

# **ELDERLY & END OF LIFE CARE** **FOR PEOPLE WITH CKD**

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# Aims of the session

- To understand the aging population and the implications to health and social care
- To understand the prevalence and implications of older people living with CKD and frailty
- To consider how we deliver shared decision making and plan care to meet the needs of this group
- To discuss the end of life care pathways for people with CKD

# Knowing your Patient

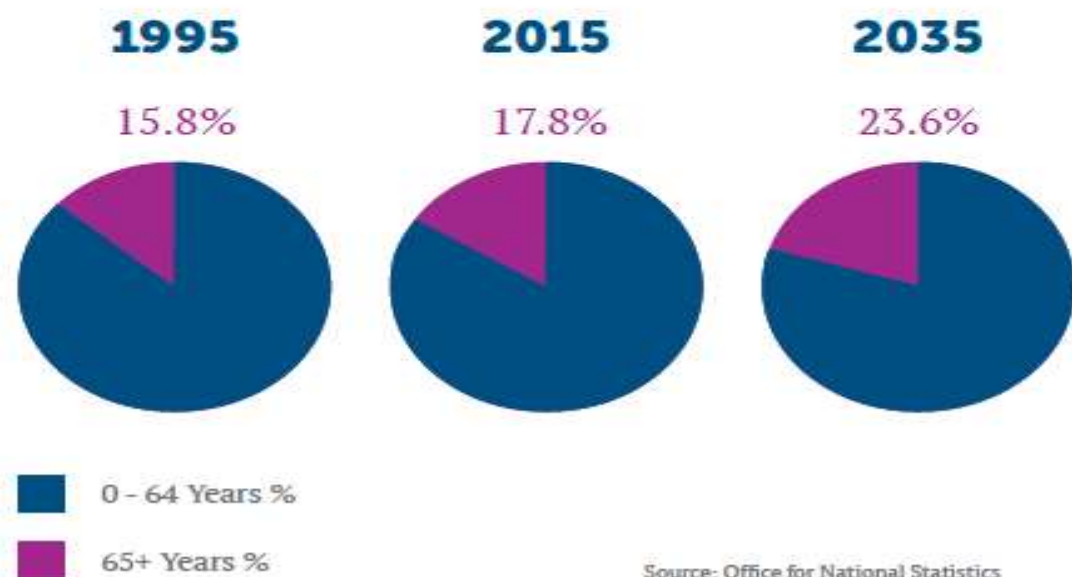
Even when we are at our most frail and aged, when there is no modern medicine to help us, when there is no benefit in being in a hospital, we still may choose to:

‘... not go gentle ... rage, rage against the dying of the light.’

BMJ primary care 2016 **William Mackintosh** poet **RS Thomas**



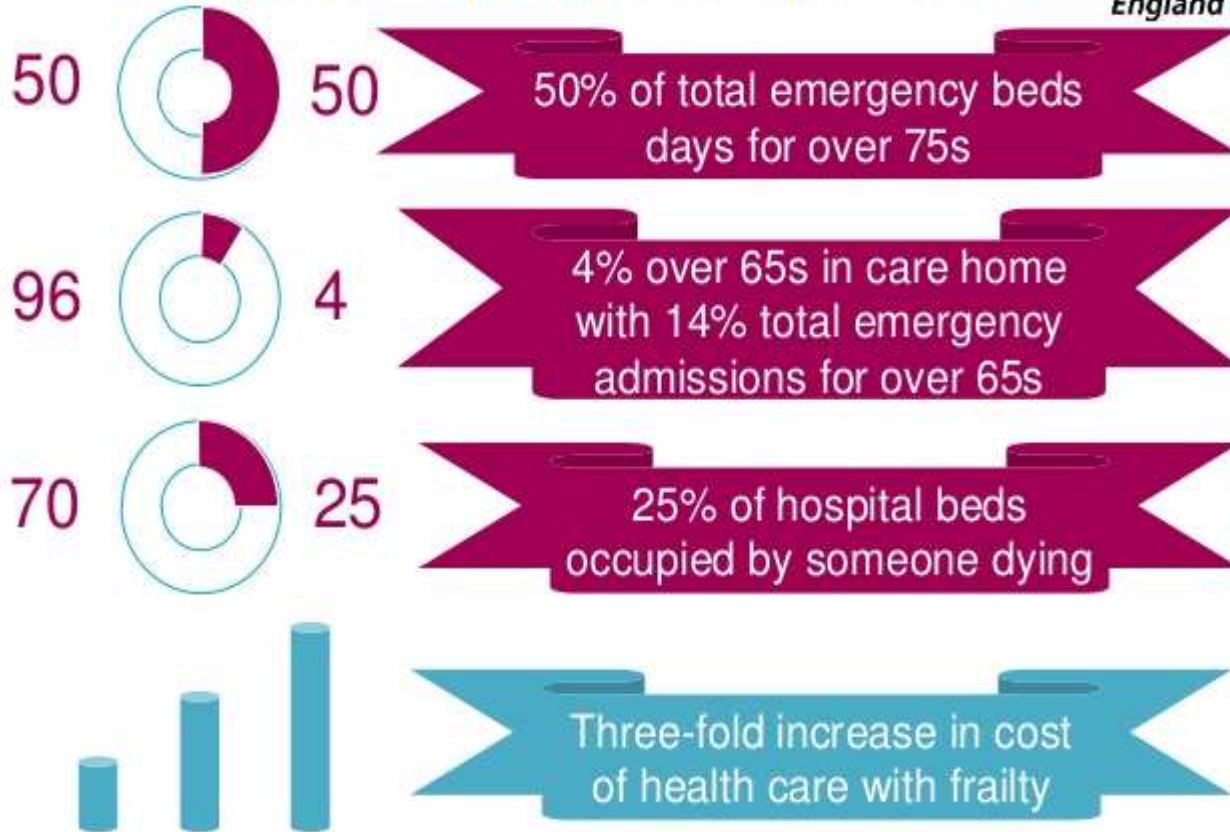
## THE INCREASE IN THE UK'S POPULATION AGED 65+ FROM 1995 - 2035



Source: Office for National Statistics



## Long term conditions: some facts



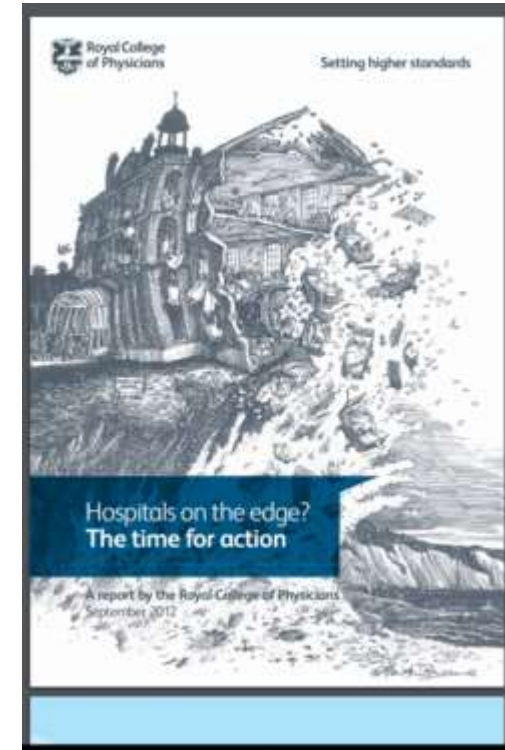
- 3 million people > 80
- More people in the UK > 60 than < 18
- Number of centenarians increased by 73% in past decade
- The population of those >75 is expected to double over the next 30 years
- By 2086 1 in 3 will be >60

**50% > 80 have 3+LTC**

# Problems with Hospital Care !

*It is often said that in people aged 80 or more for every 10 days of bed rest in hospital, the equivalent of 10 years of muscle aging occurs.....*

*It is not uncommon for patients, particularly older patients, to be moved four or five times during a hospital stay. Every ward move puts at least one day on a length of stay and has a detrimental impact on patient experience*





Overstretched A&E units are “places of terror” for elderly and vulnerable people, the nursing union’s congress has heard. [The Royal College of Nursing \(RCN\)](#) said there was no longer only a winter crisis but a year-round crisis with older people bearing the brunt, as some were left on trolleys for up to 20 hours. June 2015 The Guardian



# The burden of multimorbidity

Applying NICE guidelines to a 78 year old woman with previous myocardial infarction, type-2 diabetes, osteoarthritis, COPD, and depression...

- ❑ 11 drugs (and possibly another 10)
- ❑ 9 lifestyle modifications
- ❑ 8-10 routine primary care appointments
- ❑ 8-30 psycho-social interventions
- ❑ Smoking cessation appointments
- ❑ Pulmonary rehabilitation

**“I’d like my life back please!”**



# How can we do Better and Prepare ?

- Understand the needs of older people
- Recognise frailty and what it means
- Apply principles and models of care across a range of LTC's

# Where have we come from ?

## Paternalism

The doctor is always right ...based on a belief of the patients best interest...but the power imbalance and dominance took over..... Described by philosopher Michael Foucault as the 'clinical gaze' . 'The physician's power of observation, his clinical gaze, aided by technology, gave him a vantage point inaccessible by mere mortals, and thus, incontrovertible'. (Chandler Marrs, PhD 2013)



*"When we want your opinion,  
we'll give it to you."*

# A shift In focus...legislation and evidence

Where we are heading..

The patient is at the Centre-  
**Individualised Care**

Patient centred care is now the focus  
incorporating  
motivational theories  
self regulatory theories and  
**'shared decision making'**

'No decision about me without me'  
(Health and social care act 2012)



# Empowering patients

As the patients' organisation National Voices puts it: personalised care will only happen when statutory services recognise that patients' own life goals are what count; that services need to support families, carers and communities; that promoting independence need to be the key outcomes of care; and that patients, their families and carers are often 'experts by experience'.

Five year forward view 2018

*The traditional view of older people emphasises experiences of loss and decline, growing body to challenge this view as an inadequate explanation for experiences which older people themselves identify as wellbeing, autonomy, togetherness, security of which they manage through self care and inner strength....(Moyle et al 2011)*

# What is Being Shared

## Clinician

- Diagnosis
- Cause of disease
- Prognosis
- Treatment Options
- Outcome probabilities

## Patient

- Experiences of illness
- Social circumstances
- Values/beliefs
- Preferences
- Attitude to risk

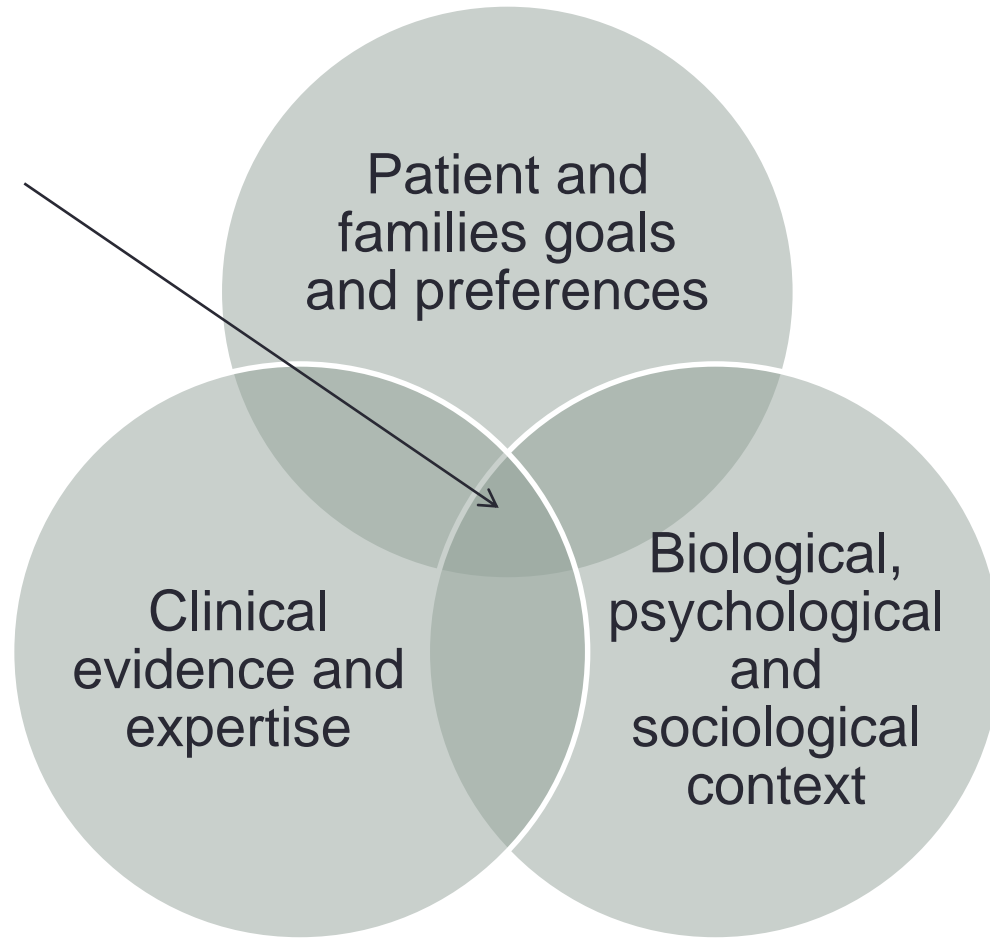


SDM

Patient and  
families goals  
and preferences

Clinical  
evidence and  
expertise

Biological,  
psychological  
and  
sociological  
context



# Key Clinical Questions

- What is frailty?
- Is there a diagnosis?
- How can we tell?
- Why does it matter?
- What are the influences?
- What can we do?



# What Does Frailty Mean to You?



# What is Frailty?

- No precise definition
- General agreement that it reflects a vulnerability to adverse health outcomes

*Frailty is a complex syndrome of biological, social and psychological causes which is distinct but overlaps with multimorbidity.*

*Abellan Van Kan et al 2010*

- Overall this terminology highlights an increased disease burden and demands of healthcare resources with ageing.

# What is frailty?

*“ I know it when I see it but what I see may not be the same as what everyone else sees”*

Community dwelling adults aged 65+ = 7% - 12%

Community dwelling adults aged 85+ = 25% - 50%

## The Frailty Paradox

**Not recognised**

**Not diagnosed**

**Not recorded**

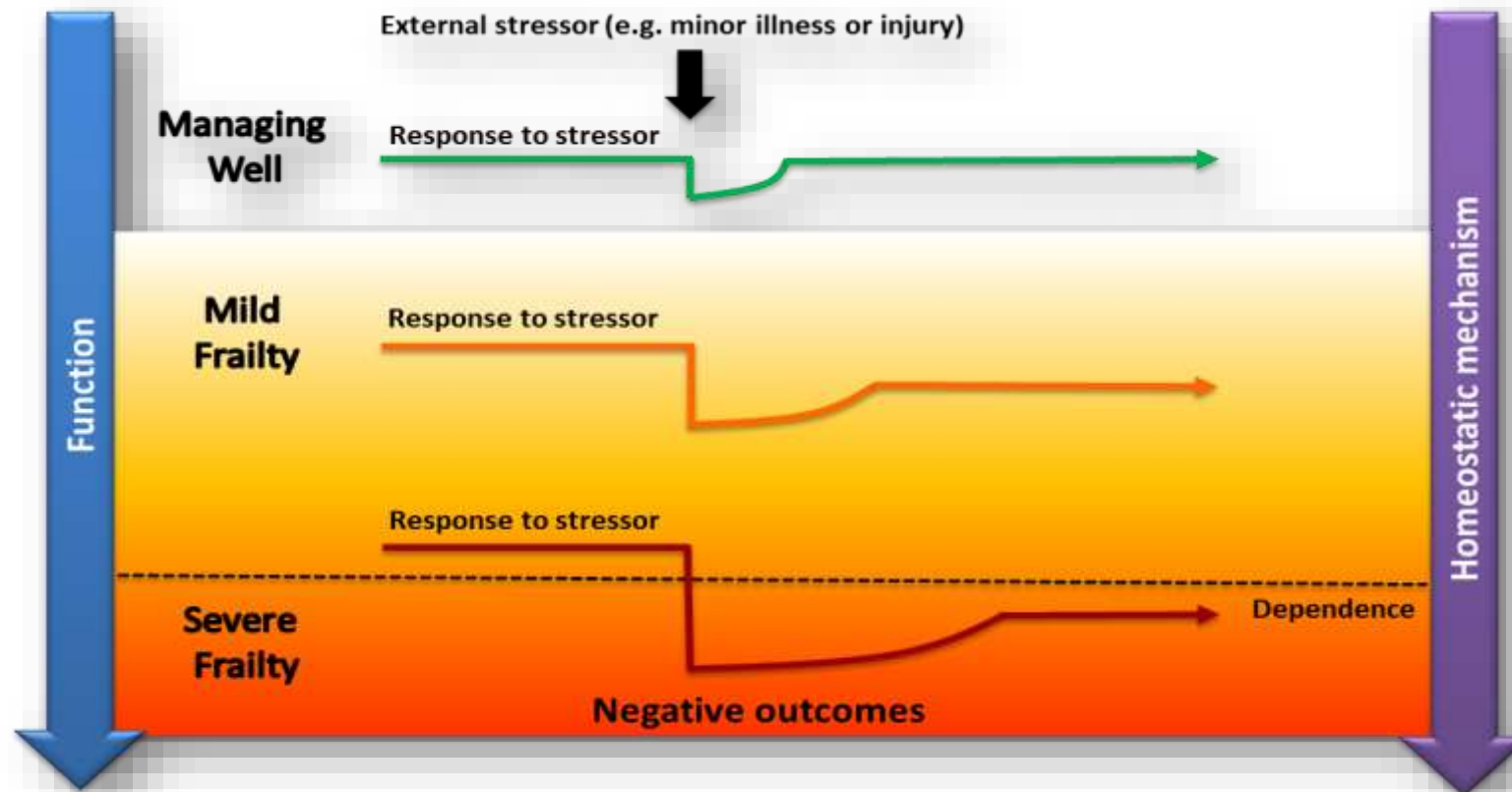


Chen, X, Genxiang, M, Sean X (2014) Frailty Syndrome: an overview. Clinical Interventions in Aging  
2014:9 433–441



# What is Frailty?

- Multidimensional syndrome of loss of reserves (energy, physical ability, cognition, health) that gives rise to vulnerability





# Consider frailty as a long-term condition

- Frailty shares the features of the typical long-term (chronic) conditions e.g. diabetes, COPD
  - Common
  - Costly at an individual and societal level
  - Episodic crises
  - Typically progressive (but not always!!!)
  - Potentially modifiable
- **If we think about frailty as a long-term condition we can begin to apply internationally established models of primary/community care management to:**
  1. Implement the available research evidence
  2. Identify the critical gaps for research

# Evidence for community-based interventions

Intervention	Outcome
Comprehensive geriatric assessment of older people	14% reduction in nursing home admission
Comprehensive geriatric assessment of 'frail' older people	10% reduction in hospital admissions
Community-based post discharge care	13% reduction in nursing home admission 15% reduction in hospital admission
Group-based education (supported self-management)	40% more likely to be living at home
Falls prevention	8% reduction in falls
Exercise interventions	Improved function
Reducing inappropriate polypharmacy	Reduced falls/hospitalisations

# Frailty Identification

- Frailty phenotype

Fried et al. J Gerontol A Biol Sci Med Sci (2001) 56 (3): M146-M157

- PRISMA 7
- Rockwood score clinical frailty scale
- Efl- electronic frailty index
- Functional tests, timed up and go, hand grip strength

## Clinical Frailty Scale\*



**1 Very Fit** – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.



**2 Well** – People who have **no active disease symptoms** but are less fit than category 1. Often, they exercise or are very **active occasionally**, e.g. seasonally.



**3 Managing Well** – People whose **medical problems are well controlled**, but are **not regularly active** beyond routine walking.



**4 Vulnerable** – While **not dependent** on others for daily help, often **symptoms limit activities**. A common complaint is being “slowed up”, and/or being tired during the day.



**5 Mildly Frail** – These people often have **more evident slowing**, and need help in **high order IADLs** (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.



**6 Moderately Frail** – People need help with **all outside activities** and with **keeping house**. Inside, they often have problems with stairs and need **help with bathing** and might need minimal assistance (cuing, standby) with dressing.



**7 Severely Frail** – **Completely dependent for personal care**, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).



**8 Very Severely Frail** – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.



**9. Terminally Ill** - Approaching the end of life. This category applies to people with a **life expectancy <6 months**, who are **not otherwise evidently frail**.

### Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

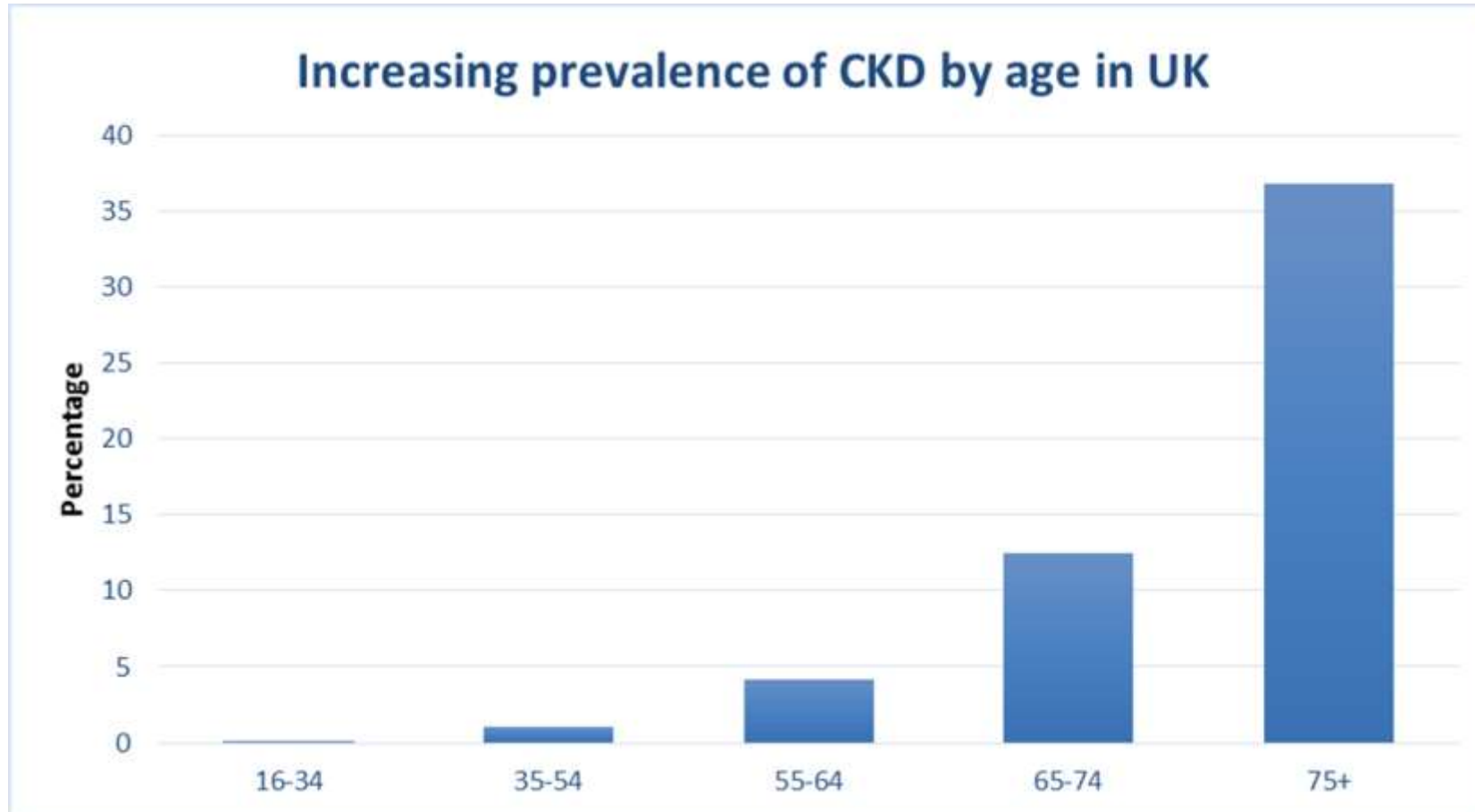
In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia**, they cannot do personal care without help.

\* 1. Canadian Study on Health & Aging, Revised 2008.  
2. K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489-495.

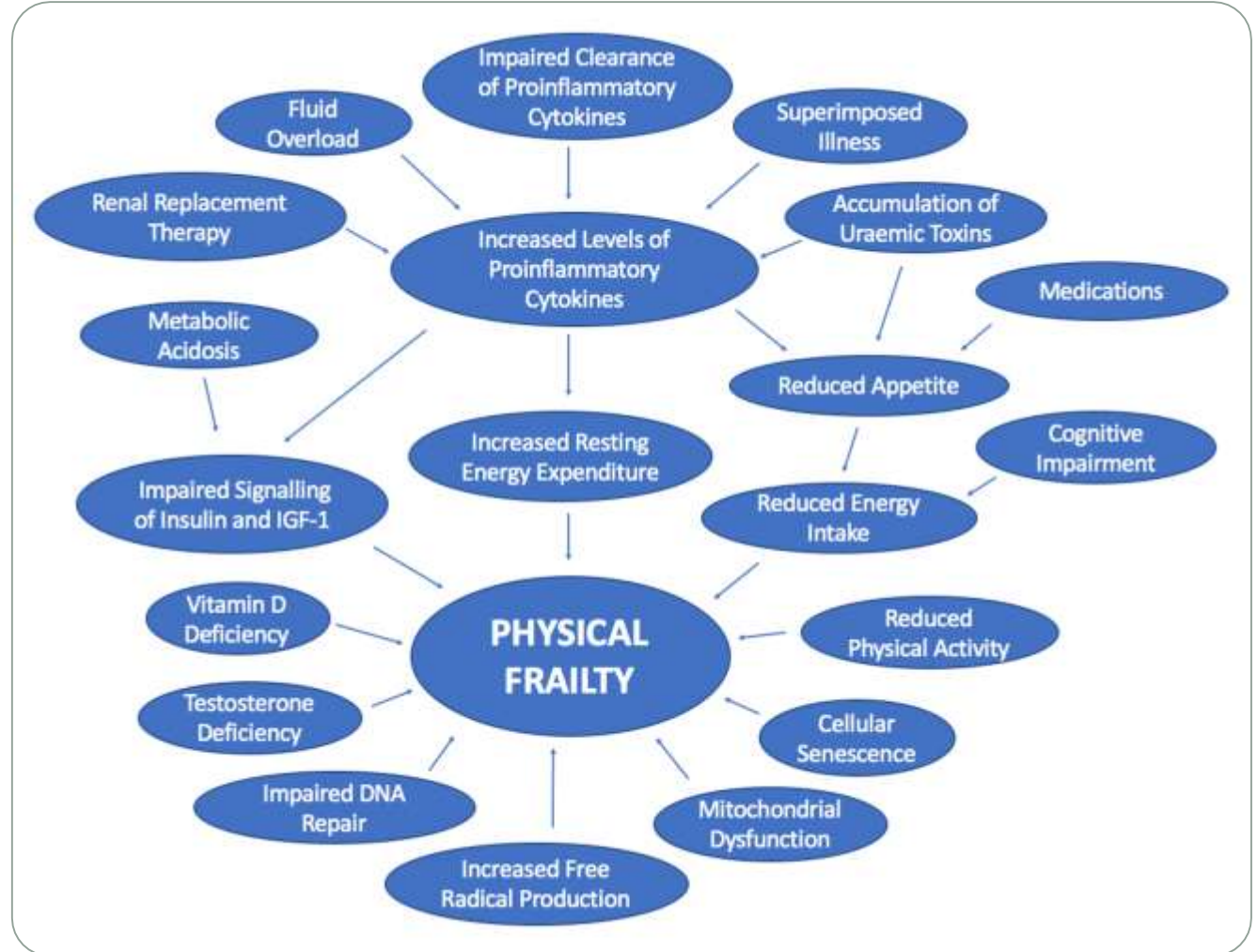
© 2007-2009, Version 1.2. All rights reserved. Geriatric Medicine Research, Dalhousie University, Halifax, Canada. Permission granted to copy for research and educational purposes only.

# People living with CKD by age



# Frailty and CKD

- Pathophysiological processes associated with CKD propagate frailty trajectory



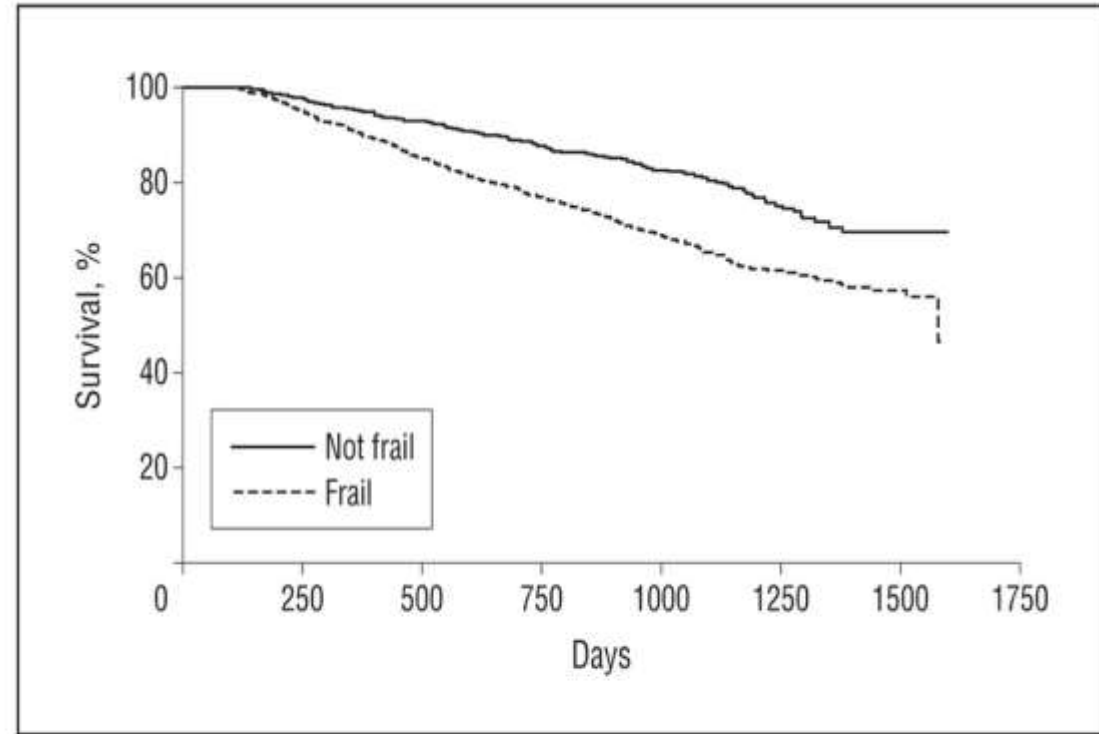


# Frailty and Outcomes in CKD

- Frailty in those with CKD G1-4 is associated with an increased risk of death or requiring dialysis (HR 2.5; 95% CI 1.4–4.4)
- Frailty at dialysis initiation
  - Independent risk factor for first hospitalisation (HR 1.26; 95% CI 1.09–1.45)
  - Associated with an increased risk of mortality (HR 1.57; 95% CI 1.25–1.97)

Am J Kidney Dis. 2012 Dec;60(6):912-21.

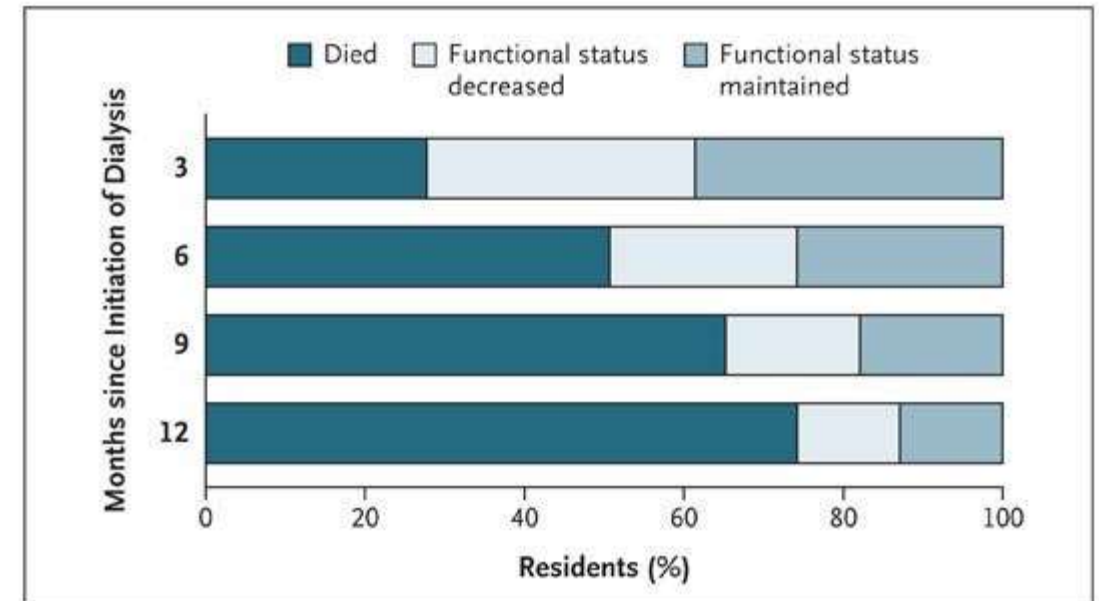
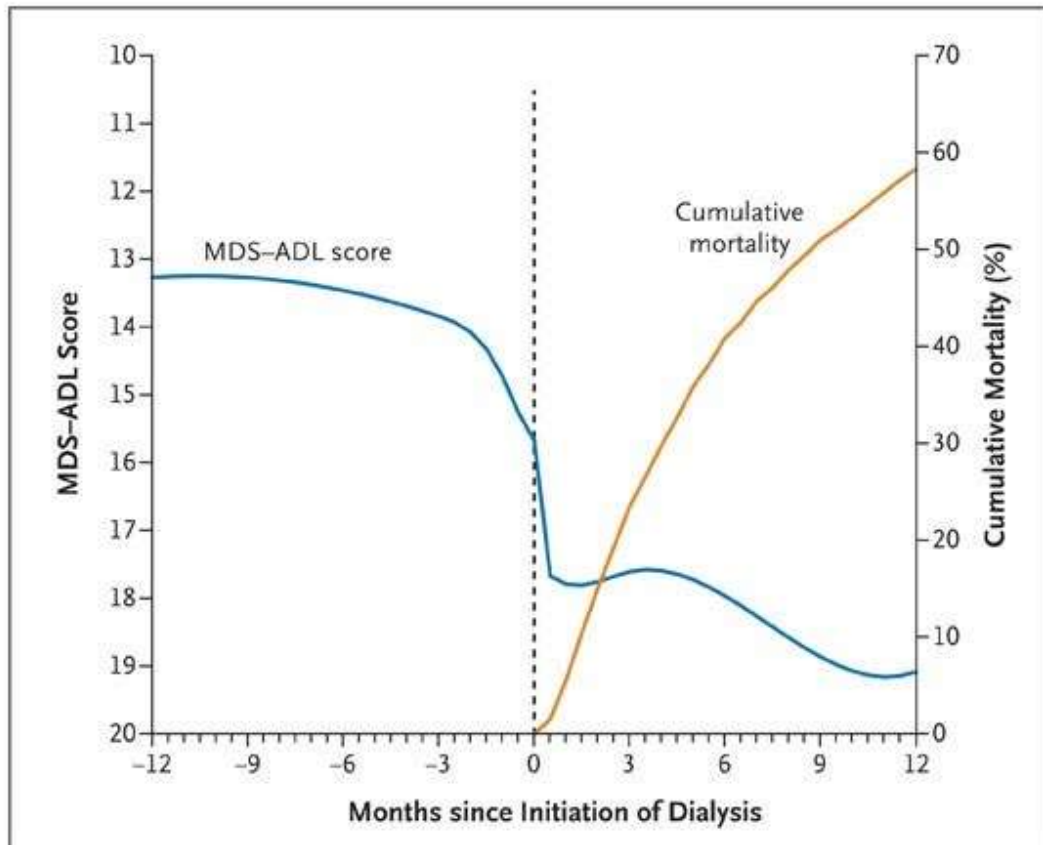
Arch Intern Med. 2012 Jul 23;172(14):1071-7.



**Figure 1.**

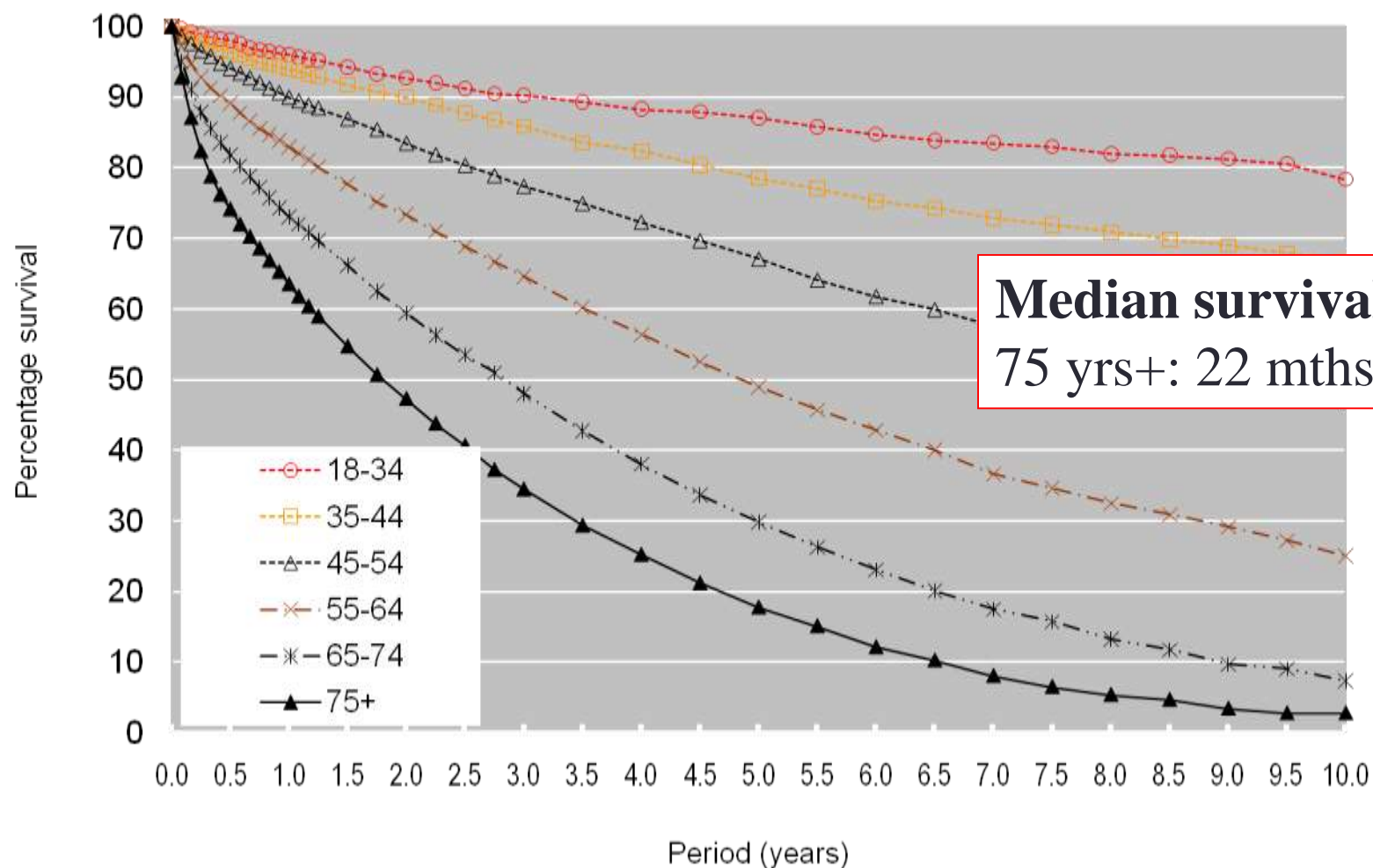
Time to death. Kaplan-Meier plot of the unadjusted association between frailty and survival.

# Functional Status of Elderly Dialysis Patients



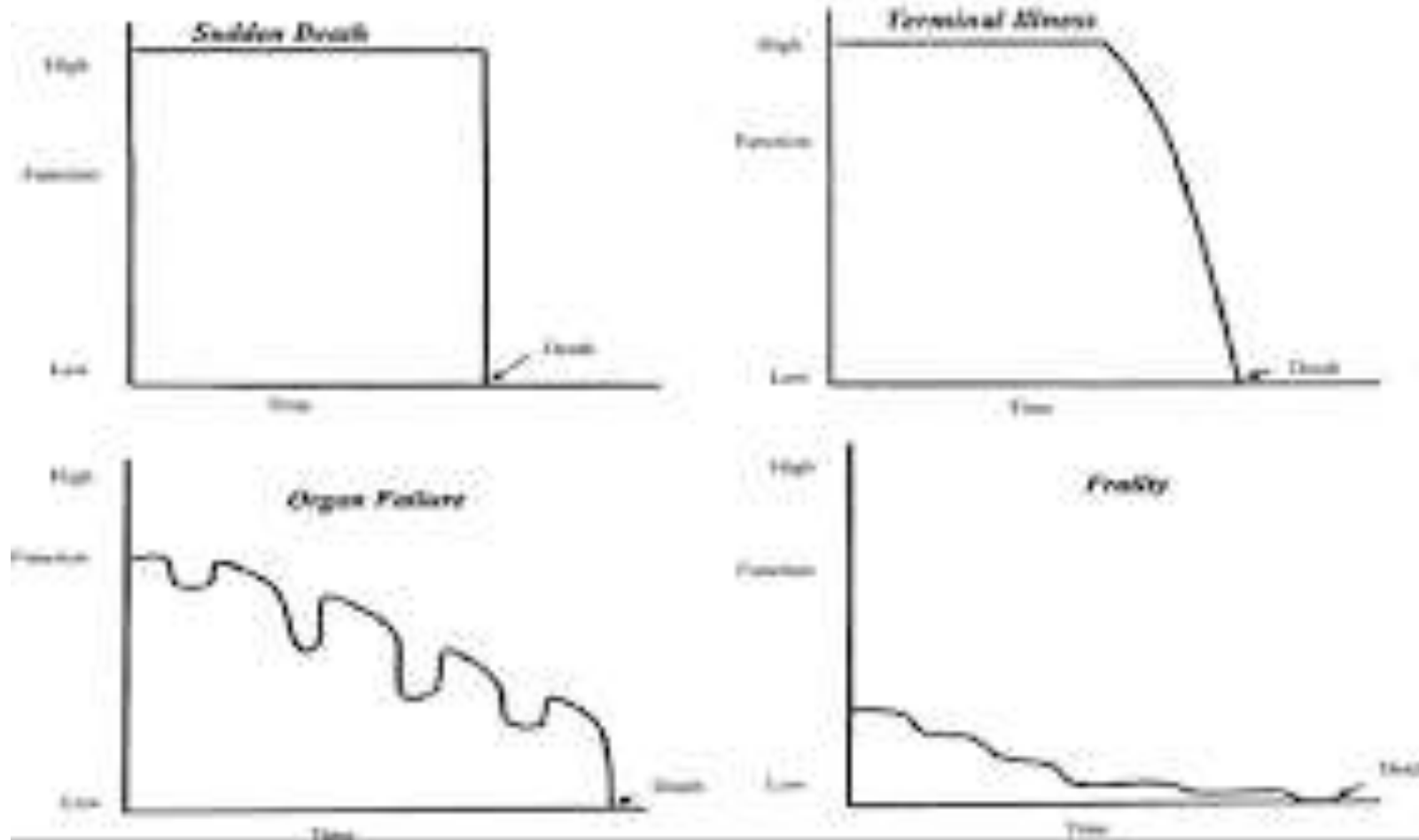
*N Engl J Med* 2009; 361:1539-1547

# 10 year survival of incident RRT patients, 1997-2006 cohort



# Illness Trajectory

Proposed Trajectories of Dying



# Frailty and QoL in CKD

- Frailty independently associated with at least a 20-point lower score in the following domains:
  - Physical functioning
  - Role limitations due to emotional problems
  - Energy/fatigue
  - Social functioning
  - Pain
- Frailty is the most important predictor of poor QoL

# Comprehensive Geriatric Assessment

- Why is it important ?

*The comprehensive geriatric assessment (CGA) is now recognised as an international gold standard for assessments (including frailty) of older people in clinical practice, both in secondary and primary care.*

( Clegg, Andrew; Young, John; Iliffe, Steve; Rikkert, Marcel Olde;Rockwood, Kenneth (2013) Frailty in the Elderly **The Lancet** 381 752-762)



# Domains of the CGA

- **Physical Symptoms**
  - include pain, underlying LTCs
- **Mental Health Symptoms**
  - include memory, mood
- **Level of function in daily activity**
  - include personal care and life functions
- **Social Support Networks –**
  - include informal and formal
  - Consider family/carer needs
- **Living Environment**
  - state of housing, facilities and comfort.
- **Level of Participation and individual concerns**
- **Compensatory mechanisms and resourcefulness which the individual uses to respond to having frailty.**

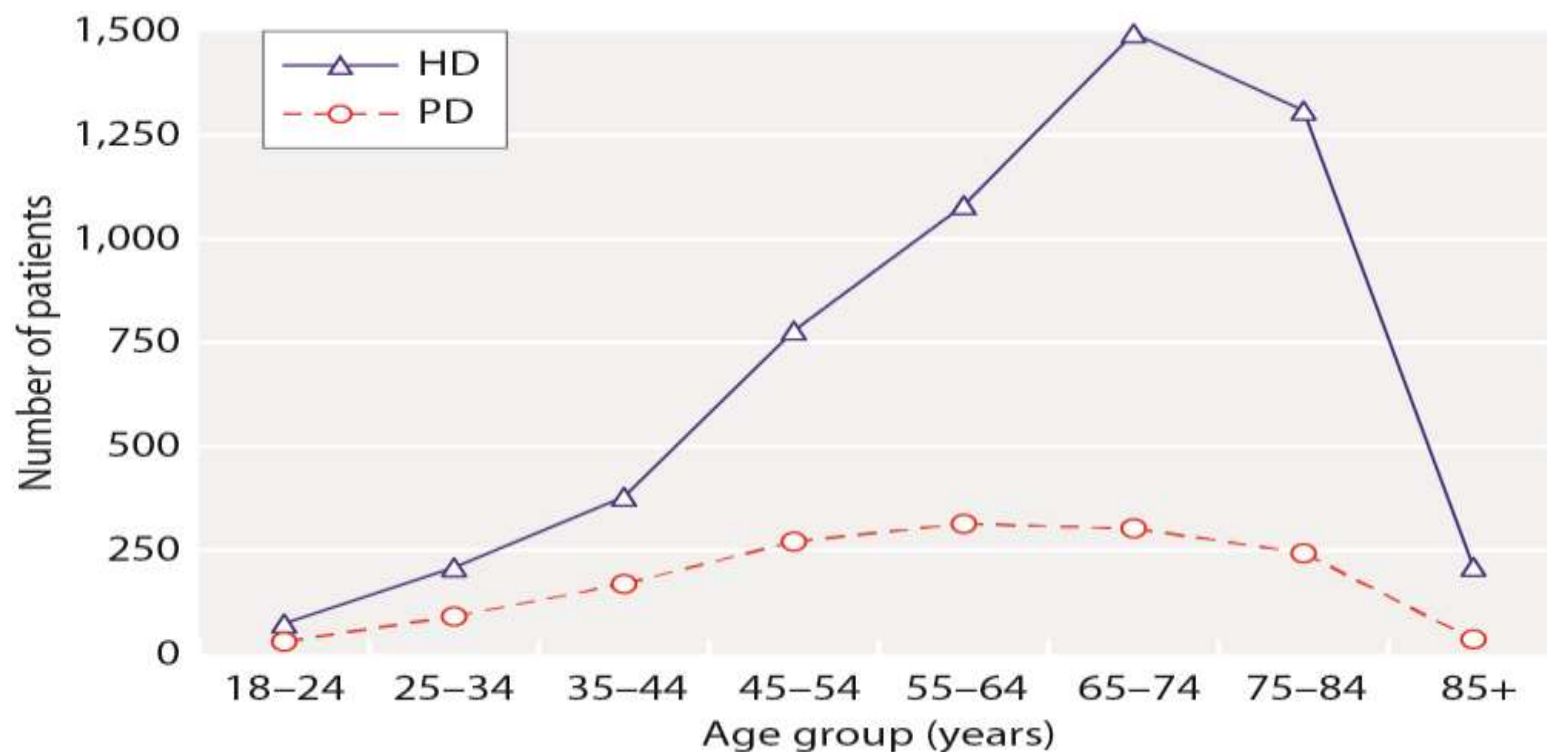


# Using CGA in a renal population

- Can the domains used in the general population be transferable ?
- How do we deliver a CGA in practice, who when how ???
- Do we need geriatricians?
- What access to we have to the wider MDT including therapy??
  
- Will it improve outcomes??
- How will it influence affect decision making ?

# Dialysis Incident by Age

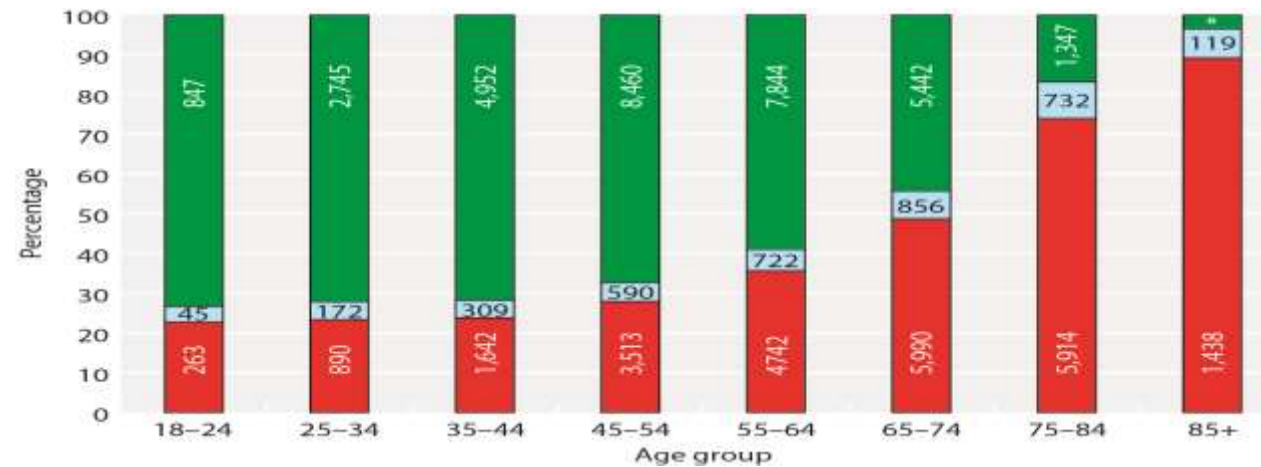
**Figure 1.5.** Number of incident dialysis patients in 2015, by age group and initial dialysis modality



## Assumptions of Choice- do the elderly chose HD ???



**Figure 2.7.** Treatment modality distribution by age in prevalent RRT patients on 31/12/2015  
\*N = 550



UK Renal Registry 19th Annual Report

UK Renal Registry 13th Annual Report

# Choice



## Key questions

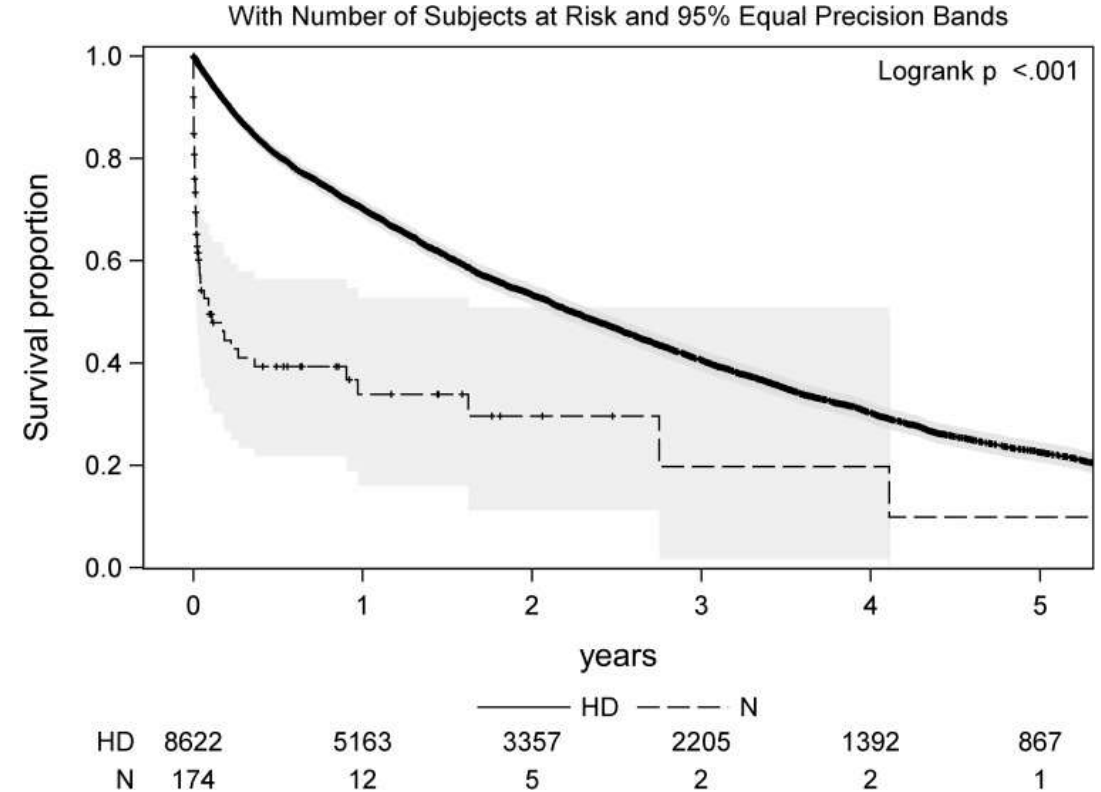
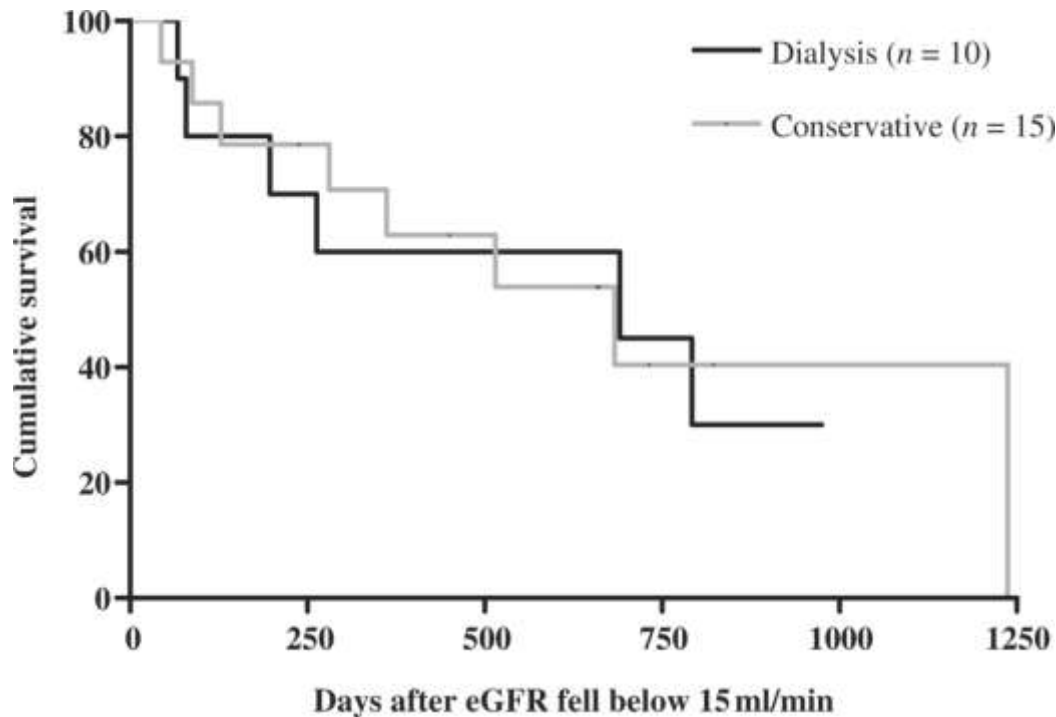
1. Will the patient derive overall benefits from dialysis ?
2. What are the parameters that should be employed to derive benefit ?
3. Do you offer conservative care ?
4. Time limited trial on dialysis
5. How to deal with family that insists on dialysis when no patient benefit
6. What sort of assistance can be offered?



### Potential benefits and burdens of dialysis for frail elderly patients

Potential Benefits of Dialysis	Potential Burdens of Dialysis
Life extension	Procedures for access: access placement, fistulograms/stent placement, access failure, and access complications/steal syndrome
Symptom relief: fatigue/weight loss, loss of appetite, and sleep disturbance	Time spent undergoing dialysis: three times per week treatment for standard in-center hemodialysis and time spent traveling to and from dialysis
Improved quality of life: ability to do the activities that bring a patient joy and fulfillment	Increased hospitalizations and setbacks: acute illness, functional decline, and transition to skilled nursing facility
Social aspects of dialysis: supportive environment of the dialysis unit and support from fellow dialysis patients	Symptoms related to dialysis itself or its complications: cramping, postdialysis fatigue, pain/ischemia related to access, and bone mineral disease/calciophylaxis

## Kaplan–Meier survival curves for those with high comorbidity, comparing dialysis and conservative groups



Murtagh F E M et al. *Nephrol. Dial. Transplant.* 2007;22:1955-1962

[Roman Reindl-Schwaighofer](#) et al [PLoS One](#). 2017; 12(7): e0181345



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## Survival by Dialysis Modality—Who Cares?

Martin B. Lee\* and Joanne M. Bargman†

In light of the recent emphasis on patient-centered outcomes and quality of life for patients with kidney disease, we contend that the nephrology community should no longer fund, perform, or publish studies that compare survival by dialysis modality

*Clin J Am Soc Nephrol* 11: 1083–1087, 2016. doi: 10.2215/CJN.13261215





# What do Patients Want?

- Honesty
  - Communication being asked 'what is important for them'
  - Regular not one off conversations
  - Choice and involvement
  - Hope
  - Someone to talk too
  - Reduced symptom burden
  - QOL is important
- 
- Clinicians generally avoid difficult conversations but patients don't!

Meet Joan

82 year old she opted for home based  
treatment of assisted APD was on treatment  
for 4 years

No admissions until the end of her life

No infections

Lived alone

Great family support

Severe osteoarthritis and fibromyalgia, chronic  
pain

Should she have had an ACP?



Meet Derek

He is 83 years old

He has type 2 diabetes and CKD stage 4 and is meeting the pre dialysis team to discuss his options

He lives alone is widowed and has two children

He has many interests drives and manages all his ADL'S but has a cleaner 1 x week

Is he frail ??

**Clinical Frailty Scale®**

 <b>1. Very Fit</b> - People who are robust, active, energetic, and motivated. These people commonly exercise regularly. They are among the fittest for their age.	 <b>3. Severely Frail</b> - Completely dependent for personal care, from whatever cause (physical or cognitive). Even so they remain stable and not at high-risk of dying within ~ 6 months.
 <b>2. Well</b> - People who have no active disease symptoms but are less fit than category 1. Often they exercise or are active occasionally (e.g. occasionally).	 <b>4. Very Severely Frail</b> - Completely dependent, approaching the end of life. Typically they could not recover even from a minor illness.
 <b>3. Managing Well</b> - People whose medical problems are well controlled, but are not regularly active beyond routine walking.	 <b>5. Terminally Ill</b> - Approaching the end of life. The category applies to people with a life expectancy < 6 months, who are not otherwise evidently frail.
 <b>4. Vulnerable</b> - While not dependent on others for daily help, often symptoms limit activities. A common complaint is being "shoved up", and/or being tired during the day.	
 <b>5. Mildly Frail</b> - These people often have more evident slowing, and need help in high order ADLs (bathing, transportation, heavy housework, medication). Typically mild frailty progressively impairs shopping and walking outside doors, meal preparation and housework.	
 <b>6. Moderately Frail</b> - People need help with all outside activities and with keeping houses inside; they often have problems with stairs and need help with bathing and might need minimal assistance (e.g., standing) with dressing.	

**Scoring frailty in people with dementia**  
The degree of frailty corresponds to the degree of dementia. Current symptoms in mild dementia include forgetting the details of a recent event, though still remembering the event itself, repeating the same question(s) and need with/without.

In moderate dementia, recent memory is very impaired even though they sometimes can remember their past life events well. They also do personal care with prompting.

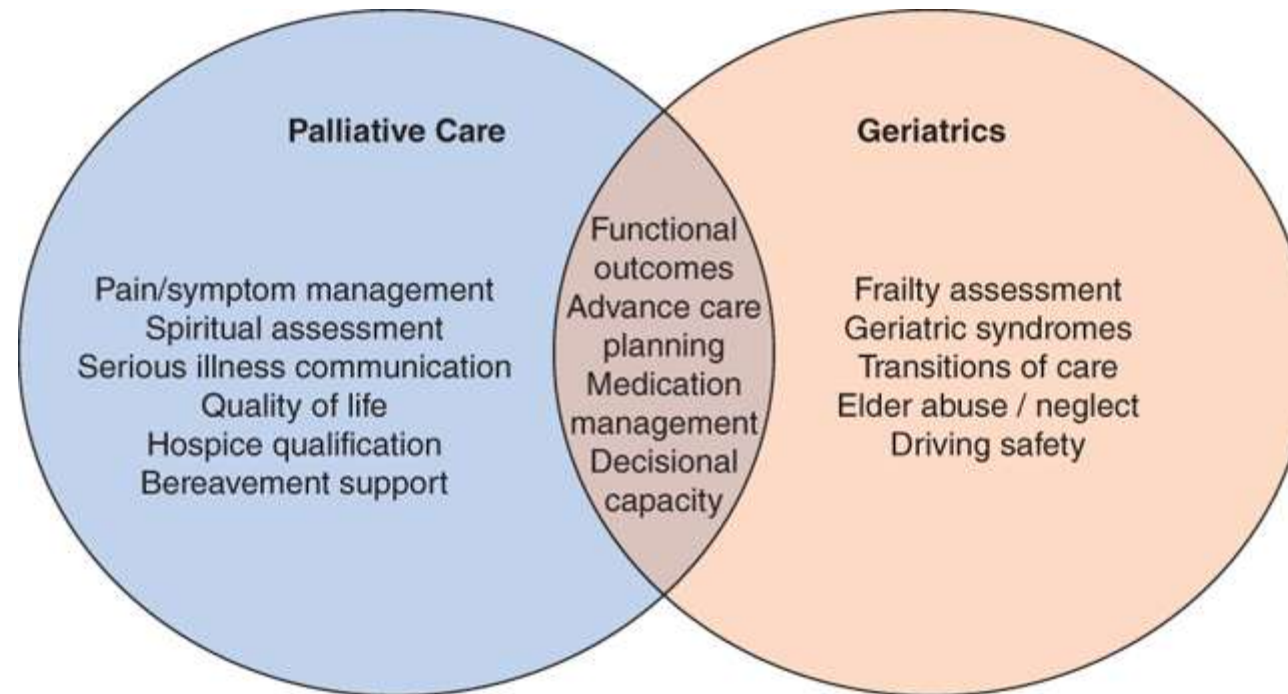
In severe dementia, they cannot do personal care without help.

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Should he have an advanced care plan ?



# Models of Care




Source: J.B. Halter, J.G. Ouslander, S. Studenski, K.P. High, S. Asthana, M.A. Supiano, C. Ritchie, W.R. Hazzard, N.F. Woolard: Hazzard's Geriatric Medicine and Gerontology, Seventh Edition, [www.accessmedicine.com](http://www.accessmedicine.com) Copyright © McGraw-Hill Education. All rights reserved.

- What is your understanding of where you are and of your illness?
- Your fears or worries for the future
- Your goals and priorities
- What outcomes are unacceptable to you?
- What are you willing to sacrifice and not?
- And later, what would a good day look like?

Atul Gwande Being Mortal

## Critical Time Points for people with CKD

- 
- CKD :Interdisciplinary care planning & education about the disease process
  - CKD: What are the biopsychosocial, cultural and spiritual values of the patients, families and carers
  - ESRD: Interdisciplinary care planning, education about dialysis, palliative care and hospice
  - ESRD: Does the patient want to initiate dialysis
  - END OF LIFE: Does the patient wish to withdraw dialysis?
  - END OF LIFE: Review goal of care and advance care planning



## Serious Illness Conversation Guide

CONVERSATION FLOW	PATIENT-TESTED LANGUAGE
1. <i>Set up the conversation</i> Introduce the idea and benefits Ask permission	SET UP "I'm hoping we can talk about where things are with your illness and where they might be going — <b>is this okay?</b> "
2. <i>Assess illness understanding and information preferences</i>	ASSESS "What is your <b>understanding</b> now of where you are with your illness?" "How much <b>information</b> about what is likely to be ahead with your illness would you like from me?"
3. <i>Share prognosis</i> Tailor information to patient preference Allow silence, explore emotion	SHARE <b>Prognosis:</b> "I'm worried that time may be short." or "This may be as strong as you feel."
4. <i>Explore key topics</i> Goals Fears and worries Sources of strength Critical abilities Tradeoffs Family	EXPLORE "What are your most important <b>goals</b> if your health situation worsens?" "What are your biggest <b>fears and worries</b> about the future with your health?" "What gives you <b>strength</b> as you think about the future with your illness?" "What <b>abilities</b> are so critical to your life that you can't imagine living without them?" "If you become sicker, <b>how much are you willing to go through</b> for the possibility of gaining more time?" "How much does your <b>family</b> know about your priorities and wishes?"
5. <i>Close the conversation</i> Summarize what you've heard Make a recommendation Affirm your commitment to the patient	"It sounds like _____ is very important to you."
6. <i>Document your conversation</i>	CLOSE "Given your goals and priorities and what we know about your illness at this stage, I <b>recommend...</b> " "We're in this together."

Meet Joan

Referred for PD

She lives alone

She is 82 years old has myeloma and poor prognosis

She had expressed wishes on what she did and didn't want and wasn't sure dialysis would be 'right for her'

Stable eGFR 8

Son was always with her in clinic and very supportive

Discussed her wishes regularly

Wishes for dying and where



Described what and how symptoms would change

Involved GP and wider teams



# Symptoms in ESRD patients—on dialysis, in the end-of-life

- fatigue/tiredness 71% (12% to 97%),
- pruritus 55% (10% to 77%),
- constipation 53% (8% to 57%),
- anorexia 49% (25% to 61%),
- pain 47% (8% to 82%),
- sleep disturbance 44% (20% to 83%),
- anxiety 38% (12% to 52%),
- dyspnea 35% (11% to 55%),
- nausea 33% (15% to 48%),
- restless legs 30% (8% to 52%),
- depression 27% (5% to 58%)

Health characteristics	Prevalence
Dependency	36.1 to 93.8%
Cognitive impairment	75%
Frequent behavioural symptoms	66%
Malnutrition	30%
Use of NHS resources	86.6%
Medications	8 (median number)
Comorbidities	6.2 (mean number)
Gordon et al, 2014	

*Murtagh et al. AdvChronicKidDis2007, 14:82-9*

*Kidney International (2015) 88, 447–459*

*Gordon et al. AgeAgeing(2014) 43(1): 97–103*

# What Do We Mean by Dying ?

- 'Palliative care should be considered from diagnosis onwards and integrated into care for people with any condition that means they may die in the foreseeable future' WHO 2014

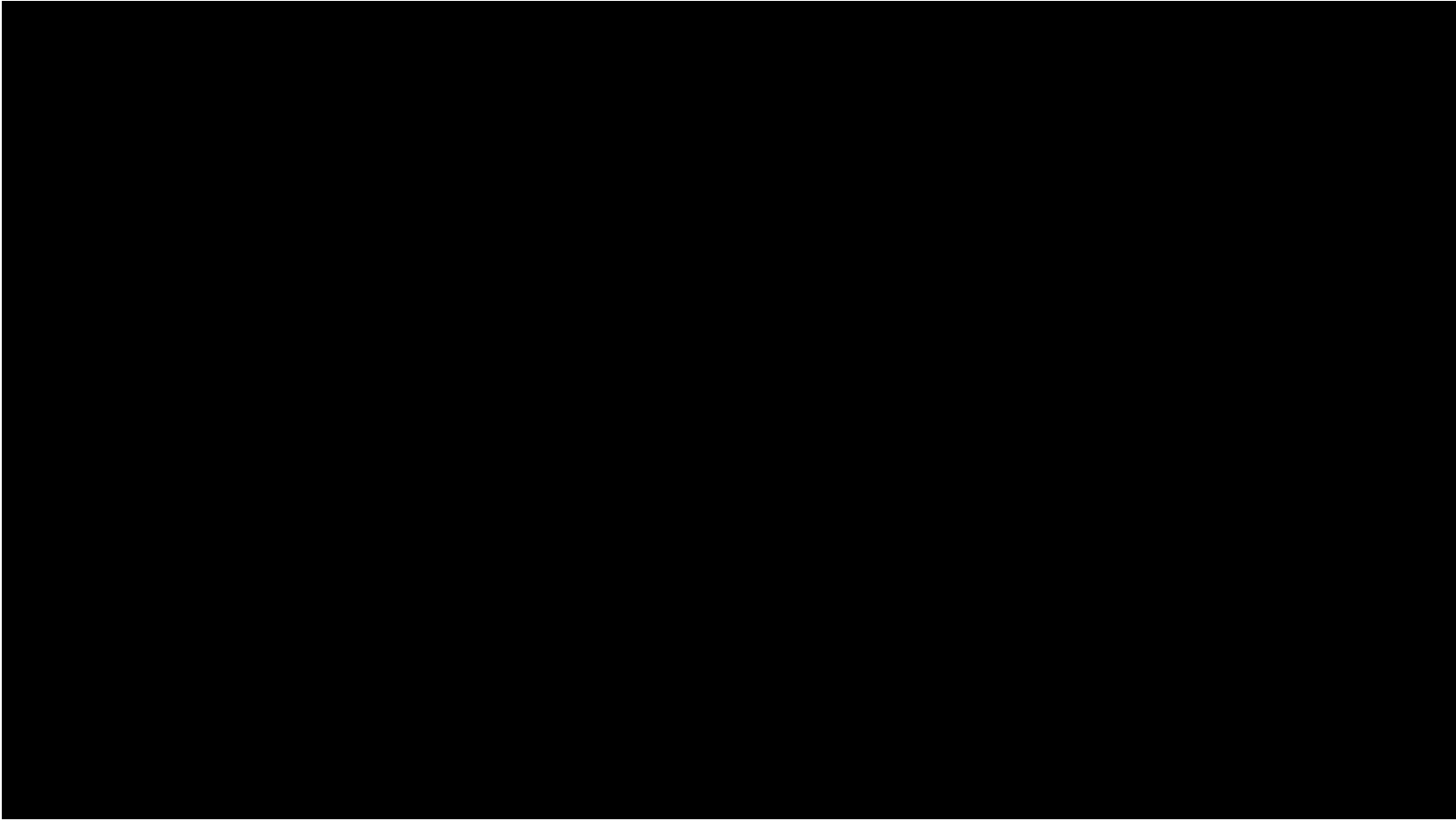
## WHY IS IT IMPORTANT?

- Evidence for early palliative care improves QOL, helps avoid burdensome interventions, reduces hospital admissions and choices are aligned to their priorities

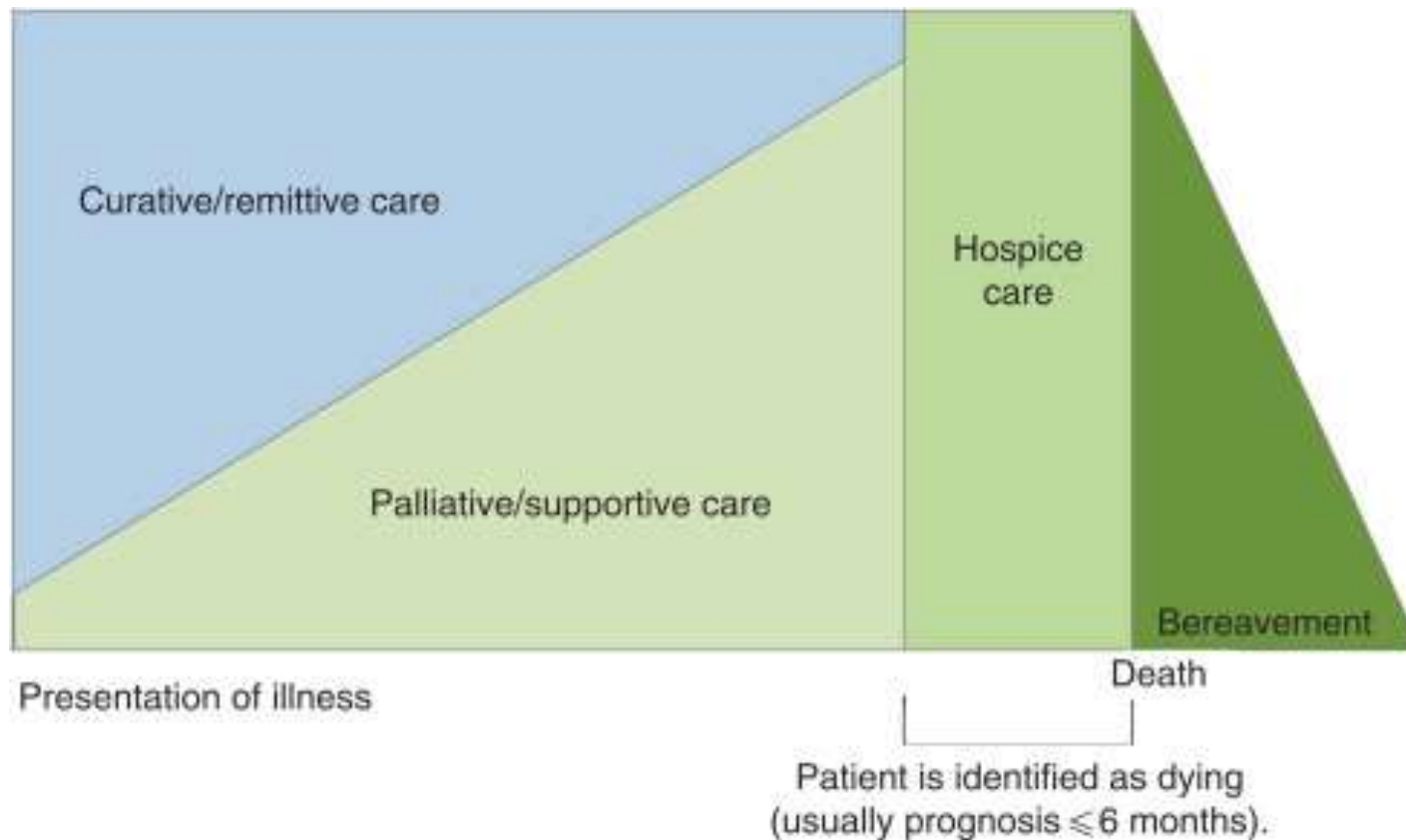
Scott A Murray et al BMJ 2017

# Signs of Decline; How do we know ?

- The surprise question: Would you be surprised if the patient were to die in the next months, weeks or days? (Berger and Hedayti 2012)
- General indicators of decline, physical, functional, symptoms burden, dialysis burden, frailty (GSF 2011)
- Cognitive dysfunction, new serious diagnosis, failing PD does not want to transfer to HD, recurrent admissions (Meeus and Brown PDI 2015)
- Patient choice .....wanting to stop dialysis



# Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care



# Food for Thought.....

Sir William Osler noted in 1901 that 'pnuemonia may well be called the friend of the aged. Taken off by it in an acute , short, not often painful illness, the old man escapes those 'cold graduations of decay' so distressing to himself and to his friends'. Pneumonia in this context could nowadays be replaced by sepsis.....

*A point prevalence study of sepsis the high incidence of frailty and severe comorbidities make most sepsis deaths neither attributable to sepsis, nor preventable through timely and effective health care*

Lancet 2019

# Take Home Messages

- The population is getting older with more complex health needs
- Need to integrate frailty and CGA as a gold standard for all over 65 years with a LTC
- Embed ACP into those early conversations at diagnosis and prognosis changes
- Help prepare patients for end of life ensuring their holistic needs are met