

1 **End-of-life care for frail older people**

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1 **Abstract**

2 Most people die when they are old, but predicting exactly when this will occur is unavoidably
3 uncertain. The health of older people is challenged by multi-morbidity, disability, and frailty. Frailty is
4 the tendency to crises or episodes of rapid deterioration. These are often functional or non-specific
5 in nature, such as falls or delirium, and recovery is usually expected. Health-related problems can be
6 defined in terms of distress and disability. Distress is as often mental as physical, especially for
7 people with delirium and dementia. Problems can be addressed using the principles of supportive
8 and palliative care, but there is rarely a simple solution. Most problems do not have a palliative drug
9 treatment, and the propensity to adverse effects means that drugs must be used with caution.

10 Geriatricians use a model called comprehensive geriatric assessment, including medical, functional,
11 mental health, social and environmental dimensions, but also use a variety of other models, such as
12 the acute medical model, person-centred care, rehabilitation, alongside palliative care. Features
13 such as communication, family engagement and advance planning are common to them all. These
14 approaches are often consistent with each other, but their commonalities are not always
15 recognised. The emphasis should be on making the right decision at a given point in time, taking
16 account of what treatment is likely to deliver benefit, treatment burden, and what is wanted.

17 Choices are often limited by what is available and feasible. Palliative care should be integrated with
18 all medical care for frail older people.

1 **Introduction**

2 Most people die when they are old, or very old. In the United Kingdom (UK), half die over 80 years
3 old; a quarter of women, and one in eight men, die over 90 (Figure 1). This pattern is repeated
4 throughout developed economies. Death in older ages is less unexpected than for younger people,
5 and is often at the end of a fulfilled, natural lifespan, but older people still take pride in coping,
6 keeping going, and getting better in the face of declining health.¹

7 <<Figure 1: about here>>

8 Risk of death from non-communicable diseases increases with age, including from ischaemic heart
9 disease, stroke, chronic respiratory disease and cancer. Survival in old age is accompanied by multi-
10 morbidity, frailty and disability. By the age of 80 most people have multiple diagnoses,² whose
11 effects accumulate and interact. Disabling chronic conditions are the main causes of practical
12 problems. One in three of us will die with dementia; osteoarthritis is the commonest cause of
13 disability; stroke and hip fracture can result in severe disability; sensory impairments inhibit
14 occupation and inclusion; depression is common and debilitating.

15 Frailty describes a state of vulnerability to crises: episodes of acute deterioration, including delirium,
16 falls, or immobility, which often lead to hospital admission. Prevalence of frailty increases with age;
17 about one-quarter of people over 80, and most people over 90, are frail. It is associated with, but
18 distinct from, multi-morbidity and disability. Stressor events themselves may be quite minor, or may
19 be multiple: illnesses, injuries, drug reactions and psychological or social adversities. Outcomes in
20 frail people tend to be poorer than in those without it, but are uncertain in terms of both survival
21 and restoration of physical and mental abilities.³

22 Disability is the inability to perform functional activities, such as walking, personal care, remaining
23 continent, and behaving in a safe and acceptable manner. Disability causes dependency, reliance on
24 help from other people, which is costly and brings physical and emotional burden for the caregiver.

25 Healthcare services and professionals may become frustrated at the diversity of problems presented
26 to them by older people, and the limitations of the 'medical model' (based on diagnosis and specific
27 treatment) in providing solutions (table 1). Instead, it is suggested that a supportive and palliative
28 approach may be beneficial.⁴

29 <<Table 1. About here>>

30

1 This paper aims to describe the health problems experienced by frail older people; how they relate
2 to care and planning at the end of life; the applicability of supportive and palliative care; additional
3 healthcare approaches that are needed to provide appropriate and comprehensive care; and some
4 similarities and differences between them.

5 **A good death**

6 Most policy defines 'the end of life' as the last 12 months, but this can only be identified with
7 certainty in retrospect. Palliative care has been defined as managing 'problems associated with life-
8 threatening illness' (World Health Organisation) and being for 'advanced, progressive, incurable
9 illness' (National Council for Palliative Care), which may stretch over many years.

10 We have a working definition of a good death:⁵

- 11 - treated as an individual with dignity and respect
- 12 - without pain or other symptoms
- 13 - in familiar surroundings
- 14 - in the company of family or friends.

15

16 In the context of a longer trajectory, we might add maintaining physical and social function, purpose
17 and enjoyment of life.

18 Palliative care aims to enable a good death, through: addressing holistic needs (physical,
19 psychological, social, existential); emphasises open communication (about diagnosis, prognosis and
20 choices); encourages planning for the future (including preferred place of care), and reducing
21 treatment burden.

22 **Unpredictable trajectories which endure over prolonged time frames**

23 The supportive or palliative approach is valid for frail older people, but their healthcare is complex.
24 In acute illness, the effects of treatment cannot always be predicted, due to the impact of frailty.
25 'Cure' of chronic diseases such as arthritis, dementia or macular degeneration, or restoration of
26 normal function, is often not possible.

27 In the UK, 10% of older medical inpatients die, and half will be dead within a year.⁶ But identifying in
28 advance who will die is difficult or impossible. Four trajectories of dying have been described in care
29 homes (anticipated, unexpected, uncertain and unpredicted; table 2). Anticipated deaths were
30 mostly well-managed within the care homes. The uncertain and unpredicted deaths occurred in
31 hospital and were associated with crises and uncertainty, including after catastrophic events such as

1 stroke and hip fracture. Despite this, most of those admitted to hospital during the study period
2 survived.⁷

3 <<Table 2. About here>>

4 Sick older people often look like they are dying, especially if suffering from hypoactive delirium,
5 which may (or may not) recover. These episodes may be recurrent, with a 'roller coaster' trajectory
6 more commonly seen than 'slow dwindling'.^{8,9} Much effort has been devoted to prognostication,
7 with mixed results. No more than half of those identified using the 'surprise question' (would you be
8 surprised if this person died in the next year?), or the Supportive and Palliative Care Indicator Tool
9 (SPICT), will be dead a year later.¹⁰ Prognostic scores, including frailty scores, are no better.¹¹ The
10 most frail group on the electronic Frailty Index have only 50% mortality after 4 years.¹² While these
11 tool are useful in stratifying populations into those at more or less chance of dying, they are
12 insufficiently valid to determine individual prognoses. Many practitioners recall having 'fingers
13 burnt' getting it wrong, recalling times when they mistakenly anticipated the end of life in conditions
14 such as heart failure, respiratory disease or dementia, which they found emotionally and
15 professionally difficult.¹³ The corollary to the 'surprise question' is 'would you be surprised if this
16 person were alive in a year's time?'

17 Geriatricians, general practitioners and others, navigate this uncertainty, treating the treatable,
18 providing opportunities for rehabilitation, making judgements about worthwhile investigation, and
19 location of care. Pioneer geriatricians realised that even severe disability could result from treatable
20 pathology, and that function may be restored through rehabilitation. These remain core principles in
21 geriatric medicine. Increasingly, this approach is applied in acute and emergency care: acute illness
22 can cause non-specific functional decline, requiring skill to assess, investigate and rehabilitate, while
23 avoiding futile and burdensome intervention, including unnecessary hospital admission.

24 'Parallel' or 'twin track' care which delivers active medical interventions alongside palliative
25 approaches often cause confusion in systems reliant on the bureaucracy of care plans and escalation
26 policies. Heuristic decision-making (simple pragmatic rules) at the end of life has been shown to be
27 useful in dementia care, positively influencing care plans for eating and swallowing, agitation and
28 restlessness, life-sustaining treatment and routine nursing care.¹⁴

29 **Symptom burden when palliation with drugs alone is insufficient**

30 'Problems' comprise a wide spectrum, but divide broadly between distress and disability, and occur
31 in people with vulnerable social circumstances. In a representative population, in the week before
32 death, reported symptoms included fatigue (83%), breathlessness (50%), pain (48%), confusion

1 (36%), anxiety (31%), depression (28%), and nausea (25%).¹⁵ More generally, problems include
2 immobility, falls, behaviours that challenge, incontinence, constipation, poor appetite and,
3 swallowing and dehydration.¹⁶ Mental and behavioural distress are prominent amongst people who
4 may be dying with delirium or dementia: amongst hospital-admitted patients 10-20% had delusions
5 or hallucinations, 20% were agitated or aggressive, a third each depressed, anxious, apathetic or
6 awake at night.¹⁷

7 Geriatricians use a framework called comprehensive geriatric assessment (CGA), comprising medical,
8 functional, mental health, social and environmental dimensions, which has been demonstrated to
9 reduce death, disability and care home placement (table 1).¹⁸ CGA must be sensitive to transitions in
10 care as circumstances change. If someone is thought to be in their last few days, relief of distress
11 can be prioritised. However, practical problems are often driven by acute illness or injury, which may
12 require standard medical diagnosis and ('curative') treatment. Acute illness or injury is assessed
13 alongside with baseline function, personal goals and preferences. Functional problems determine
14 how much help a person needs, and whether they can live on their own; addressing these problems,
15 or determining that they are insoluble, requires multi-disciplinary assessment and rehabilitation. The
16 frequent occurrence of cognitive and other mental health problems requires mental health expertise
17 and the delivery of person-centred care. Many problems do not have simple palliative drug
18 treatments: attempts to manage them in this way have sometimes led to harm, illustrated by
19 historic misuse of antipsychotic drugs (to try to suppress difficult behaviours in dementia)¹⁹ and
20 opiate analgesic drugs (for chronic non-cancer pain)²⁰. When we do use drugs, we have to balance
21 beneficial and adverse effects, to which frail older people are particularly sensitive. Many problems
22 require long-term practical (human) assistance.

23 'Person-centred care' is a bio-psycho-social model for people with dementia or delirium (table 1). It
24 stresses respect for 'personhood': valuing, empathising, individualising care, and using relationships
25 to promote wellbeing and reduce distress. Individualising means dealing with physical and mental
26 health problems, making the most of retained abilities, understanding the person's biography,
27 personality and social resources, and respecting preferences. Acute medical care can be adapted to
28 be person-centred, and palliative care can be done this way as well.²¹

29 **A problem with language**

30 A review of supportive and palliative care for older people described a framework containing all of
31 these elements without identifying them as such (table 3): palliative and other healthcare
32 practitioners do not speak the same language.⁴

1 The word 'palliative' may be too culturally-associated with cancer care. The support needed by frail
2 older people at the end of life may be little different from 'standard' health and social care which, in
3 many countries, is delivered by well-established geriatric medical and social care services. The
4 distinction between acute, sub-acute and community care is blurred, with multiple hospital
5 readmissions, post-acute or 'intermediate' care focusing on rehabilitation, and approaches to living
6 well with long-term conditions, including combined health and social care, such as that delivered in
7 care homes. At the same time these services are often underprovided compared with need, and
8 work under extreme operational pressure. Problems at the end of life may be but an example of a
9 more general problem of appropriate health and social care for older people living with frailty and
10 disability.

11 **Re-defining the purpose of care at the right time, to ensure the principles of a good death are**
12 **upheld**

13 Framing medical treatment in terms of 'effective' and 'wanted' care may be a powerful way to
14 support better healthcare choices and decision-making. Effective care is that which has a reasonable
15 prospect of delivering health gain, in terms of the balance between likely benefits and burdens.
16 Wanted care will include care that can be delivered in the place the person most wants to be,
17 including home.

18 The purpose of care should be considered explicitly when someone is nearing the end of a long life,
19 with emphasis on managing problems and patient-centeredness. Meticulous assessment and
20 management of problems can embrace acute medical, rehabilitation and mental health, as well as
21 more overtly 'palliative' approaches. What varies are treatment goals, and the information used to
22 reach decisions. Goals may be difficult to specify in a crisis, when health status has changed rapidly,
23 and when survival and recovery are uncertain. This often leads to a presumption of attempts to
24 'rescue', or preserve life, which may later be regretted. Some people want and hope for recovery,
25 some do not, especially after repeated admissions, or when the trajectory is inexorably downwards.
26 This applies equally in assessment for rehabilitation (a tension between 'no rehabilitation potential'
27 and 'palliative rehabilitation'), or prolonged mental health treatments (for example, recurrent or
28 intractable severe depression).

29 Despite the emphasis on enabling people to die at home, many find that circumstances, such as
30 living alone, challenging behaviours, or falling, make it impossible. In the UK, only 20% die at home;
31 most (57%) die in hospital, unless they have dementia, when death is more often in a care home. But
32 place of death is of relatively low priority for many older people, with greater concerns over being a
33 burden on family, freedom from distress, and treatment with compassion.²²

1 **A specialist skill set**

2 An emphasis on making the right decision at a given point in time means that health care
3 practitioners need fluency in practical ethics. The ethical system called principlism considers
4 consequences of interventions (benefits and burdens) and rights (autonomy and justice), but can be
5 difficult to apply when available information is imperfect, decisions have to be made rapidly, or
6 when mental capacity is lacking. Ethical frameworks that prioritise communication and relationships,
7 and practitioner virtues, are also needed to negotiate agreement with patients and families.²³

8 The chances of an intervention delivering what is wanted with an acceptable level of burden or risk
9 is a technical question, but how those are weighed may vary between individuals. Questions of
10 equity, distributive justice and non-discrimination are political and professional, but are important if
11 we are to value people regardless of age and disability. To respect autonomy, determining what
12 people want, requires opportunity, information, and time for consideration. We strive for shared
13 decision-making, but in reality patients may defer to professional authority (a generational
14 phenomenon), or have no strong opinion. Contrived or impractical choices are unhelpful. A
15 ‘concordance’ approach encourages practitioners to be empathetic and understand the patient’s
16 perspective, and to negotiate a mutually-respected position. The difficulty with any consultation of
17 this nature is in pre-empting the many uncertainties, and keeping options flexible enough to change
18 if things improve or deteriorate, as they inevitably will. This is no different from deciding about any
19 aspect of medical care, although many difficult decisions for frail older people are made in an
20 emergency, and where the person is not able to engage. In these cases, proxy or best interests
21 decision-making is required, via a formal process, and varying according to legal jurisdictions.
22 Person-centeredness cannot always be assured in these circumstances.

23 **Much care is provided by families which needs recognition and support**

24 Illness affects families and networks as well as individuals, and this support is fragile. Sudden and
25 unexplained functional decline makes coping at home difficult. 40% of older patients admitted to
26 hospital live alone, and 28% are from care homes. 25% of main carers are elderly spouses, often in
27 poor health themselves; 40% are adult children, with competing domestic and work priorities; 25%
28 are more distance relatives or unrelated. There are high levels of carer strain and breakdown. 10%
29 have no family or friends who could advocate for them.²⁴

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1 **Creating supportive and trusted relationships between patients, care-providers and healthcare**
2 **decision-makers to develop and enact meaningful Advance Care Planning**

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4 Properly done decision-making can be time consuming and difficult; it helps if someone has
5 communicated their wishes in advance. Advance care planning (ACP) is a process in which future
6 care is negotiated and recorded in anticipation of loss of mental capacity. It is possible to deliver,
7 and can change outcomes, but is perceived as difficult and is under-utilised. Older people (and their
8 families) vary in what they want, and how they want to make decisions. Some want to preserve
9 autonomy and control; and increasingly do so through advance care planning. Some families want to
10 make decisions and provide care together, and legal provisions for proxy decision-making can enable
11 this, if arranged before mental capacity is lost. Many do not want to think about the future, living for
12 today; this forms an important part of many older peoples' identities,¹ and challenging it can be
13 profoundly unwelcome, making advance care planning unlikely. Some people are less concerned
14 with the type of care, than whether it is effective and perceived of being of high quality.²⁵

15 ACP can help, but may not provide all the answers. Decision-specific planning is difficult when there
16 is no terminal diagnosis, and an uncertain future trajectory. Broad decisions about specific
17 interventions can be discussed with some confidence when we know that they would be futile (such
18 as cardio-pulmonary resuscitation, or ventilation), or in the face of imminent death. But we struggle
19 to discuss uncertainty, especially in circumstances when we have limited involvement in overall care
20 (such as acute admissions). Given the constraints within which we work, we may need to abandon,
21 as a profession and society, the presumption of intervention to preserve life at a time of crisis in
22 extreme age and frailty. In the absence of formal or informally expressed information on specific
23 preferences and wishes, this prospect will require consummate professionalism and virtues, and
24 legal reform in many jurisdictions to ensure appropriate supportive or palliative care is not perceived
25 as 'no care'.

26 **Conclusion**

27 Current UK end of life care policy emphasises 'ambitions and foundations', broad general principles
28 rather than specific guidance (table 4). These are wholly generic, and apply to all medical disciplines,
29 across much of contemporary healthcare. They are of particular relevance for frail older people, and
30 should be embedded in routine practice, rather than seen as a separate approach for those who are
31 dying.

32 Not all deaths are without problems, but many of the things that make deaths as good as they can
33 be are already happening. We need a more systematic focus on management of distress, better

1 advance care planning, inclusive decision-making, and intensive community services that allow
2 people to die at home if they choose. A palliative and supportive focus does not mean 'no active
3 treatment', and may include treating infections, metabolic derangement or fractures to relieve
4 distress, or rehabilitation to reverse functional decline. Each treatment decision should deliver the
5 most appropriate care for an individual at that time.

6 Comprehensive geriatric assessment, person-centred care and palliative and supportive models can
7 all be used to deliver this, and are in many respects identical.

8 **Key messages**

- 9 - most people die when they are old, and experience multi-morbidity, frailty and disability
- 10 - problems comprise a complex mix of crises, physical and mental distress, functional limitations
11 (disabilities), and social and carer issues
- 12 - meeting these needs requires a range of approaches, including acute medical, comprehensive
13 geriatric assessment, person-centred care, mental health, social care and palliative care
- 14 - these approaches are not inconsistent with each other, but require careful attention to
15 individualisation and decision-making

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19 Rowan Harwood and Hannah Enguell are geriatricians with an interest in end of life care. This
20 material is based on clinical, research and teaching experience with frail older people, discussions
21 with families and colleagues, including patient and public involvement representatives, and
22 literature reviewed for Professor Harwood's inaugural lecture at the University of Nottingham. He is
23 guarantor. Both authors contributed to, edited and approved the final text.

24 **Conflicts of interest**

25 There are no conflicts of interest

26 **Licence**

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1 Table 1. Models of medical care for older people

Model	Aim
Prevention	Reduce disease occurrence or recurrence, especially for individuals at risk
Medical	Diagnosis to explain problems, specific therapy to cure or minimise the effects of disease
Rehabilitation	Maximising functional ability through 1) restoration of abilities (reablement), 2) adaptation of the physical and social environment (resettlement) and 3) coming to terms with changed ability, resetting ambitions and goals (readjustment), using a multi-disciplinary, problem-solving approach
Person-centred dementia care	Enhancing wellbeing and personhood of someone living with dementia, by promoting identity, comfort, inclusion, attachment and occupation
Palliative	Improving quality of life of patients and families facing life-threatening illness, through prevention and relief of suffering. Early identification, assessment and treatment of pain and other physical, psychosocial and spiritual problems.
Social	Adaptation of the environment, provision of human help, aids or appliances, to compensate for the effects of for disability, infirmity or old age

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3 Table 2: Trajectories of death in care homes (from ⁷)

Trajectory	Description
Anticipated	Inexorable deterioration, approach of death identified in advance
Unexpected	Sudden death or very rapid decline
Uncertain	Prolonged and dramatically fluctuating course
Unpredicted	Sudden catastrophic events such as stroke, heart attack or hip fracture, with complications, or prolonged deterioration

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5 Table 3: Elements of supportive care for frail older people identified from a systematic literature
6 review (from ⁴)

Care principle	Examples
1. Ensuring fundamental aspects of care are met	Symptom control, physical function, hydration and nutrition, oral care
2. Communicating and connecting with the patient	Information provision, psychological and emotional support,
3. Carer and family engagement	Carer and family communication, support and education
4. Building up a picture of the person and their circumstances	Clinical, functional and psychosocial assessment
5. Decisions and advice about best care for the person	Shared decision-making and care planning
6. Enabling self-help and connection to wider support	Self-management, rehabilitation, support groups
7. Supporting patients through transitions in care	Appropriate hospital admission, specialist medical and therapy referrals, discharge planning

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1 Table 4: Ambitions and Foundations for end of life care

Ambitions	Foundations
Each person is seen as an individual	Personalised care planning
Fair access to care	Education and training
Maximising comfort and wellbeing	Evidence and information
Care is coordinated	Co-design of services
All staff are prepared to care	Shared records
Each community is prepared to help	24hours/7day access to services
	Involving, supporting and caring for those important to the dying person
	Leadership

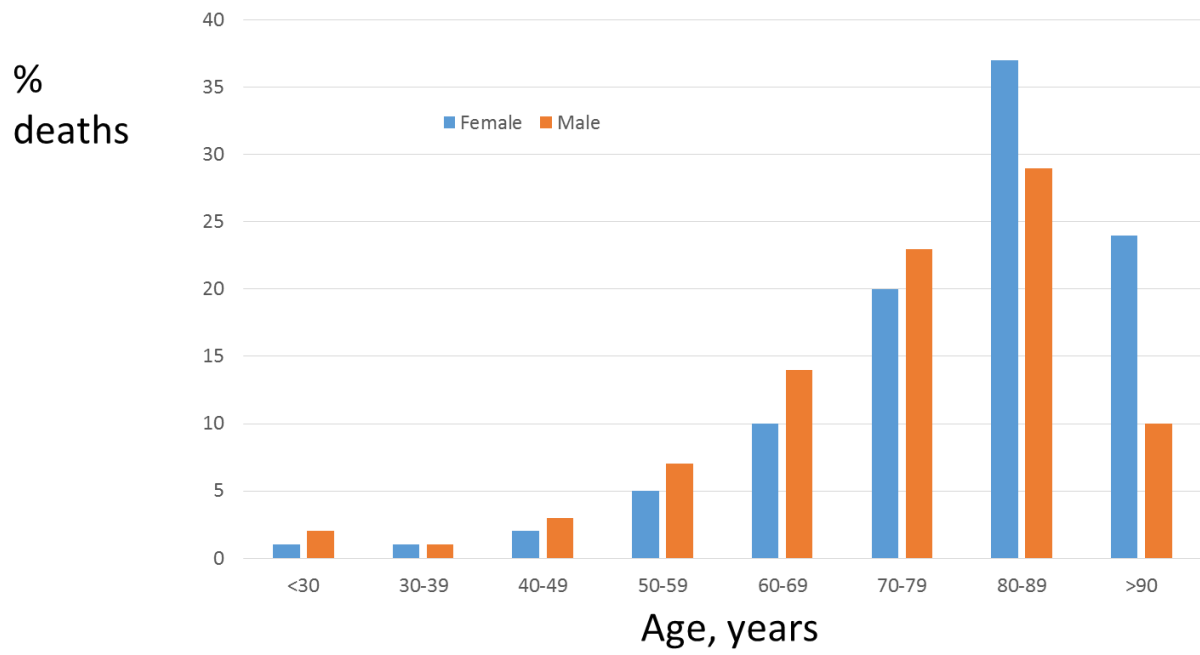
2 From: Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020;

3 National Palliative and End of Life Care Partnership; London, NHS England, 2015.

4 www.endoflifecareambitions.org.uk

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1 Figure 1: Age at which deaths occurred, UK 2017. (Source: Office for National Statistics,
2 www.ons.gov.uk).



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