

# End of life care is everyone's business

Coalition of Frontline Care Report

November 2024

We urge the Government to invest in training and support for the frontline generalist health and care workforce to make a radical change in the care for older people nearing the end of life.



#### Coalition Members

The Gold Standards Framework - National Care Forum - Homecare Association - Community Hospitals Association  
The Associated Retirement Community Operators - Care England - British Geriatrics Society

# Foreword

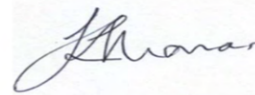
As a doctor working for over forty years with hundreds of teams in all settings across the country to improve end of life care, I believe there has never been a more important opportunity than now to transform care for more people in their final years of life in our country.

The numbers requiring end of life care is rising as the population ages. The pattern is changing, with more dying with age-related conditions with an even greater need for health and social care collaboration. The current system is particularly failing vulnerable older people in their final years, with almost a third of all emergency hospital admissions being people in their final year of life.

Yet the potential impact of training and supporting the frontline health and care workforce has often been missed. This under-recognised opportunity to invest in our hard-working teams across the country could deliver a radical change for our population, now and in future, building on some inspiring examples of excellence already here.

A recent poll suggested 67% agreed that Government should provide more resources and training for end of life care as a national priority. We seek action to empower and upskill the frontline workforce, with investment in more training and specialist support, along with changes at service, system and national levels. Nothing else would be as effective in helping the NHS achieve its policy ambitions.

This Coalition Report, with contributions from all members, makes the case for change, points to the future and helps us aspire to the best of care towards the end of life – the kind of care we would like for ourselves and our families. We seek a chance to radically change the quality of care for more people nearing the end of life. And we urge the Government to invest in its frontline workforce – because end of life care is everyone’s business.



Professor Keri Thomas OBE  
MB BS, MRCGP, DRCOG, MSc (PaII Med), SFFMLM  
Chair of the Coalition of Frontline Care, and Founder and Chair of The GSF Centre in End of Life Care

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# 1. Executive summary

We urge the government to invest in training and support for the frontline generalist health and social care workforce to make a radical change in the care for older people nearing the end of their life.

## 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.

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 (GSF) charity.

## 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 home, 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.

## Our calls to action

**We call for a radical transformational shift in the care for people nearing the end of life.** This needs investment by national government and ICB system levels to enable the mobilising and support of the frontline workforce.

**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.

**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.

**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.

- 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.**

## 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.

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 to the community, prevent over-hospitalisation and deliver the transformational

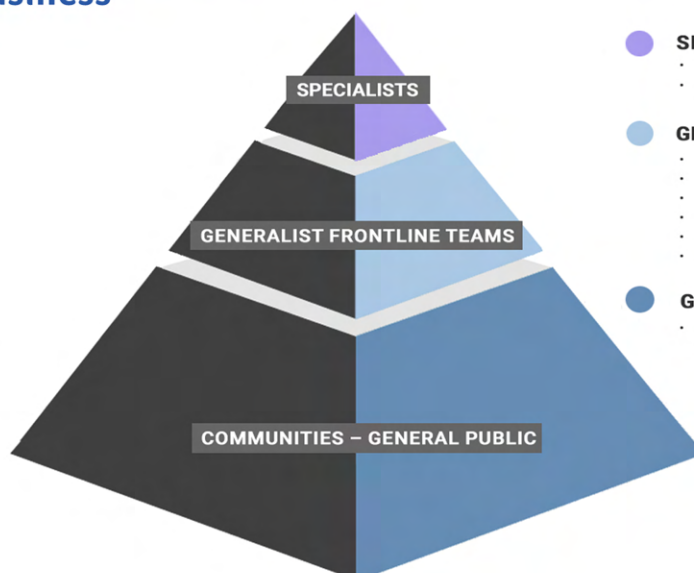
## The Assisted Dying debate

The discussion about the proposed bill shines a spotlight on the importance of improving the consistency and availability of high quality of 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 eg see [British Geriatric Society](#) and [GSF positions](#).

## 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 support for frontline teams from specialists, end of life care could improve for more people.



## 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.

**This 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.



## 2. Why change is needed – the case for change is strong

### ‘The NHS is broken not beaten’

There are significant problems but also transferable successful solutions emerging, which could lead to a step-change in care if we take the opportunity of reform and change as part of the NHS ten-year plan. Rt. Hon Wes Streeting himself has said that we face 'the perfect storm of the combination of an ageing population, increasing complexity and rising costs that could "shipwreck" the NHS if not addressed soon.<sup>1</sup>

### The current system is not working

These challenges affect the whole of the very NHS and social care systems we all depend on. In particular the system is failing those most in need – older people in their final years and their families.

#### Doing nothing is not an option.

The data and evidence points to the seriousness of the current situation (see Box 1) – more people living and dying with age-related conditions, the rising death rate, and increasing numbers of people needing quality end of life care now and in future.<sup>2</sup>

By 2040, the number of people living with major illnesses is projected to surge by 38%, placing unprecedented demands on primary care and emergency services.<sup>3</sup> The lack of preventative care often results in avoidable hospitalisations, creating a cascade effect on bed availability, waiting times, and healthcare resources.

Beyond these systemic challenges lies a profound human cost: patients and their families experience distress when remaining in hospital settings, rather than receiving care in the comfort of their homes – where most would prefer to be.

And with a post-Covid workforce crisis in many areas,<sup>5</sup> and limited specialist support,<sup>6</sup> it feels to many on the frontline as an uphill struggle of Sisyphean proportions just to keep going.

### Box 1: End of life care in numbers

- About 650,000 die/ year – approximately 25% more deaths by 2040
- 85% of deaths occur in people over 65, 75% deaths in people over 70
- Place of death: 44% people die in hospital, 29% at home, 20% in care homes and 4% in hospices
- Most people (60–70%) do not die where they choose
- Early identification is possible and helps improve EOLC
  - 1% population
  - 30% hospital patients
  - 80% care homes residents
- Hospital admissions in last year of life
  - 25% hospital admissions
  - 21% hospital bed days
  - 30% inpatients at any one time
  - 72% people had emergency admission
  - Almost  $\frac{1}{3}$  of all emergency admissions are for people in last year of life<sup>4</sup>
- Workforce
  - Frontline generalist workforce of 3m (1.2m NHS and 1.8m social care approx)
  - Specialist palliative care – approx 10,000
  - Geriatricians – consultants 2500
  - Dementia specialists – 400 Admiral nurses
- There are inequalities in end of life care services with poorer people having reduced longevity, more conditions and receiving less access to care (OHID)
- Workforce crisis – depleting numbers in the health and care workforce
- Use of specialists – only about 11% people in final year require specialist palliative care
- Costs – estimated about a third of the NHS budget is used in care for people in their final year of life

## Time for change – solutions in our midst

The Chief Medical Officer affirmed that 'maximising the health and life chances of older adults should be a major national priority,' highlighting that many live well despite increasing multi-morbidities in later life. He recommended reducing risks of over-treatment by advance care planning, enhancing generalist skills, and supporting people's preferences for quality of life rather than quantity.<sup>7</sup>

Many more could be enabled to live well and die well at home in accordance with their wishes, with better staff training and stronger support.<sup>8</sup>

We know that for many, decline can be anticipated, and that early identification can enable proactive planning and better end of life care including those with frailty.<sup>9</sup> Yet there is currently little investment in preventative, system-based training for the workforce caring for these people.

If 40% of crisis admissions can be prevented, through enhanced enablement and training of the under-recognised frontline health and social care teams, surely investing in mobilising this frontline workforce should be part of the solution included in any future NHS plans. Quality improvement End of Life Care training such as GSF QI Training Programmes can dramatically decrease hospital admissions and deaths.<sup>10</sup>



### INCREASE



- Early identification of patients
- Offering Advance Care Planning discussions
- More dying where they choose
- Improved experience of care, positive feedback from families and carers
- Improved bereavement support

### DECREASE



- Fewer hospital emergency admissions
- Fewer hospital deaths
- Decreased length of stay
- Fewer crises, and A&E contacts
- Decrease costs to the NHS

Box 2: Impact of training of frontline generalists demonstrating change in outcomes – moving from reactive care to proactive care.

This could reduce over-hospitalisation and increasing bed access for others, making economic and practical sense. And this would help with the government's targets of shifting from hospital to community care, upstream prevention of crises and reducing waiting times.

Without such a radical change to preventative community care and health and care collaboration, our NHS and care systems will continue to face unprecedented pressures and costs, potentially failing patients, staff and our population as a whole.

This could become mainstream if rolled out nationally, benefitting thousands and producing a step-change in care.<sup>11</sup>

Change is within our reach – great care is already happening in all settings (see section four and [Appendix](#)).

# 3. What are the benefits of upskilling the workforce?

## Our workforce is our strength

We believe there is a strong case to shift resources to support the frontline workforce, who are fundamental to the delivery of high-quality integrated care, benefitting some of the most vulnerable in our society.

Our workforce is our strength. Generalist palliative care skills can be taught and implemented by the frontline workforce across all health and care settings, with significant impact.

Investing in upskilling and supporting the frontline workforce would reap benefits at many levels.

### a) Humanitarian benefits

**More could live well and die well at home with better staff training and support.**

- A better care experience for more older people
- More people living and dying where they choose, usually home
- Reduced emergency admissions to hospital and hospital deaths
- Better support for families and carers, reducing the impact of protracted grief

Research shows that given the choice, most people would prefer to die at home or in a care home,<sup>12</sup> yet almost half die in hospital, with repeated emergency hospital admissions in their final year<sup>13</sup> and many having a poor experience of care.

We believe things could be different and that we must strive to ensure quality care at the end of life for all.

**Cost effectiveness estimates of training frontline staff eg GSF training of care homes.**

- For the cost of three nights in hospital, one team could be GSF trained.
- For the cost of one average hospital admission, three teams could be GSF trained.

### b) Economic benefits

**Economic and proactive measures – minimal investment results in major rewards through preventative care.**

- Earlier identification and advance care planning reduces unplanned admissions, costs and improves quality of life
- More targeted NHS spend for people in the final years of life, with care aligned to their agreed advance care plans, reducing crises and waste.
- Reduced avoidable hospital admissions for older people, easing pressure on hospitals, helping to reduce waiting times
- Improved social care provision reducing delayed discharges enabling more home care

Currently it is estimated that around a third of the NHS budget is spent on caring for people in the final years of life, and often on crisis interventions resulting from under investment in preventative community support. Pressures in social care have a direct impact on the NHS – delayed hospital transfers causing many patients to remain in hospital due to lack of availability of social care.<sup>14</sup> With almost half emergency hospital admissions of care home residents considered preventable,<sup>15</sup> a small investment reaps considerable benefits.

Taking a proactive, preventative approach is cost-effective and frees hospital capacity. For example, a large seven-year South London study demonstrated more dying at home and decreased hospital deaths after GSF training and facilitation.<sup>16</sup>

**Without action, we risk both a rise in over-hospitalisation and inadequate home care.**



## c) Workforce benefits

### A better trained workforce delivers more and boosts recruitment and retention.

- A more flexible and integrated workforce bridging health and social care
- Improved levels of staff confidence and satisfaction, higher staff morale and retention of staff with improved consistency
- Improved access and support from specialists in palliative care, geriatrics etc
- Care homes can increasingly be 'the hospices of the future' for people with age-related conditions

If we invest in training and support for the generalist workforce, notably those in social care, staff satisfaction, morale and retention are all enhanced by effective training.<sup>17</sup>

Many people with dementia live and die in care homes – the 'hospices of the future'.<sup>18</sup> There is good evidence that care homes that undertake specific training in end of life care, provide excellent levels of care, with decreased hospital admissions and more dying at home<sup>19</sup> with high levels of staff satisfaction.

The valuable role of the less well recognised providers of quality end of life care should be affirmed and enhanced, particularly community hospitals, domiciliary care, retirement communities and others. They play a vital role in bringing care closer to home and reducing over-hospitalisation for many.

## d) Policy benefits

Investing in the skills of the generalist workforce would help the Government to deliver its policy objectives of reforming the NHS, to shift care towards the community, prevent over-hospitalisation and deploying technology to support best practice.

Despite the last Labour Government investing in the first NHS End of Life Care Strategy in 2008 (including the UK roll out of GSF to all GP practices), most policy initiatives have failed to deliver the system wide transformation that is so needed, largely because of a lack of investment in the health and care workforce. This could radically change with national, service and workforce level recommendations we make here.

### Delivering Government policy objectives.

- Cost effective system transformation
- A shift in care provision to the community with more localised services including primary care and hospitals – 'home first'
- Prevention by early identification and proactive care, anticipating and addressing needs early, averting crises, reducing hospital stays
- A better resourced, empowered social care system working in tandem with the NHS as part of fully integrated population-based end of life care.

**Planning policy for the future.** We urge the Government to include such investment in the frontline health and care workforce as a key part of the NHS 10 year-plan.

This is an exciting opportunity to mobilise, upskill and support the three million-strong workforce would reap benefits at multiple levels.





# 4. Change is within our reach

## The best of care for the rest of care

These benefits are attainable. It is possible to ensure that more are supported to live and die well. There are already examples of innovation and transferable good practice across the health and social care system (some here from different Coalition members or in the Appendix). With investment in, and a higher priority for, enabling generalist skills in caring for older people approaching the end of life, the potential impact is huge.

Where frontline staff across varied settings have received further training in end of life care to strengthen their generalist skills, this has enabled key tangible improvements in proactive, personalised care, enabling more to live and die where they choose and reducing over-hospitalisation. The collaborative working between generalists such as GPs, care homes and specialists also improves, with more appropriate and speedier referrals.

Generalist palliative and end of life care skills can be taught and implemented by frontline teams in all settings, as part of practical measured improvements, leading to increased proactive care through earlier identification, advance care planning and care coordination.



The Gold Standards Framework (GSF) provides Quality Improvement training and accreditation across all sectors.<sup>20</sup> For over 25 years, GSF has trained and accredited thousands of generalist frontline teams in health and social care.<sup>21</sup>

### Generalist EOLC skills in GSF training

- Proactive care - early identification
- Personalised care - assessing needs - offered advance care planning discussions
- Place of care/death planning coordinated care - more dying in place of choice
- Preventing over-hospitalisation, reducing admissions, stays and deaths in hospital
- Providing top quality care experienced by patients, families and staff

The GSF Accreditation Awards are endorsed and co-badged by the Coalition of Frontline Care members in their respective areas. These exemplar GSF-accredited teams show what is possible to achieve, inspiring others with transferable solutions.<sup>22</sup> Tailored GSF training and accreditation includes both health and social care teams, with some teams 6th time re-accredited after 20 years. It can therefore become part of the 'common vocabulary' of a population-based approach to end-of-life care<sup>23</sup> within the new integrated care systems, complementing other providers' training efforts.

Overall Impact - examples from GSF Accredited teams across health and care settings					
GSF Accredited teams or GSF pilot areas	1.Proactive: Patient early identification rates	2.Person-centred: ACP discussions offered	2.Place: Dying in preferred place of care	4.Preventing: over hospitalisation	5.Provision of quality care: Experience of care and carers support
GP Practices	58% of those that died were identified on register	62% offered ACPs	Over 55% dying where chose	43% died in hospital	Improved experience of care
Hospitals	44% Identified	68% Offered ACPs	More dying where they choose	Fewer people dying in hospital	Improved support for family and carers
Care Homes	About 95% residents identified early	80% - 89% residents had ACPs	85% - 87% residents died in the care home	14%- 13% residents that died in hospital	100% offered bereavement support
Domiciliary care	Improved identification	Increase in offering ACP	56% died in preferred place	28% died in hospital	86% offered bereavement support
GSF Cross Boundary Care Metrics (Notts ICB)	47% Identified	Increase in offering of ACP 47%	53%-79% died in place of choice	Halving hospital admissions, reducing ED attendance	Positive feedback from relatives /carers

## Best practice exemplars from Coalition Members

Here are a few exemplars from the frontline suggested by coalition members, showing excellence in care for people nearing the end of life in different settings, and the real difference this can make. They include some less well recognised but vitally important areas of community hospitals, retirement communities, and, domiciliary care, as well as underpinning areas of primary care, care homes and hospitals. These frontrunning transferable solutions point to what is possible to achieve if all frontline teams were well trained and supported.

They demonstrate that top quality care is possible, giving proactive, personalised and coordinated care, moving from reactive to proactive care, reducing hospitalisation and enabling more to live and die well in the community or at home if they wish. This also impacts the culture of care described here and the workforce satisfaction of teams at the bedside.

Coalition members support and co-badge GSF Accreditation in their own sectors, but also support all providers to strive to improve the quality of care provided for all. For more details of coalition members and impact details from GSF accredited teams see [Appendix](#).

### Grosvenor House Care Home – NCF example

*"Identifying patients as a GSF patient, helps because a lot of these patients are either struggling already and just having that open conversation alone is reassuring them"*

### Primary Care Dorset GP Practice – GSF example

*"Since completing GSF we have more than halved the number of days identified patients spend in hospital"*

### Cape Hill Sandwell – GSF Primary Care example

*"We have noticed a significant decrease in the number of crises and hospital admissions. GSF has shown this busy inner city practice... can improve care for this vulnerable patient group"*

### Retirement Village – ARCO [Extra Care ECCT](#)

*"GSF trained Staff feel supported and the care we deliver is to a gold standard, with better teamwork and collaboration with GPs"*

### Bluebird North Gloucestershire Domiciliary Care – GSF Domiciliary care example

*"Staff are confident to listen to people and have conversations that are meaningful and impactful to a person at the end of their life"*

### Cornwall Community Hospital – Community Hospital Association (CHA)

*"GSF accredited ward provides a 'cuddle bed' to support a married couple to be together as one partner was dying"*

### Dudley Coronary Care Unit – GSF Acute Hospital example

*"The GSF training means we have better conversation with our patients about end of life and palliative care. This helps us manage expectations and most importantly helps patients and families have great end of life care"*

### Queens Hospital Romford – GSF training and accreditation of many wards

*"When we get it right our gold patients really do get the care they deserve Identifying patients as a GSF patient, helps because a lot of these patients are either struggling already and just having that open conversation alone is reassuring them"*

### ICS Mid Notts BPB – GSF example

*"Getting the GSF culture embedded within all frontline services can't be emphasised enough"*

Using GSF in different settings, the impact has been impressive – more people identified on register, more advance care plans recorded, more dying where they choose (almost 80%), reduced ED attendance and hospital admissions (almost halved).

### Digital – Airedale Goldline – GSF Digital example

Goldline 24/7 helpline for GSF Gold patients. Following GSF training in three settings across Airedale, Goldline was developed for GSF identified or 'gold' patients, a 24/7 hour telephone helpline with experienced clinical advice, support and guidance enabling greater help for families and enabling more to die at home. See [Goldline: 10 years on](#).



# 5. What next? Our Calls to Action and Conclusions

There are many pockets of excellence across health and social care generalist frontline teams that prove that top quality care is possible, being proactive to anticipate needs, personalised to focus on peoples' preferences, supporting families, reducing hospitalisation and enabling more to live and die well.

Now is the time for a significant roll-out of best practice across the country for a national transformational change intervention to ensure 'the best of care for the rest of care.'

**Calls to Action.** We, as the Coalition of Frontline Care for People Nearing the End of Life are calling for a three-level cumulated approach to improve end of life care: at **national** policy and reform level, ICB system level and workforce service levels.

## 1. 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.

- 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 shifts to community and prevention of hospitalisation.
- 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.
- Prioritise the enhanced development of the social care workforce as part of the planning for the National Care System.

## 2. 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.

- Accelerate real integration of health and social care in the support received by people nearing the end of life.
- 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.
- Integrating digital tools enabling effective integrated joined-up care coordination, collaboration and communication.

## 3. The Frontline Workforce

To shift policy as part of the NHS 10-year plan, with development of the social care workforce, the National Care System and focussed CQC regulation on care providers and ICBs.

- **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, 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.
- **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.
- **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.
- **Digital/Technological/AI.** Digital enablers eg for identification, communication and problem-solving.

# Conclusions

## Who we are. The Coalition of Frontline Care

The Coalition of Frontline Care represents the majority of the frontline generalist workforce in health and social care (over three million) providing most of the hands-on care for most people nearing the end of life in our country.

## What we are seeking?

We seek Government investment for training and support for the frontline workforce to enable more to receive better end of life care. To be effective, changes should be in three levels – national policy reforms, ICB system level and workforce level.

## Why we are asking this?

Investment in training and support for the frontline workforce, who give most hands-on care, would make the biggest difference in improving end of life care for more people. With the ageing population, and more living and dying with age-related conditions, there is urgent need for better end of life care now and in future.

## What difference would this make?

Multiple benefits include humanitarian, economic, workforce and policy areas are described, specifically helping the NHS meet its aims of improving community care, preventing over-use of hospitals, enabling the workforce, integrating health and social care and providing better care for more people.

**We urge the Government to make a radical change in the care for older people nearing the end of life, by investing in training and support for the frontline health and care workforce, plus changes in whole-system health and care.**

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## Authors

Lead author: Professor Keri Thomas (GSF).  
Sally Greenbrook, Sarah Mistry (BGS), Liz Jones (NCF),  
Daisey Cooney (HCA).

Contributions from: Kirsty Protherough, (CHA), Sarina Kiayani, Michael Voges (ARCO), Professor Martin Green, Ioan Bishop, Cai Parry (CE), Julie Armstrong Wilson (GSF) Lucy Pain, Jonathan Ellis and the GSF team.