



Integrated Palliative Nephrology- Helping persons with kidney disease live their best life.

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Disclosure

- I am a palliative care physician and as such, I care for people
 - Living with serious illness
 - Approaching the last part of their lives
- I am the medical director of a non-profit organization-Victoria Hospice Society
 - I believe that our communities would benefit from acknowledging the “Value in Dying” as a way to “Value our living”

Objectives and Outcomes

- Describe the evolution of palliative care models for end of life only, to their current integration into chronic disease management.
- Outline the multidimensional domains required of our health systems to support meaningful, person and family centered outcomes.
- Commit to one of the many ways in which the learner can make changes in their clinical, administrative or patient advocacy activities to improve whole person centered care.

Let's start at (a)
beginning.....

*Cecily Saunders-The
Grandmother of Hospice
Palliative Care.*

*You Matter Because You are
You, and you matter until
the end of your life.*

*And we will help you live
until you die.*



Gerard

86 year old retired farmer with chronic kidney disease.

He continues to be active in his garden, visiting with family.

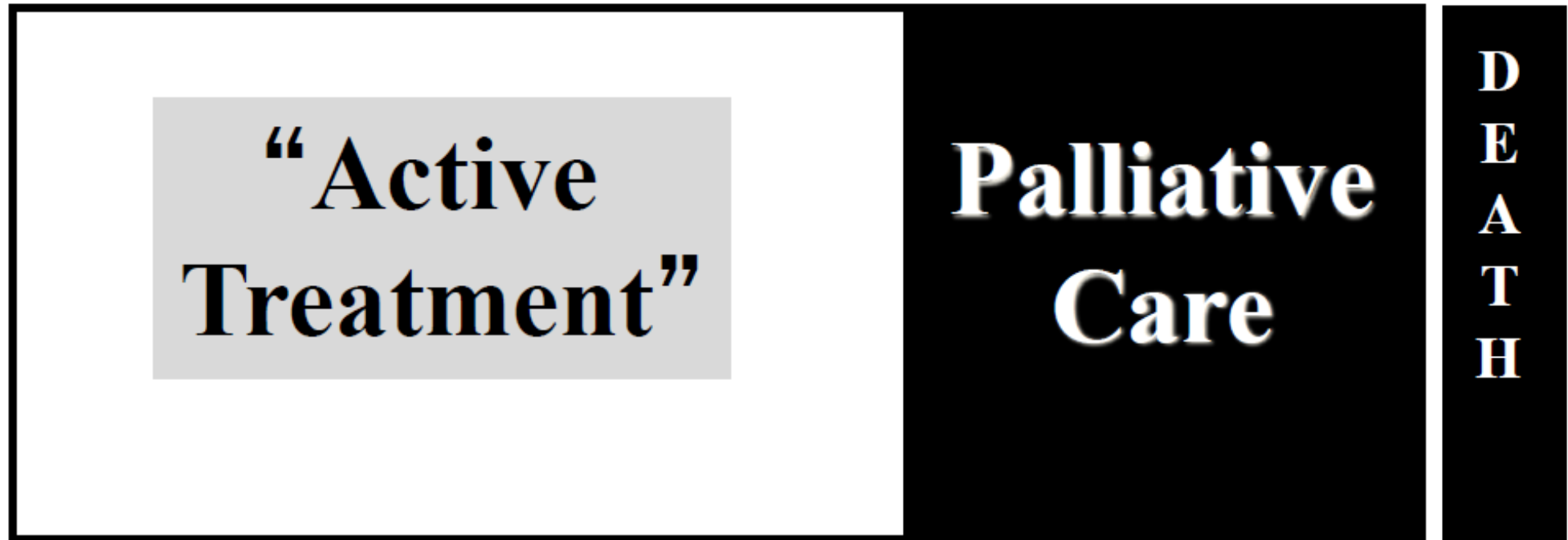
He develops a cancer in his lung which is treated with chemotherapy and radiotherapy.

He “wants everything”

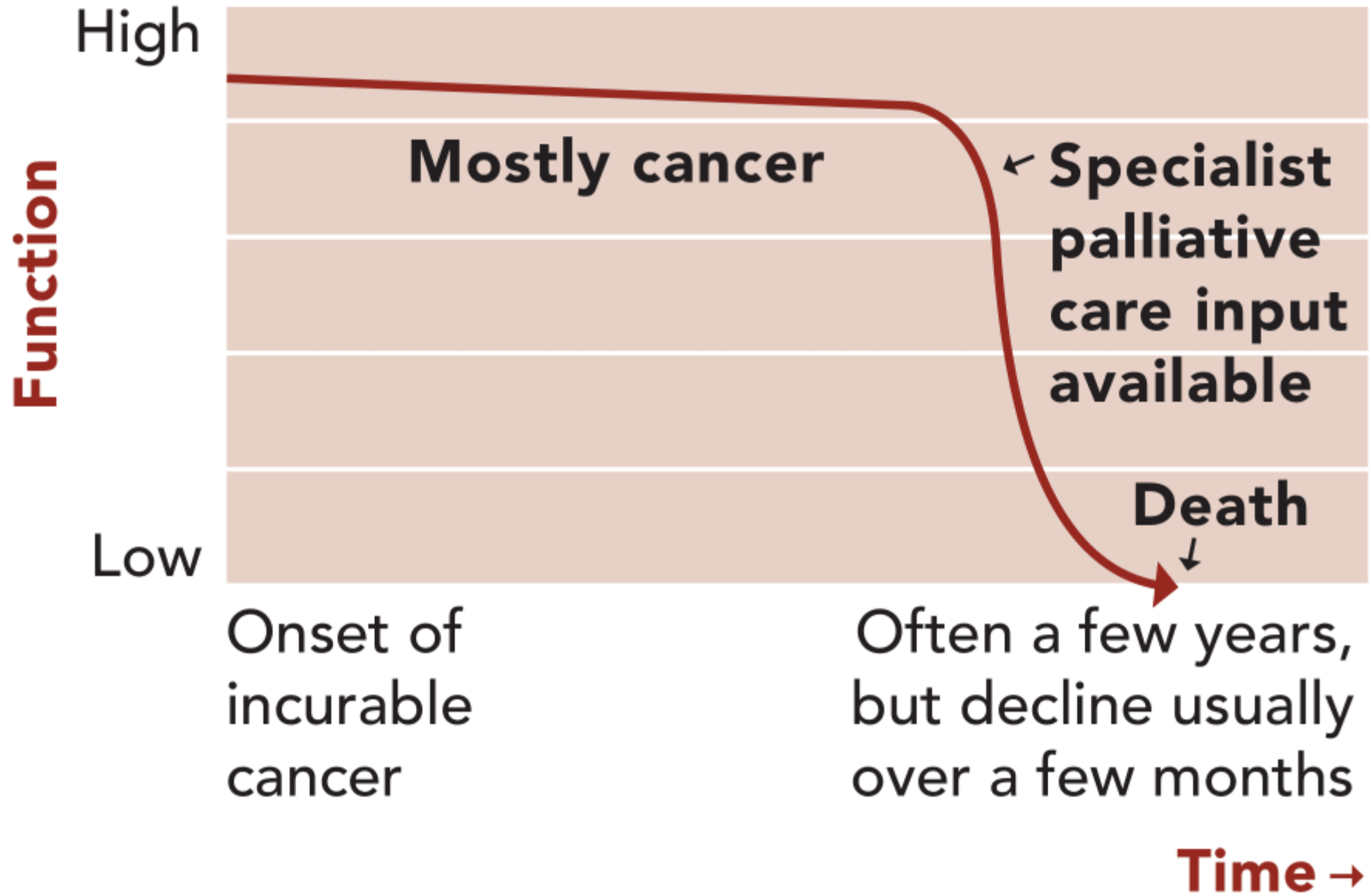
More importantly, he wants to know what to expect from the future.



Very early model for Hospice-Palliative Care



Short period of evident decline



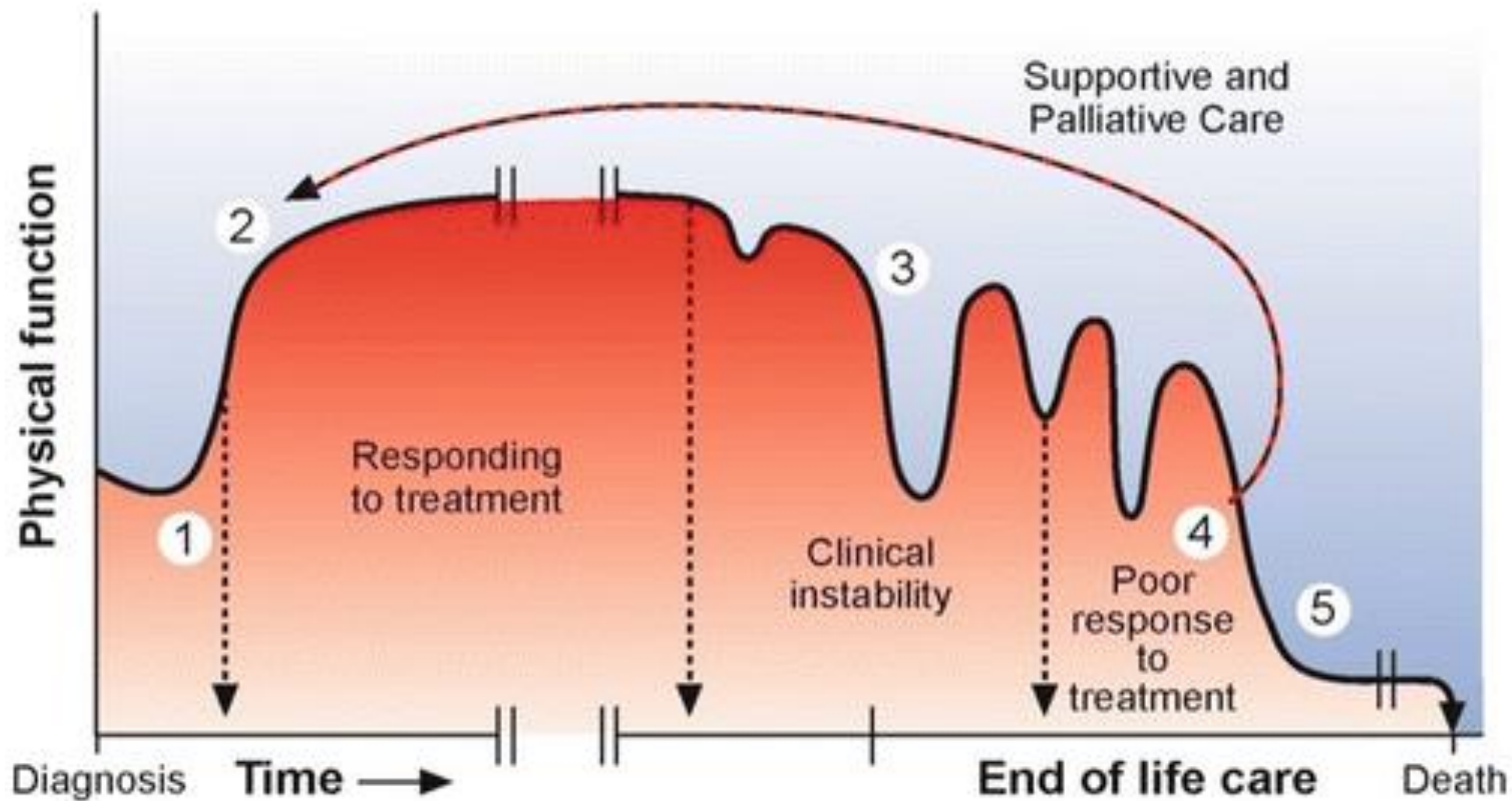
Gerard

86 year old retired farmer with chronic kidney disease.

He has a number of other medical problems, including heart disease

Gerard and his daughter want to know what to expect.





..... Sudden death event

— Transplant

Palliative Approach Dr.
Joanne Lynne

When does chronic
disability/disease
become dying??

When is it time to
institute a palliative
approach?



Who definition of 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

Prevents and relieves suffering

Through the early identification,

Correct assessment and

Treatment of pain and other problems,

Whether physical, psychosocial or spiritual

- 1992, first paper arguing that **Palliative Care is a Human Right**

Evolving model of palliative care



Gerard

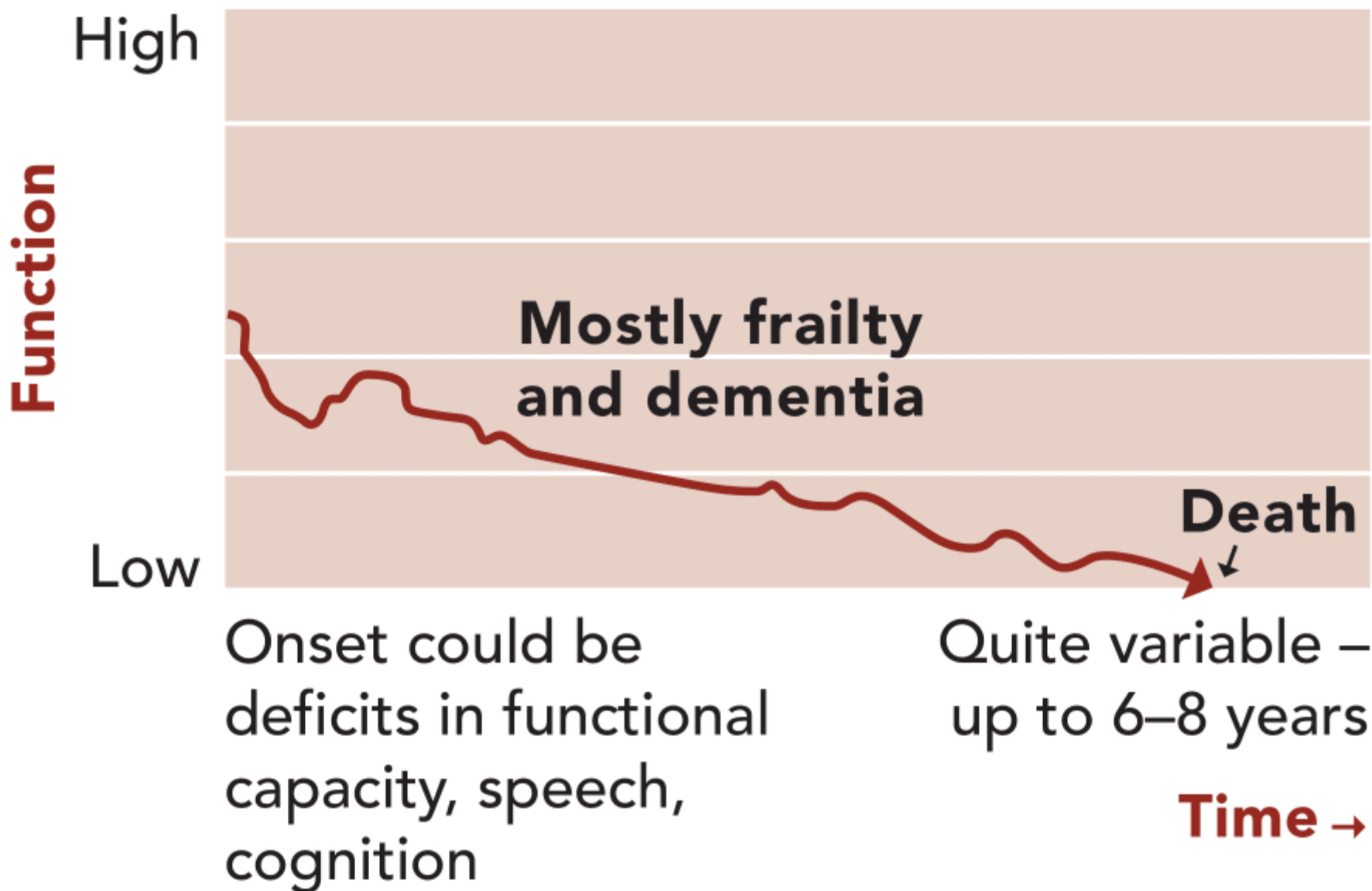
86 year old retired farmer with chronic kidney disease.

He has developed dementia and is getting very frail, spending most of his time sitting, no longer in his garden.

What does his future look like?



Prolonged dwindling

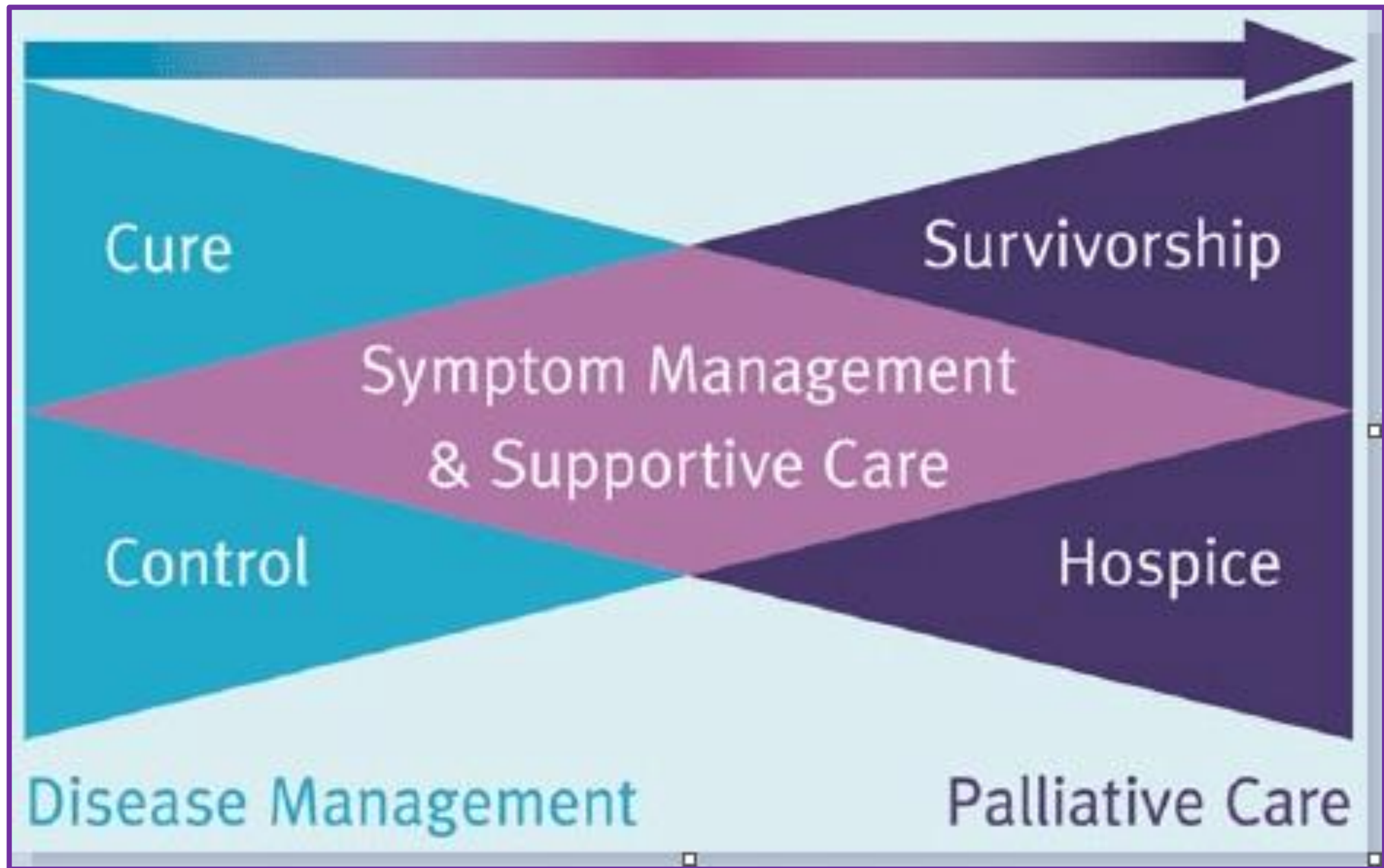


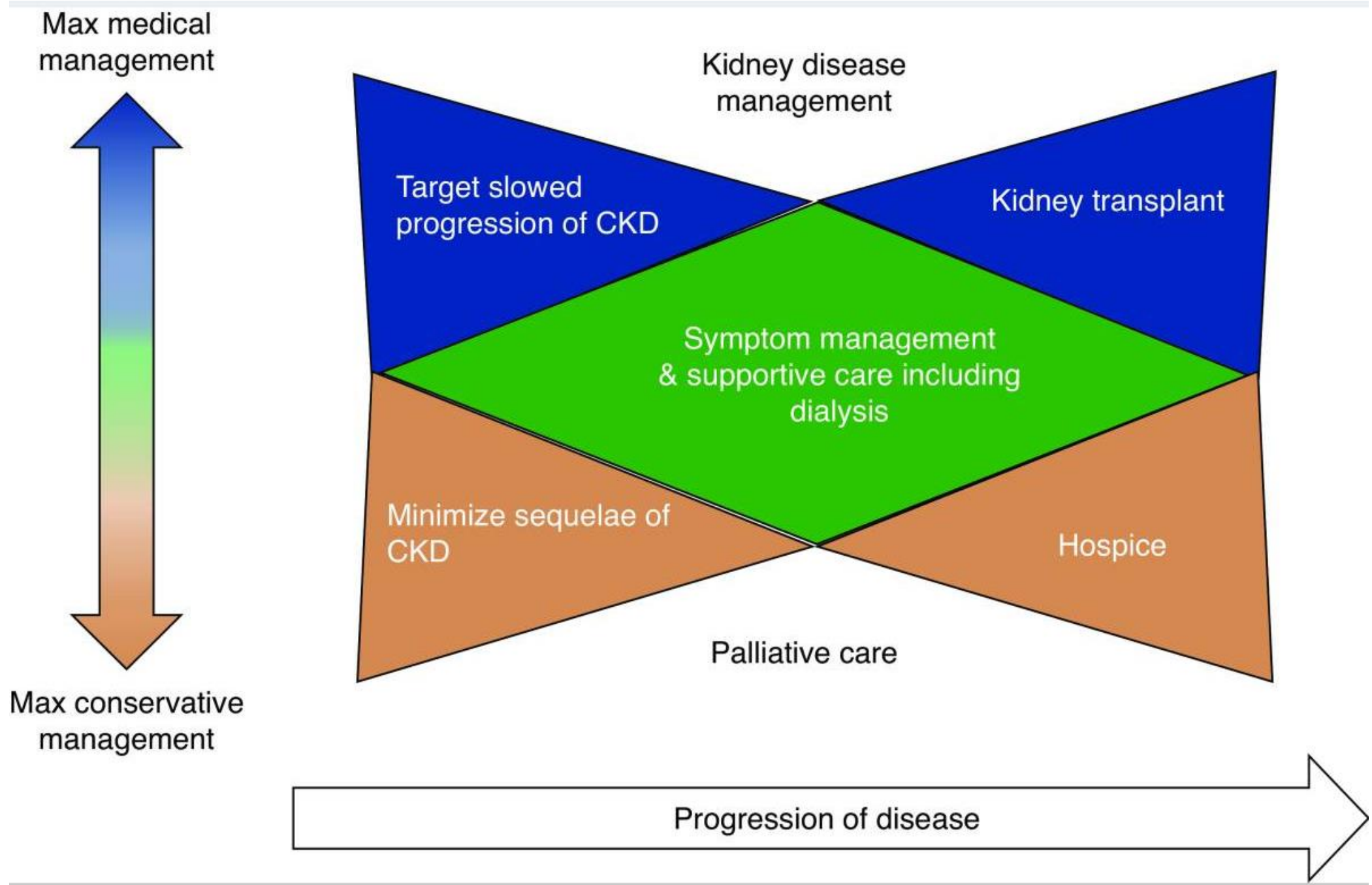
Gerry

21 year old woman with dialysis dependent kidney disease

What does her future look like?







What do we mean when we talk about integrated palliative care for patients with chronic kidney disease?

Group work

Expert Communication

Address Symptom Experience and Burden

Psychosocial Care and Cultural Proficiency

Spiritual Care and Dignity Conservation

Transitions as Illness progresses

Anticipatory Grief and Bereavement

Expert communication

SERIOUS ILLNESS CONVERSATION
Exploring Key Topics

*"What are your most important **goals** if your health situations worsens?"*

*"How much does your **family** know about your priorities and wishes?"*

*"What is your **understanding** now of where you are with your illness?"*

*"If you become sicker, how much are you **willing to go through** for the possibility of gaining more time?"*

Understand

Family

Trade Offs

We're in this together

Fears and Worries

Sources of Strength

Critical Abilities

*"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?"*


*"What are your biggest **fears and worries** about the future with your health?"*

SSC SPECIALIST SERVICES COMMITTEE

PQI PHYSICIAN QUALITY IMPROVEMENT

BC Centre for Palliative Care

island health



What Matters to Me
A Workbook for People with Serious Illness

NAME

DATE

ARIADNE LABS the conversation project

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Serious Illness Conversations in advanced kidney disease: a mixed-methods implementation study; Thamcharoen et al; BMJ Support Palliative Care Actions; 2021

My Symptom Checklist*

It is important that your care team understand and monitor your symptoms over time. This checklist helps us do this. For more information, please see letter on the other side of this form.

Date: _____ (DD-MMM-YYYY)

Time: _____ (HR 24:MI)

PATIENT INFORMATION/LABEL

Name: _____

Address: _____

Phone: _____

PHN: _____

Please circle the number that best describes how you have been feeling over the PAST WEEK with each symptom.

Scale: 0 = no symptom

10 = the worst possible for the symptom

No pain		Worst possible pain
Not tired (tired= lack of energy)		Worst possible tiredness
Not nauseated		Worst possible nausea
Not depressed (depressed= feeling sad)		Worst possible depression
Not anxious (anxious= feeling nervous)		Worst possible anxiety
Not drowsy (drowsy= feeling sleepy)		Worst possible drowsiness
Best appetite (feeling hungry)		Worst possible appetite
Best feeling of wellbeing (wellbeing= how you feel overall)		Worst possible feeling of wellbeing
No shortness of breath		Worst possible shortness of breath
No itch		Worst possible itch
No problem sleeping		Worst possible problem sleeping
No restless legs		Worst possible restless legs

Any other symptom or concern? Please specify then rate below: _____

No symptom Worst possible symptom

This section to be completed by staff.

Scale completed by: (check one)

- Patient
- Care Team Member Assisted
- Family Member
- Patient refused (note why if known)

See progress notes for follow up on symptoms

Care plan updated

Results entered in PROMIS

Enter date: _____ Entered by: _____

B.C. INTER-PROFESSIONAL PALLIATIVE SYMPTOM MANAGEMENT GUIDELINES



SYMPTOMS TO EXPLORE

- PAIN**
- FATIGUE**
- PRURITUS**
- SEVERE BLEEDING**
- CONSTIPATION**
- NAUSEA & VOMITING**
- DYSPHAGIA**
- ANOREXIA**
- DEHYDRATION**
- RESPIRATORY CONGESTION**
- DYSPNEA**
- COUGH**
- HICCOUGHS**
- TWITCHING/ MYOCLONUS/SEIZURES**
- DELIRIUM**
- OTHER SYMPTOMS**
- REFRACTORY SYMPTOMS / PALLIATIVE SEDATION**
- NURTURING PSYCHOSOCIAL AND SPIRITUAL WELL-BEING**



DOWNLOAD PRINTER FRIENDLY PDF VERSION



AUDIENCE

Inter-professional clinicians working with adults living with advanced life-limiting illnesses. Though these guidelines were created for adults, the symptoms may also be experienced by children. See additional resources within each guideline specific to pediatrics, illnesses such as cancer, and your organization/region.



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BACKGROUND



CLINICIAN INTRODUCTION



ACKNOWLEDGEMENTS



FIRST NATIONS PERSPECTIVE ON HEALTH & WELLNESS

CONTRIBUTING PARTNERS



Psychosocial Care.

2. Canadian Problem Checklist:

Please check all of the following items that have been a concern or problem for you in the past week including today:

Emotional: <ul style="list-style-type: none"><input type="checkbox"/> Fears / Worries<input type="checkbox"/> Sadness<input type="checkbox"/> Frustration/Anger<input type="checkbox"/> Changes in appearance<input type="checkbox"/> Intimacy / Sexuality<input type="checkbox"/> Coping<input type="checkbox"/> Change in sense of self<input type="checkbox"/> Loss of interest in everyday things	Informational: <ul style="list-style-type: none"><input type="checkbox"/> Understanding my illness and/or treatment<input type="checkbox"/> Talking with the health care team<input type="checkbox"/> Making treatment decisions<input type="checkbox"/> Knowing about available resources<input type="checkbox"/> Quitting smoking<input type="checkbox"/> Medications	Social/Family: <ul style="list-style-type: none"><input type="checkbox"/> Feeling a burden to others<input type="checkbox"/> Worry about family / friends<input type="checkbox"/> Feeling alone<input type="checkbox"/> Relationship difficulties
Practical: <ul style="list-style-type: none"><input type="checkbox"/> Work / School<input type="checkbox"/> Finances<input type="checkbox"/> Getting to and from appointments<input type="checkbox"/> Accommodation<input type="checkbox"/> Child/Family/Elder care	Spiritual: <ul style="list-style-type: none"><input type="checkbox"/> Meaning/Purpose of life<input type="checkbox"/> Faith	Physical: <ul style="list-style-type: none"><input type="checkbox"/> Concentration/Memory<input type="checkbox"/> Sleep<input type="checkbox"/> Weight<input type="checkbox"/> Constipation / Diarrhea<input type="checkbox"/> Swallowing<input type="checkbox"/> Falling/Loss of balance

Spiritual Care

- Dignity in Care
- *What do I need to know about you to take the very best care of you?*

Promoting patient-centred palliative care: a scoping review of the patient dignity question. Arantzamendi et al. Curr Opin Support Palliat Care. 2016

Building and Strengthening the Palliative Approach in Partnership.

Community

- Community Nursing
- Primary Care Physician
- Community social Work
- Community Allied health
- Mental health workers
- Community programs-together against poverty, others
- Palliative Specialty programs when things get complex
- Hospices for the dying time
- MAID programs

In the Renal Program

- Bedside nursing
- Nutrition
- Pharmacy
- Social Work
- Nephrologists
- Inpatient units
- Palliative specialty programs when things get complex

Strengthening Palliative Approach through Research-SPA-LTC

**Develop a team
to champion a
palliative
approach**

**Complete a self-
assessment**

**Educate and
coach the whole
team**

**Optimize use of
external
consultants**

**Continuously
strengthen a
palliative
approach**

Building Organizational Capacity



A Pilot evaluation of the Strengthening a Palliative Approach in Long-Term Care (SPA-LTC) program; Kaasalainen et al; MC Palliat Care 2020

Assisting With Transitions-systems

- Care navigation can be very bumpy
 - What are we doing to address urgency?
 - Relationships with community care programs?
 - Relationships with palliative Care programs?
 - Relationships with community hospice programs?
 - Relationships with Primary Care?
- Psychological transitions from
 - Wellness
 - Chronic illness/living
 - Approaching the end/living
 - Dying time

Grief and Bereavement

MyGrief.ca

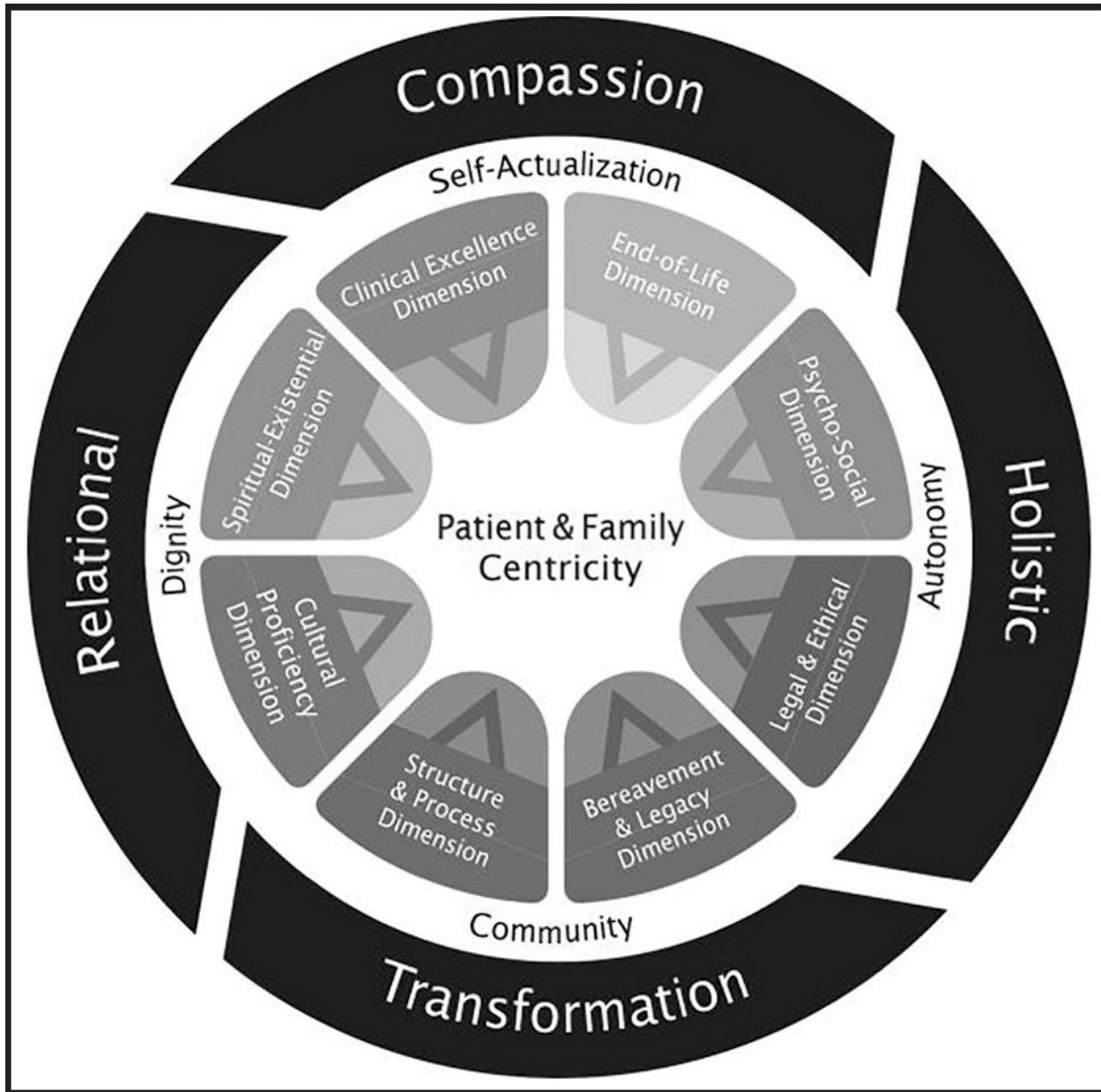


Because losing someone is hard...

Confidential and free, MyGrief.ca helps you to understand and move through your grief.



- In your own place, at your own pace
- Developed by people who have "been there" and grief specialists
 - Features "real life" stories and experiences
 - A resource for professionals



An Interdisciplinary Framework for
Palliative and Hospice Education and Practice

Dyess et. al.
J Holist Nurs Actions
Sept 2020

Call to Action in Team

- How Can you Strengthen the Palliative Approach in Renal Disease to Provide Integrated Palliative Nephrology?
 - Patient Advocacy?
 - Clinical excellence?
 - Research/Quality Improvement?
 - Collaboration
 - Ensuring Respect for the Person/Culture?
 - Systems Change?
 - Education?
 - Bereavement programs?