

# **Saying no to dialysis: choosing conservative care for end-stage kidney disease**

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Susan Wong, MD, MS

# Thanks to our speaker!

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## Dr. Susan Wong

- Nephrologist at the VA Puget Sound Health Care System in Seattle
- Acting Instructor in the Division of Nephrology at the University of Washington
- Conducts research on treatment practices and end-of-life care for patients with kidney disease.
- Her work describes the patient-, provider- and system-level factors that shape these treatment practices.

“I can’t imagine that dialysis is going to improve anything about the way I live right now. I really don’t understand my life between now and when I am not alive. I suppose I should ask that question but I haven’t. It is almost as if [the nephrology clinic visit] is not the right setting for those things. It is always one that talks about solving a health problem and getting better and now maintaining a level of health and not getting any worse. To ask questions about what happens when it should get worse or what I should be expecting...it seems like it is a different topic that doesn’t belong in this discussion. I don’t know where it would belong.”

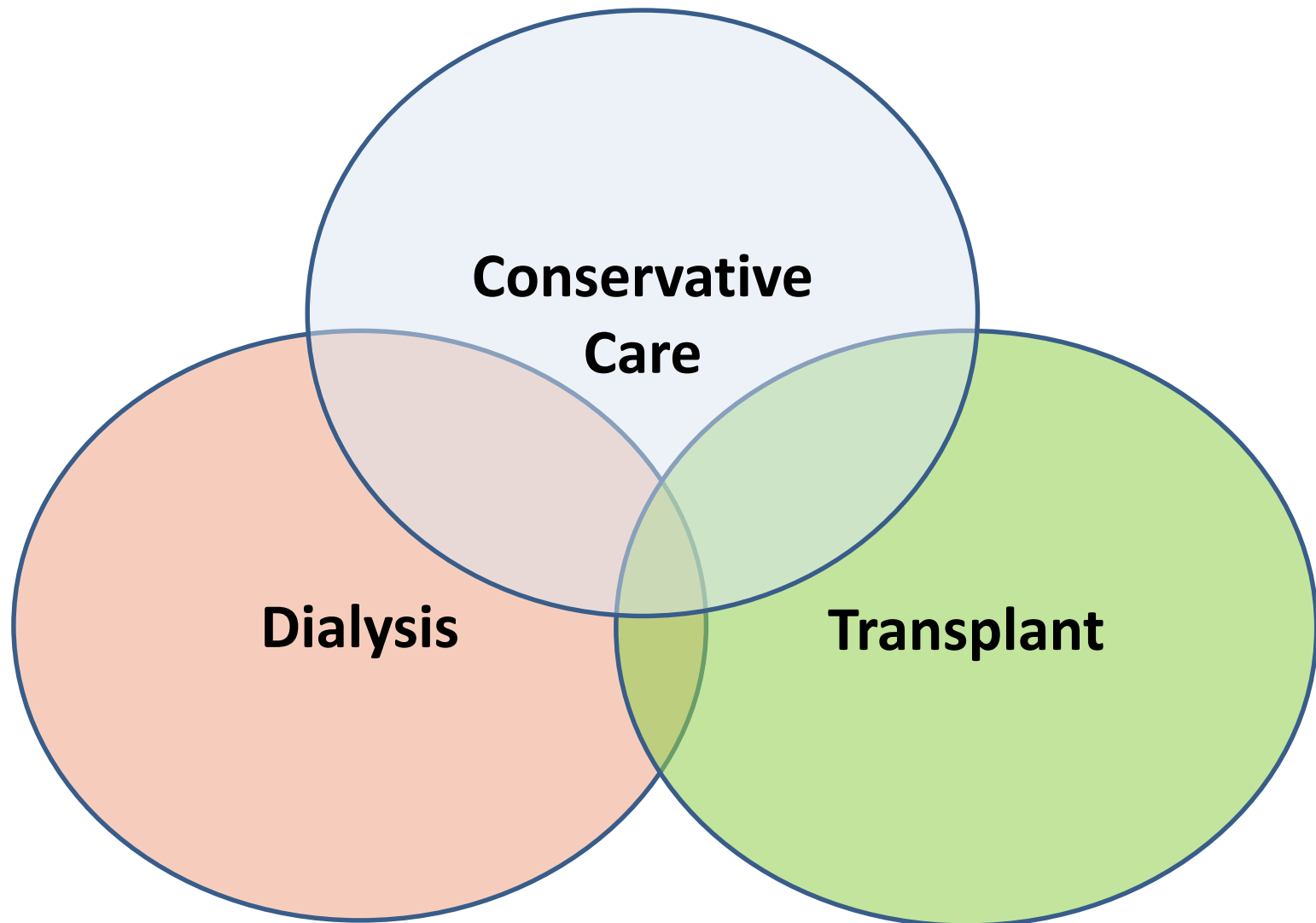
# Outline

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- 1. Who receives conservative care?**
- 2. Why have some patients chosen conservative care?**
- 3. What is conservative care?**

# Treatment choices

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# 1. Who receives conservative care?

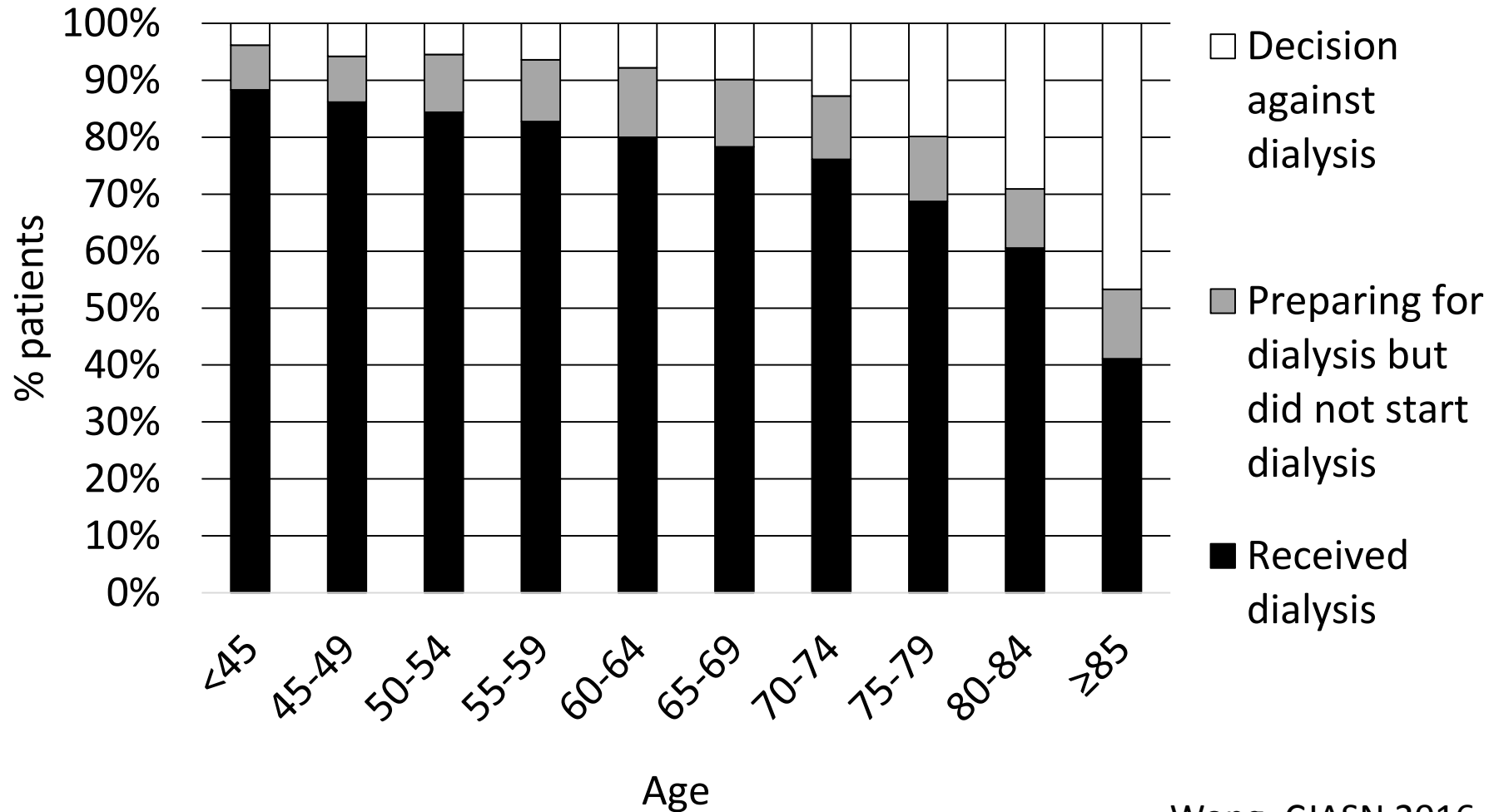
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# Trends in conservative care

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- 1 in 7 patients who reach the advanced stages of kidney disease (stage 5 or <15% kidney function) pursue conservative care.

# Treatment decisions of patients with stage 5 advanced kidney disease





# Trends in conservative care

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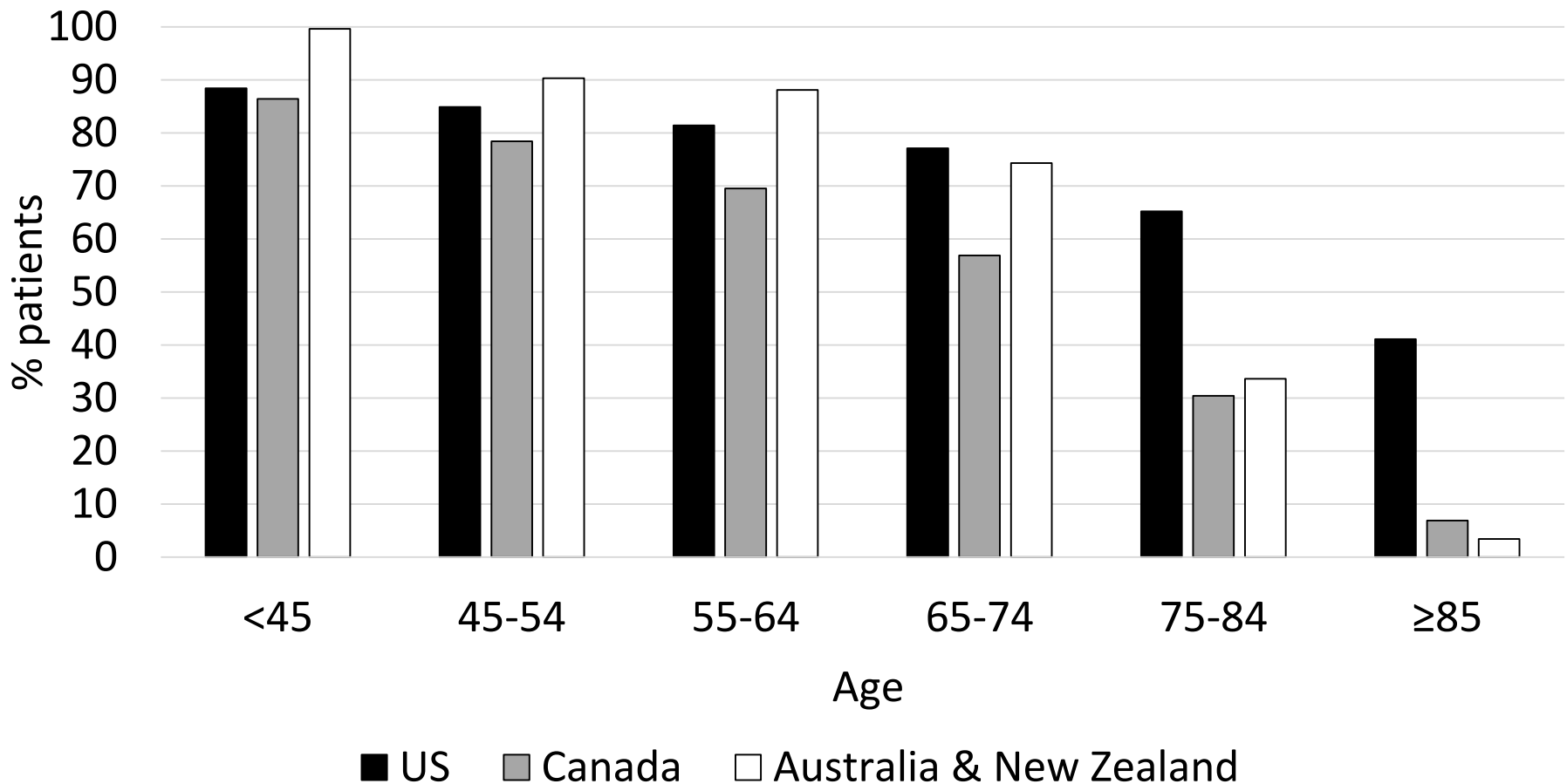
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- Conservative care is more common among patients who are older and white, and have more comorbid illnesses.

# Trends in conservative care

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- 1 in 7 patients who reach the advanced stages of kidney disease (stage 5 or <15% kidney function) pursue conservative care.
- Conservative care is more common among patients who are older and white, and have more comorbid illnesses.
- Conservative care is less common in the US than in other developed countries.
  - In other countries, for every one patient who receives dialysis, another patient does not.

# Proportion of patients with stage 5 advanced kidney disease who went on to receive dialysis



## **2. Why have patients opted for conservative care?**

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# What conservative care might offer

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- Conservative care is an alternative treatment for persons who do not view dialysis as aligned with their healthcare goals.

# Healthcare goals & values

*“Will I live to see my daughter get married?”*

**Longevity**

**Quality of life**

*“Can I still travel, have energy to garden?”*

**Independence**

*“Will my wife need to quit her job to take care of me?”*

**Relationships**

*“Can I stay at home or does this mean a nursing home?”*

“I am nearly 94 so that’s is and at the moment I feel fine so that’s my life story...just **let nature take its course**...I’m getting old now.”

“I couldn’t face all that coming up to the hospital nearly every day...Three times a week isn’t [dialysis]? **I’ve lived a good life...I want to stay at home** and not be travelling to the hospital.”

“Well, it’s for no reason really...What is the point? There isn’t any. **You have to accept the inevitable.**”

“I don’t want to be a nuisance to anybody...I am nearly 97 so **[dialysis] is not really worth it for sake of the few months which it would give me.**”

“I can’t drive and I live out of town so [dialysis] is relying on hospital transport and I mean you could be waiting hours...**I just couldn’t cope with [dialysis].**”

“It did occur to me that **[on dialysis] you were, sort of, living for tomorrow, for your next treatment,** for tomorrow, for your next treatment. And it made me think, well, I wonder if **it’s better to live as best you can** and let time take its course.”



# What conservative care might offer

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- Conservative care is an alternative treatment for persons who do not view dialysis as aligned with their healthcare goals.
- For some patients, life expectancy (how long you will live) with conservative care may be similar to that with dialysis.

**Life expectancy after reaching stage 5 advanced kidney disease for older patients (75+ years) with significant comorbidity**

Study author, Year	Country	Median survival with dialysis, months	Median survival with conservative care, months
Murtagh, 2007	United Kingdom	23	23
Chandna, 2011	United Kingdom	26	20
Hussain, 2013	United Kingdom	29	24
Shum, 2014	Hong Kong	36	24
Verberne, 2016	Netherlands	36	30

# What conservative care might offer

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- Conservative care is an alternative treatment for persons who do not view dialysis as aligned with their healthcare goals.
- For some patients, life expectancy (how long you will live) with conservative care may be similar to that with dialysis.
- Patients who receive conservative care may have similar symptoms and quality of life as those who receive dialysis.

## Comparison of symptoms in patients on dialysis versus conservative care

	Prevalence		Severity score (0-none; 10-severe)	
	Dialysis	Conservative	Dialysis	Conservative
Fatigue	75%	69%	5.5	5.9
Itch	66%	58%	5.6	4.3
Pain	38%	49%	4.1	4.2
Muscle cramps	40%	33%	4.1	4.1
Sexual problems	34%	9%	6.8	3.3
Limb swelling	29%	31%	4.4	4.1
Restless leg	13%	13%	4.1	3.7
Difficulty sleeping	62%	49%	5.4	5.8

## **3. What is conservative care?**

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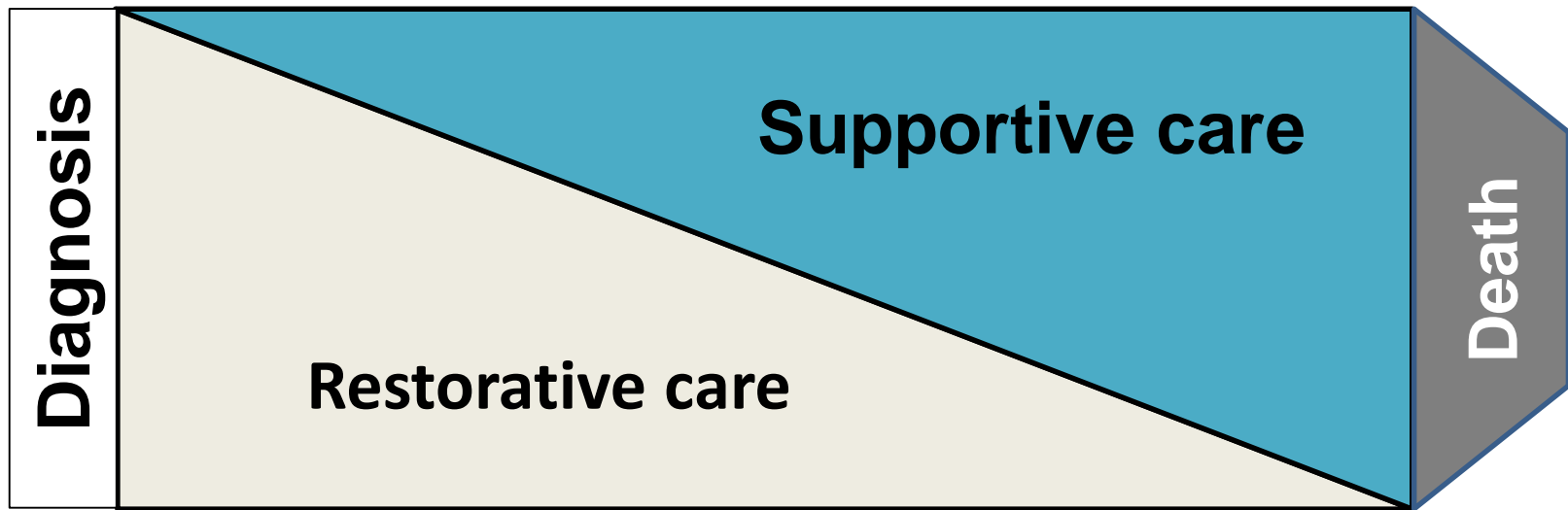
# Attributes of conservative care

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1. Available from diagnosis to death.
2. Balance between restorative and supportive care.
3. Interdisciplinary approach to care.
4. Clear communication about prognosis and anticipatory guidance.
5. Family and caregiver support.

# Supportive care vs. Restorative care

Supportive care: **patient-specific approach** to care that aims to reverse, halt or minimize how disease impacts a patient's life.



Restorative care: **disease-specific approach** to care that aims to reverse, halt or minimize the disease process.

## **Disease-specific Approach**

Anemia → Erythropoetin

Edema → Furosemide

Acidosis → Sodium bicarbonate

Proteinuria → Lisinopril

Hyperphosphatemia → Calcium  
acetate



## Disease-specific Approach

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## Philosophical shift in care

## Patient-specific Approach

What concerns do you bring to our appointment today?

What are your goals for your healthcare?

What is most important to you when facing serious illness?

## Disease-specific Approach

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## Philosophical shift in care

## Patient-specific Approach

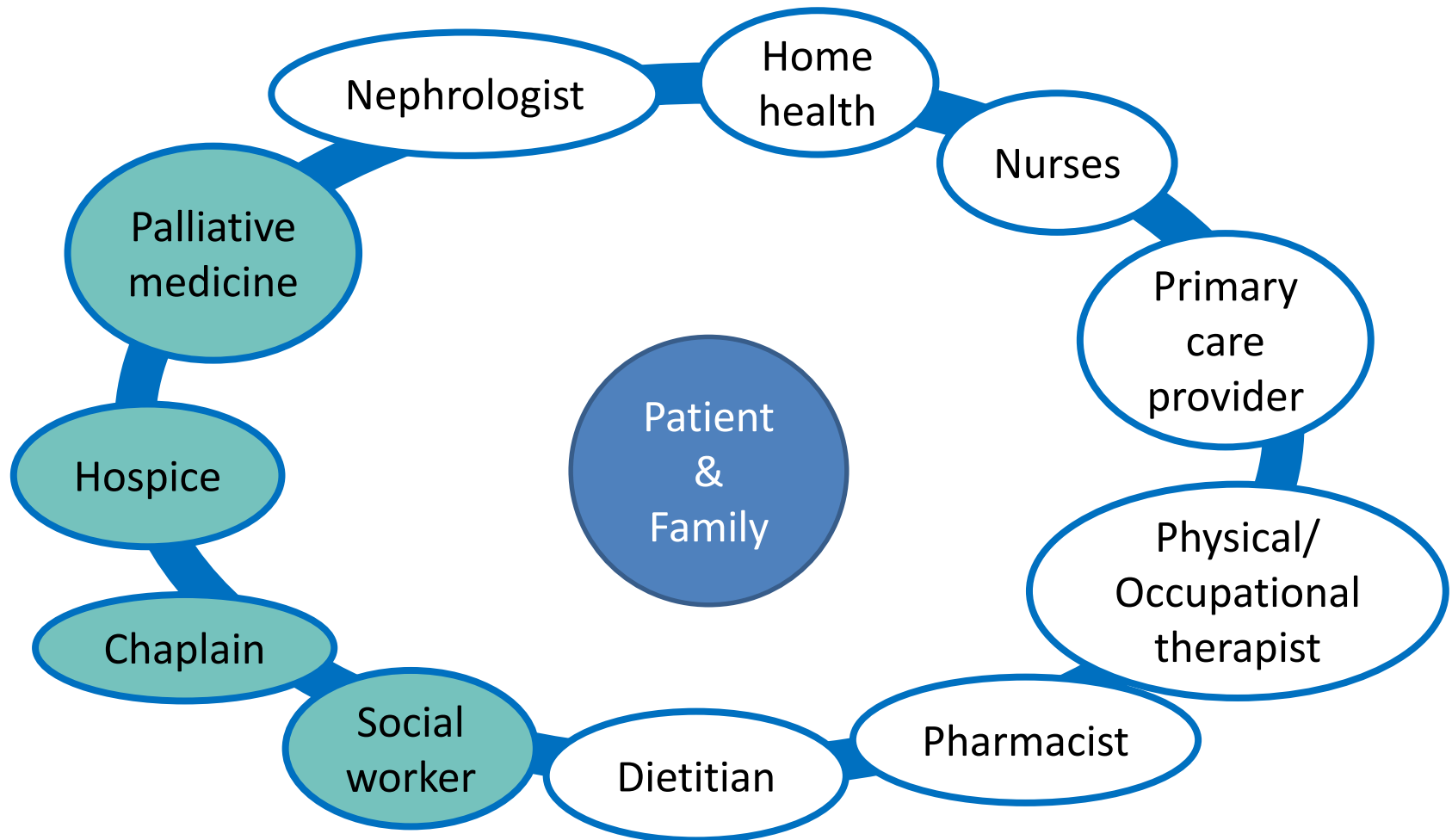
Fatigue → Reduce  
medications

Itch → gabapentin, UVB,  
emollients

Being at home → Advance  
directive

Staying connected  
with loved ones → Creating  
legacy

# Interdisciplinary care



# Social worker

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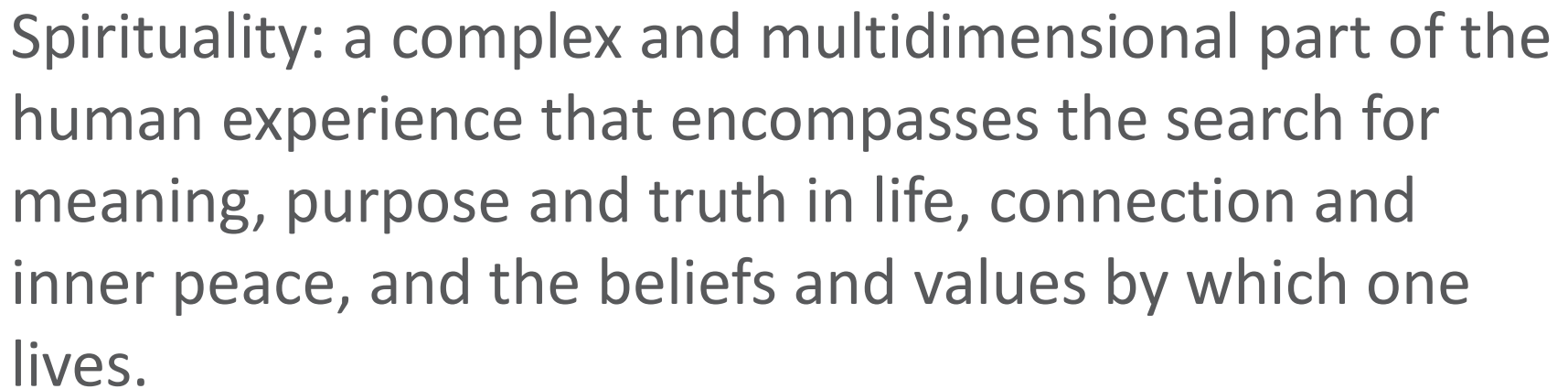
- Helps patients and families solve and cope with everyday problems that arise or are impacted by serious illness.
- Addresses emotional, financial, housing, and caregiving needs.
- Provides individual support and/or helps patients navigate local, state or federal resources.



# Chaplain

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- A non-denominational cleric who provides spiritual support to patients & families facing serious illness.
- A licensed provider with higher education (typically in theology, religion or philosophy) and has completed an internship/residency training



Spirituality: a complex and multidimensional part of the human experience that encompasses the search for meaning, purpose and truth in life, connection and inner peace, and the beliefs and values by which one lives.

# Palliative medicine provider

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- Specially-trained consulting doctors and nurses who assist primary providers (ex. primary care doctors, nephrologists).
- Their focus is on providing relief from symptoms and stress of serious illness occurring at any point in time during the disease course.
- Outpatient, inpatient and home-based.



# Hospice

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- Services focused on providing expert medical care to patients and families near the end of life (usually last 6 months of life) and after death (bereavement services).
- Services are an entitlement paid for by Medicare (aged +65 years), Medicaid, the VA and many private insurances.
- Home- or institution-based.



# Hospice services

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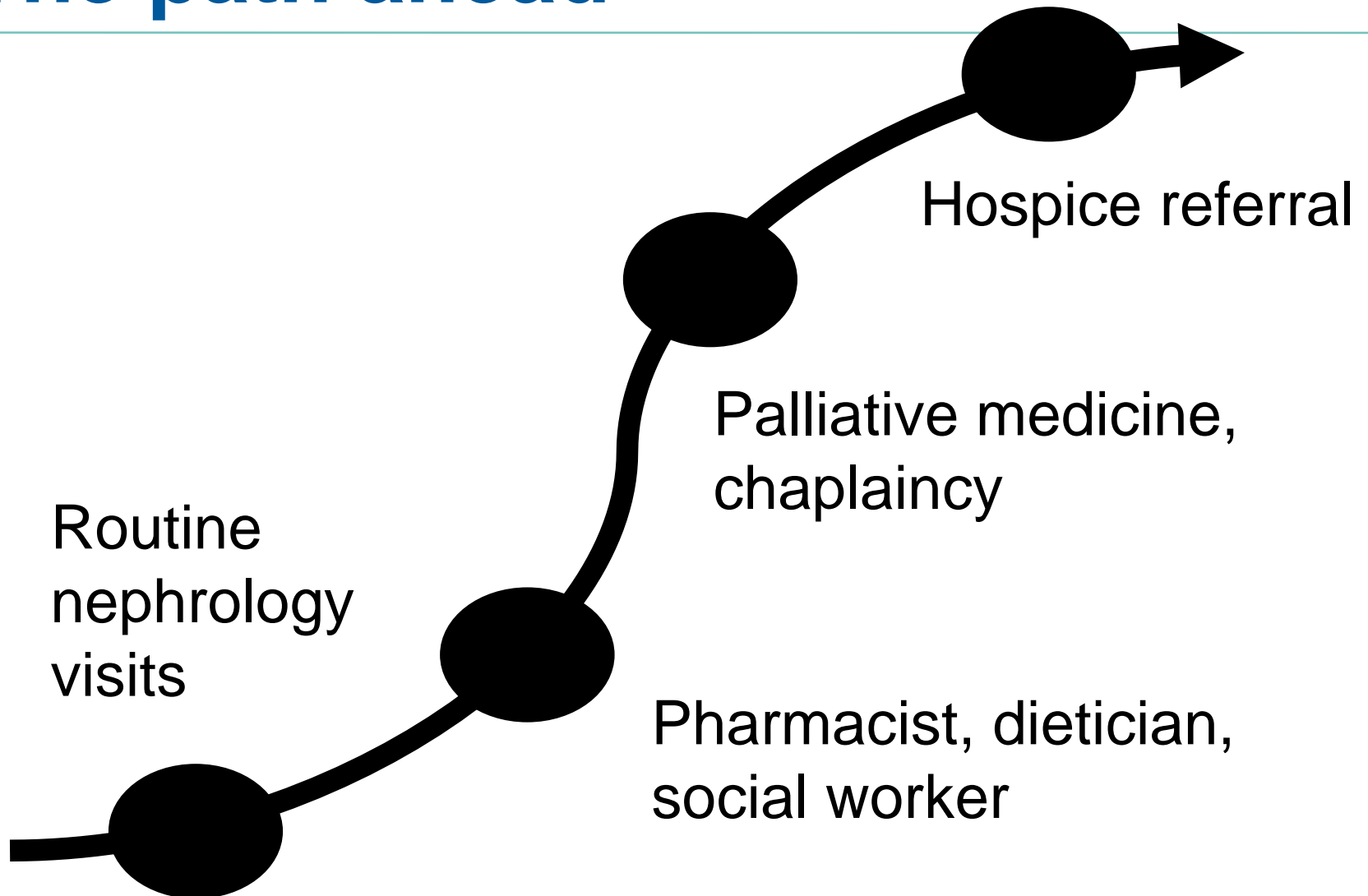
- Medical advice.
- Medications.
- Home visits.
- 24/7 on-call nursing.
- Assistance with personal care needs and practical household support.
- Financial counseling.
- Companionship and compassionate support.
- Bereavement counseling and support groups.
- Funeral assistance.





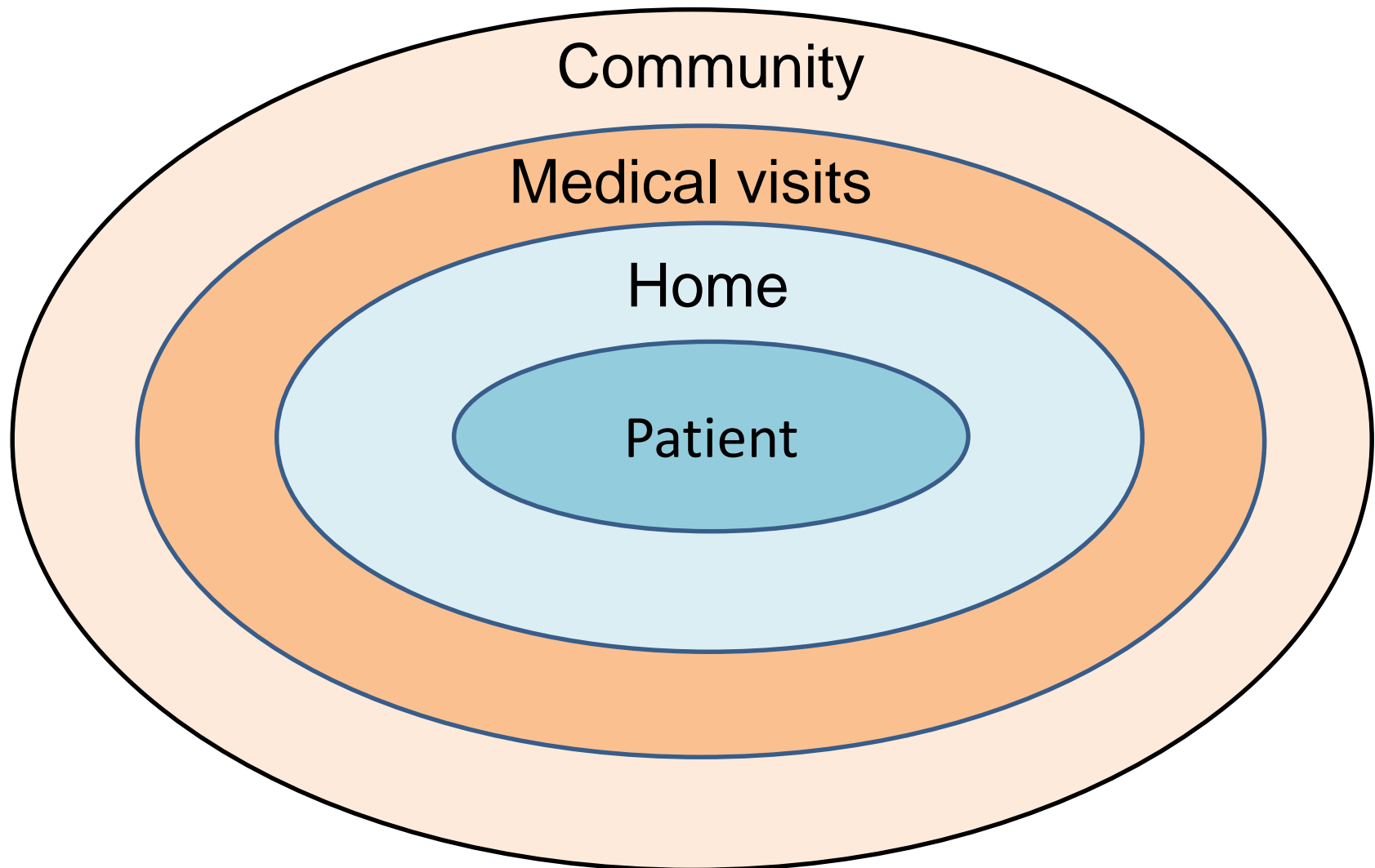
# The path ahead

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# Spheres of energy

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# Conclusion

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1. Conservative care is a reasonable therapeutic alternative to dialysis.
2. Conservative care is best suited for patients when it upholds the values and healthcare goals of patients.
3. Conservative care is a patient- (and family-) centered, interdisciplinary approach to care from diagnosis to death.

# Join us for next month's webinar!

## Tuesday, May 30, 2-3 p.m. (ET)



### Dr. Brigitte Schiller

- Chief Medical Officer, Satellite Healthcare
- Leads Quality and Medical Policy Strategy and oversees the clinical strategy and development of Satellite Healthcare to improve patient outcomes

## *“Humanizing dialysis”*

### Join us to learn about:

- How patients can achieve a full life by matching with the best treatment option for their lifestyle
- The data on the current distribution of ESRD treatment methods from the US and worldwide
- What is needed for a more individualized approach to ESRD care. How can we humanize dialysis care?

Go to [www.KidneyFund.org/webinars](http://www.KidneyFund.org/webinars) to learn more and register!