Palliative and End of Life Care Commission – Call for Evidence

1. **In what capacity are you providing evidence?**

Third Sector Organisation

2. **Name of organisation/institute**

British Geriatrics Society (BGS)

3. **What is your special interest in Palliative and End of Life Care?**

The BGS is the membership organisation for all UK healthcare professionals engaged in the treatment and care of older people. Since 1947 our members have been at the forefront of transforming the quality of care available to older people. Our vision is for a society where all older people receive high-quality patient-centred care when and where they need it. We currently have over 5,300 multidisciplinary members including geriatricians, nurses, GPs, allied health professionals and pharmacists working in acute, primary and community care settings.

BGS members are specialists in caring for older people at various stages of older age and with complex health conditions common in later life, such as frailty, dementia, and multimorbidity. Therefore, they have extensive skills, capabilities and experience in caring for people nearing the end of their natural life. The BGS has more than fifteen Special Interest Groups (SIGs) concentrated on different aspects of geriatric medicine and older people's care. This submission has been drafted with expertise from our End of Life Care SIG.

4. **Describe what is working well in the provision of Palliative and End of Life Care**

Specialist and generalist palliative and end of life care in the UK is under-resourced, meaning many people do not receive the care they need at the end of life. Despite this, there are areas of good practice across the UK and national investment is needed to ensure that everyone receives the care that they need at the end of life.

The majority (65%) of deaths are in those over the age of 75 who die at the end of their natural lifespan.[i] [ii] [iii] Those who die in older age often have multiple long term conditions, including frailty, often resulting in complex non-linear dying trajectories. Healthcare professionals specialising in older people's healthcare, such as geriatricians, have expert understanding of these conditions and are able to identify when someone is in the last months of their life. Therefore, BGS members recommend that good palliative and end of life care for older people should stem from what is working well in geriatric medicine; based on the principles of living and dying well with frailty. Comprehensive Geriatric Assessment (CGA) is a multidisciplinary holistic assessment that considers the health and well-being of the whole individual, leading to the development of a plan to address issues of concern to the older person. Through assessment, healthcare professionals can identify when a person may be reaching the end of their life, and interventions can be put in place to support a good death, including advance care planning. CGA facilitates person-centred care focussed on meticulous assessment of problems, open communication with patients, families, and other stakeholders, setting realistic goals and expectations, discussions of the benefit versus burden of active treatment, anticipating and planning for the future, and attention to social, emotional, psychological, and spiritual aspects of care. For those nearing the end of life, CGA, alongside holistic care and honest conversations about treatment options, enables people to prepare for death and be supported to spend their remaining time as they would wish. Holistic assessments, such as CGA, should be offered to all older people reaching the end of life to ensure end of life care needs are met.

It is vital that older people living with multimorbidity and advanced frailty have access to urgent rapid response services and palliative and end of life care 24 hours a day. These services need to be integrated to ensure any acute decline is fully assessed, enabling a person centred treatment plan to be initiated. This plan should balance the goals of prolonging life and treating symptoms in order to relieve unnecessary suffering and admission to hospital, enabling more people to live and die at home or in their care home. Without these services, many have no choice but to present at A&E, which can be a distressing experience. In areas where rapid response services are working well, better end of life care is facilitated.

There are many examples of 24/7 support telephone lines which provide palliative care support for patients, relatives, friends, and healthcare professionals. For example, Arthur Rank Hospice Charity in Cambridgeshire run a Palliative Care Hub which is a free phone service available through dialling 111, for 24 hours, seven days a week. The phone line connects to a Clinical Nurse Specialist, who is able to provide advice and support, including the ability to despatch nurses to see patients, avoiding ED admissions. A 24/7 national helpline that connects patients to local services will help alleviate inequality in service provision, and ensure patients receive the support they need in a timely manner. This will also reduce delays in access to urgent primary care and social care, alongside reducing unnecessary hospital admissions.

People are enabled to have a good death in areas where GP practices know their client group; there are well-resourced community services, such as district nurses and palliative care; seamless team working happens across services; and good support processes are in place for the person dying and their family.

Currently, around 20% of deaths of those over the age of 65 take place in a care home.[iv] The number of deaths occurring in care homes is set to double over the next 25 years, and care homes are set to become the most common place of death.[v] This is due to an increase in people dying in their normal place of care, and an expected increase in the number of older people being cared for in care homes, especially as dementia rates are increasing. Therefore, investment is needed to ensure that care home staff are well-equipped to provide excellent healthcare including palliative and end of life care and to avoid unnecessary hospital admissions. There are many examples of care homes providing good end of life care to older people reaching the end of their life, such as Nightingale House, in Clapham, London. The BGS recommends that care homes with excellent end of life care facilities should become the hospices of the future, enabling residents to die in a setting attuned to their care needs and wishes of how they would like to die.

Hospices provide a gold standard level of palliative and end of life care, but there are not enough of them to support everyone at the end of life. This is especially the case for older people with multiple conditions and frailty, who are less likely to be admitted to a hospice compared to those with single terminal conditions. As a result, only a small minority of older people (5%) die in a hospice.[iv] Some hospices have outreach programmes that bring the benefits of their approach to people living with frailty. For example, Hospice UK have a programme called Extending Frailty Care, aimed at supporting 11 hospices support high quality care for older people living with frailty.

5. What steps need to be taken to ensure better service funding and commissioning?

A strategic shift is needed in the commissioning and funding of palliative and end of life care (PEoLC) to focus on the needs of an ageing population. This needs to shift away from predominantly focusing on specialist palliative care to focusing on how palliative and end of life care can be improved across the whole health and social care system. This is important because there will never be enough palliative care specialists to care for the large number of people dying each year. Research by Marie Curie suggests that only 35% of ICBs report that they significantly or fully understand PEoLC population health needs.[vi] It is vital that this is addressed to ensure that the PEoLC needs of the majority are prioritised in commissioning and funding.

There are approximately 670,000 deaths every year in the UK,[vii] of whom around 65% are people aged over 75.[viii] [ix] [x] The majority of those who die each year have multiple long-term conditions and/or frailty, rather than a single condition such as cancer or motor neurone disease. Over 60% of people over the age of 85 have more than one long-term condition[xi] which is associated with a higher risk of hospital admission and death.[xii] Up to half of people over the age of 85 years live with frailty[xiii] and people with severe frailty are five times more likely to die within a year than older people without frailty.[xiv] Those with frailty and multimorbidity have an uncertain non-linear dying trajectory, making it hard to predict when someone will die, but expert understanding of these conditions can help to identify people who may be in the last year of their lives. This group of people are likely to require significant health and social support over a considerably longer period than those dying of a single condition. Their care is mainly provided by the three million generalist health and social care workforce, rather than the 20,000 specialist workforce.[xv] In fact, half of all people who die, largely older adults, have no contact with specialist palliative care.[xvi] Investment is needed to support this workforce to provide palliative and end of life care to the majority of those dying each year.

Research suggests that only one in four ICBs have incorporated PEoLC in their Integrated Care Strategy.[i] Recently, NHS England have provided grants to hospices, but this is the setting for just 5% of deaths in those over the age of 65, with hospitals (40%) being the most common place of death followed by the person's home (30%) and care homes (20%).[xvii] Investment is needed on a national level focusing on a whole system approach, addressing the needs of the majority, those dying in older age. ICBs should be required to put together a strategic plan illustrating how they will meet the PEoLC needs of their local population. National funding should be made available to ICBs who can illustrate they will invest in a whole system approach to PEoLC, recognising the importance of the generalist workforce. This should be complemented by a national information campaign, aimed at the general public, highlighting key facts and statistics about who is dying.

The whole health and care system is under resourced, creating a huge amount of pressure on healthcare professionals across services. As a result, services are under-staffed, fragmented, and not joined up. This includes palliative and end of life care services, resulting in many not receiving the care they need. Social care, which is vital in allowing many at the end of life to remain at home, is also underfunded. This results in delayed discharges from hospital, meaning many older people die in hospital waiting for social care support packages to be put in place.

6. How would you want to address the inequitable access to Palliative and End of Life Care?

The current palliative and end of life care model in the UK does not serve an ageing population, particularly older people with dementia, multimorbidity and frailty. Older people face a great degree of diagnostic and prognostic uncertainty, unpredictability and escalating care needs which do not fit into traditional models of palliative care. Individuals with frailty may therefore not be recorded on end of life care registers, and are therefore less likely to receive the care they need. Considering that the majority of deaths each year occur in older age, this inequity needs to be urgently addressed. A new model of palliative care is needed, incorporating the principles of geriatric medicine. This should focus on a whole system and life course approach to palliative and end of life care, incorporating services across the health and social care system, and focussed on person-centred care. This will require the upskilling of the generalist workforce and other specialties, such as geriatricians, GPs, and nurses and AHPs, on palliative and end of life care issues. As outlined in the Chief Medical Officer's annual report 2023, generalist skills are essential in caring for an ageing population with increasing multimorbidity.[xviii]

A life course approach to ageing well will facilitate better provision of palliative and end of life care in older age. The Ageing Well programme, as set out in the NHS Long Term Plan, had the potential to be transformative for older people's healthcare but has faced significant budget cuts. An important strand in this work is proactive care, now largely unfunded, which is an approach that proactively identifies older individuals living in the community who may have frailty and are therefore vulnerable to a decline in health. Through identification of such people at risk, end of life care preparation, such as advance care plans, and care support can start at an earlier stage before someone reaches a crisis point and presents at hospital. End of life care should be driven by what matters to the older person receiving the care and identifying needs as early as possible. BGS members tell us that it is often the individuals with the strong support networks, such as families that can advocate for the person, who are able to secure good care. Proactive identification of individuals needing end of life care would help to address this inequity.

What matters to people at the end of their lives should drive planning of end of life are services and support. Awareness that the end of life may be close should inform all clinical care for people with multiple long-term conditions and frailty. This enables proactive and compassionate communication with people and their families about how to spend their remaining time and where they wish to die. This can be documented and respected through Advance Care Planning. Most (78%)[xix] of the public are unaware of the term 'advance care planning' and one study revealed that less than a third of respondents discussed end of life wishes in the last year of their life or formally documented their wishes.[xx] Uptake is particularly low among older people living with frailty, as well as ethnic minority groups, with cultural differences and language barriers often cited as a barrier to engagement with advance care planning services and resulting in inequitable access to quality end of life care. Honest conversations about the approaching end of life can facilitate consideration of realistic treatment options and shared decision-making to avoid over-medicalisation. Instead, people can be supported to live their remaining days in the right place for them with appropriate health and social care support focussed on their individual needs. A public information campaign is needed focused on the importance of advance care planning, and targeted at groups where uptake is low, such as older people with frailty and ethnic minority groups.

7. What are the top three barriers to delivering optimal Palliative and End of Life Care?

1. There is an outdated model of palliative and end of life care in the UK which does not serve an ageing population. Traditional models of palliative and end of life care focus on decline due to one condition, such as cancer or motor neurone disease. Therefore, older people with multiple conditions, who are the majority of those dying each year, often do not receive the care they need. The current model is not adequate to support a future of increasing deaths due to multimorbidity.

2. There is a lack of service alignment and communication across the health and social care system which hinders seamless end of life care. For example, BGS members tell us the lack of communication between social care professionals and ambulance services regarding information noted in RESPECT forms often results in advance care plans not being adhered to.

3. There is a lack of support and training for the frontline generalist health and social care workforce supporting end of life care, particularly in managing uncertainty and parallel planning. These skills are vital in supporting the increasing number of deaths due to frailty and multimorbidity. Social care providers may not be confident managing uncertainty and risk around end of life care, which may lead to unnecessary conveyance to hospital.

8. What are the top three things you would change to improve the service?

1. The model of palliative and end of life care in the UK needs to shift towards supporting an ageing population, where most people die with multiple conditions and/or frailty rather than single conditions. This needs to recognise the importance of skills to improve timely recognition of terminal decline due to underlying disease processes including multimorbidity, advanced dementia and severe frailty; and use tools and data to determine who may have needs associated with being in the last phase of life.

2. Education and training on end of life care should be available for all generalist health and social care professionals supporting people at the end of life, including training on managing uncertainty and parallel planning for different scenarios. The BGS supports training provided by the Gold Standards Framework. Additionally, the whole healthcare workforce needs to have an understanding of frailty and end of life care. National Clinical Directors should be held accountable for how their services identify and address end of life care needs. Guidelines need to be put into the context of the individual and all branches of healthcare should be able to ask patients “what matters to you” and deliver end of life care based on what is important to the individual and their loved ones.

3. End of life care services should be driven by what matters to people at the end of their lives. Advance care planning should inform all clinical care for people with multiple health conditions and facilitate honest conversations about the approaching end of life. This should involve discussion about realistic treatment options and shared decision making to avoid over-medicalisation. More people should be able to die in their preferred place of death. Currently, 75% do not die in the place of their choosing and the

workforce is needed across care settings in order for this to change. There is evidence that older people prefer local services and value continuity of care, and therefore, primary care needs to be strengthened to support the end of life care needs of this patient group. Primary care is often cheaper, cost effective, and results in less emergency admissions.

9. **What steps do you believe need to be taken to improve public literacy concerning Palliative and End of Life Care options?**

Coverage of the Assisted Dying Bill has skewed the debate, leaving people with a distorted understanding of when and how most people die. Death is a natural process at the end of life and the large majority of people die in older age at the end their natural lifespan. Better provision of end of life care could enable more people to die well with supportive care in a place of their choosing. The BGS advocates for a public information campaign about death and dying, building on Dying Matters week, which de-medicalises death and encourages people to discuss mortality, better understand 'ordinary dying' at the end of life, plan ahead and express personal wishes.

10. **How do you believe that Palliative and End of Life Care provision could be better co-ordinated?**

End of life for older people rarely takes a pathway approach requiring care and support from just one service. Depending on needs and services available in different areas, older people will receive care and support from a range of services. This will include primary, community, and acute healthcare; social care; care homes; voluntary organisations; and hospices. Services need to be aligned to optimise seamless transfers of care, share information across services, minimise avoidable delays and deliver appropriate, timely palliative and end of life care 24/7. To achieve this, effective health communication systems are needed to share information, including advance care plans incorporating advance decisions to refuse treatment and preferred place of death, between specialists, generalists and informal carers who are involved at the end of life. There is technological fragmentation within the NHS, with different parts of the system using different software and hardware to capture information about patients. Therefore, there are limitations in the ability for staff across services to work together and share care records, including advance care plans. One solution would be the introduction of a national standardised approach to data and information-sharing across services supporting palliative and end of life care.

11. **If there is research that you would want to draw to the attention of the Commission, which would help to improve Palliative and End of Life Care, please provide or note this here**

- BGS End of Life Care Key Messages: https://www.bgs.org.uk/sites/default/files/content/attachment/2025-02-19/BGS%20EOLC%20Key%20Messages.pdf
- BGS ten recommendations for improving end of life care: https://www.bgs.org.uk/sites/default/files/content/attachment/2025-03-21/EOLC%20Commission%20asks_1.pdf
- BGS End of Life Care portal: https://www.bgs.org.uk/end-of-life-care-portal

- Chief Medical Officer's annual report 2023: health in an ageing society (page 200-201): https://www.gov.uk/government/publications/chief-medical-officers-annual-report-2023-health-in-an-ageing-society
- The PALLUP Study: Improving home-based palliative care for older people: https://www.surrey.ac.uk/research-projects/pallup-study-improving-home-based-palliative-care-older-people
- Gold Standards Framework: https://www.goldstandardsframework.org.uk/
- End of life care is everyone's business: Coalition of Frontline Care Report: https://www.goldstandardsframework.org.uk/coalition-of-frontline-care

12. Any other information you would wish to share with the Commission

The BGS urges the commission to consider the needs of the ageing population, focusing on improving end of life care for everyone. This requires the recognition of the importance of the generalist workforce in providing end of life care for older people, and the skills needed to identify when someone with multiple conditions and frailty may be reaching the end of life. The palliative care specialist workforce will never be large enough to cope with the end of life care needs of the whole population.

The BGS is happy to assist further with contributing towards the commission's recommendations.

We have provided the commission with ten recommendations, which we hope will be considered when drafting the final report. We have published these recommendations on our website: https://www.bgs.org.uk/sites/default/files/content/attachment/2025-03-21/EOLC%20Commission%20asks_1.pdf

The BGS has also developed some End of Life Care Key Messages, outlining evidence and statistics, which we urge the commission to consider: https://www.bgs.org.uk/sites/default/files/content/attachment/2025-02-19/BGS%20EOLC%20Key%20Messages.pdf

13. Please provide your name and email if you would be prepared to give oral evidence or attend one of the Commission's round tables:

- Name: British Geriatrics Society
- Email: l.aldridge@bgs.org.uk

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[i] Office for National Statistics, 2024. Deaths registered in England and Wales: 2023. Available at: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistr ationsummarytables/2023 (accessed 22 January 2025).

[ii] National Records of Scotland. Birth, deaths, marriages and life expectancy. Available at: https://www.nrscotland.gov.uk/statistics-and-data/births-deaths-marriages-and-life-expectancy/ (accessed 22 January 2025)

[iii] Northern Ireland Statistics and Research Agency, 2024. Registrar General Annual Report 2023 Cause of Death. Available at: https://www.nisra.gov.uk/publications/registrar-general-annual-report-2023-cause-death (accessed 22 January 2025).

[iv] Office for Health Improvement & Disparities, 2025. Palliative and end of life care profiles January 2025 update: statistical commentary. Available: https://www.gov.uk/government/statistics/palliative-and-end-of-life-careprofiles-january-2025-update/palliative-and-end-of-life-care-profiles-january-2025-update-statistical-commentary (accessed 24 January 2025).

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[v] Bone A, Gomes B, Etkind S N, Verne J, Murtagh F E, Evans C J, and Higginson, I J, 2017. What is the impact of population ageing on the future provision of end-of-life care? Population-based projections of place of death. Palliative Medicine. 32(2):329-336. doi:10.1177/0269216317734435

[vi] Marie Curie, 2023. Palliative and end of life care in Integrated Care Systems. Available: https://www.mariecurie.org.uk/document/palliative-end-of-life-care-integrated-care-systems-survey-report-2023 (accessed 19 March 2025).

[vii] Office for National Statistics, 2023. Vital statistics in the UK: births, deaths and marriages. Available: https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/vitalstatisticspopulationandhealthreferencetables. (Accessed 22 January 2025).

[viii] Office for National Statistics, 2024. Deaths registered in England and Wales: 2023. Available at: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2023 (accessed 22 January 2025).

[ix] National Records of Scotland. Birth, deaths, marriages and life expectancy. Available at: https://www.nrscotland.gov.uk/statistics-and-data/births-deaths-marriages-and-life-expectancy/ (accessed 22 January 2025).

[x] Northern Ireland Statistics and Research Agency, 2024. Registrar General Annual Report 2023 Cause of Death. Available at: https://www.nisra.gov.uk/publications/registrar-general-annual-report-2023-cause-death (accessed 22 January 2025).

[xi] Age UK, 2023. The State of Health and Care of Older People, 2023. Available: https://www.ageuk.org.uk/siteassets/documents/reports-and-publications/reports-and-briefings/health-- wellbeing/age-uk-briefing-state-of-health-and-care-july-2023-abridged-version.pdf (accessed 29 January 2025).

[xii] Coalition of Frontline Care, 2024. End of life care is everyone's business. Available: https://www.goldstandardsframework.org.uk/cdcontent/uploads/files/Coalition%20of%20Frontline%20Care%20Report%20November%202024%20- %20compressed%20-%2026.11.24%20edits.pdf (accessed 29 January 2025).

[xiii] Clegg A, Young J, Iliffe S, Rikkert M O, and Rockwood, K, 2013. Frailty in elderly people. Lancet. Mar 2;381(9868):752-62. doi: https://doi.org/10.1016/s0140-6736(12)62167-9

[xiv] Clegg A, Bates C, Young J, Ryan R, Nichols L, Ann Teale E, Mohanned M A, Parry J and Marshall T, 2016. Development and validation of an electronic frailty index using routine primary care electronic health record data. Age and Ageing. 2016;45(3):353-60.

[xv] Coalition of Frontline Care, 2024. End of life care is everyone's business. Available: https://www.goldstandardsframework.org.uk/cdcontent/uploads/files/Coalition%20of%20Frontline%20Care%20Report%20November%202024%20- %20compressed%20-%2026.11.24%20edits.pdf (accessed 29 January 2025).

[xvi] Marie Curie, 2024. Time to care: Finding from a nationally representative survey. Available: https://www.mariecurie.org.uk/globalassets/media/documents/policy/beol-reports-2024/beol-2024-time-to-carereport.pdf (accessed 24 January 2025).

[xvii] Office for Health Improvement & Disparities, 2025. Palliative and end of life care profiles January 2025 update: statistical commentary. Available: https://www.gov.uk/government/statistics/palliative-and-end-of-life-careprofiles-january-2025-update/palliative-and-end-of-life-care-profiles-january-2025-update-statistical-commentary (accessed 24 January 2025).

[xviii] Department of Health and Social Care, 2023. *Chief Medical Officer's annual report 2023: health in an ageing society.* Available: https://www.gov.uk/government/publications/chief-medical-officers-annual-report-2023-health-in-an-ageing-society (accessed 21 March 2025).

[xix] Marie Curie, 2021. Public Attitudes to death, dying and bereavement in the UK. Available: https://www.mariecurie.org.uk/globalassets/media/documents/policy/public-attitudes-to-death-and-dying-reportfinal.pdf (accessed 29 January 2025).

[xx] Marie Curie, 2024. Available: https://www.mariecurie.org.uk/globalassets/media/documents/policy/policypublications/2024/n401b_padd_briefing_final.pdf (accessed 24 January 2025).