

STRENGTHENING PALLIATIVE AND END-OF-LIFE CARE IN CARE HOMES: AN ACTION PLAN TO MEET CURRENT AND FUTURE NEEDS

Policy recommendations from the
CovPall Care Homes study

'It was undignified.... It was dismal, it was really awful ... the fact that I couldn't care in the way I would like to care. You want to care with someone holding their hands, and sitting, and playing music and you know all of that. There were no frills.'

Manager, Residential Care Home, CovPall Care Home Participant

Authors: Professor Katherine Sleeman, Dr Andy Bradshaw, Dr Sophia Ostler, India Tunnard, Dr Anna Bone, Professor Claire Goodman, Dr Stephen Barclay, Professor Irene Higginson, Dr Clare Ellis-Smith, Professor Catherine Evans

OVERVIEW

Since the start of the Covid-19 pandemic, tens of thousands of people have died in care homes across the UK. Considerable media and policy attention has focused on excess mortality and infection control within care homes. However, little attention has been given to how the pandemic affected the provision of palliative and end-of-life care within care homes.

Palliative care is treatment, care and support for people with life-limiting illnesses, and their families, friends and carers. Palliative care aims to identify and relieve the symptoms and concerns that people living with life-limiting illnesses experience, whether physical symptoms such as breathlessness or pain, or emotional, social, or spiritual concerns.

The **CovPall Care Homes study** aimed to examine the response of care homes to meet the rapidly increasing need for palliative and end-of-life care for residents during the COVID-19 pandemic. The study comprised an initial online survey to 107 care home senior staff (April – September 2021), followed by 27 in-depth interviews (June – October 2021).

The findings were discussed in a series of conversations with stakeholders including care home staff, family carers, academics, and policy experts. From this we developed ten policy recommendations for palliative and end-of-life care in care homes, in five areas:

- 1. Valuing the role of care homes and care home staff**
- 2. Support for care home managers**
- 3. Workforce development, training, and support in delivering palliative and end-of-life care**
- 4. ‘Spirit of partnership’: Integration with primary and specialist palliative care**
- 5. Digital inclusivity**

Our recommendations inform, extend, and align with existing policies and initiatives. These include, but are not limited to, The NHS Long Term Plan (including the Framework for Enhanced Health in Care Homes), the Health and Social Care Integration White Paper, the NHS Digital Programme, the Ambitions for Palliative and End of Life Care Framework, and the Health and Care Bill.

Our recommendations inform policy implementation to equip all care homes with the resources and capacity needed to deliver high quality, personalised palliative and end-of-life care. This is especially important in light of the ageing population, inequitable access to end-of-life care services, and the projected increase in older people living and dying in care homes.

1. Valuing the role of care homes and care home staff

CHALLENGE: Care homes and their staff are able to deliver high-quality, personalised palliative and end-of-life care. Despite taking on more palliative and end-of-life care responsibilities during COVID-19, care home staff felt that their role in the wider health and social care system was often ignored and undervalued by the government, public, and media. This had tangible impacts including not being prioritised in the distribution of PPE and testing kits, staff feeling stressed, and low morale. This lack of recognition and resources directly affected how safe and confident staff felt in providing palliative and end-of-life care for older people, especially those with COVID-19.

'I don't think that the health authority phoned us once ... The health service was not supportive, and it was upsetting when we'd phone our regular suppliers for PPE or things like that and we're being told: 'Oh, it has to be directed to the NHS' like we were nothing. And you just felt that care homes were kind of left out in the cold.'

Manager, Nursing Home

POLICY RECOMMENDATIONS

1. Ensuring parity of esteem and equal partnership in decision making

Care homes have a vital role in providing palliative and end-of-life care in the UK. By 2040 care homes may be the most common place to die in England and Wales. However, policy and planning to drive investment in the sector have not kept pace with growing demand. Care homes must be positioned as equal and valued partners within the health and social care system. This is through better funding, staffing, and equal partnership in decision making for palliative and end-of-life care provision at local, regional, and national levels.

2. Boosting the National Profile

National recognition of care homes as specialist services that play an essential role as providers of high-quality personalised palliative and end-of-life care is needed. This can be achieved by local/national campaigns and community-based initiatives that highlight this essential role.

2. Support for care home managers

CHALLENGE: Care home managers are key in supporting their teams to deliver high-quality palliative and end-of-life care. Ensuring that care home managers themselves have adequate emotional and practical support is crucial. The CovPall Care Homes survey found high levels of staff stress (70%), staff shortages (45%), and that 27% of staff had suffered losses. Managers who felt adequately informed (i.e., had access to clear information, advice, guidance, and support) were able to support their team to provide palliative and end-of-life care. Yet, many care home managers felt overwhelmed and unsupported, particularly in the face of constantly changing information. Many care home managers also perceived a lack of autonomy in making decisions.

‘Staff value the support from their manager more than external sources of support... In my experience, the best form of support, or at least the form of support that is most valued by my staff team, is to make sure the care home managers are as trained as possible in how to cope with staff emotional problems and that the care home managers get the support that they need in order to do that.’
Manager, Residential Care Home

POLICY RECOMMENDATIONS

3. Creating networks for peer support

Initiatives that foster collaborations and connections between care home managers, alongside creating alliances with hospices, would strengthen palliative and end-of-life care by facilitating the sharing of practice, skills, knowledge, support, and advice.

4. Providing a single source of trusted information

Policy and guidance need to be created collaboratively with care homes and be provided by a single, trusted source. It should be written in clear and concise language, with clear instructions on changes required, how they should be implemented, and where staff can access supporting information.

5. Supporting decision making

Care home managers are trained professionals with expertise in palliative and end-of-life care. They should be empowered and enabled to make decisions that are tailored to their care home and residents’ needs.

3. Workforce development, training, and support in delivering palliative and end-of-life care

CHALLENGE: Our Care Home Expert panel told us that care home managers are often attracted to social care because they are passionate about providing palliative and end-of-life care. However, our study identified variation between residential and nursing homes in how confident staff felt in being able to deliver good palliative and end-of-life care. Residential care home staff felt less confident in independently reacting to and coping with common symptoms at the end of life compared to nursing homes. Many staff did not feel that training was adequate, tailored, or timely enough.

‘For the nurses in small care homes that perhaps don’t get access to training as much as nurses in larger care homes ... I think training days are really good, not just for the information that’s given, but for the opportunity to actually discuss issues, and actually hear from other people ... so that people are really kind of thinking all the time: ‘How can we do this?’ ‘How can we provide end of life care better, or keep to a very good standard, rather than it slipping.’

Registered Nurse, Nursing Home

POLICY RECOMMENDATIONS

6. Supporting workforce development in palliative and end-of-life care to address the social care workforce crisis

Career pathways and opportunities must be created that attract and retain staff into care home roles, including graduate nurses and healthcare assistants. Good support for palliative and end-of-life care in care homes to attract graduates could help address the social care workforce crisis. Enhancing knowledge and skills in palliative and end-of-life care through undergraduate and postgraduate opportunities is essential. Better conditions of work for all, including pay and Continuing Professional Development funding, is also essential.

4. **‘Spirit of partnership’: integration with primary and specialist palliative care**

CHALLENGE: Having access to support and specialist advice from external services was crucial in the delivery of palliative and end-of-life care. COVID-19 provided opportunities for care homes to create new, and strengthen already-existing, links across the health and social care sector. A sense of partnership, strong community ties, and positive relationships helped foster integrated working between care homes and primary and palliative care services. However, not all care homes were integrated in their local health and social care systems. Being unable to access timely specialist advice and support disrupted care homes’ ability to provide good palliative and end-of-life care, especially in the context of out-of-hours/crisis care.

‘Our major source of stress when dealing directly with deteriorating health and end-of-life care was caused by the interminable wait to be able to access NHS24 out of hours... Accessing out of hours help and support was outrageously difficult ... Why do care home managers not have access to the same "hotline" that pharmacists and others have - why must we be left at the mercy of 111 and pharmacists ... this stress could be removed along with the risk of a resident being needlessly in pain.’

Manager, Residential Home

POLICY RECOMMENDATIONS

7. Palliative care representation within multidisciplinary team meetings in care homes

Palliative care services should be considered an integral part of care home multidisciplinary team meetings. These should be used as opportunities to actively involve care home staff in decision-making and for timely access to specialist advice and support to guide the delivery of palliative and end-of-life care. Primary care teams should involve care home staff in discussions about residents on the register for palliative and end-of-life care where possible

8. Care home representation within integrated care systems

All care homes must be well integrated into the wider health and social care system to deliver high quality palliative and end-of-life care. Universal representation of care homes within integrated care systems is essential. Models of care that support this should be developed and monitored.

5. Digital inclusivity

CHALLENGE: During the pandemic, our survey showed that 90% of care homes increased their use of telehealth interventions to deliver palliative and end-of-life care. Remote/digital devices were used to communicate with healthcare professionals for patient care (88%), with families (78%), for remote monitoring and assessment (53%), and for staff education (56%). However, faulty/insufficient equipment and poor Wi-Fi in old buildings meant many care homes were not able to harness the power of digital ways of working to support palliative and end-of-life care.

“We then had to introduce video calls. Our I.T. wasn't great, so it was a challenge for us to do that... but we soon adapted... We had one lady who was end of life, before the pandemic, [her daughter] used to come in and read her a book... So she carried on doing that, but did it with the iPad next to her. And that was really something that was really comforting for her daughter because she still felt that bit of involvement although she physically couldn't be there”
Manager, Nursing Home

POLICY RECOMMENDATIONS

9. Include care homes in digital strategies

Care homes are an essential part of national digital healthcare strategies (e.g., NHS Digital Programme). For effective end-of-life care, there should be an agreed level of I.T. support and infrastructure for care homes. For integrated working between health and social care, interoperable systems should be at the heart of digital transformations, improving integrated working between health and social care. A vital component is ensuring access to shared patient records (e.g., Electronic Palliative Care Coordination Systems).

10. Equity-centred approach

An equity-centred approach to future digital changes and policy - in which care homes keep abreast with technological advancements - is crucial to ensure that care homes can harness the potential of digital working for delivery of high-quality palliative and end-of-life care. Ensuring staff are trained, resourced, and supported to use digital technology for end-of-life care, including symptom assessment, remote monitoring and access to training, is essential.

CovPall Care Homes

Study public involvement group reflections

'This report is really important and something I've been banging on about for 10 years. Something needs to change'

Janice Tausig, Public Involvement Member

We are a group of family members and friends of people resident in care homes. We have first-hand experience of palliative and end-of-life care and how it is delivered in care homes. As a group, we strongly believe that the work of care homes and their staff needs to be better valued by the government and public. This means placing the same level of value on social care staff as on health care staff. This disparity of recognition was exemplified during the COVID-19 pandemic.

'From visiting relatives and friends over the years, I was acutely aware that care home members of staff don't receive the esteem that is afforded to staff working in health care. I am pleased that this research addresses that'

Margaret Ogden, Public Involvement Member

We are delighted that this report brings attention to the large amount of high-quality palliative and end-of-life care that is delivered in care homes, something that is too often forgotten or misunderstood. Valuing care home staff means acknowledging them as leading providers of palliative and end-of-life care, supporting them to maintain their well-being, and providing them with appropriate training and support.

We feel that a key characteristic of palliative and end-of-life care in care homes is something that the research team called 'relationship-centred care'. This is characterised by staff who invest considerable time in 'knowing the person' through nurturing close relationships with residents and their families over prolonged periods of time. This powerful term conveys the importance of the very specific type of care provided in care homes. It is vital to recognise and address the factors that prevent the delivery of relationship-centred care.

We strongly believe that care homes need a seat at the decision-making table as, currently, care workers are not being recognised. In part, this includes involving them in multidisciplinary meetings where they can work collaboratively with GPs, community nurses and specialists in palliative and end-of-life care. Care homes should also be included at commissioning levels, ensuring equal status of care homes and an appreciation/understanding of their role in the delivery of palliative and end-of-life care. We are pleased that this report advocates for these priorities.

We believe that the policy recommendations proposed within this report are realistic and essential to ensure parity of esteem for the sector and make sure that the right policies are in place to improve the provision of palliative and end-of-life care in care homes now and in the future.

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Contact

For more information, please contact

Professor Katherine Sleeman

Katherine.sleeman@kcl.ac.uk

Or visit:

<https://www.kcl.ac.uk/cicelysaunders/research>

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