ariadnelabs.org) between Brigham and Women’s Hospital and the Harvard T.H. Chan School of Public Health, in collaboration with Dana-Farber Cancer Institute. Licensed under the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 International License, <http://creativecommons.org/licenses/by-nc-sa/4.0/>

SI-CG 2017-04-18



© 2015-2017 Ariadne Labs: A Joint Center for Health Systems Innovation (www.ariadnelabs.org) between Brigham and Women’s Hospital and the Harvard T.H. Chan School of Public Health, in collaboration with Dana-Farber Cancer Institute. Licensed under the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 International License, <http://creativecommons.org/licenses/by-nc-sa/4.0/>

SI-CG 2017-04-18



<https://www.ariadnelabs.org/serious-illness-care/>



Sample conversation: <https://youtu.be/ehf8Q8RDcLE>

# NURSE

## STATEMENTS FOR ARTICULATING EMPATHY

STEP	EXAMPLE	NOTES
<b>NAME</b>	<i>"It sounds like you are frustrated."</i>	In general, turn down the intensity a notch when you name the emotion.
<b>UNDERSTAND</b>	<i>"This helps me understand what you are thinking."</i>	Think of this as another kind of acknowledgement. Stop short of suggesting that you understand everything (you don't).
<b>RESPECT</b>	<i>"I can see that you've really been trying to follow our instructions."</i>	Praise also fits in here: e.g. <i>"I think you have done a great job with this."</i>
<b>SUPPORT</b>	<i>"I will do my best to make sure you have what you need."</i>	Making this kind of commitment is a powerful statement.
<b>EXPLORE</b>	<i>"Could you say more about what you mean when you say that..."</i>	Asking a focused question prevents this from seeming too obvious.



VitalTalk. (2024). *Courses.*

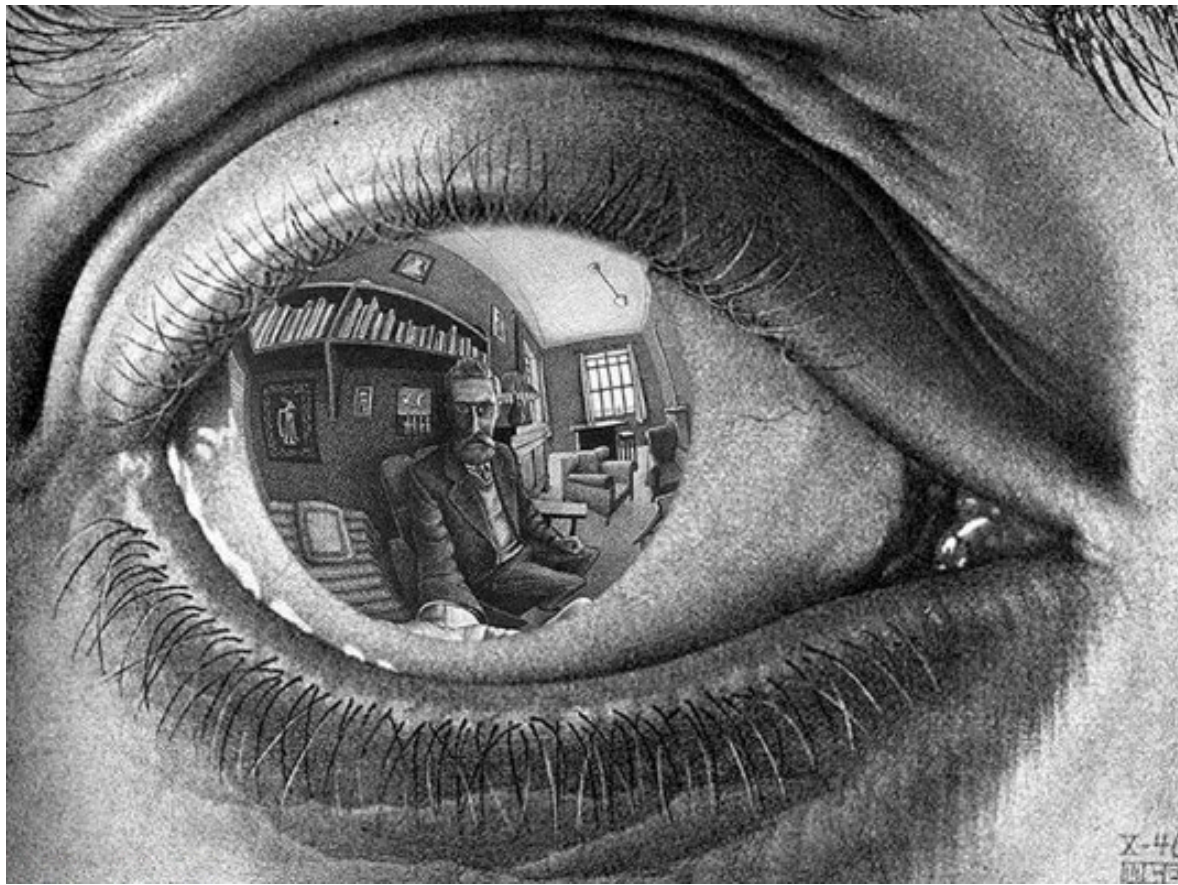
<https://www.chooseyourpath.vitaltalk.org>

# “Fighters”



VitalTalk. (2024). *Clinicians*. <https://www.vitaltalk.org/clinicians/>  
Vimeo. (2023). <https://vimeo.com/188609687>





“What is spoken of as a “clinical picture” is not just a photograph of a sick man in bed; it is an impressionistic painting of the patient surrounded by his home, his work, his relations, his friends, his joys, sorrows, hopes and fears.”

**Journal of the American Medical Association (JAMA 1927; 88:877-882)**

**From a talk delivered to a group of Harvard Medical students by Dr. F Peabody  
on October 21, 1926**





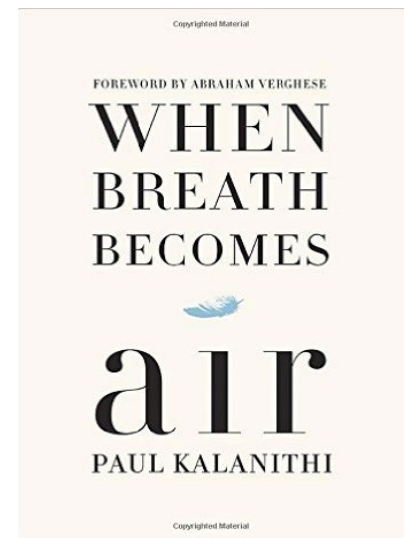




“my highest ideal was not saving lives—everyone dies eventually—but guiding a patient or family to an understanding of death or illness. When a patient comes in with a fatal head bleed, that first conversation with a neurosurgeon may forever color how the family remembers the death, from a peaceful letting go (“Maybe it was his time”) to an open sore of regret (“Those doctors didn’t listen! They didn’t even try to save him!”). When there’s no place for the scalpel, words are the surgeon’s only tool”

Excerpt From

Kalanithi, Paul. [“When Breath Becomes Air.”](#)







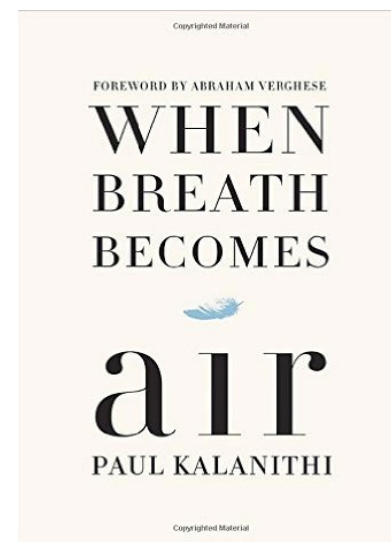
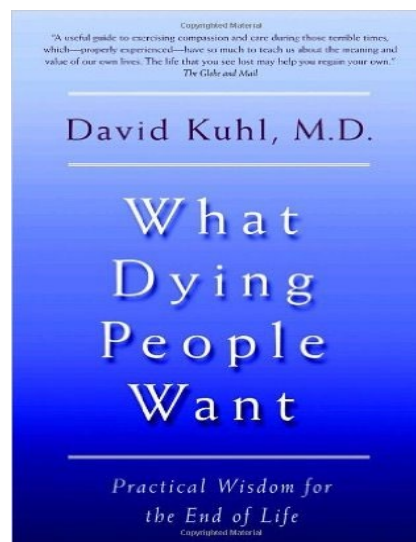
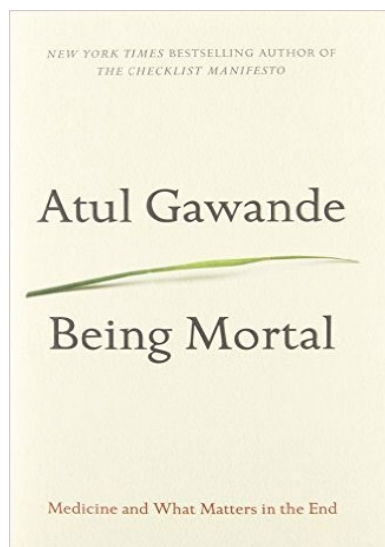
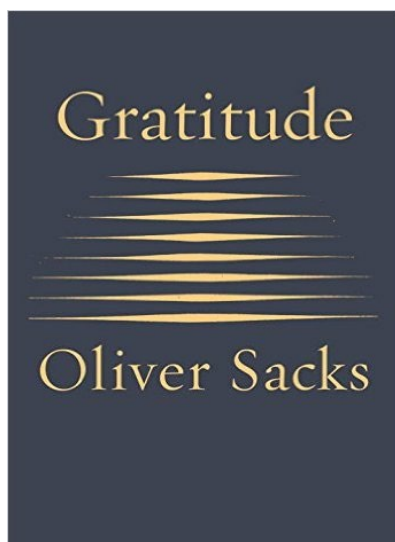








# Additional Resources



“Final Weeks and Days: What to expect”



# References

1. World Health Organization. (2020, August 5). *Palliative Care*. [www.who.int  
https://www.who.int/news-room/fact-sheets/detail/palliative-care](https://www.who.int/news-room/fact-sheets/detail/palliative-care)
2. Hawley, Pippa. (2015, January). *The Bow Tie Model of 21<sup>st</sup> Century Palliative Care*. Canadian Virtual Hospice. [https://www.virtualhospice.ca/en\\_US/Main+Site+Navigation/Home/For+Professionals/For+Professionals/The+Exchange/Current/The+Bow+Tie+Model+of+21st+Century+Palliative+Care.aspx](https://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/For+Professionals/For+Professionals/The+Exchange/Current/The+Bow+Tie+Model+of+21st+Century+Palliative+Care.aspx)
3. The University of Edinburgh. (2022). *SPICT*. <https://www.spict.org.uk/the-spict/>
4. Youtube [Video]. <https://youtu.be/ehf8Q8RDcIE>
5. Ariadne Labs. (2024). *Serious Illness Care*. <https://www.ariadnelabs.org/serious-illness-care/>
6. Youtube [Video]. <https://youtu.be/ehf8Q8RDcIE>
7. VitalTalk. (2024). *Courses*. <https://www.chooseyourpath.vitaltalk.org/>
8. VitalTalk. (2024). *Clinicians*. <https://www.vitaltalk.org/clinicians/>
9. Journal of the American Medical Association (JAMA 1927; 88:877-882)

