Network Recording Declaration

During this ECHO session discussions will be recorded so that people who cannot attend will be able to benefit at another time. Filming is regarded as ‘personal data’ under the Data Protection Act 2018 General Data Protection Regulations (GDPR), under that law we need you to be aware that:

• This Data will be stored with password protection on the internet.
• This Data will be available for as long as your network continues to meet and will then be taken down from the internet and either stored securely at the Superhub or deleted.

Your ongoing participation in this ECHO session is assumed to imply your agreement to the use of your data in this way.

If you are NOT willing for your data to be used in this way, please LEAVE the session at this point.
The Palliative and End of Life Care and Dementia ECHO Knowledge Network

Week 3: Frailty and Dementia
Introductions
Call out for:

1. Change ideas for making this network more collaborative

2. Contributions for the Dementia Bulletin
# Agenda

<table>
<thead>
<tr>
<th>Time</th>
<th>Event Description</th>
<th>Speaker/Position</th>
</tr>
</thead>
<tbody>
<tr>
<td>14:50</td>
<td>Presentation on ‘Frailty in Dementia’</td>
<td>Dr Jemima Collins, Academic Clinical Lecturer in Geriatric Medicine, The University of Nottingham</td>
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<tr>
<td></td>
<td>Followed by questions and group discussion</td>
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<tr>
<td>15:30</td>
<td>Case presentation 1</td>
<td>Maggie Candy, Nursing Consultant, Cavendish Professionals Homecare</td>
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<tr>
<td></td>
<td>Followed by Group Discussion</td>
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<tr>
<td>16:00</td>
<td>Case presentation 2</td>
<td>Sophie Dodsworth, Dementia Palliative Care Nurse, Derbyshire Community Health Services NHS Foundation Trust</td>
</tr>
<tr>
<td></td>
<td>Followed by Group Discussion</td>
<td></td>
</tr>
</tbody>
</table>
ECHO Session Evaluation

Help to shape the sessions

Quick questions with additional comments welcome

3 minutes to complete

Link will be given in the Chatbox towards the end of the session.
Dr Jemima Collins
Academic Clinical Lecturer in Geriatric Medicine,
The University of Nottingham
Frailty, Dementia and End of Life Care

ECHO Network for Palliative and End of Life Care and Dementia
19.10.2021

Dr Jemima Collins, MB.Ch.B, MRCP, M.D.
NIHR Academic Clinical Lecturer in Geriatric Medicine / ST7
University of Nottingham
Who is Frail?

Photo Credits:
Shutterstock, Alamy, theimagedirect.com
What is Frailty?

- A) A Description
- B) A Disease
- C) A Disability
- D) A Syndrome
Frailty as a Risk Factor for Falls Among Community Dwelling People: Evidence From a Meta-Analysis

Mel-Hsun Cheng, BNS\textsuperscript{1}, & Shu-Fang Chang, PhD\textsuperscript{2}

\textsuperscript{1}Registered Nurse, Department of Radiology, Cardinal Tien Hospital, Xindian, New Taipei City, Taiwan
\textsuperscript{2}Professor, School of Nursing, College of Nursing, National Taiwan University of Nursing and Health Sciences, Taipei, Taiwan

Frailty is the most problematic cause of homoeostasis after a stressor event and as a consequence of cumulative decline in many physiologic systems during a lifetime. This cumulative decline depletes homeostatic reserves until minor stressor events trigger disproportionate changes in health status. In landmark studies, investigators have developed valid models of frailty and these models have allowed epidemiological investigations that show the association between frailty and adverse health outcomes. We need to develop more efficient methods to detect frailty and measure its severity.

The impact of frailty and delirium on mortality in older inpatients

Eamonn M. P. Eeles\textsuperscript{1}, Susan V. White\textsuperscript{1}, Sinead M. O'Mahony\textsuperscript{1}, Antony J. Bayer\textsuperscript{1}, Ruth E. Hubbard\textsuperscript{1}

\textsuperscript{1}Department of Geriatric Medicine, Cardiff University, Cardiff, UK

A total of 102,130 community-dwelling older adults ≥65 years of age who had experienced a fall were compiled to investigate the relationship between frailty and falls. The meta-analysis results compared with robust older adults, frail older adults demonstrated a higher risk for falls, followed by prefrail older adults. Further studies of different frailty indicators to predict the fall incidence rates yielded nonsignificantly different outcomes. In short, studies suggest that vascular health or osteoporotic fracture indicators are effective risk factors for falls in older people. Finally, this study confirmed with robust older adults, frail older adults were more likely to experience recurrent falls.

Conclusions: Frailty is a crucial healthcare topic of people with geriatric syndromes. Frail older adults are likely to experience recurrent falls. In addition, the evidence-based study indicated that once older people enter the prefrail stage, they are likely to experience falls. Therefore, older adults should be evaluated.
Frailty is...

- Age-related
- Syndrome with multiple causes and contributors
- Characterised by diminished physical strength and endurance
- Loss of physiological reserve
- Increased vulnerability to stressors

But Frailty is Not...

- Inevitable
- Irreversible
- Unmanageable

Fit for Frailty

Consensus Best Practice Guidance for the care of older people living with frailty in community and outpatient settings - published by the British Geriatrics Society and the Royal College of Nursing in association with the Royal College of General Practitioners and Age UK

Part 1: Recognition and management of frailty in individuals in community and outpatient settings

How to use this guide

This summary guide will be relevant to anyone who may be called on to provide support to older people living with frailty, including nurses, GPs, social workers, care staff, generalists, and informal carers. It explains how to recognise frailty and offers advice on how to improve the individual’s health and wellbeing.

Why is frailty important?

Older people living with frailty are at risk of dramatic deterioration in their physical and mental wellbeing, often possibly small, overlooked or overlooked, which challenges their health, growth, nutrition, social connection or social isolation.

https://www.bgs.org.uk/sites/default/files/content/resources/files/2019-02-08/BGS%20Toolkit%20FINAL%20FOR%20WEB_0.pdf
Measuring Frailty

**Fried Criteria**


- Unintentional Weight Loss
- Weakness
- Exhaustion
- Slowness
- Reduced physical activity

**CSHA Frailty Index**

Rockwood et al. CMAJ 2005; 173(5): 489-95

Appendix 1: List of variables used by the Canadian Study of Health and Aging to construct the 70-item CSHA Frailty Index

- Changes in everyday activities
- Head and neck problems
- Poor muscle tone in neck
- Bradykinesia, facial
- Problems getting dressed
- Problems with bathing
- Problems carrying out personal grooming
- Urinary incontinence
- Toileting problems
- Bulb difficulties
- Rectal problems
- Gastrointestinal problems
- Problems cooking
- Sucking problems
- Problems going out alone
- Impaired mobility
- Musculoskeletal problems
- Bradykinesia of the limbs
- Poor muscle tone in limbs
- Poor limb coordination
- Poor coordination, trunk
- Poor standing posture
- Irregular gait pattern
- Falls
- Mood problems
- Feeling sad, blue, depressed
- History of depressed mood
- Tiredness all the time
- Depression (clinical impression)
- Sleep changes
- Restlessness
- Memory changes
- Short-term memory impairment
- Long-term memory impairment
- Changes in general mental functioning
- Onset of cognitive symptoms
- Clouding or delirium
- Paranoid features
- History relevant to cognitive impairment or loss
- Family history relevant to cognitive impairment or loss
- Impaired vibration
- Tremor at rest
- Postural tremor
- Intention tremor
- History of Parkinson's disease
- Family history of degenerative disease
- Seizures, partial complex
- Seizures, generalized
- Syncope or blackouts
- Headache
- Cerebrovascular problems
- History of stroke
- History of diabetes mellitus
- Arterial hypertension
- Peripheral pulses
- Cardiac problems
- Myocardial infarction
- Arrhythmia
- Congestive heart failure
- Lung problems
- Respiratory problems
- History of thyroid disease
- Thyroid problems
- Skin problems
- Malignant disease
- Breast problems
- Abdominal problems
- Presence of snout reflex
- Presence of the palmar reflex
- Other medical history
Measuring Frailty (2) – in practice

Clinical Frailty Scale*

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

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

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

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

**Mildly Frail** – These people often have more bone loss, and need help in high order IADLS (e.g., transportation, housework, medication). Typically, mild frailty progressively improves and walking outside alone, meal preparation housework.

**Moderately Frail** – People need help with all side activities and with keeping house. Inside, they have problems with stairs and need help with simple daily activities (e.g., dressing).

**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).

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

**Terminally Ill** – Approaching the end of life. This category applies to people with a life expectancy <4 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 recognizing 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.

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[Comprehensive Geriatric Assessment, BGS](https://www.bgs.org.uk/sites/default/files/content/resources/files/2021-02-08/BGS%20Toolkit%20-%20FINAL%20FOR%20WEB_0.pdf)
COVID-19 and the Frailty Aspect

**The Clinical Frailty Scale: of Frailty in Older Patients COVID-19. The COPE Study**

Jenima T. Collins, Roxanna Short, Ben Carter, Terence J. Quinn, Arturo Vilches-Moraga, Míriam McCartney, Kathrin Haan

**The effect of frailty on survival in patients with COVID-19 (COPE): a multicentre, European, observational cohort study**


**Association of frailty with mortality in older inpatients with Covid-19: a cohort study**

Darren Aw, Lauren Woodrow, Giulia Ogliari, Rowan Harwood

Health Care of the Older Person, Nottingham University Hospitals NHS Trust, Queen’s Medical Centre, Nottingham NG7 2UH, UK
Dementia, and its association with Comorbidities

- Definition of Dementia:
  Memory loss in addition to changes in language, perceptual-motor, executive function, learning, attention and social cognition.

- Prevalence of 3 or more comorbidities in people with dementia 21.6% vs 11.2% in people with no dementia

- Prevalence of 4 or more comorbidities 2.5x more in people with dementia compared to people without dementia

- Prevalence of 5 or more comorbidities almost 4x as much in people with dementia compared to those without
Dementia – one directional relationship with Frailty?

- 5 year cohort study, 2022 older people
- Frail / Non-frail groups at baseline
- Incident dementia at 5 years
  - 22.8% in frail group
  - 8.9% in non-frail group

- Meta-analysis data, 14302 participants
- People with frailty were 1.47x more likely to get dementia
- People with frailty AND cog impairment were 5.36x more likely to get dementia
Dementia, and its association with Frailty (1)

- So, while dementia is strongly associated with comorbidities and physical frailty....

Dementia ≠
Comorbidities ≠
Frailty

Photo Credit: Jeff Moore
Dementia Friends Campaign
Image via PA from bbc.co.uk/news
Dementia, and its association with Frailty (2)

- Many problems that may give rise to frailty syndrome in people living with dementia involve declining...
  - Planning
  - Judgment
  - Situational (safety) awareness
  - Problem solving
  - Processing speed

Even before you add in physical comorbidities which contribute to frailty!
If you have both cognitive impairment and frailty, you are more likely to be more functionally impaired at the end of life (Cohen-Mansfield et al, 2018).

How do we recognise the beginning of the end?

- Inability to walk, or do purposeful activity
- Loss of weight or appetite
- Recurrent infections
- Incontinence
- Swallowing difficulties
- Increased hospital admissions

But it’s really hard to predict!

Theoretical trajectories of dying, from Lunney et al, JAGS 2002.
Challenges in End of Life Care in Dementia

- People with dementia are less likely to be offered palliative care than people without dementia

- Trajectory often unclear

- Consequences of treatment (benefits or burden) vs Rights (autonomy and justice)

- People vary in what they want for the future

- Many die in hospital due to a stressor event e.g. infection, and deteriorate acutely. Most die in care homes
Dementia and End of Life Care in Care Homes

- 69% of people living in care homes have dementia
- Median 2 years to death from admission to care home
- Approx 33% people >85 or older die in a care home
- 40% of people with dementia will die at home or in a care home with no access to nursing care or palliative care services

- People with dementia may receive poorer quality care than their cognitively intact counterparts

- A good relationship between healthcare professionals and care home staff is key to whether health interventions achieve desired outcomes
Improving Care for People with Dementia and Frailty

- Hospital Care
  - Avoiding unnecessary admissions
  - Dementia friendly wards
  - Flexible visiting times
  - Avoid excessive medication

- Community Care
  - Link / Support Workers
  - Admiral Nurses
  - Third Sector Organisations
  - More joined-up working between services
Improving Care for People with Dementia and Frailty at the End of Life

- Advanced Care Planning (how can we do it better?)
- What matters to you? (and the people who are important to you)
- Management of distress – physical and mental
- The right decision, at the right time, treatment benefit vs treatment burden
- Building carer resilience and support
Helpful resources

- https://www.dementiauk.org/get-support/understanding-changes-in-behaviour/understanding-dying/
Take Home Messages

- Frailty is an age related, complex, multifactorial syndrome that is characterised by loss of physical reserve and increased vulnerability to stressors

- Definition of frailty, and how to measure it in practice

- Comprehensive Geriatric Assessment

- Frailty and Dementia frequently coexist but not the same

- How can we identify the challenges in end of life care provision for patients living with frailty and dementia, in order to do it better?
References

The Palliative and End of Life Care and Dementia
ECHO Knowledge Network

The Lantern Model of Nursing

ECHO ID: 922 6638 2904
Maggie Candy RN
Nursing Consultant & John’s Campaign Ambassador, Cavendish Homecare
Overview of Presentation

1. Why use the Lantern Model?
2. Background
3. What we did
4. Barriers
5. Impact
6. Discussion
Why pilot the Lantern Model?

1. Good fit with person centered ethos
2. Contemporary and relevant
3. Nurse led but for all staff
4. Suitable for all care areas
5. Identifies the unique contribution of nursing
6. Supports staff
Background

1. Our services - care at home
2. Increased demand all services
3. Staff – very experienced / small teams
4. Staff live in / intense periods of care
5. Person centered and family led - E.g., Support “John’s Campaign” in dementia
My Background

1. Previous care home management experience both as Manager/regionally
2. Keen on quality in all dementia, palliative and end of Life services
3. Care home – “Outstanding” CQC rating
4. But unable to make previous end of life project successful with staff
5. John’s Campaign Ambassador
Benefits of a Good Death

• Death is not a medical event – it is the most intimate and personal journey

• “I expect a good death and am confident my end of life wishes will be met” National Dementia Strategy, 2014

• “Suffering is only intolerable when no-one cares”

• “How people die remains in the memories of those who remain behind” Dame Cicely Saunders

• Only one chance to get this right!

• “You matter because you are you and you matter to the last moment of your life. We will do all that we can not only to help you die peacefully, but also to live until you die”
Introducing the Lantern Model: a contemporary model of nursing for people at the end of life

Heather Richardson and Marie Cooper
The Offer of the Model
The Lantern Model

• Inspired by and dedicated to nurses
• Provides new clarity to the unique contribution of nursing
• Relevant to nurses in any setting
• Reflects contemporary thinking about death that:
  • Is relevant to current practice
  • Underpinned by best practice
  • Not a completed work but one to build on
What we did?

- Contacted St. Christopher's Hospice – access to webinars and model notes shared
- Target group for pilot – x 10 Registered Nurses including management
- Marie Cooper was guest speaker at first meeting – also provided self-assessment tools
- Monthly on-line meetings to discuss each webinar
- Obtained feedback from staff via 121 meetings
- Head Office participation celebration planned
The Cavendish Team
The Four Webinars

1. Getting to know the person in the patient

2. The art and science of nursing

3. Person pre-requisite of The Lantern Model

4. Advancing the profession of nursing and it’s offer at end of life
Personal Pre-requisites

- Compassion
- Self-knowledge
- Confidence
- Generosity
- Courage
It’s Focus and Structure

- Focused on the notion of personhood – beyond patients only
- Evidence based
- Practice orientated
- Tested and refined
- Recognises inter-relationships between different domains

Person centered nursing framework. McCormack and McCance 2006/10/17
Nurses and care workers are most likely present at time of death. They are in a unique position to go through that journey with the individual.

The art and the science of care promotes an authentic relationship between the nurse and those they care for.

**Nursing Processes**

1. **Connecting**
   
   “Hello, I would like to get to know you and find out what is important to you”

2. **Future planning**
   
   “Tell me what you would like your future to look like and let me suggest how I can help you achieve it”

3. **Coaching and caring**
   
   “I have skills and knowledge to share, encouragement to offer and care available when you can no longer care for your self yourself”

4. **Accompanying**
   
   “I am here to help as and when you need me”
Component Parts

The model has seven key components described in the narrative below.

Outcomes
High-quality nursing seeks to make a difference to people’s health and lives. At the heart of our model are the outcomes nurses working to this model can expect to achieve on behalf of those for whom they provide care.

Context of care
These outcomes reflect contemporary challenges and opportunities which nurses of today and tomorrow will want to grasp, and the macro context shaping their practice.

Processes of nursing care
Nurses will contribute to these outcomes through various processes of care that they deliver directly and in which they are central.

Support by the wider multi-disciplinary team (MDT)
Some nursing processes are most effective when they are supported by input on the part of other professionals also involved in end of life care.

Personal prerequisites
The nurse will only enact their processes of care and work effectively as part of the MDT if they have the right personal prerequisites.

Organisational conditions
The nurse’s impact will be enhanced if organisational conditions to support their effort are optimum.

Key tenets that shape and guide the care provided
The best nursing at the end of life is rooted and supported by key tenets which serve to guide all their efforts.
Constraints

• Current climate not ideal for new ideas
• All staff very busy keeping safe
• Not all staff familiar with technology
• Difficult to get groups of staff together
• On-going comments from staff said that they feel under valued by visiting professional’s
Acknowledgement of the wider MDT

1 Recognising dying
“My care is at its best when others help identify when someone is coming to the end of their life and would benefit from additional/different support”

2 Inviting important conversations about today and the future
“My care is at its best when others contribute to important conversations that people want to have about their future”

3 Providing enhanced symptom management, psychosocial care and rehabilitation
“My care is at its best when other members of the team identify and deliver a range of interventions alongside nursing, which helps people maintain their quality of life and their functionality”

4 Supporting continuity of care
“My care is at its best when colleagues work collaboratively with me and across organisational and other boundaries to enable continuity of care”

5 Caring for colleagues
“My care is at its best when I know other colleagues look out for me and my wellbeing, mindful of the stress we all experience”
Staff Outcomes

• Person centered care evidenced
• Staff enjoyed pilot of model—especially “Human Flourishing” and “Nurses as wounded healers” concepts of thoughts/idea’s
• Future development opportunities - family post death bereavement pack help
• Plans to include model in induction with all staff

My care is at its best when:
• I have time and work in a healing environment ....
  • I can gain access to other expertise
  • I feel valued.....
• I can continue to learn and develop my skills
• I know I am supported to be creative and flexible in my work
Lantern Model Outcomes

- The outcomes identified reflect contemporary preferences, values and concerns

  - I Understand what is happening
  - I can still enjoy life
  - You see me as a person, and I know that I matter
  - I feel safe
  - I feel involved and know I have a part to play in shaping the future
  - I am confident to participate in care

- Knowledge
- Comfort
- Dignity and respect
- Safety
- Opportunity to participate
- New skills and confidence
Discussion

• Is it time to put “Love” back into nursing?
• Quality of life versus extending life?
• Recent press issues highlighting “futile treatments” offered to cancer patients
• Everybody matters in dignified care
Final Thoughts

Continue the conversation invitation:
• November 3rd @ 4.00- 5.30 free webinar with Professor Phil Larkin and Nurse Consultant Maggie Bisset ‘Relational Care – the Touchtone of Nursing’
https://www.stchristophers.org.uk/care_news/lanternmodel

“The Lantern Model could help nurses hone their skills, focus their efforts and work with their colleagues to achieve the right outcomes for a patient, their families and carers.” – Professor Greta Westwood, PhD, RN, CEO, Florence Nightingale Foundation
Thank you

Email address: Maggie@cavendishhomecare.com

Lantern Model:
https://www.stchristophers.org.uk/care_news/lanternmodel

John’s Campaign:
https://johnscampaign.org.uk/

Cavendish Homecare:
https://cavendishhomecare.com/
Sophie Dodsworth,
Dementia Palliative Care Nurse,
Derbyshire Community Health Services
NHS Foundation Trust
Frailty and Dementia
Case study
Dementia Palliative Care ECHO

Sophie Dodsworth
Dementia Palliative Care Nurse RGN
88 year old lady with a new diagnosis of Moderate Vascular Dementia
PMH: Asthma, CVA 2019

Referred to the Dementia Palliative Care Team by the Community Matron for support with nutrition and hydration
Lived at home with elderly Husband
Husband and Niece had nominated LPA for health and finance
Several community services were supporting including GP, DN team, CPN, Community Matron, Social worker and Local Dementia support services
Holistic Assessment

* **Physical**
  - PMH
  - Falls/ prevention of falls
  - Continence
  - Rockwood score
  - Performance status
  - Skin integrity
  - Nutrition/ hydration
  - Medication/ compliance

* **Emotional/ psychological wellbeing**
  - Carers strain
  - Independence
  - Understanding of the condition

* **Personal**
  - Life storey work / This is me
  - Spiritual/ religious needs
  - Quality of life
  - Carers agenda

* **Social support**
  - Carers strain
  - Care package
  - Funding for care
  - Maintaining independence

* **Information/ communication**
  - Family network
  - Contact numbers
  - Sharing ACP and conversations about future wishes

* **Spiritual wellbeing**
  - Independence
  - Being together as a support network

* **Control**
  - Choice, dignity
  - Treatment plan
  - Advanced care planning
  - Lasting Power of Attorney
  - Preferred place of care/ death

* **Out of hours/ Emergency**
  - Advanced care planning
  - OOH plan
  - Carers support
  - Contact numbers
  - Anticipatory medication

* **Living with your illness**
  - Follow up care
  - ADLS
  - Cognitive reablement
  - Palliative care register
  - Anticipatory grief

* **After care**
  - Bereavement support
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.

3. © 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.
Main problems
Identified by IPOS DEM

- Weight loss
- Isolation / refusing social care support
- Falls
### Phase of Illness

<table>
<thead>
<tr>
<th>Phase</th>
<th>This is the current phase if...</th>
<th>This phase ends when...</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stable</td>
<td>Patient's problems and symptoms are adequately controlled by established plan of care and further interventions to maintain symptom control and quality of life have been planned and family/carer situation is relatively stable and no new issues are apparent.</td>
<td>The needs of the patient and/or family/carer increase, requiring changes to the existing plan of care.</td>
</tr>
<tr>
<td>Unstable</td>
<td>An urgent change in the plan of care or emergency treatment is required because the patient experiences a new problem that was not anticipated in the existing plan of care and/or the patient experiences a rapid increase in the severity of a current problem and/or family/carer's circumstances change suddenly impacting the patient.</td>
<td>The new plan of care is in place, it has been reviewed and no further changes to the care plan are required. This does not necessarily mean that the symptom/crisis has fully resolved but there is a clear diagnosis and plan of care (i.e. patient is stable or deteriorating) and/or death is likely within days (i.e. patient is now dying).</td>
</tr>
<tr>
<td>Deteriorating</td>
<td>The care plan is addressing anticipated needs, but requires periodic review because the patient's overall functional status is declining and the patient experiences a gradual worsening of existing problem(s) and/or the patient experiences a new, but anticipated, problem and/or family/carer's circumstances change gradually worsening distress that impacts on the patient.</td>
<td>Patient condition plateaus (i.e. patient is now stable) or an urgent change in the care plan or emergency treatment and/or family/carer's circumstances experience a sudden change in their situation that impacts on patient care, and urgent intervention is required (i.e. patient is now unstable) or death is likely within days (i.e. patient is now dying).</td>
</tr>
<tr>
<td>Dying</td>
<td>Dying: death is likely within days.</td>
<td>Patient dies: we are sure patient condition changes and death is not longer likely within days (i.e. patient is now stable or deteriorating).</td>
</tr>
<tr>
<td>Deceased</td>
<td>The patient has died. Bereavement support is provided to family/carers is documented in the deceased patient's clinical record.</td>
<td>Case is closed.</td>
</tr>
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</table>

### Karnofsky score

**What is patient's current functional status? (Australian modified Karnofsky Performance Status):**

<table>
<thead>
<tr>
<th>AKPS Score</th>
<th>Description of Performance Status</th>
</tr>
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<tbody>
<tr>
<td>100%</td>
<td>Normal, no complaints, no evidence of disease</td>
</tr>
<tr>
<td>90%</td>
<td>Able to carry on normal activity, minor signs or symptoms of disease</td>
</tr>
<tr>
<td>80%</td>
<td>Normal activity with effort, some signs or symptoms of disease</td>
</tr>
<tr>
<td>70%</td>
<td>Cares for self, but unable to carry on normal activity or to do active work</td>
</tr>
<tr>
<td>60%</td>
<td>Able to care for most needs, but requires occasional assistance</td>
</tr>
<tr>
<td>50%</td>
<td>Considerable assistance and frequent medical care required</td>
</tr>
<tr>
<td>40%</td>
<td>In bed more than 50% of the time</td>
</tr>
<tr>
<td>30%</td>
<td>Almost completely bedfast</td>
</tr>
<tr>
<td>20%</td>
<td>Totally bedfast and requiring extensive nursing care by professionals and/or family</td>
</tr>
<tr>
<td>10%</td>
<td>Comatose or barely arousal, unable to care for self, requires equivalent of institutional or hospital care, disease may be progressing rapidly</td>
</tr>
<tr>
<td>0%</td>
<td>Dead</td>
</tr>
</tbody>
</table>

**References:**
Personalised Support

- Maintained regular contact and built trust

- Regular communication with the patients Niece

- Worked closely with physical, mental health and social care colleagues
  Multiple Joint visits and phone calls

- Large text information

- Hearing support

- A Capacity assessment was completed to establish if the patient had capacity to decline social care support at home.
Advance Care Planning

- RESPECT Form
- Out of hours care plan
- This is Me Document
- Dementia UK Advanced Care Plan
Crisis point

* Patient and husband continued to decline social support

* Support worker from the Community Mental Health team commenced regular support to introduce and encourage social care support

* Although this helped build trust social support was not implemented before the patient sadly fell and fractured her hip

* The patient was transferred to a nursing home for assessment following acute admission and this became her permanent place of care

Best interests meeting and MDT approach may have prevented crisis
Conclusions

* Importance of recognising frailty as a long term condition

* Importance of the MDT approach

* Importance of advance care planning
References

* Hospice UK (2014) revised-first-assessment-kch-nov-2014 (hospiceuk.org)
* NHS RightCare: Frailty Toolkit Optimising a frailty system (2019)
* UK Research and innovation (2021) Empowering Better End of life Dementia Care (EMBED-Care Programme)
* Rockwood Clinical Frailty Scale - CGA Toolkit Plus (cgakit.com)
ECHO Session 1 Evaluation

Help to shape the sessions

https:// surveymonkey.co.uk/r/19_Oct_2021_Dementia
Thank you for joining today's session

Next session:
11 January 2021, 14:45 – 16:45

Topic: Rare Dementias at End of Life