

High-quality end of life care for older people with frailty: helping people to live and die well

Guidance from the British Geriatrics Society provides practical advice to support healthcare professionals who are involved in caring for frail, older people in the last phase of life.

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Introduction

In May 2020, the British Geriatrics Society published a body of guidance entitled ‘End of Life Care in Frailty’ with the aim of promoting the provision of ‘high-quality, person-centred care’ for older people approaching the end of their lives (British Geriatrics Society, 2020). Freely available on the British Geriatrics Society website, the guidance is aimed at doctors, nurses and allied healthcare professionals and represents the culmination of a collaborative effort by over 30 experts caring for people in the last year of their lives. Frailty as a concept has attracted increasing research interest over the past decade and the British Geriatrics Society guidance stems from the evolving evidence base for management of frail older people. Its publication in the midst of the COVID-19 pandemic is timely given the association between advancing age and mortality from the disease (Zhou et al, 2020).

The guidance is presented across 23 sections ranging from the broader concepts of identification of frailty and advance care planning, to management of common, but potentially difficult to manage, symptoms at the end of life and in a person’s final days. Practical examples demonstrate how simple interventions may help improve quality of life. Provision of care for patients across a range of settings, including prisons, is addressed. Patients’ cultural and spiritual needs (that are often overlooked) are explored as well as the importance of psychological and social support. A dedicated section outlining the resources available for each topic signposts the reader to further relevant information.

Identifying frailty

The main focus of the guidance centres on the identification of frailty, prognostication and advance care planning. Frailty is still under-recognised at the end of life. Healthcare professionals may lack confidence to identify frail patients in the absence of other comorbidities or chronic illness. As a result, there is a risk that people are denied opportunities to be involved in decision making about their own care, and are subsequently more likely to be admitted to hospital in their last year of life, endure perhaps futile life-prolonging interventions and die in hospital without prior consideration of their preferred places of care and death (which in many cases is their own home) (Ali et al, 2019). This is counter to the idea of supporting older people with frailty ‘to complete their lives well in the last phase of life’ (Krawczyk and Gallagher, 2016). Proactive identification of frail patients using validated tools such as the Electronic Frailty Index (Clegg et al, 2016) and Clinical Frailty Scale (Rockwood et al, 2005) is promoted to prompt person-centred discussions and support decision making.

Many of us are familiar with the graphical representation of the expected trajectory of frailty: progressive decline with episodes of acute deterioration followed by slow and partial recovery (**Figure 1**). The guidance acknowledges how highly unpredictable the chronology of decline can be. Having established that a person is severely frail, it is still difficult to know with certainty when they are approaching the end of life. Thus, early advance care planning is recommended and to be effective should be responsive to changes in condition and circumstances. Individuals will have their own sets of values, beliefs and preferences, and a focus on patient choice and empowerment is emphasised, rather than denying access to care. Healthcare professionals are urged to carefully weigh up the burdens and benefits of any potential interventions rather than automatically pursuing a protocol-driven response.

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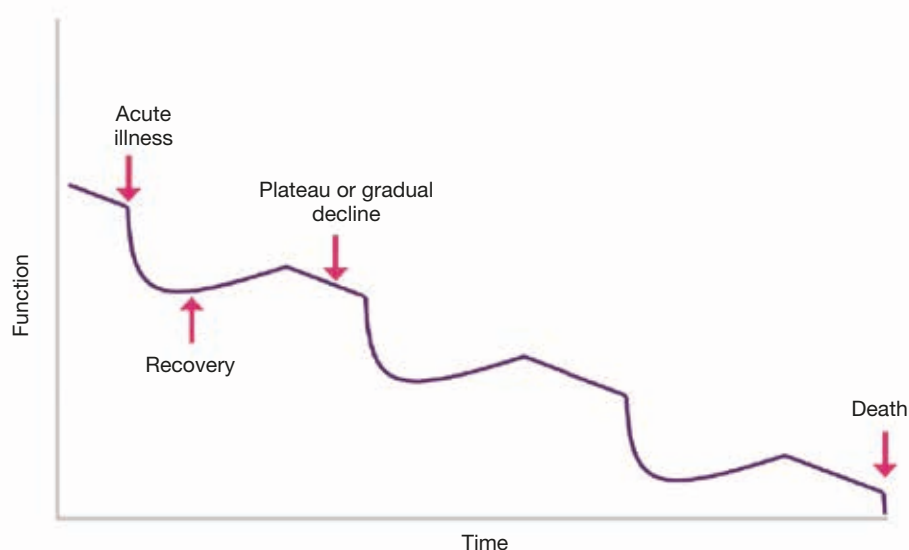


Figure 1. Expected trajectory of decline in older people with frailty at the end of life. From British Geriatrics Society (2020).

Advance care planning

Although planning for the end of life might seem like an uncomfortable topic, there is evidence that most older people are receptive to open and honest conversations (Sharp et al, 2013). In recognition that communicating prognostic difficulties to patients and their families can be challenging (Krawczyk and Gallagher, 2016), ‘parallel planning’ for both recovery and death is suggested as a way to help handle uncertainty. Ultimately establishing goals of care when the patient is well, including consideration of responses to potential urgent care needs, aims to avoid hurried decision making in a crisis. The idea of advance care planning being an ongoing dialogue, rather than a once-only conversation, is important. However, with concurrent involvement of multiple professionals over the course of the patient’s remaining life, the impact on continuity of care and patient experience should be considered.

The responsibility for advance care planning extends beyond clinicians, and the multidisciplinary team including care home staff, paramedics and community teams are encouraged to be opportunistic in opening discussions around the potential for deterioration and death, ascertaining patient wishes and sharing decision making with patients and their families. However, there is a delicate balance between ‘making every contact count’ and ensuring that appropriately trained decision makers are involved at the right time. Reflecting this, education providers are encouraged to be role-specific. One suggestion is to train care home staff to identify patients approaching the end of life, through implementation of clinical tools such as SPICT-4ALL (The University of Edinburgh, 2017), so that appropriate patients can be identified and flagged for a personalised review. Specialist input is required where there are complex issues including medicine management and legal and ethical issues. Advanced communication skills training may be of benefit to those engaging in the nuanced discussions around prognostication and goals of care. The British Geriatrics Society guidelines emphasise the need for the use of clear and unambiguous language and call on clinicians not only to listen well but also to ask well. While the experience gained from putting these skills into practice cannot be substituted, some example questions and phrases are provided as a useful starting point for the less experienced and can be adapted depending on the situation.

The importance of good communication between professionals also cannot be understated. Effective communication can be impeded by boundaries between primary, secondary and social care. Alleviating these boundaries might require a re-think of how services are structured and how documentation and sharing of contemporaneous information can be made easier. In caring for frail, older people clinicians must remember their role as advocates and challenge inappropriate language and outdated thinking that may inhibit access to care.

Key points

- Recent British Geriatrics Society guidance addresses end of life care in frailty.
- Person-centred care is the key message, with promotion of early identification of frailty to guide conversations about advance care planning.
- ‘Parallel planning’ can help deal with prognostic uncertainty.
- High quality care involves effective communication between multidisciplinary team members, patients and their carers.

Conclusions

The provision of high-quality end of life care for our frailest patients comprises early identification of frailty and initiation of effective advance care planning that is patient-centred, individualised and responsive rather than pathway-driven. Good communication between patients, their families and multi-professional team members is paramount. In a dynamic and busy healthcare setting, this remains challenging but the new guidance dismantles some of the complexities of caring for patients in the last phase of their lives. The guidance is easily digestible, resource rich and of use to specialists and non-specialists alike. Everyone involved in the care of frail patients should be proactive in sharing and enacting their recommendations.

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Acknowledgement

Figure 1 is reproduced by kind permission from the British Geriatrics Society.

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