

LIVING AND DYING WELL: REIMAGINING PALLIATIVE CARE FOR OLDER PEOPLE

BRIEFING FOR POLICYMAKERS

POLICY CONTEXT

By 2036, 2.6 million people in the UK (3.5% of the total population) are projected to be over 85 years old, an upward trend that will continue. This age group will account for over 50% of all deaths. Older people living with frailty and Multiple Long-Term Conditions (MLTC) will become the main recipients of palliative care, yet there is limited evidence about their specific needs.

There is inequity in access to palliative care in older age. Those without families are particularly vulnerable.

There is a legal, moral and clinical imperative for palliative care services to contribute to the support that people with Frailty and MLTC need as they near the end of their lives. Rethinking community care must include reversioning palliative care to support those living longer with progressive conditions. Integrated Care Boards will be failing in their duty unless they listen to and understand the complex care needs of older people with progressive MLTC.

Reconnecting Living and Dying requires, over time, upstreaming and aligning palliative care provision to local communities.⁵

KEY RESEARCH FINDINGS

Palliative care is often seen as focusing on the final stages of a terminal disease, determined by time until death. Older people, living and dying over time, face a double bind in accessing palliative care. Neither they, nor welfare services, view older people as appropriate for referral, and opportunities are missed to support quality of life in their final years. Tailored palliative and end of life care is lacking, with multiple care professionals delivering poorly coordinated services leading to mistakes and confusion, with poor outcomes.

Whilst older people may live with vulnerabilities, they are also resilient and capable, and this must be taken into consideration. Identifying the palliative care needs that matter most to older people with frailty/MLTC requires the recognition of their strengths and concerns, as well as their physical needs, across a continuum of living and dying.

These include:

- Trust in care providers – trust is eroded by high staff turnover
- Not to feel lonely, alienated and invisible
- Opportunities to discuss current and future care needs.
- Support with administration and optimisation of medicines.
- Services and interventions to support mobility.

Supporting end of life provision for this growing and underserved population necessitates a shift to tailored multidimensional tools and community focused integrated care services.

In other words: a person-centred approach.

Palliative Care for Frailty: Resources

The University of Surrey has worked with practitioners, older people and carers to develop a film, resources and toolkit to support the development of an integrated person-centred end of life workforce. Scan the QR code to access.



Understanding Frailty and Multiple Long-Term Conditions (MLTC)

Frailty is age related and describes the gradual loss of inbuilt physiological reserves that leads to sudden, potentially fatal health deteriorations following seemingly small events, such as a minor infection. It is a long-term condition and closely linked with multimorbidity also known as Multiple Long-Term Conditions (MLTC). MLTC refers to the presence of two or more long-term health conditions and is associated with increased mortality, lower quality of life, and greater use of healthcare services, including unplanned hospital admissions.

Older people living with frailty and/or MLTC who are in their last phase of life, may have many weeks, months or even years to live.

There is a requirement for easy and consistent access to a variety of non-specialist personalised palliative care delivered by primary, community, acute and urgent care and crucially social services, as well as palliative care specialists.

A targeted response to care concerns is required based on quality rather than quantity of life - *biological* rather than *chronological* and *stereotypical* responses, and should be based on what matters most to the person.

Whilst the NHS has set [Ambitions for Palliative and End of Life Care, 2021-2026](#) which includes a framework of local best practice developed by the National Palliative and End of Life Care Partnership, however systemic inequitable access to palliative care services means they are currently not resourced to deliver it. There is an urgent need to realign commissioning and service delivery and the health and social care workforce to meet the needs of the majority of those at the end of life- older people.

There needs to be more alignment between policy and vision so that funding, regulation, workforce and performance policies match the intention of changing the focus of the health and care system towards primary and community health and care services."

- The Kings Fund

"My whole mind is set on getting decent carers, get that out of the way and I don't think I'd have a worry in the world"

- Dave, PALLUP study participant.

Listening to Older People: What matters to them?

The University of Surrey's [PALLUP study](#) has been listening to the voices of older people with frailty/ MLTC living in the community, their families, and carers, to understand needs in the last phase of life, and how services and systems can change to meet them. By listening to the clients' needs policy makers will be better placed to develop more effective services to support people with frailty/ MLTC to live the fullest lives possible in their final years.

Joining up services is essential, involving the 'right' people, which often includes family, who in turn may require support. Building a triangle of care for the older person enables them to express their individual choices, incorporate the views of the people important to them, and service providers.



visual minute by www.newpossibilities.co.uk @AnnaGeyer_NP

Rethinking palliative care services

The experiences of older people with frailty/MLTC nearing the end of their lives are often poor, characterised by overtreatment in an attempt to prolong life, alongside too little palliative care. There is a fear that moving to palliative care means nothing will happen, yet the transition should be the antithesis of this.

People often fall between services focused on living independently or dying imminently and end up feeling 'done to' rather than 'cared about', with little consideration given to their desires, capabilities, and strengths.

Palliative care should support people to be as comfortable as possible while maximising the quality of their remaining life when illness is incurable. If we use expected time to death as the sole basis for identifying need and support at the end of life, many older people are excluded. Indeed, the idea of time-based approaches – referring older people to palliative care when time to death is recognised – is problematic. Instead, the focus should be on a holistic assessment of needs over time when someone has been identified as having complex care needs.

“Patients’ preferences are ultimately the key to improving overall outcomes and quality of life.”

- Chief Medical Officer's [Annual Report 2023](#)

Relationships and connectivity sit at the heart of this person-centred approach to care: recognising and understanding each person's physical, psychological, social, spiritual, and practical needs and concerns, encompassing both living and dying. Sadly, the voices of older people are often overlooked, such as in consenting to a particular service or treatment.

Older people must be seen as part of the solution, not the problem. Having choices and independence is important, and the progressive loss of independence causes frustration and fear.

RELATIONSHIPS & CONNECTIVITY



VISUAL DEVELOPED
BY NEW POSSIBILITIES
ANNA OYER

POLICY RECOMMENDATIONS

❑ **Integrated Care Boards need to integrate palliative care earlier for older people with progressive frailty/MLTC to ensure higher quality of life.**

Research by Marie Curie suggests that only 35% of ICBs report that they significantly or fully understand PEOLC population health needs. It is vital that this is addressed to ensure that the PEOLC needs of the majority are prioritised in commissioning and funding.

❑ **Different ways of working, different partnerships across health and social care and a sharing of power** are required to enable a focus more on holistic assessment and delivery of care around of what matters most to the person rather than emphasis on clinical needs and prognosis. Our research shows that social and practical needs are often prioritised by older people. The recognition and inclusion of social and the unpaid care workforce is essential to personalised end of life care for older people. Moving palliative care upstream requires investment in upskilling the health care workforces including paid domiciliary and unpaid family carers.

❑ **The PALLUP Toolkit and video should be used in NHS trusts**, which includes training to:

- understand frailty and how to identify and assess needs.
- develop person-centred approaches to care.
- communicate effectively and compassionately.
- collaborate and integrate with other agencies and professionals.

The PALLUP video is already being used internationally by health and social care providers raising awareness and shaping professional practice to the complexities of supporting older adults with frailty, emphasising the importance of person-centred care, communication, and shared decision-making.

❑ **Healthy ageing must include healthy dying.**

Holistic Advance Care Planning conversations should be used to support proactive and compassionate communication with people and their families to ensure what matters most to them drives their EOLC. See our resources, created with older people, on [conversations on living and dying](#).

❑ **Caring for older people approaching the end of life is everybody's business.** There are approximately 670,000 deaths every year in the UK, of whom around 65% are people aged over 75. Older people are likely to require significant health and social support over a considerably longer period than those dying of a single condition. We need a public education programme which focuses on ageing well including completing life well, for example initiatives like the [Royal Surrey Frailty Academy](#), which helps raise awareness, individualises care and supports understanding the ageing journey, including palliative care. As a society we have a civil and moral responsibility to care for the older generation, but families and friends often feel ill-equipped to support.

❑ **Establish an independent Commissioner for Older People and Ageing** to ensure that policymaking across government considers the long-term needs of our ageing population and gives older people a real voice that reflects their views and experiences.

“Hospitals are the most costly way to manage health and yet they have become the first resort for many patients.

There are more imaginative solutions than simply building more ‘sickness factories.’”

- The Times Health Commission

ABOUT THE AUTHOR

Professor Caroline Nicholson is a Professor of Palliative Care and Ageing in the School of Health and Medical Sciences at the University of Surrey. Contact Professor Nicholson at c.nicholson@surrey.ac.uk if you would like to learn more about her research, invite her to speak at your event, or collaborate with the Living and Dying Well Team.

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