End-of-life care for frail older people

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ABSTRACT
Most people die when they are old, but predicting exactly when this will occur is unavoidably uncertain. The health of older people is challenged by multimorbidity, disability and frailty. Frailty is the tendency to crises or episodes of rapid deterioration. These are often functional or non-specific in nature, such as falls or delirium, and recovery is usually expected. Health-related problems can be defined in terms of distress and disability. Distress is often mental as physical, especially for people with delirium and dementia. Problems can be addressed using the principles of supportive and palliative care, but there is rarely a simple solution. Most problems do not have a palliative drug treatment, and the propensity to adverse effects means that drugs must be used with caution. Geriatricians use a model called comprehensive geriatric assessment, including medical, functional, mental health, social and environmental dimensions, but also use a variety of other models, such as the acute medical model, person-centred care, rehabilitation, alongside palliative care. Features such as communication, family engagement and advance planning are common to them all. These approaches are often consistent with each other, but their commonalities are not always recognised. The emphasis should be on making the right decision at a given point in time, taking account of what treatment is likely to deliver benefit, treatment burden and what is wanted. Choices are often limited by what is available and feasible. Palliative care should be integrated with all medical care for frail older people.

INTRODUCTION
Most people die when they are old, or very old. In the UK, half die over 80 years old; a quarter of women, and one in eight men, die over 90 (figure 1). This pattern is repeated throughout developed economies. Death in older ages is less unexpected than for younger people, and is often at the end of a fulfilled, natural lifespan, but older people still take pride in coping, keeping going and getting better in the face of declining health.1 Risk of death from non-communicable diseases increases with age, including from ischaemic heart disease, stroke, chronic respiratory disease and cancer. Survival in old age is accompanied by multimorbidity, frailty and disability. By the age of 80 most people have multiple diagnoses, whose effects accumulate and interact. Disabling chronic conditions are the main causes of practical problems. One in three of us will die with dementia; osteoarthritis is the most common cause of disability; stroke and hip fracture can result in severe disability; sensory impairments inhibit occupation and inclusion; depression is common and debilitating.

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

Disability is the inability to perform functional activities, such as walking, personal care, remaining continent and communicating, with all medical care for frail older people.

Healthcare services and professionals may become frustrated at the diversity of problems presented to them by older people, and the limitations of the ‘medical model’ (based on diagnosis and specific treatment) in providing solutions (table 1). Instead, it is suggested that a supportive and palliative approach may be beneficial.4 This paper aims to describe the health problems experienced by frail older
Features

Figure 1  Age at which deaths occurred, UK 2017 (adapted from Office for National Statistics 26).

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 multidisciplinary, problem-solving approach. |
| Person-centred dementia care | Enhancing well-being 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 disability, infirmity or old age. |

A GOOD DEATH
Most policy defines ‘the end of life’ as the last 12 months, but this can only be identified with certainty in retrospect. Palliative care has been defined as managing ‘problems associated with life-threatening illness’ (WHO) and being for ‘advanced, progressive, incurable illness’ (National Council for Palliative Care), which may stretch over many years.

We have a working definition of a good death5:
- Treated as an individual with dignity and respect.
- Without pain or other symptoms.
- In familiar surroundings.
- In the company of family or friends.

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

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

UNPREDICTABLE TRAJECTORIES WHICH ENDURE OVER PROLONGED TIME FRAMES
The supportive or palliative approach is valid for frail older people, but their healthcare is complex. In acute illness, the effects of treatment cannot always be predicted, due to the impact of frailty. ‘Cure’ of chronic diseases such as arthritis, dementia or macular degeneration, or restoration of normal function, is often not possible.
In the UK, 10% of older medical inpatients die, and half will be dead within a year. But identifying in advance who will die is difficult or impossible. Four trajectories of dying have been described in care homes (anticipated, unexpected, uncertain and unpredicted; table 2). Anticipated deaths were mostly well managed within the care homes. The uncertain and unpredicted deaths occurred in hospital and were associated with crises and uncertain and unpredicted; table 2). Anticipated deaths were mostly well managed within the care homes. The uncertain and unpredicted deaths occurred in hospital and were associated with crises and uncertainty, including after catastrophic events such as stroke and hip fracture. Despite this, most of those admitted to hospital during the study period survived.

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

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

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

### SYMPTOM BURDEN WHEN PALLIATION WITH DRUGS ALONE IS INSUFFICIENT

‘Problems’ comprise a wide spectrum, but divide broadly between distress and disability, and occur in people with vulnerable social circumstances. In a representative population, in the week before death, reported symptoms included fatigue (83%), breathlessness (50%), pain (48%), confusion (36%), anxiety (31%), depression (28%) and nausea (25%). More generally, problems include immobility, falls, behaviours that challenge, incontinence, constipation, poor appetite, and swallowing and dehydration. Mental and behavioural distress is prominent among people who may be dying with delirium or dementia: among hospital-admitted patients 10%–20% had delusions or hallucinations, 20% were agitated or aggressive, a third each depressed, anxious, apathetic or awake at night.

Geriatricians use a framework called comprehensive geriatric assessment (CGA), comprising medical, functional, mental health, social and environmental dimensions, which has been demonstrated to reduce death, disability and care home placement (table 1). CGA must be sensitive to transitions in care as circumstances change. If someone is thought to be in their last few days, relief of distress can be prioritised. However, practical problems are often driven by acute illness or injury, which may require standard medical diagnosis and (‘curative’) treatment. Acute illness or injury is assessed alongside baseline function, personal goals and preferences. Functional problems determine how much help a person needs, and whether they can live on their own; addressing these problems, or determining that they are insoluble, requires multidisciplinary assessment and rehabilitation. The frequent occurrence of cognitive and other mental health problems requires mental health expertise and the delivery of person-centred care. Many problems do not have simple palliative drug treatments: attempts to manage them in this way have sometimes led to harm, illustrated by historic misuse of antipsychotic drugs (to try to suppress difficult behaviours in dementia) and opiate analgesic drugs (for chronic non-cancer pain). When we do use drugs, we have to balance beneficial and adverse effects, to which frail older people are particularly sensitive. Many problems require long-term practical (human) assistance.
‘Person-centred care’ is a biopsychosocial model for people with dementia or delirium (table 1). It stresses respect for ‘personhood’: valuing, empathising, individualising care, and using relationships to promote well-being and reduce distress. Individualising means dealing with physical and mental health problems, making the most of retained abilities, understanding the person’s biography, personality and social resources, and respecting preferences. Acute medical care can be adapted to be person centred, and palliative care can be done this way as well.21

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

The word ‘palliative’ may be too culturally associated with cancer care. The support needed by frail older people at the end of life may be little different from ‘standard’ health and social care which, in many countries, is delivered by well-established geriatric medical and social care services. The distinction between acute, subacute and community care is blurred, with multiple hospital readmissions, postacute or ‘intermediate’ care focusing on rehabilitation, and approaches to living well with long-term conditions, including combined health and social care, such as that delivered in care homes. At the same time these services are often underprovided compared with need, and work under extreme operational pressure. Problems at the end of life may be but an example of a more general problem of appropriate operational pressure. The information used to reach decisions. Goals may be difficult to specify in a crisis, when health status has changed rapidly, and when survival and recovery are uncertain. This often leads to a presumption of attempts to ‘rescue’, or preserve life, which may later be regretted. Some people want and hope for recovery, some do not, especially after repeated admissions, or when the trajectory is inexorably downwards. This applies equally in assessment for rehabilitation (a tension between ‘no rehabilitation potential’ and ‘palliative rehabilitation’), or prolonged mental health treatments (eg, recurrent or intractable severe depression).

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

REDEFINING THE PURPOSE OF CARE AT THE RIGHT TIME TO ENSURE THE PRINCIPLES OF A GOOD DEATH ARE UPHOLDED
Framing medical treatment in terms of ‘effective’ and ‘wanted’ care may be a powerful way to support better healthcare choices and decision-making. Effective care is that which has a reasonable prospect of delivering health gain, in terms of the balance between likely benefits and burdens. Wanted care will include care that can be delivered in the place the person most wants to be, including home.

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

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A SPECIALIST SKILL SET
An emphasis on making the right decision at a given point in time means that healthcare practitioners need fluency in practical ethics. The ethical system called principlism considers consequences of interventions (benefits and burdens) and rights (autonomy and justice), but can be difficult to apply when available information is imperfect, decisions have to be made rapidly, or when mental capacity is lacking. Ethical frameworks that prioritise communication and relationships, and practitioner virtues, are also needed to negotiate agreement with patients and families.23
The chances of an intervention delivering what is wanted with an acceptable level of burden or risk is a technical question, but how those are weighed may vary between individuals. Questions of equity, distributive justice and non-discrimination are political and professional, but are important if we are to value people regardless of age and disability. To respect autonomy, determining what people want, requires opportunity, information and time for consideration. We strive for shared decision-making, but in reality patients may defer to professional authority (a generational phenomenon), or have no strong opinion. Contrived or impractical choices are unhelpful. A ‘concordance’ approach encourages practitioners to be empathetic and understand the patient’s perspective, and to negotiate a mutually respected position. The difficulty with any consultation of this nature is in preempting the many uncertainties, and keeping options flexible enough to change if things improve or deteriorate, as they inevitably will. This is no different from deciding about any aspect of medical care, although many difficult decisions for frail older people are made in an emergency, and where the person is not able to make decisions and provide care together, and legal representation is required, via a formal process, and varying in an emergency, and where the person is not able to make decisions and provide care together, and legal jurisdiction to ensure appropriate supportive or palliative care is not perceived as ‘no care’.

**MUCH CARE IS PROVIDED BY FAMILIES WHICH NEEDS RECOGNITION AND SUPPORT**

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

**CREATING SUPPORTIVE AND TRUSTED RELATIONSHIPS BETWEEN PATIENTS, CARE PROVIDERS AND HEALTHCARE DECISION-MAKERS TO DEVELOP AND ENACT MEANINGFUL ADVANCE CARE PLANNING**

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

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

**CONCLUSION**

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

Not all deaths are without problems, but many of the things that make deaths as good as they can be are already happening. We need a more systematic focus on management of distress, better ACP, inclusive decision-making and intensive community services that allow people to die at home if they choose. A palliative

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

Adapted from Ambitions for palliative and end of life care.27
and supportive focus does not mean ‘no active treatment’, and may include treating infections, metabolic derangement or fractures to relieve distress, or rehabilitation to reverse functional decline. Each treatment decision should deliver the most appropriate care for an individual at that time.

CGA, person-centred care and palliative and supportive models can all be used to deliver this, and are in many respects identical.

### Key messages

- Most people die when they are old, and experience multimorbidity, frailty and disability.
- Problems comprise a complex mix of crises, physical and mental distress, functional limitations (disabilities) and social and carer issues.
- Meeting these needs requires a range of approaches, including acute medical, comprehensive geriatric assessment, person-centred care, mental health, social care and palliative care.
- These approaches are not inconsistent with each other, but require careful attention to individualisation and decision-making.

### References

1. Nicholson C, Meyer J, Flatley M, et al. Living on the margin: understanding the experience of living and dying with frailty in old age. *Soc Sci Med* 2012;75:1426–32.
2. Barnett K, Mercer SW, Norbury M, et al. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *The Lancet* 2012;380:37–43.
3. Clegg A, Young J, Iliffe S, et al. Frailty in elderly people. *The Lancet* 2013;381:752–62.
4. Nicholson C, Morrow EM, Hicks A, et al. Supportive care for older people with frailty in hospital: an integrative review. *Int J Nurs Stud* 2017;66:60–71.
5. Department of Health. End of life care strategy: promoting high quality care for all adults at the end of life. London: Department of Health, 2008.
6. Clark D, Armstrong M, Allan A, et al. Imminence of death among hospital inpatients: prevalent cohort study. *Palliat Med* 2014;28:474–9.
7. Barclay S, Froggatt K, Crang C, et al. Living in uncertain times: trajectories to death in residential care homes. *Br J Gen Pract* 2014;64:e576–83.
8. Murray SA, Kendall M, Boyd K, et al. Illness trajectories and palliative care. *BMJ* 2005;330:1007–11.
9. Goodlin SJ. Palliative care in congestive heart failure. *J Am Coll Cardiol* 2009;54:386–96.
10. De Bock R, Van Den Noortgate N, Piers R. Validation of the supportive and palliative care indicators tool in a geriatric population. *J Palliat Med* 2018;21:220–4.
11. Hippisley-Cox J, Coupland C. Development and validation of QMortality risk prediction algorithm to estimate short term risk of death and assess frailty: cohort study. *BMJ* 2017;358.
12. Clegg A, Bates C, Young J, et al. Development and validation of an electronic frailty index using routine primary care electronic health record data. *Age Ageing* 2016;45:353–60.
13. Elliott M, Nicholson C. A qualitative study exploring use of the surprise question in the care of older people: perceptions of general practitioners and challenges for practice. *BMJ Support Palliat Care* 2017;7:32–8.
14. Davies N, Mathew R, Wilcock J, et al. A co-design process developing heuristics for practitioners providing end of life care for people with dementia. *BMJ Palliat Care* 2016;15:68.
15. Klingenberge M, Willems DL, van der Wal G, et al. Symptom burden in the last week of life. *J Pain Symptom Manage* 2004;27:5–13.
16. Stow D, Spiers G, Matthews FE, et al. What is the evidence that people with frailty have needs for palliative care at the end of life? A systematic review and narrative synthesis. *Palliat Med* 2019;33:399–414.
17. Goldberg SE, Whittamore KH, Harwood RH, et al. The prevalence of mental health problems among older adults admitted as an emergency to a general Hospital. *Age Ageing* 2012;41:80–6.
18. Ellis G, Gardner M, Tsiachristas A, et al. Comprehensive geriatric assessment for older adults admitted to hospital. *Cochrane Database of Systematic Reviews* 2017;322.
19. Banerjee S. The use of antipsychotic medication for people with dementia: time for action. London: Department of Health, 2009.
20. Volkow ND, Frieden TR, Hyde PS, et al. Medication-Assisted therapies — tackling the opioid-overdose epidemic. *N Engl J Med* 2014;370:2063–6.
21. Goldberg SE, Bradshaw LE, Kearney FC, et al. Care in specialist medical and mental health unit compared with standard care for older people with cognitive impairment admitted to General Hospital: randomised controlled trial (NIHR team trial). *BMJ* 2013;347:f4132.
22. Pollock K. Is home always the best and preferred place of death? *BMJ* 2015;351.
23. Hughes JC, Baldwin C. Ethical issues in dementia care: making difficult decisions. London: Jessica Kingsley, 2006.
24. Bradshaw LE, Goldberg SE, Schneider JM, et al. Carers for older people with co-morbid cognitive impairment in general Hospital: characteristics and psychological well-being. *Int J Geriatr Psychiatry* 2013;28:681–90.
25. Hill SR, Mason H, Poole M, et al. What is important at the end of life for people with dementia? the views of people with dementia and their carers. *Int J Geriatr Psychiatry* 2017;32:1037–45.
26. Office for National Statistics. Available: www.ons.gov.uk
27. Ambitions for palliative and end of life care. A national framework for local action 2015–2020. In: National palliative and end of life care partnership. London, NHS England, 2015. www.endoflifecareambitions.org.uk