

Frailty and End of Life Care Everybody's Business



StChristopher's



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#PALLUPstudy

Agency, equity, equality, visibility, choice,
rights- all people should have access to
personalised end of life care...

Aim to cover in this presentation-

What Frailty is (and is not...)

Why does Frailty matter to you in your place of work

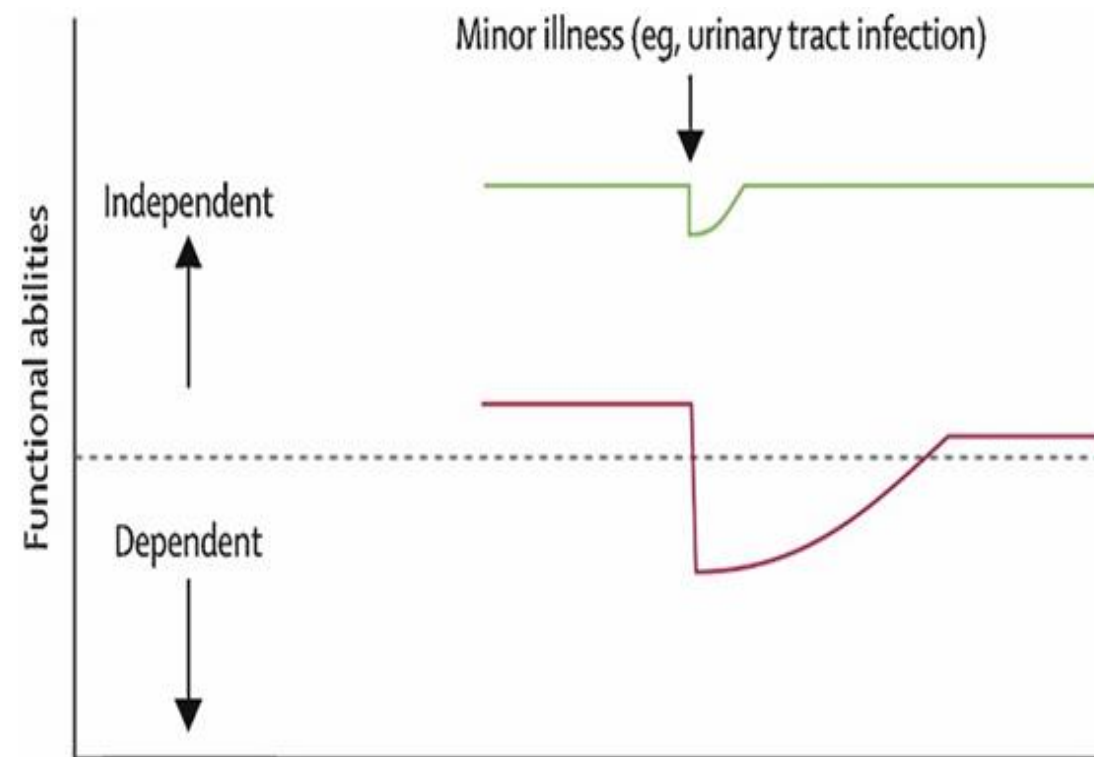
When should Frailty/Multiple Long Term Conditions be a factor in end of life care

The PALLUP study and **How** the work might assist you?



What is Frailty - A Long Term Condition


- Frailty is a **clinical syndrome of physiological decline** in late life, characterized by marked vulnerability to adverse health outcomes. A long term condition
- Older people living with frailty are at risk of adverse outcomes such as **dramatic changes** in their physical and mental wellbeing after an apparently minor event, such as an infection or new medication.
- **Reduced recovery potential**
- “Adverse outcomes include reduced mobility, loss of independence or death.
- Around 10 per cent of people aged over 65 years have frailty, rising to between a quarter and a half of those aged over 85.







Identifying Frailty- mild- moderate- severe

The Clinical Frailty Scale-if the person is acutely unwell score how they were 2 weeks ago

CLINICAL FRAILTY SCALE

	1	VERY FIT	People who are robust, active, energetic and motivated. They tend to exercise regularly and are among the fittest for their age.
	2	FIT	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 , even if occasionally symptomatic, but often are not regularly active beyond routine walking.
	4	LIVING WITH VERY MILD FRAILITY	Previously “vulnerable,” this category marks early transition from complete independence. 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	LIVING WITH MILD FRAILITY	People who often have more evident slowing , and need help with high order instrumental activities of daily living (finances, transportation, heavy housework). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation, medications and begins to restrict light housework.

	6	LIVING WITH MODERATE FRAILITY	People who 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	LIVING WITH SEVERE FRAILITY	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	LIVING WITH VERY SEVERE FRAILITY	Completely dependent for personal care and approaching 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 living with severe frailty . (Many terminally ill people can still exercise until very close to death.)

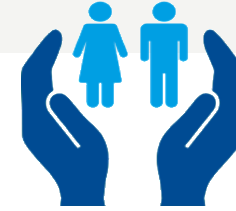
SCORING FRAILITY IN PEOPLE WITH DEMENTIA

The degree of frailty generally 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. In **very severe dementia** they are often bedfast. Many are virtually mute.

Why does Frailty matter where you work?

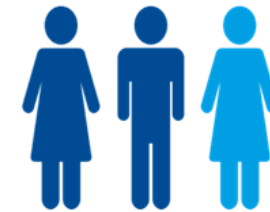
- If a person is severely frail they are X 5 more likely to die in a year than if not (Clegg et al 2016)
- Best predictor of mortality in community dwelling older people, surpassing the predictive ability of co-morbidity and biological age (Morrell et al 2017)
- Currently older people with frailty undertreated by palliative care and over treated in “aggressive medical interventions
- Care transitions costly for person, family and Health /Social Care (Hunter & Orlovic 2018)
- Caring for older people with frailty must integrate Palliative Care with Older Peoples Care (Nicholson et al 2019)
- **Frailty can be made better or worse through our interventions**



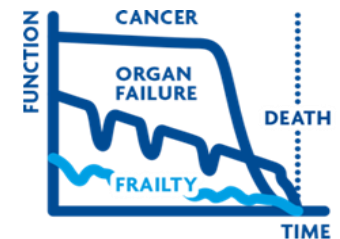
- Palliative care in our communities must double by 2040



- 83% of health spending is in the last year of life.
- Cost borne by older person, their family and services



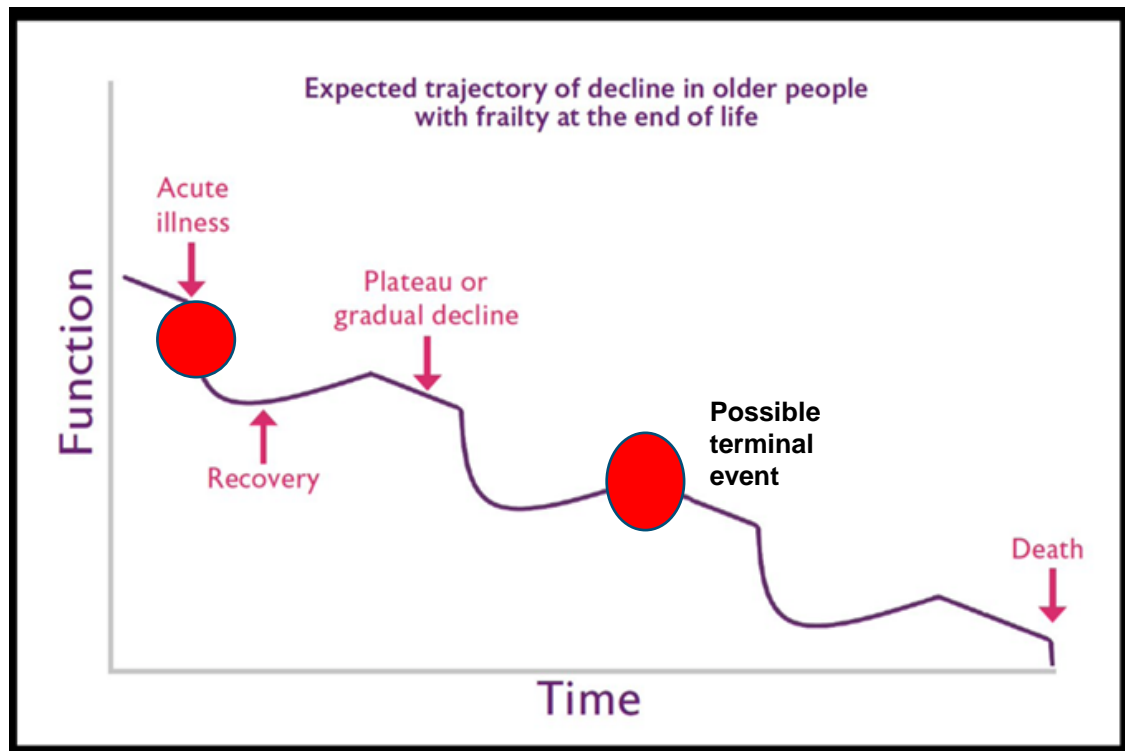
- **Most of “our” dying population are old & frail**
- **The rest have multi-morbidity**



- People with different illnesses have different needs and die differently

When should Frailty be a factor in End of Life Care ?

In the context of severe frailty, it can be particularly difficult to predict prognosis. However, people and their families can make choices about current and future care as long as uncertain recovery and benefits/burdens of different types of care are explained. Parallel planning for recovery or deterioration is essential in the context of acute illness.



There is often a long phase where a person (with frailty) 'could' die

This is very dependant on intercurrent and unpredictable events

It can feel like a long time to be 'dying'... the long walk home

(M Wilson 2017)



Knowing when someone is going to die (prognostication) may be less helpful than knowing what matters to a person (preferences and needs)

The PALLUP study

StChristopher's
More than just a hospice

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NIHR National Institute
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**The PALLUP Study:
Equipping community
services to meet the
palliative care needs of
older people with frailty
approaching the end
of life: a mixed
methods study**

Professor Caroline Nicholson
Dr Richard Green

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- Understanding need-
- Survey of current practice
- Collecting patient and carer experience and service response in real time-
- Together developing key features and resources to embed in service provision



visual minute by www.newpossibilities.co.uk @AnnaGeyer_NP

**Addressing inequity in palliative care provision
for older people living with multimorbidity.
Perspectives of community-dwelling older
people on their palliative care needs: A scoping
review**

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Helen King², and Richard Green¹ 

Palliative Medicine

1-23

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DOI: 10.1177/02692163221118230

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How might PALLUP assist You ?

- Difficulties with managing activities of daily living
- Practical Help -Mobility Aids and other people
- Physical/functional dependence -
- Mood
- Difficulties managing medications
- Loneliness
- Continuity of Social support
- The vital and often unsupported role of unpaid Carers
- Care Closer to home AND
- **Resilience, humour, strength.....**

<https://www.surrey.ac.uk/living-and-dying-well-research/living-advancing-frailty-educational-film>

Get involved...<https://www.surrey.ac.uk/living-and-dying-well-research>

End Of Life Care and Frailty – How you might respond

- Talking about a different phase of life where healthcare goals may change, balancing quality against quantity of life.
- Dual approach- affirming life and preparing for death
- Talking about benefits and burdens of healthcare – understanding the impact of frailty on response to illness and recovery
- Understanding that just **because "we" can does not mean we should**
- Early Conversations with older people and those that are important to them
- Recognising that older people with frailty are people – with huge strengths as well as vulnerabilities
- Awareness that the end of life may be close should inform all clinical care for older people with Frailty and/or multiple long-term conditions



With Thanks...

The Older People, their families, services providers and volunteers who have informed and taken part in the study



FUNDED BY

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Caroline Nicholson (ICA Senior Clinical Fellowship, ICA-SCL-2018-04-ST2-001) is funded by Health Education England (HEE) / National Institute for Health Research (NIHR) for this research project. The views expressed are those of the author and not necessarily those of the NIHR, HEE, NHS or the UK Department of Health and Social Care.

