Palliative Care and the Frail Elderly

By Dr Joanne Brady
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19th May 2016
The global elderly explosion: Number of old people is rising faster than ever - and will DOUBLE in 30 years

- Report: Some 8.5% of people worldwide - 600m - are now aged 65 or over
- By 2050, number of people in this age bracket will rise by 17% to 1.6bn
- The 'oldest old' - people over 80 - is expected to triple in the next 30 years
- Life expectancy predicted to rise by 8 years - to 76.2 - by 2050, report said

By MADLEN DAVIES FOR MAILONLINE
Frailty will be the major public health challenge of the 21st century - it is a global societal issue not just medical
Frailty: the ‘subtacular\(^1\)’ death?

- An elderly patient with advanced dementia and Parkinson’s disease was sent to the emergency department from a nursing home on a Friday evening. The patient was unconscious and an ECG showed acute myocardial ischaemia.
- The patient’s wife had requested that the patient should not have active treatment but the home care staff called the GP in a panic when his condition deteriorated.
- The GP had never met the patient and sent him to hospital. Little information was provided. A middle-ranking doctor in accident and emergency called a consultant. They struggled to work out what best to do.
- Eventually, an end of life pathway was started. The patient died in emergency admissions shortly afterwards \(^2\).

Learning objectives

• What do we mean by frail elderly
• Why is it an issue for palliative care
• Some ideas about what we can do
Frailty

- Progressive physiological process marked by declines in function and reserve as well as increased vulnerability to morbidity and mortality

- Often seen but not recognised - leads to unnecessary investigations

- Clinically
  - general weakness
  - weight loss
  - fatigue
  - slowed performance
  - generalised state of low activity
Frailty

- Gradual progressive downward spiral
- Inability to recover from trivial illness
- Confusing for families
- Increased risk of death - similar to metastatic cancer
- Associated with ageing but not exclusive to ageing
happy 60th/80th picture
"I Run While Talking to God"
- Fauja Singh

Turbaned Tornado Fauja Singh
turns 104 yr Old Today!
NHS winter crisis deepens: A&E targets missed as 'frail and elderly' are blamed for bedblocking levels reaching record highs

- There were 160,000 days lost to delayed discharges in month of October
- 1,923,326 A&E attendances - the highest for month since records began
- Ambulance trusts failed to meet target for most urgent type of calls
- Phone service 111 missed target to answer 95% of calls within a minute

By KATE PICKLES FOR MAILONLINE

NHS England missed many of its waiting time targets in October as it struggled to cope with early winter pressures, figures released today have revealed.

Key measures were not met for A&E waiting times or for ambulance response times while there were more than 160,000 days lost to delayed discharges or 'bedblocking.'

Record numbers of patients are stuck in hospital beds because care has not been set up for them at home, experts have warned.

They are causing casualty units to become progressively overcrowded with patients prevented from being moved from trolleys onto wards due to a lack of space.
Why frailty is an issue for palliative care?

- ageing population
- bed blocking
- hospitals and care homes full of old people
- hard to recognise end of life
- lots of unmet symptom needs
- poor access to services
- less equity for continuing care
- older carers
- poly-pharmacy
- co morbidity

NEW CQC REPORTS ON INEQUITIES IN END OF LIFE CARE
Ageing population

• Proportion of people globally over 60 will rise from 10% to 22% in 2050

• the oldest old (> 80) will triple in next 30 years

• Life expectancy rising - more time being old.

• UK - 83% of deaths are in people >65
Hospitals

- Up to 70% of acute hospital beds are currently occupied by older people, and half of these have cognitive impairment

- These people are known to have worse outcomes - length of stay, mortality, institutionalisation

- A 2010 census of hospital patients in Lancaster and Sheffield shows that a third of patients have palliative care needs (according to GSF criteria)

- Patients with palliative care needs are overwhelmingly frail, older people, with multiple co-morbidities and multiple previous admissions to hospital

  Gardiner et al: Extent of palliative care need in the acute hospital setting: a prospective survey of 2 acute hospital. Palliative medicine
Revolving doors and transitions

- 30 older adults with 67 moves in the last 3 months of life
- Important care decisions transferred at the same time as patients
- Leads to crisis rather than anticipatory care

Care homes

- Older people admitted to NH have an estimated life expectancy of 9-12 months
- Those with dementia have the shortest life expectancy
- Self funders live longest and funded care places are associated with shorter prognosis and higher nursing needs.
- The nursing home population is changing over time to people with higher needs yet the funding and infrastructure and support is not following.
- They have the greatest need but the least access to NHS services
- A whole systems approach is needed not just a focus on inadequacies of care home staff

1. Seymour et al: Do NH have the support they need to provide end of life care (pall med 2011)
2. British geriatrics society 2012: failing the frail, a chaotic approach to commissioning healthcare services in care homes.
Care in crisis?

• “The lack of investment in care workers, .....in sharp contrast to the level of responsibility and skills required to provide quality home care.” (Equality and human rights commission, 2012:96)

• “There are huge issues around the funding of care being in crisis, but there is a deeper and hidden crisis around the quality of care.” (Age UK, evidence to select committee on social care, para 68, vol 1)
Equity in the Provision of Palliative Care in the UK: Review of Evidence

Josie Dixon, Derek King, Tihana Matosevic, Michael Clark and Martin Knapp

Personal Social Services Research Unit
London School of Economics and Political Science

April 2015
It’s not fair

- Having a cancer diagnosis is the primary determinant of access to specialist palliative care
- 88% of palliative care inpatients - cancer
- 75% of new referrals to hospital support and outpatients services - cancer

YET

- Cancer accounts for only around 29% deaths
- Falling to 10% in the over 90s
- Only 16% of SPC is provided to people over 85 although 39% of deaths occur in this age group
The concentration of death in old age

Figure 1.1: Number of deaths by age in England, 2008 (labels give percentage of deaths)

### Availability of Specialist Palliative Care Services: ‘Disease Apartheid’ Dr Keri Thomas

#### Hospice and Palliative Care:
- Single disease
- Relatively small population
- Cared for in a specialist centre
- Rolls Royce Standard for a few

#### Older People living with frailty:
- Multiple co-morbidity
- Enormous and growing population
- Cared for by Primary Care in the Community
- Ford Fiesta service for majority
A different ending
Addressing inequalities in end of life care
Overview report

MAY 2016
Older people

A DIFFERENT ENDING:
ADDRESSING INEQUALITIES IN END OF LIFE CARE

The independent review of the Liverpool Care Pathway, More Care Less Pathway, highlighted the care of older people at the end of life as a particular concern. Our review showed that older people’s experiences of end of life care are mixed.

Attitudes of staff

Respect for older people and their individual needs, wishes and choices was a particular problem. Some people told us about poor communication in relation to people’s treatment and care in care homes in the last year of life, with staff sometimes ignoring the observations and input of family members. One carer described how staff at her father’s care home failed to make sure that he was eating and drinking by not helping him to feed himself, and said that they paid little attention to her father’s preferences. She felt that there was a lack of compassion in communicating about her father, and said “they really weren’t bothered”.

While we have rated 96% of end of life care services in acute hospitals as caring, people told us that this was not always their experience of care for older people. Some people said they felt health and care staff viewed the lives of older adults as less valuable than younger adults, which had an impact on the care they received. One person told us that their partner, who was 90 and who died in hospital, had received little medical care for his condition until he became acutely ill shortly before he died. She said: “Maybe at 90, I don’t know, they think you’ve had your life...”

We also saw this attitude in the way health and care staff talked to people and their families, with people telling us that staff showed a lack of compassion in the way staff spoke to them. One person was told by staff “not to phone the hospital as they’d be busy”, and another person was told in the presence of his mother that she “probably only had a day left”. Recent research has highlighted the importance of communicating effectively with older people and their families at the end of life. Where communication was ineffective, people felt unsure about what was happening with their relative and were distressed by the experience of their relative’s end of life care.

Sometimes people and their families said they did not have a say in decisions about their care. For example, one person told us their mother was transferred from hospital to a nursing home without any discussion, and was not given the opportunity to look at the nursing home before she was discharged, “they basically told me, ‘you have no say in it... she’s going.’”

1 Caswell G, Pollock K, Harwood R, Poreck D; Communication between family carers and health professionals about end-of-life care for older people in the acute hospital setting: a qualitative study, BMC Palliative Care, August 2015, 1:14:35
People with dementia

A DIFFERENT ENDING: Addressing inequalities in end of life care

As our population ages, conditions that are more likely in old age are becoming increasingly common. Dementia and Alzheimer’s disease are the leading cause of death for women, and research shows that 30% of people aged 65 or over will die with dementia.¹

The Prime Minister’s Challenge on dementia 2020 highlights the importance of end of life care to people who have dementia. Good end of life care supports people and those important to them to have a good quality of life, with pain and other symptoms well-managed. Dignity and choice are central to this.

Our review supports existing evidence that there are a number of barriers that prevent people with dementia receiving good end of life care, including lack of identification and planning, unequal access to care, and poor quality of care.²

Identifying the end of life phase

Although dementia as a cause of death is increasing, health professionals do not always recognise it as a life limiting condition. As a result, the end of life phase is not always identified early enough or planned for effectively. In some areas we saw that the national initiative to improve diagnosis of dementia was having an impact. However, it was not always clear how these practices improved end of life outcomes for people with dementia.

This is supported by feedback from families and carers of people with dementia who were sometimes unsure about when the end of life phase began, suggesting that people were not clearly identified as approaching the end of life. For some people, the end of life phase can start much earlier than the last year of life. One person told us:

“I guess I would’ve known when she first had her diagnosis of dementia that it was a journey towards her death, so that would probably have been 15 years ago.”

Identifying dementia early, so that people have the opportunity to consider advance care planning and make meaningful choices at an appropriate time, is particularly important as the person will progressively lose the mental capacity to make decisions about their end of life care.

Communication

Talking to people and families about advance care planning can be challenging and sensitive. However, people who have dementia have a greater need for early and ongoing conversations about end of life care in the last phase of life as part of their wider treatment and care planning. This is supported by conversations with family as well as health and care

¹ Dixon J, King D, Matosevic T, Clark M and Knapp M, Equity In Palliative Care In The UK, PSSRU, London: London School of Economics/Marie Curie
² Marie Curie and Alzheimer’s Society, Living and dying with dementia in England: barriers to care, 2014
just like for them to be more understanding of our culture and the way we are.”

The experiences of the people we spoke to in our review highlight how important it is for commissioners and providers of end of life care, in all health and care settings, to listen and respond to people in their local communities in order to understand and meet their individual needs. This should include people from different equality groups and people who may be vulnerable because of their circumstances, whose needs are often overlooked.

Commissioners and providers do not always consider the needs of everyone in their community

There is variation in the quality of end of life care services, and in the extent to which they are meeting the needs of people from the groups included in the review. Some health and care services provide outstanding, responsive, personalised care that meets people’s individual needs. However, while over 90% of hospices we have inspected are rated by CQC as good or outstanding, 42% of end of life care services in acute hospitals are inadequate or require improvement.

Local approaches to organising and delivering end of life care to different groups are variable, and the end of life care needs of people from some groups are not always considered and understood. Under the Equality Act 2010, commissioners and providers have a legal duty to consider the needs of individuals in their day-to-day work. We found that not all commissioners and providers are fulfilling this duty in relation to the delivery of end of life care.

A strategic, equality-led approach at local level that prioritises and delivers personalised care in the last phase of life is essential to ensure good care for everyone. Some commissioners, services and health and care staff are already doing this well, and others can learn from them. We found good examples of services supporting improvement in quality of end of life care for specific groups. Hospices can play a key role through engaging local communities, delivering care based on individual need, and supporting others to do the same.

Recommendations

Achieving good quality, personalised care at the end of life for everyone is the responsibility of the health and care system and the wider community. CQC supports the vision outlined in the Ambitions for Palliative and End of Life Care and we want to see the six ambitions achieved. We are committed to working as a member of the National Palliative and End of Life Care Partnership and playing our part in encouraging the improvements needed.

In order to ensure that each person gets fair access to care we have identified specific actions, which we believe need to be addressed as a priority. These are summarised as follows.

Full details are available on page 31.

CQC encourages:

1. Leaders of local health and care systems to work together to develop a plan for delivering good quality, equitable end of life care for everyone in their community.

2. Commissioners and providers to fulfil their duties under the NHS Constitution, the Health and Social Care Act 2012 and the Equality Act 2010 to reduce inequalities, eliminate discrimination and advance equality when developing, arranging or delivering end of life care.

3. Commissioners and providers to ensure that staff who care for people who may be approaching the end of life, including care home staff, have the knowledge, skills and support they need.

4. Hospices to champion an equality-led approach, engage communities, deliver equitable end of life care, and support others to do the same.
5. **GPs** to ensure that everyone with a life-limiting progressive condition has the opportunity to have early and ongoing conversations about end of life care, and is given a named care coordinator.

**What CQC will do:**

1. Reflect the importance of good quality, personalised end of life care for everyone in the development of our future regulatory approach, and encourage improvement in the quality of end of life care for the groups considered in this review.

2. In services that receive a rating for end of life care, including hospitals, community health services, and hospices, we will reflect the importance of end of life care meeting the needs of people from different groups, and strengthen our assessment of whether end of life care services are meeting the needs of these groups.

3. In services that provide end of life care but do not currently receive a specific rating, including adult social care services and GPs, we will include an assessment of the quality of end of life care and whether it is meeting the needs of different groups. In GP assessments, we will assess whether the service is ensuring early conversations and coordinated end of life care for people from different groups.

4. In services that provide health or social care to people who are vulnerable because of their circumstances, we will consider how the service identifies and communicates with people and, if relevant, delivers end of life care.

5. We will use our independent voice to share our findings and insight about the quality of end of life care to encourage improvement at local and national level.
Challenges to providing end of life care for older people with frailty

- Different disease trajectories
- Size of the problem
- Multiple co morbidities
- Mental capacity issues

These challenges are an argument for not getting involved in frailty
So what is the trajectory of frailty?

Source: Murray, S.A. et al

- Cancer (n=5)
- Organ failure (n=6)
- Physical and cognitive frailty (n=7)
- Other (n=2)
2. Size of the problem

Percentage distribution of all deaths by age group for selected years, UK
www.ons.gov.uk
3. Multiple Co-Morbidity

Epidemiology of multimorbidity and implications for healthcare, research, and medical education: a cross-sectional study
Karen Barnett, Stewart W Mercer, Michael Norbury, Graham Watt, Sally Wyke, Bruce Guthrie
Lancet 2012; 380: 37–43
Mental capacity Issues

• 1 in 20 people age 70-79 have dementia

• 1 in 5 people aged 80 and over have dementia

• 1 in 3 age 95 and over have dementia

• 70-80% of people living in care homes have a form of dementia
Symptom burden in frailty

Symptom burden in community-dwelling older people with multimorbidity: a cross-sectional study

Jeanette Eckerblad1, Kersi Theander2, Anne Ekdahl3,4, Mitra Unosson3, Ann-Britt Wrevel3, Anna Millberg1,2, Barbro Krevers3 and Tiny Jaarsma1

Abstract

Background: Globally, the population is ageing and lives with several chronic diseases for decades. A high symptom burden is associated with a high use of healthcare, admissions to nursing homes, and reduced quality of life. The aims of this study were to describe the multidimensional symptom profile and symptom burden in community-dwelling older people with multimorbidity, and to describe factors related to symptom burden.

Methods: A cross-sectional study including 378 community-dwelling people ≥75 years, who had been hospitalized ≥3 times during the previous year, had ≥3 diagnoses in their medical records. The Memorial Symptom Assessment Scale was used to assess the prevalence, frequency, severity, distress and symptom burden of 31 symptoms. A multiple linear regression was performed to identify factors related to total symptom burden.

Results: The mean number of symptoms per participant was 8.5 (46), and the mean total symptom burden score was 0.52 (0.4). Pain was the symptom with the highest prevalence, frequency, severity and distress. Half of the study group reported the prevalence of lack of energy and a dry mouth. Poor vision, likelihood of depression, and diagnoses of the digestive system were independently related to the total symptom burden score.

Conclusion: The older community-dwelling people with multimorbidity in this study suffered from a high symptom burden with a high prevalence of pain. Persons with poor vision, likelihood of depression, and diseases of the digestive system are at risk of a higher total symptom burden and might need age-specific standardized guidelines for appropriate management.

Keywords: Chronic disease, Older people, Symptom assessment

Background

Chronic conditions among older people represent some of the largest health care challenges of this century, and one which will affect both the socioeconomics and the health care system [1]. Globally, the population is ageing and people can now live with several chronic diseases for decades [2]. Chronic diseases tend to increase with old age. An international systematic review reported that approximately 62% of all the people aged between 65–74 years, and 81.5% of people above 85 years suffer from multiple chronic diseases [3]. A co-occurrence of ≥2 diseases, where at least one is chronic, is defined as multimorbidity [4]. Multimorbidity is a condition with a high impact on functional impairment and quality of life [5,6], and is a condition that often results in a variety of different symptoms [7].

In a number of studies, older people have been reported to suffer from various symptoms. These reports have been based on measurements of a single symptom such as depression [8], fatigue [9], sleep disorder [10] or pain [11]. Other studies have been based on only one symptom dimension, usually intensity or severity [12,13]. The use of a multidimensional approach with the aforementioned dimensions is advocated both in research [14] and clinical practice [15]. A multidimensional assessment may also serve as a sufficient patient-reported outcome and it has
Analgesia prescribing in advanced dementia

A prospective cohort study examining the treatment of pain following hip #. 59 cognitively intact elderly patients vs 38 patients with advanced dementia 44% of the cog intact patients reported their pain as severe or very severe pre-operatively, and 42% reported similar pain post-operatively Half of these patients were prescribed inadequate analgesia for their level of pain.

The patients with advanced dementia received one-third the amount of opioid analgesia as the cognitively intact patients, suggesting that the majority of dementia patients were in severe pain postoperatively.


Communication problems in dementia may lead staff to believe that pain not expressed is pain not experienced. Pain manifesting as aggression or agitation may be labelled as “difficult behaviour”
So what does good end of life care look like in frailty?

- **Step 1**: Discussions as the end of life approaches
  - Open, honest communication
  - Identifying triggers for discussion.

- **Step 2**: Assessment, care planning and review
  - Agreed care plan and regular review of needs and preferences
  - Assessing needs of carers.

- **Step 3**: Co-ordination of care
  - Strategic co-ordination
  - Co-ordination of individual patient care
  - Rapid response services.

- **Step 4**: Delivery of high quality services in different settings
  - High quality care provisions in all settings
  - Acute hospitals, community, care homes, extra care housing, hospices, community hospitals, prisons, secure hospitals and hostels
  - Ambulance services.

- **Step 5**: Care in the last days of life
  - Identification of the dying phase
  - Review of needs and preferences for place of death
  - Support for both patient and carer
  - Recognition of wishes regarding resuscitation and organ donation.

- **Step 6**: Care after death
  - Recognition that end of life care does not stop at the point of death
  - Timely verification and certification of death or referral to coroner
  - Care and support of carer and family, including emotional and practical bereavement support.

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**Social care**

**Spiritual care services**

**Support for carers and families**

**Information for patients and carers**
How do you recognise end of life in older people?

- GSF Frailty
- GSF Dementia
- Surprise question
- Disease specific prognostic tools
- Rockwood Frailty Scale
- Electronic frailty index
GSF: Frailty

- Multiple co morbidities with signs of impairments in day to day functioning

- At least 3 of:
  - weakness
  - slow walking speed
  - low physical activity
  - Weight loss (>10% over 6 months, also albumin < 25)
  - Self reported exhaustion

- Deteriorating karnofsky score - decreasing performance status

- These are prognostic criteria in frailty and they Should be on GSF/end of life register
**GSF Prognostic Indicator: Dementia**

"Would you be surprised if the patient died in the next days/weeks/months?"

<table>
<thead>
<tr>
<th>All of the following</th>
<th>Plus any of the following</th>
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<tbody>
<tr>
<td>No consistently meaningful verbal communication</td>
<td>10% weight loss in previous 6/12 (with no cause)</td>
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<tr>
<td>Reduced ability to perform ADLs</td>
<td>Reduced oral intake</td>
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<td>Unable to walk unassisted</td>
<td>Serum albumin 25g/l</td>
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<td>Unable to dress unassisted</td>
<td>Severe pressure sores (grade 3-4)</td>
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<td>Doubly incontinent</td>
<td>UTI</td>
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<td>Barthel score &lt;3</td>
<td>Aspiration pneumonia</td>
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<td>Recurrent fevers</td>
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Rockwood Frailty Scale

Electronic frailty index

<table>
<thead>
<tr>
<th>Activity limitation</th>
<th>Ischaemic heart disease</th>
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<tr>
<td>Anaemia &amp; haematinic deficiency</td>
<td>Memory &amp; cognitive problems</td>
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<td>Arthritis</td>
<td>Mobility and transfer problems</td>
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<td>Atrial fibrillation</td>
<td>Osteoporosis</td>
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<td>Cerebrovascular disease</td>
<td>Parkinsonism &amp; tremor</td>
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<td>Chronic kidney disease</td>
<td>Peptic ulcer</td>
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<td>Diabetes</td>
<td>Peripheral vascular disease</td>
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<td>Dizziness</td>
<td>Polypharmacy</td>
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<td>Dyspnoea</td>
<td>Requirement for care</td>
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<tr>
<td>Falls</td>
<td>Respiratory disease</td>
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<td>Foot problems</td>
<td>Skin ulcer</td>
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<td>Fragility fracture</td>
<td>Sleep disturbance</td>
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<td>Hearing impairment</td>
<td>Social vulnerability</td>
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<tr>
<td>Heart failure</td>
<td>Thyroid disease</td>
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<td>Heart valve disease</td>
<td>Urinary incontinence</td>
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<tr>
<td>Housebound</td>
<td>Urinary system disease</td>
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<tr>
<td>Hypertension</td>
<td>Visual impairment</td>
</tr>
<tr>
<td>Hypotension/syncope</td>
<td>Weight loss &amp; anorexia</td>
</tr>
</tbody>
</table>
Electronic frailty index

Proportion alive

Time

Fit
Mild frailty
Moderate frailty
Severe frailty
Triggers for prognosticating in frailty

- New diagnosis of life limiting condition
- Step change in treatment
- Multiple admissions
- Admission to care home
- When ever a reassessment of needs (inc death of spouse)
HOW TO SUCK EGGS
Questions to establish peoples priorities.

- What is your understanding of where you are with your condition or illness at this time?
- What are your fears and worries for the future?
- What are you goals if time is short?
- What outcomes would be unacceptable to you?
Don't underestimate me. I know more than I say, think more than I speak, & notice more than you realize.
• Traingle of care
  • Patients
  • Carers and families
  • Professionals
Risk and mental capacity

- Atul Gawande - “Being mortal” book opened my eyes
- The balance between autonomy and risk
- Have we gone to far - are we too risk averse
- What level of risk are WE willing to live with
- What level of risk are the TRIANGLE willing to live with
- HOW do we decide, WHO decides
- People can have priorities other than living longer or being safe
When we stop taking risks, we stop living life.

Robin Sharma
What else can we do

• Work with teams to recognise and “diagnose” frailty
• Severe frailty - encourage to put on palliative care register
• Pro active case finding and management
• Use integrated comprehensive assessment and care and support tools
• Comprehensive geriatric assessment
• Medication tools - STOP/START
What else can we do

- Advance care planning - various care home models being researched (Google: Liz Sampson)
- Care home nurse practitioners/ACP facilitators
- Escalation planning/ceiling of care - DNAR/Emergency care and treatment plan
- Jenner health centre (lots of useful tools on their website) e.g. - RICH Remain in care home
What can/should specialist palliative care do?

- Education
- Leadership
- Help develop models of end of life care (research, share learning)
- Direct care - complex, specialist
- Partnerships - Care of elderly teams, GPs, mental health, social services, falls teams
- Integrated care models with palliative care involvement
- Care homes - education, joint posts with commissioners
- Society - start conversations about dying, expectations, peoples wish and priorities
- Government - fund the right care in the right place e.g. care homes education, infrastructure, access to same as everyone else
Dementia at North London Hospice

- Dementia - priority area for improvement - external scrutiny via quality account
- Dementia friends - now mandatory awareness training all staff and volunteers
- 3 levels education - 1 whole study day, team teaching
- Introduced PAINAD
- Dementia action alliance
- Dementia friendly environment audit (except the art)!
- Data collection
- Board engagement
- Partnership working with dementia charities - carers, support group, singing
- Hospice enabled dementia care (Hospice UK) section 5 checklist
There is no such thing as "right;" the very concept needs to be replaced with "progressively less wrong."

~ Paul Grobstein
Hospice enabled dementia care
The first steps

A guide to help hospices establish care for people with dementia, their families and carers