Coalition of Frontline Care for People Nearing the End of Life

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27 September 2023

Dear Secretary of State and Minister,

Ensuring high quality care for people in the final years of life, across health and social care.

We call on the Government to make a radical transformational shift in the care for older people nearing the end of their lives, through support and investment at service, system and national levels. This includes (1) enhanced core training in proactive, personalised end of life care (EOLC) for the three million generalist frontline workforce in health and social care, (2) system changes for Integrated Care Boards (ICBs) enhancing inter-sector collaboration, community care and preventing over-hospitalisation, and (3) nationally, a shift in policy and CQC regulation. EOLC is everyone's business. Care for people nearing the end of their life is a major part of delivering good health and care services and all parts of the system are involved. Funding should be prioritised from new or existing resources. With the ageing population, acting on this unrecognised opportunity could reap benefits at multiple levels, leading to a step-change in care to meet the needs of older people in their final years of life.

We write to you as a coalition of leading organisations from across health and social care, united by a desire to promote best practice in care for older people in their final years of life, by enabling the frontline workforce. Together we represent most of the health and social care workforce who care for most people in their last years of life (in hospitals, community, care homes, domiciliary care, retirement villages, etc.), and the leading provider of EOLC training, the Gold Standards Framework (GSF) charity.

We believe everyone deserves top quality care as they near the end of life. Most hands-on care for older people in their final years is given by the frontline health and care workforce. It makes sense, therefore, to ensure that those giving *most* care to *most* people in their final years, in any setting, are well trained in proactive, personalised EOLC, and supported by wider Integrated Care Systems (ICSs), policies, and CQC regulation.

The case for change is strong. **The current system is not working and is failing those most in need, notably older people in their final years.** As the population ages, with death rates predicted to increase by 25% by 2040 and numbers aged over 85 set to double[i], the issue of the fractured interdependence of health and care is likely to escalate. Health and care systems must shift towards care for people with age-related conditions such as dementia, now the UK's leading cause of death. Many more could be cared for and die at home with better staff training and stronger support[ii] in accordance with the wishes of the voting public[iii]. In a recent survey, **two thirds of UK adults backed a call for the government to provide more resources and training for EOLC as a national priority**[iv]. We believe there is a strong case to shift resources to something that is central to the delivery of high-quality integrated care, for the benefit of the most vulnerable people in our society.

Improvements in this area would lead to four key areas of benefit: (1) humanitarian; (2) economic and practical; (3) workforce; and (4) helping attain national strategic policy aspirations - as outlined below.

1. **Humanitarian - more could live well and die well at home with better staff training and support.**

One of the few certainties in life is that we will all die. Despite this, many people in their final years have a poor experience of care. Repeated surveys confirm that most would prefer to die at home or in their care home[v] supported by their familiar care providers. Yet almost half die in hospital, with repeated emergency hospital admissions in their final year[vi]. Sadly, many do not have their EOLC needs recognised or met. Too often we hear of older people enduring poor quality care and the distress of families navigating a system not fit for purpose. We believe things could be different and that we must strive to ensure quality care at the end of life for all.

2. **Economic and practical - minimal investment results in major rewards through preventative care.**

About one third of the NHS budget is spent caring for people in the last year of their lives, much of which could be better spent with proactive, personalised planning and crisis prevention**.** People in their last year of life constitute about 1% of the population, 30% of hospital patients at any time[vii] and about 80% of care home residents. They also represent 25% hospital bed days and almost a tenth of hospital admissions[viii]. About 40% of emergency hospital admissions of care home residents are considered preventable[ix]. These avoidable admissions both distress patients and families and further stretch NHS capacity, reducing access for acutely ill patients and increasing waiting times. Without intervention, we risk a rise in over-hospitalisation and inadequate home care[x]. However, a small investment reaps considerable reward, taking a proactive, preventative approach. For example, for the cost of 2 nights in hospital or 1-2 weeks in a care home, a whole team could be GSF trained and accredited, fulfilling peoples' choices, reducing hospitalisation and freeing capacity.

3. **Workforce - a better trained workforce delivers more and boosts recruitment and retention.**

Our workforce is our strength. The vast majority of care for people in their final years is given by the three million frontline generalist staff across the NHS and social care. Hospices and palliative are specialists (workforce about 10,000) and are highly valued colleagues, though in practice account for only a fraction of the care provided to people in the last years of life, with about 5% of deaths taking place in hospices. We need *both* enabled, well-trained, up-skilled generalists *and* support from specialists working together. It is therefore essential that we invest in training and support for the generalist workforce, most notably those in social care who are often omitted from NHS plans. Recognition through investment, enabling the workforce to provide high-quality care, will boost staff retention, morale[xi], and, if scaled up, improve cross-boundary collaboration in ICBs.

4. **National policy – this would help deliver Government policy objectives.**

The NHS Long Term Plan[xii] affirmed the importance of proactive, personalised care for people in the last year of life. The 2022 Health and Care Act[xiii] builds on the interdependence of health and care through ICSs and population-based thinking. Statutory Guidance to ICBs on this subject highlights the need for workforce skill mix, access to specialist palliative care and quality care across all settings[xiv]. Extending this mandate to generalist EOLC training would complement and bolster existing government policy and lead to improved collaboration with system-wide benefits. The NHS Long Term Workforce Plan[xv] highlights the need for improved recruitment, retention and reform, but excludes the social care workforce. Levels of staff satisfaction, morale and retention are enhanced by confidence-boosting EOLC training such as GSF[xvi]. Inclusion by the regulators of generalist EOLC training in ICBs and care providers is vital to the success of this reform.

These benefits are attainable. Everyone dies, yet each person only dies once. It is within our power to ensure that more are supported to live and die well. There are several examples of EOLC training , with encouraging progress. For over 25 years, GSF has been training and accrediting thousands of generalist frontline teams in health and social care[xvii]. These GSF Accreditation Awards are endorsed and co-badged by these Coalition co-signatories in their respective areas, and the exemplar GSF accredited teams show what is possible to achieve.

We, as a coalition of leading health and care frontline organisations, urge you to improve EOLC:

1. **<u>At workforce service level</u> - to support all frontline generalist staff in health and social care to receive enhanced training to provide quality, proactive, compassionate care for people nearing the end of life;**
2. **<u>ICB System level</u> - scale this up in ICBs for whole-system approaches to integrated joined-up care; and**
3. **<u>Nationally</u> - policy and CQC regulation to support better care for older people nearing the end of life.**

We would be grateful to hear your response to the points outlined in this letter and would welcome the opportunity to meet with you to discuss them in more detail.

Yours sincerely,

Coalition of Frontline Care for People Nearing the End of Life

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References

[i] ONS Jan 12 2022 Population and Projections End of Life care report
[ii] NAO End of Life Care Report https://www.nao.org.uk/reports/end of life-care/
[iii] Government Choice in End of Life Care Report (2015) https://www.gov.uk/government/publications/choice-in-end-of-life-care
[iv] June 2023 Survation Poll –Gold Standards Framework 25th Event (Blue Lozenge) https://www.goldstandardsframework.org.uk/25-years-of-gsf
[v] National Survey of Bereaved People (2015)
https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015#main-points
[vi] Public Health England Report 2020 https://www.gov.uk/government/publications/older-peoples-hospital-admissions-in-the-last-year-of-life/
[vii] Clark et al Imminence of death among hospital inpatients: Prevalent cohort study Palliative Med DOI: 10.1177/0269216314526443
[viii] https://www.gov.uk/government/publications/older-peoples-hospital-admissions-in-the-last-year-of-life/
[ix] Health Foundation (2019) https://www.health.org.uk/publications/reports/emergency-admissions-to-hospital-from-care-homes
[x] Bone Higginson et al. *What is the impact of population ageing on the future of end of life care?* Palliative. Med (2017)
https://journals.sagepub.com/doi/10.1177/0269216317734435
[xi] GSF Accredited Care Homes Survey (2023)
[xii] NHSE Long Term Plan (2019) https://www.england.nhs.uk/publication/the-nhs-long-term-plan/
[xiii] Health and Care Act 2022 https://www.legislation.gov.uk/ukpga/2022/31/contents/enacted
[xiv] Palliative and End of Life Care Guidance to ICBs 2022 https://www.england.nhs.uk/wp-content/uploads/2022/07/Palliative-and-End-of-Life-Care-Statutory-Guidance-for-Integrated-Care-Boards-ICBs-September-2022.pdf
[xv] NHS Long Term Plan 2023 https://www.england.nhs.uk/publication/nhs-long-term-workforce-plan/
[xvi] Sept 2023 Survey of GSF Accredited teams assessing impact GSF Impact Survey
[xvii] https://www.goldstandardsframework.org.uk/25-years-of-gsf