Meeting the needs of the majority at the End of Life: Older Adults living with Frailty

University of Worcester
Centre for Palliative Care 16th April 2015

Dr Maggie Keeble
MBBS MRCGP DipPallMed
GPwSI in Older People and Palliative Care
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
### Availability of Specialist Palliative Care Services: ‘Disease Apartheid’

<table>
<thead>
<tr>
<th>Hospice Care:</th>
<th>Frail Elderly:</th>
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<tbody>
<tr>
<td>Single disease</td>
<td>Multiple co-morbidity</td>
</tr>
<tr>
<td>Relatively small population</td>
<td>Enormous and growing population</td>
</tr>
<tr>
<td>Cared for in a specialist centre</td>
<td>Cared for by Primary Care in the Community</td>
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<tr>
<td>Rolls Royce Standard for a few</td>
<td>Ford Fiesta service for majority</td>
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From ‘Equity of Provision’ Report

• Having a cancer diagnosis is the primary determinant of access to specialist palliative care

• **88%** of palliative care inpatients & **75%** of new referrals to hospital support and outpatient services were for people with a cancer diagnosis

• cancer accounts for only around **29%** of deaths
• only 16% of specialist palliative care is provided to people aged 85 or over, although 39% of deaths occur in this age group.

• So why the difference?
Disease trajectories are very different

Making it difficult to recognise when the end is approaching
Differences – single disease vs frailty

- Different disease trajectories
- Not always obvious that death is approaching
- Size of the problem – huge and growing
- Multiple co-morbidity
- Availability of Specialist Palliative Care services
- Mental Capacity issues
- Increased dependency on Care Homes
Multiple Co-morbidity
Multiple Co–Morbidity at 85+

<table>
<thead>
<tr>
<th>Conditions</th>
<th>%</th>
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<tbody>
<tr>
<td>1 or more conditions</td>
<td>93</td>
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<tr>
<td>2 or more conditions</td>
<td>82</td>
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<tr>
<td>3 or more conditions</td>
<td>64</td>
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<td>4 or more conditions</td>
<td>44</td>
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<tr>
<td>5 or more conditions</td>
<td>30</td>
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<tr>
<td>6 or more conditions</td>
<td>18</td>
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<tr>
<td>7 or more conditions</td>
<td>10</td>
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<tr>
<td>8 or more conditions</td>
<td>5</td>
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</tbody>
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Dementia 'affects 80% of care home residents'

By Nick Triggle
Health correspondent, BBC News

More than 320,000 of the 400,000 people living in care homes in England, Wales and Northern Ireland now have dementia or severe memory problems, the Alzheimer's Society charity estimates.

It said the figure was almost 30% higher than previous estimates because of the rise in the ageing population and improvements in data collection.
Frailty

- Frailty is a distinctive health state related to the ageing process in which multiple body systems gradually lose their in-built reserves.

- Around 10% of people aged over 65 years have frailty, rising to between a quarter and a half of those aged over 85 years.
Implications of Frailty

- Vulnerable to sudden deterioration in condition with relatively mild insults
- Increased chance of dying during a deterioration
- Recognition that frailty is a ‘chronic evolving pathology that leads to death’ (Pialoux 2012)

- So how do we determine if someone is frail........?
Diagnosing Frailty

‘Fit for Frailty’ BGS recommends:

- Prisma 7
- Gait Speed – time to walk 4m
- Rockwell Frailty Scale
- Edmonton Frail Scale

(Preferred Reporting of Systematic Reviews and Meta-Analysis)
Prisma 7 Questions:

1. Are you more than 85 years?
2. Are you Male?
3. In general do you have any health problems that require you to limit your activities?
4. Do you need someone to help you on a regular basis?
5. In general do you have any health problems that require you to stay at home?
6. In case of need can you count on someone close to you?
7. Do you regularly use a stick, walker or wheelchair to get about?

Score positive if >/= 3
Gait speed

• Participants are asked to walk a short distance (4 metres) at their usual pace. Participants complete one practice and then two timed trials.

• Raw scores are recorded as the time in seconds required to walk 4 metres on each of the two trials, with the better trial used for scoring.

• The test takes approximately 3 minutes to administer.
Rockwood Frail Scale

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.

Acute Hospital Admission over 85

• ‘Imminence of death among hospital inpatients: Prevalent cohort study’  David Clark et al published online 17 March 2014 Palliat Med

• **Participants:** In total, 10,743 inpatients in 25 Scottish teaching and general hospitals on 31 March 2010.
Acute Hospital Admission over 85

- All ages – 28% dead within 12m
- Over 85 – 45% dead within 12m
- Male and over 85 – >50% dead within 12m
So what does good EOL Care look like for Older People living with Frailty?
Similarities

Appendix 4 The End of Life Care Pathway NHS
End of Life Care Strategy, July 2008

<table>
<thead>
<tr>
<th>Step 1</th>
<th>Step 2</th>
<th>Step 3</th>
<th>Step 4</th>
<th>Step 5</th>
<th>Step 6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discussions as the end of life approaches</td>
<td>Assessment, care planning and review</td>
<td>Coordination of care</td>
<td>Delivery of high-quality services in different settings</td>
<td>Care in the last days of life</td>
<td>Care after death</td>
</tr>
</tbody>
</table>

- Open, honest communication
- Identifying triggers for discussion
- Agreed care plan and regular review of needs and preferences
- Assessing needs of carers
- Strategic coordination
- Coordination of individual patient care
- Rapid-response services
- High-quality care provision in all settings
- Acute hospitals, community, care homes, hospices, community hospitals, prisons, secure hospitals and hostels
- Ambulance services
- 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
- 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

Support for carers and families
Information for patients and carers
Spiritual care services
Good End of Life Care

1. Realisation that death is approaching
2. Planning ahead
   - Advance Care Planning
   - Advance Statements/ADRTs
   - DNACPR status
3. Carer Support
4. Good ‘Last few days/hours of life’ care
5. Bereavement support
Mental Capacity....

....essential for:

• Advance Statement
• ADRT
• LPOA

Any decision around future care at the End of Life
Reliance on Care Home Staff

• Lack of experience
• Lack of confidence
• Young
• English may not be first language
• Rapid turnover
• Poorly paid
• What are we doing in Worcestershire to improve End of Life Planning for Older People living with Frailty?
Advance Care Planning in Care Homes
South Worcestershire CCG

SWCCG working with GPs to improve care
• Enhanced Care in Care Homes in SW
• 67 Care Homes in South Worcestershire
• 1857 Residents
• Most care homes now aligned to one GP practice
• Proactive weekly visiting
Focus on Care Homes

• Enhanced Care:
  • Care Home nurse practitioners
  • All new residents – care assessment within 2 weeks of admission
  • any resident who is admitted to Community Hospital or secondary care is to be reviewed within 72 hrs of discharge.
• Community Pharmacists in Care Homes – Medicines Optimisation and ‘Deprescribing’
Clinical Management Plans

Clinical Management Plan (Registered Care Homes) for use by Band 7 Nursing Home Practitioners

- Name
- DOB
- NHS Number
- Male / Female
- Marital Status
- Address
- Type of Residence
- Postcode
- Telephone Number
- Next of Kin
- NoK Contact Numbers
- Allergies
- Current Health Concerns
- DNAR Status
- Would you be surprised if this patient died within the next 6 – 12 months? Yes / No
- If the answer is NO then should the patient be considered for inclusion on the Palliative Care Register? Yes / No
- End of Life wishes (Preferred place of care i.e. home / hospital)
- Comments
- Completed by
- Designation
- Signature
- Date
- GP Signature
- Date
• Admission Avoidance Service via ECT
• Provision of night support – various
• Use of just in case boxes and anticipatory medication in Care Homes
• Recognition that Residential Care Homes CAN cope with the dying phase and eager to do so for their residents
• CHC prepared to fund EOL care in ‘non–registered’ home if permanent resident
• By linking with Enhanced Care Teams and District nurses provided 24/7 advice and support to Care Homes

• All residents/relatives have opportunity to discuss End of Life wishes

• DNACPR decisions made with patients if capacity or following discussion with proxy if not – following best interest guidelines
Escalation Plans – ECAP

Worcestershire Health and Care
NHS
South Worcestershire Clinical Commissioning Group

Emergency Care Action Plan

Residents Name: Known as:
DOB
NHS Number
Care Home
G P details
Hospital Consultant

Date and sign page when completed:

Mental capacity issues

Does the resident have mental capacity to decide about the Emergency Care Action Plan?
If yes, has this Emergency Care Action Plan been discussed and agreed with the resident?
If no, see capacity assessment/other interest decisions documentation
If no resident made any Advance Decisions (refusals or preferences)?
If no resident given lasting Power of Attorney for Health and Welfare?
If no one is their most appropriate Health Care Representative?
This might be spouse, child, friend, carer, - someone involved in their care and perceived to be acting in their best interests - if none of the above it may be appropriate to involve an IMCA
Has this Emergency Care Action Plan been discussed and agreed with their Health Care Representative?
Is there anyone else who should be informed? (see below) - All first degree family members should be informed

Names
Relationship
Agree with above?
Phone
To be contacted?

Please notify:
GP
OOH (Harmoni)
WMAS of Category of Care.

Suggested review date if appropriate:

NB: This advice should be reviewed and updated at appropriate intervals. It may not be applicable if the situation changes. It should be used with re-assessment and views of the patient and others at the time, including if Emergency Department attendance or hospital admission is necessary.

E-CAP – V1 12.05.14
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Greensleeves

Decision about CPR

CASTLE Front page for ACP (with ACP documents behind)
Unplanned Admissions DES - GPs

• Identify the top 2% of their patients most at risk of hospital admission
• Offer proactive care assessment and care plan incorporating End of Life wishes
• Review all patients within 72 hours of transfer or admission
• Regular review at least 3mthly
• Basis template provided
Proposed Local Incentive Scheme for Proactive Care for Frailty 2015

• CCG are working on a local scheme to encourage practices to recognise and diagnose frailty with a view to putting those with severe frailty on the Palliative Care Register

• This should lead to improved advance care planning and increased avoidance of inappropriate and unwanted admissions to hospital
The Future

• Extend Proactive Care model to all Older People living with Frailty
• Sharing of standard data set – GPs Hospices Acute Trust H&CT OOH - EPaCCS
• Data available in real time
• Integrated Comprehensive Assessment – compiled by recognised by and shared by – to include Social Care VCS DC and Care Homes
Making the case for change

Electronic Palliative Care Co-ordination Systems
Useful resources

- Deciding Right website
- c-a-s-t-l-e.org.uk
- goldstandardsframework.org.uk
- AgeUK website and booklets
- Dying Matters Website
- Onside Advocacy
  www.onside-advocacy.org.uk
Reading List

- Fit for Frailty BGS 1 and 2
- PSSRU ‘Equality in the provision of Palliative Care’ April 2105
- NHS Toolkit for General Practice in Supporting Older People with Frailty 2014
- Kings Fund – Making our health and care systems fit for an ageing population
- Leadership Alliance for the Care of Dying People – One Chance to get it Right
- Safe compassionate care for frail older people – NHS England
Contact Details

• Maggie.Keeble@nhs.net
• 07798 602632
• @KeebleM