

Executive Summary, Calls to Action and Key Asks

We urge the Government, to invest in training and support for the frontline health and care workforce, to make a radical change in the care for older people nearing the end of life. See the [Coalition Report 'End of Life care is Everyone's Business' Nov 24](#)

1. EXECUTIVE SUMMARY

Our coalition

The Coalition of Frontline Care for People Nearing the End of Life is a partnership 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 in all settings, by empowering the three million-strong frontline workforce. The three key elements of this Coalition are that we focus on - 1) the care for people in the last years of life with any condition, 2) cared for by the generalist frontline workforce, 3) across both health and social care.

Together we represent the majority of the health and social care workforce who care for most people in their last years of life and the leading provider of End of Life Care (EOLC) training for frontline staff, the Gold Standards Framework Charity (GSF). See full list of Coalition Members (pg4).

Why this matters

- Every year in the UK about 650,000 people die. By 2040, this is expected to increase by 25%. So, the number of people requiring end of life care is rising.
- People in their last year of life constitute about 1% of the population, 30% of hospital patients at any time and about 80% of care home residents. They also represent 25% admissions and 21% hospital bed days.
- With the ageing population, most die with age-related conditions; dementia is now the UK's leading cause of death, plus frailty and multi-morbidities. Most cope at home until a crisis occurs.
- Almost a third of emergency admissions are for people in their final year, and 40% of admissions of care home residents are considered preventable. Training of generalist staff can drastically improve this proactive, preventative approach.
- Although most say they would prefer to die at home, or their care home, most people (44%) still die in hospital, with 29% at home and 20% in care homes. About 75% do not die where they would choose.
- Most people in the final year receive most hands-on care from generalist frontline staff. Only 11% of those in the final year need specialist palliative care.
- End of Life Care is everyone's business - we are all involved. Families, carers and communities play a vital role in supporting people nearing the end of life. providing most of the 24-hour care needed. Giving preventative support for families is helpful.
- **It is estimated that the NHS spends about a third of its budget on people in the last year of life.**

The case for change has never been stronger.

Investing in the frontline workforce caring for people nearing the end of life will help improve care for thousands, shift more care to the community, prevent over-hospitalisation, improve early anticipation and preventative proactive care and deliver the transformational change that we seek.

2. OUR CALLS TO ACTION

We, as a Coalition of leading health and care organisations, urge the Government/NHSE to improve palliative and end of life care in our country as a matter of urgency.

We call for a radical transformational shift in the care for people nearing the end of life. This needs action at three levels, national, system and workforce, with investment by national

government and ICB systems to enable the mobilising, enabling and support of the frontline workforce.

The three levels of our Coalition Calls to Action

- 1. NATIONAL:** A focus on improving end of life care, including a strategic investment in end of life care training and support for the three million strong health and social care workforce caring for older people approaching the end of life and investment in an integrated and well-regulated National Care Service. This includes policy integration through the NHS 10 Year Plan, CQC regulation to support better care for older people nearing the end of life.
- 2. SYSTEM:** Integrated Care Boards (ICB) prioritising whole-system integration and collaboration of health and care for people nearing the end of life, enhancing community care and preventing over-hospitalisation, enabling more to live and die where they choose, usually at home, scaling change up towards whole-system, population-based end of life care improvements.
- 3. WORKFORCE:** To roll out the provision of enhanced core training and support for frontline generalist health and care teams to deliver quality, proactive, personalised care for people nearing the end of life with support from specialists and investment from national and system level partners.

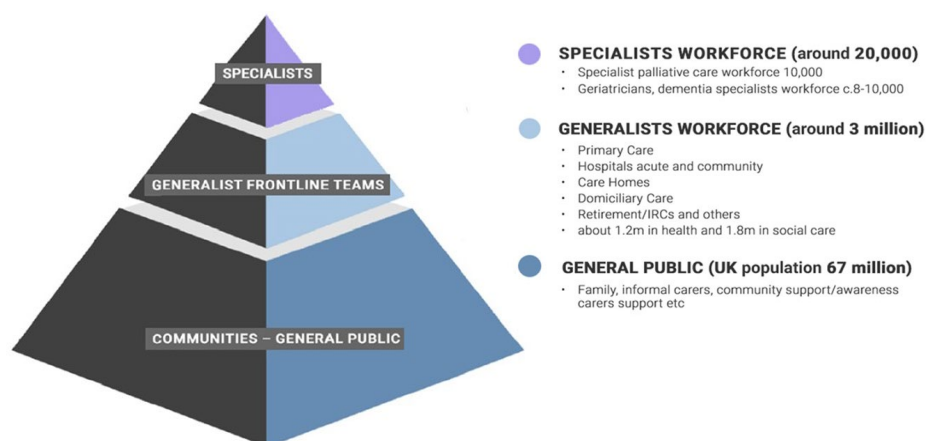
Why investment in those that provide most care matters

The vast majority of people in their final years are cared for by the three million-strong frontline generalist workforce in health and care. It makes sense, therefore, to ensure that those giving most care for most people in their final years, in any setting, are well trained to give proactive, personalised care, and supported by specialists, ICB systems and national policies. However, still most frontline staff do not receive specific EOLC training.

Without this we risk inadequate home care and rising hospitalisation

It is estimated that 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 in the community. Almost a third of all emergency hospital admissions are for people in the last year of life. This both distresses patients and families and further stretches NHS capacity, reducing access for acutely ill patients and increasing waiting times.

The recent NCEPOD report affirmed that palliative/end of life care should be core competencies for the patient-facing workforce. A small investment in improved training for generalist health and care teams reaps considerable reward, taking a proactive, preventative approach, improving specialist referral, reducing avoidable admissions. For example: for the cost of three nights in hospital, one team could be GSF trained in end of life care. For the cost of one hospital admission, three teams could be GSF trained.



The workforce: End of life care is everyone's business

MOST care for MOST people is given by 3m generalist frontline health and social care teams - all should receive EOLC training.

With better training and enablement, and with support for frontline teams from specialists, end of life care could improve for many more people in our ageing population.

The Coalition Report makes the case for change. It urges the Government, senior policy leads, ICB Chairs and Commissioners to help radically change care for people at the end of their life, by investing in training and support for the frontline generalist workforce in health and social care. We know this is key to enabling the national policy aims of the government, shifting care closer to home, preventing over-use of hospitals, reducing waiting lists and recognising the vital contribution of the workforce.

Alignment with national policy

Our calls to action align with, and help to fulfil, many of the key aspirations in national policy. We urge the Government to include investment in the frontline health and care workforce **as a key part of the NHS 10 year-plan** which would help the Government deliver its policy shifts i.e.:

1. **Community Care** - shifting more care from hospitals to communities, being **proactive** to identify early, assess and plan to **reduce hospitalisation and delayed discharges**.
2. **Digital** - enabling the workforce to make better use of technology in health and care.
3. **Prevention** - anticipate needs, **prevent crises and over-use of hospitals**, more live and die well at home.

The Assisted Dying debate

The discussion about the proposed Bill shines a spotlight on the importance of improving the consistency and availability of high quality end of life care for all who need it in our country. There is a striking need to improve the provision of end of life care for the many thousands that need it each year, and to improve safeguards for the most vulnerable whatever the decision on assisted dying legislation. The Coalition consists of independent separate organisations, so takes no single position itself, but some members have done so (see British Geriatric Society and GSF positions).

3. OUR RECOMMENDATIONS AND KEY 'ASKS'

We believe we need BOTH enablement and support for the three million frontline generalist health and care workforce caring for people nearing the end of life AND support from specialists in palliative care, geriatrics, dementia care and others. Specialists play a vitally important role in end of life care, but only by optimising and enabling the current frontline workforce who care for the majority of people in their final year of life, will maximal impact be seen in improving palliative/end of life care in our country.

RECOMMENDATIONS

A. National Policy and Regulation

To shift policy as part of the NHS 10-year plan and NHS reforms, including focused ICB CQC regulation on EOLC in ICBs, plus development of the social care workforce, and proposed National Care System.

- i. Ensure that the 10-year NHS plan includes specific action on workforce training and support for the three million health and social care workforce caring for people approaching the end of life. This also helps key NHS policy shift to community and prevention of hospitalisation.
- ii. Through CQC regulation with focus on end of life care in every setting for care providers and ICB regulation for better integration of health and social care for older people nearing the end of life.
- iii. Prioritise the enhanced development of the social care workforce as part of the planning for the National Care Service.

B. Integrated Care Systems

To scale up workforce for a step-change in whole system integrated health and care collaboration, enhancing quality, community care, preventing over-hospitalisation for people nearing end of life.

- i. Accelerate integration of health and social care received by people nearing the end of life.
- ii. Invest in community services to enhance 'care closer to home,' with primary care, care homes and hospital-community collaboration and recognise the importance of domiciliary care services, community hospitals and retirement communities.
- iii. Integrating digital tools enabling effective integrated joined-up care coordination, collaboration and communication.

C. The Frontline Workforce

- i. **Training.** Introduce quality improvement training programmes to include all staff who care for people with any condition in their final years of life in all health and care settings (1%, 30%, 80%). This upskilling with tangible outcomes, with tangible outcomes, at basic, intermediate, and enhanced levels some accredited. Generalist skills help **proactive planning** (early identification), **personalised care** (advance care planning) and clinical assessment for potential referrals and **coordination** of care to reduce crises, avoidable admissions, more to live and die well at home if they choose.
- ii. **Support.** Secure local access to support services and advice from specialists in palliative care, geriatrics/care of older people and dementia such as Admiral nurses, and local end of life experts.
- iii. Support staff capacity and conditions, morale, and staff retention, as part of potential social care plans and National Care Service, taking a whole system approach to workforce planning across health and social care.
- iv. **Digital/Technological/AI.** Digital enablers e.g. for identification, communication, problem-solving.

5 KEY ASKS: Summary of details at all three levels

1. **Key ask** - We seek the introduction of **End of Life Care training for the frontline workforce** with a core/mandatory quality improvement training programme in end of life care , embedding skills for the wider workforce, delivering tangible impact outcomes, for all the those involved in care for people in final year of life in every setting across health and social care.
2. **Key ask** - We seek to ensure effective **24/7 access to expert specialist support** from specialists in palliative care, geriatrics, dementia care or other specialists as needed.
3. **Key ask** - We seek end of life care to be a **key focus in ICB whole-system planning** to enable enhanced community care, better use of hospitals and effective health and social care collaboration. This includes **digital enablers** shared across the health and social care workforce to support improved delivery of care e.g. for early identification, for training, communication, interoperability across sites, prevention of hospitalisation and other areas.
4. **Key ask** - We seek end of life care as a **key focus in CQC inspections** and regulation for all care providers and for ICB regulation ,encouraging effective health and social care collaboration.
5. **Key ask** - We seek, as part of the 10-year plan, **recognition and enhancement of the social care workforce and integration of health and social care** including development of planned National Care Service .

Further details of any of the above can be clarified later

All references available in the Coalition Report

The Coalition of Frontline Care Members are: The Gold Standards Framework Charity (GSF), National Care Forum (NCF), British Geriatric Society (BGS), Care England (CE), Community Hospital Association (CHA), Homecare Association (HCA) and The Associated Retirement Community Operators (ARCO).