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All-Party Parliamentary Group
Hospice and End of Life Care

The Lasting Impact of COVID-19 on Death, Dying and Bereavement

March 2023

Supported by hospice UK

Contents

Executive Summary

The significant rise in deaths, including in people's own homes, during the COVID-19 pandemic placed huge pressure on the health and care system and led to incidences of poor care. The sheer volume of death, alongside measures to reduce the spread of infection, resulted in extreme pressure on now exhausted health and care workers and unpaid carers.

With more people expected to die in 2031 than in 2020, this should be seen as a warning sign and a message to all decision makers that palliative and end of life care, and in particular high-quality out of hours community services, needs to be prioritised.

Evidence to the APPG painted a distressing picture of the traumatic deaths that took place during the pandemic and the lasting impacts on health and care staff and grieving loved ones.

At the peak of the pandemic, hospice teams were having two or three patients dying every single day. Health and care workers across the system also had end of life care responsibilities thrust upon them with little preparation or guidance. As a result, staff struggling with distress and burn out are leaving the workforce at a risk to quality of care.

It is critical that Government and other actors respond by providing mental health support for the entire health and care workforce, including non-NHS staff, and ensuring that all health and care staff have the training they need to support people who are dying, and their loved ones. Integrated Care Boards (ICBs) should also assess their level of support for unpaid carers.

There has been a rise in complex grief disorder, due to many bereaved carers being unable to say goodbye or take part in grieving rituals and experiencing guilt as a result of the circumstances of the death of their loved one. The APPG is therefore calling on ICBs to commission and fund bereavement support services to support those with complex grief and ensure wider bereavement support is available in their area.

It is clear that the pandemic worsened the existing inequity in access to, and quality of, care experienced by minoritised groups, however, evidence to the APPG demonstrates that the extent of this harm is hidden by a lack of data. Evidence also highlights how COVID-19 exposed the fragility of the funding model for end of life care and the need for a sustainable funding solution for the hospice sector in England.

However, the pandemic also shed light on the resilience and increased collaboration and innovation by palliative and end of life care services, which were able to adopt new ways of working with great speed. It is vital that some of these innovative approaches, such as expanding out-of-hours services, training professionals across the health and care sector in end of life care, and increasing who can administer end of life care medication are further developed and rolled out across England.

Tribute to Jack Dromey MP

This report is dedicated to Jack Dromey MP, the APPG's former Co-Chair who sadly died during the course of this review.

Jack was a passionate campaigner for the hospice movement and for every person with palliative and end of life care needs. He was incredibly compassionate and always eager to speak to people with lived experience of death and dying and ensure their voices were heard at a national level.

The APPG dedicates this report to Jack and all he achieved in support of hospices and people with palliative and end of life care needs in his time as an MP.

Foreword by the APPG Co-Chairs Peter Gibson MP and Baroness Finlay of Llandaff

Death dominated the news throughout the pandemic but the significant impact of COVID-19 on palliative and end of life care has gone largely unnoticed. Our report demonstrates that we need to prioritise – not shy away from – death, dying and bereavement in our health and care system.

The huge surge in deaths due to COVID-19 meant some people did not receive the care and support they needed at the end of their lives. It placed extraordinary pressure on health and care staff and unpaid carers, who didn't always have the right skills and training to deal with people dying in their care, and exposed the fragility of funding for end of life care.

However, the high number of deaths also prompted those supporting people at end of life to adopt new ways of working and collaborate to meet the need for care.

Whilst the pandemic pushed the sector to its limits, pressures are set to increase, not recede. This is why it is vital that we use the lessons of the pandemic to prepare for the future where more people are expected to die year-on-year.

Our report makes recommendations to Government, NHS England, Integrated Care Boards, end of life care services and other actors in order to harness what the sector has learned over the past three years to improve palliative and end of life care for all. We look forward to discussing our recommendations with Government and championing their implementation.

Peter Gibson MP
APPG Chair

Baroness Finlay of Llandaff
APPG Chair

Foreword by the APPG Secretariat Toby Porter, Chief Executive of Hospice UK

Hospice UK is delighted to support the work of the All-Party Parliamentary Group on Hospice and End of Life Care, including this vital review into the lasting impact of COVID-19 on death, dying and bereavement. I am personally hugely grateful to the Chairs and Officers of the group for their steadfast support for the hospice sector and their campaigning for better palliative and end of life care for all.

As the national charity for hospice and end of life care we work to ensure that everyone affected by death, dying and bereavement gets the care and support they need, when they need it. However, it is clear from this report, that we still have a lot of work to do.

Despite the heroism of the workforce, the health and care system struggled to cope with the vast amount of death during the height of the pandemic.

Our ageing and increasing population mean that the numbers of people dying and the need for palliative and end of life care will continue to increase over the coming years. With the level of need seen in the pandemic set to become normal, it is imperative that we prioritise and strengthen our provision of palliative and end of life care.

Hospice UK will examine this report and work to implement the recommendations aimed at national organisations and the hospice sector. We also encourage actors across the system, including Government, to learn from the lessons in this report and work together to build a health and care sector that gives every person in the country what they need from their first moments of life until their last.

Toby Porter
APPG Secretariat
Chief Executive of Hospice UK

The report's key recommendations

The report's key recommendations can be largely grouped into four different themes

Funding the services that populations need

Support and training for palliative and end of life care staff

Helping people to recover from the impacts of COVID-19

Learning from the pandemic

The recommendations in full

Funding the services that populations need

It is imperative that Integrated Care Boards respond to their new duty to commission specialist palliative care, by ensuring funding decisions are based on assessments of the needs of their populations. This must include, as a priority, access to high-quality out of hours community services and support for unpaid carers. ICBs should also review how specialist palliative and end of life care services in their area can alleviate pressure on the NHS.

National Government should also conduct a review of hospice funding with the aim of developing a sustainable funding solution for this essential sector. Providers themselves need to collect and use data to ensure that the health and care system understands and responds to the palliative and end of life care needs of its local population.

The APPG's specific recommendations are that:

- Integrated Care Boards must prioritise access to high-quality out of hours community services for people with palliative and end of life care needs, for example, by ensuring the services they commission include both a specialist out of hours advice line for professionals and a single point of access for those caring for someone at the end of their life, in line with the new statutory guidance on palliative care.
- Integrated Care Boards must assess the post-pandemic need for, and availability of, services, which provide respite for unpaid carers and reinstate services closed due to COVID-19.
- The Government should conduct a review of hospice funding in England, akin to that being conducted in Wales, and work with hospices and Hospice UK to devise a sustainable funding solution for the hospice sector in England.
- Integrated Care Boards should review how specialist palliative and end of life care services in their area can alleviate pressure on the NHS.
- Health and social care providers should accurately and consistently collect data on protected characteristics, and use that data to ensure that the health and care system understands and accurately meets the palliative and end of life care needs of its local population. Hospices specifically should work together to agree a collective approach to this.

Support and training for palliative and end of life care staff

All health and care workers need to be given sufficient training in how to support people who are dying and their families. In addition, they must be trained in bereavement and how to recognise grieving people in need of additional support.

Following the large volume of death during and since the pandemic, mental health support needs to be made available to the entire health and care workforce in recognition of what they have experienced.

The APPG's specific recommendations are that:

- National Government and NHS England (NHSE) should ensure that all health and care staff have the training they need to support people who are dying, and their loved ones. All health and care staff training programmes should prioritise palliative and end of life care and palliative and end of life care training within courses needs to be delivered consistently across different providers.
- National Government should ensure that mental health support is made available to the entire health and care workforce, including non-NHS staff, at a time and place that enables them to access this support. Line managers should also be trained to identify when a staff member or volunteer requires support and signpost them to support services.
- Health and social care staff must receive culturally-informed training in bereavement, particularly how to identify those at risk of complex grief disorder, Post-traumatic stress disorder (PTSD) and others in need of additional support. They must also be able to signpost those individuals to appropriate support and services.
- Integrated Care Systems and Higher Education Institutions training health and social care professionals must cover the challenges of communicating whilst wearing personal protective equipment (PPE), particularly when caring for patients at end of life and those who might be agitated or confused, in training on communication with patients.

Helping people to recover from the impacts of COVID-19

It is more important than ever that we get better at talking about death. At a national level, Government should fund a national public information campaign on bereavement. Integrated Care Boards must then take responsibility for funding services for complex and traumatic grief and ensuring there is sufficient wider support in their areas. In the wake of the pandemic, employers should also prioritise supporting staff who are grieving or have caring responsibilities.

The APPG's specific recommendations are that:

- The Government should fund a national public information campaign on bereavement and breaking down taboos around talking about death and dying. This campaign should take a cross-sector approach and unite all the groups and organisations that have a role to play in bereavement support.
- Integrated Care Boards must commission and fund bereavement support services specifically to support those experiencing complex and traumatic grief and take action to ensure there is wider bereavement support in their areas.
- Employers should implement measures that support staff who also work as unpaid carers and increase their likelihood of remaining in the workforce, such as becoming a Compassionate Employer. Employee support programmes such as this should work together in collaboration.

Learning from the pandemic

Government, NHS England, Integrated Care Boards and end of life care services must capture what has been learnt over the course of the pandemic and support the roll-out of positive innovations and ways of working.

The experiences that people have had of operational restrictions in the pandemic must feed into future pandemic planning. Long-term trends such as the rise in deaths in people's own homes and the shift towards digital and remote health and care services should also be examined.

The APPG's specific recommendations are that:

- National organisations should share examples of good practice, innovation and collaboration in providing end of life care with their networks in order to inform others in the sector.
- NHS England should assess and roll-out innovations in the administration of palliative care medication developed during the pandemic and ensure providers are well trained and knowledgeable on any changes.
- NHS England must ensure that every unpaid carer administering medication to seriously ill patients at home feels confident, supported and well-informed on procedure.
- National Government must ensure that future pandemic planning accounts for those providing care to seriously ill people and people at the end of their life, particularly in a domiciliary setting, and includes specific guidance for hospices from the offset.
- NHS England and Integrated Care Boards should support providers to upgrade their technology and train their staff and volunteers in how to use it, in order to provide accessible virtual services.
- The COVID-19 Inquiry must examine the surge in deaths in people's own homes since the beginning of the pandemic.
- The research community should examine inequalities that may have been created through the shift to remote health and social care services, particularly for those without access to computers or whose first language is not English.

Introduction

The All-Party Parliamentary Group on Hospice and End of Life Care launched this review into the lasting impact of COVID-19 on death, dying and bereavement because its members were aware of the huge impact that the pandemic had on people receiving and providing palliative and end of life care and was in no doubt that such impacts would be widespread and long-lasting.

The APPG intended that the review would uncover changes in the way palliative and end of life care is being, and will need to be, delivered in England following the pandemic as well as the experiences people have had of death, dying and bereavement during this time. Early evidence indicated that many people who died during the pandemic did not receive the care they needed and the health and social care workforce was under unprecedented pressure.

The group sought to use its findings to make recommendations to national Government and the hospice and end of life care sector to ensure that lessons are learned from the pandemic, good practice and innovation are carried forward, and negative experiences are recognised and addressed.

After launching this review in late October 2021, the APPG received 100 submissions of evidence from a variety of perspectives, including from health and care workers, service providers, people bereaved during the pandemic, unpaid carers, membership bodies and charities. The APPG also held three themed virtual oral evidence sessions, which were attended by MPs, Peers and other stakeholders.

The evidence received provided vital insight into death, dying and bereavement during the pandemic and its lasting impact. This outcome report highlights the key findings and reflections from the evidence submitted, and makes recommendations to National Government, NHSE and the palliative and end of life care sector to address the impacts of the pandemic and support the provision of high quality palliative and end of life care across the UK.

1. Changes to the palliative and end of life care landscape driven by the pandemic

The COVID-19 pandemic put additional pressure on palliative and end of life care provision by accelerating existing trends and forcing providers to manage new operational challenges. This will continue to play a role in end of life care for the foreseeable future.

1.1: Rise in deaths

The COVID-19 pandemic led to a significant increase in the number of deaths across all settings. Between March 2020 and June 2022 there were over 130,000 excess deaths in England and Wales.[1]

This rise in death very quickly placed palliative and end of life care teams and the wider health and care system under significant strain. For example, weekly referrals to the King's College Hospital palliative care team increased from a mean of 39 in February to 75 at its peak.[2] The number of patients who died on their palliative care caseload also increased from a mean of 13 per week to 52 per week at its peak.[3]

Whilst this rise in death was driven in part by the pandemic, those who submitted evidence to this review stressed that this high demand for palliative and end of life care is a sign of what is to come.[4] On current projections, more people are expected to die in 2031 than in 2020 and mortality is due to reach 800,000 in 2040.[5]

The UK's increasing and ageing population is likely to result in more and more people living longer with multiple conditions, more complex care needs and a greater need for palliative and end of life care.[6] Whilst the demand for palliative and end of life care prompted by the pandemic was extraordinary, the sector needs to be prepared to regularly meet this level of demand within the next ten years.

Experiences of the pandemic were not universal and different communities were impacted in a variety of ways that will continue to affect them and wider society. Those from ethnic minorities have a higher risk of mortality from COVID-19 in comparison to White British people.[7] Across the pandemic people from ethnic minority communities have also reported poor quality end of life care.[8]

> *"Covid-19 has shone a harsh light on some of the health and wider inequalities that persist in our society."*[9]
>
> *Submission by NHS England*

Poor collection and recording of demographic data across the health and care system means that the full extent of the inequity in access to, and quality of, care during the pandemic and beyond is hidden. Over the pandemic, "gaps in recording ethnicity on GP systems made it difficult to see the bigger picture" regarding health inequalities.[10] A 2022 report by the Nuffield Trust also identified that many hospices do not routinely capture patient information, including ethnicity and other protected characteristics. The report recommends that commissioning organisations and hospice providers recognise the need for greater investment in hospice information infrastructure.[11]

Recommendation

Health and social care providers should accurately and consistently collect data on protected characteristics, and use that data to ensure that the health and care system understands and accurately meets the palliative and end of life care needs of its local population. Hospices specifically should work together to agree a collective approach to this.

1.2: Operational challenges to compassionate care

Measures to reduce the spread of COVID-19 had an immediate and significant impact on the delivery of palliative and end of life care services, which the health and care system will need to learn from to help prepare for future pandemics.

Closure of services

Some hospices who submitted evidence to the APPG described closing some or all of their in-patient beds or their in-person day-services at points during the pandemic to limit the spread of COVID-19.[12] Together for Short Lives said that most children's hospices initially had to close their hospice buildings and create blended models of virtual and face-to-face services as the pandemic went on.[13]

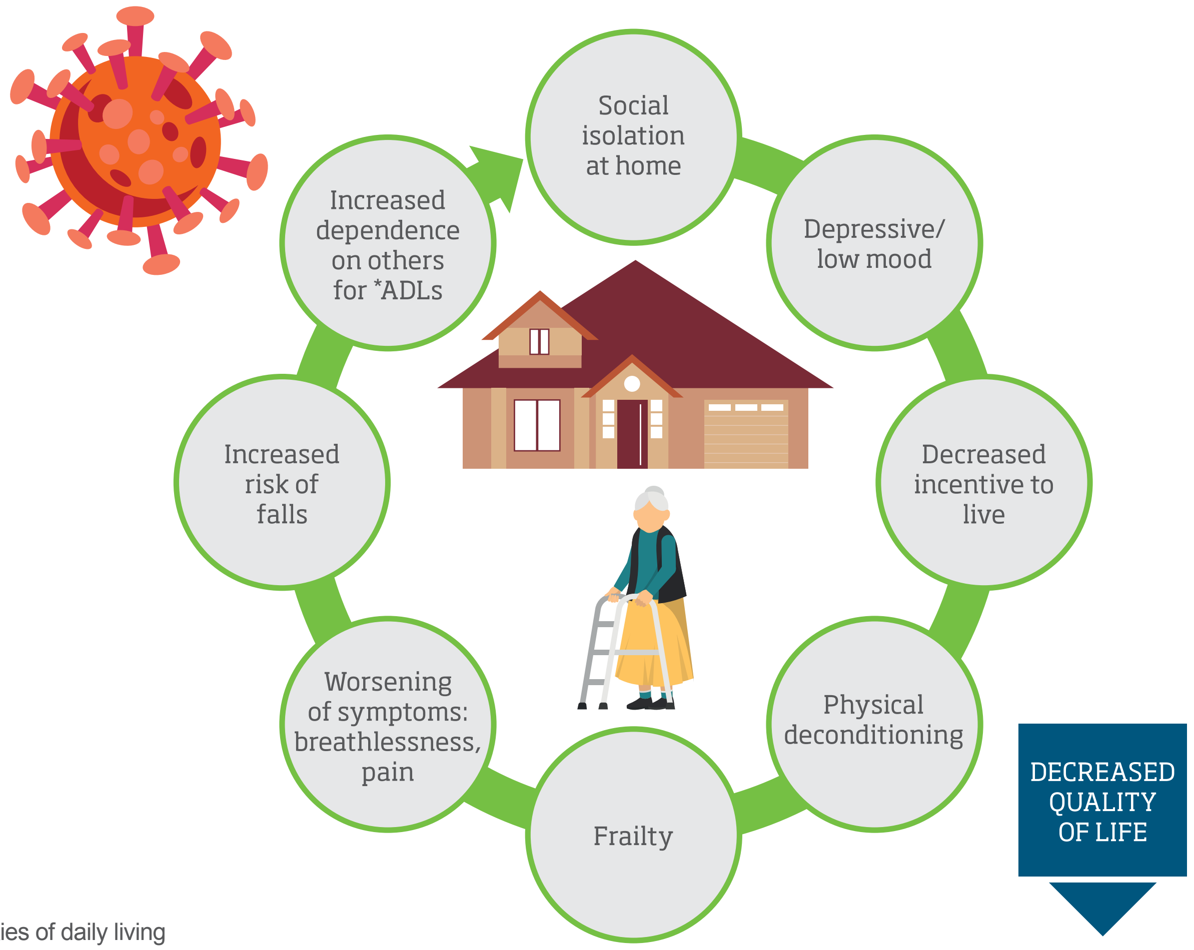
Dr Matt Sweeting from Farleigh Hospice highlighted the funding challenges that arise for hospices when they reduce their in-patient beds and expand their support in the community to meet population need. Closing in-patient units can create reputational challenges among the public, who donate money to the hospice, due to a common misunderstanding that hospices are just physical places with beds rather than services that primarily operate in the community.[14]

Evidence submitted to the APPG described how the closure or reduction of services led to worsening symptoms and lower quality of life for people with palliative and end of life care needs. The Multiple System Atrophy Trust said that, whilst hospices were "one of the only ones actively reaching out throughout the pandemic", day services, such as complementary therapies and counselling now "seem to be non-existent". This has had a "detrimental" impact on people living with MSA and their carers, who often get much needed respite from such services.[15]

> *" The major concern we have is that the pandemic has accelerated the shift towards hospices moving away from day services and the provision of more intensive day support which is so important to people with complex needs at the end of their lives."*[16]
>
> *Submission by the Multiple System Atrophy Trust*

Pressure on ambulance services also led to a reduction or complete stop in non-emergency transport services, such as routine hospice transfers or 'goodwill' non-commissioned services, such as moving a patient downstairs.[17] The Hospice of St Francis in Berkhamsted commented on how NHS hospital out-patient and follow up appointments were moved online or cancelled because staff were redeployed to care for patients with COVID-19. As a result, among patients who they would have expected to live longer, there was "rapid deterioration" in conditions, increased complexity in presentation and an increase in multi-morbidity.[18]

The reduction of services compounded the impact of social isolation and decreased activity caused by lockdowns. Joh Winter spoke to the APPG about how the lockdown led to a rapid degeneration in her mother's Alzheimer's. Her mother kept forgetting she had to stay in the house and thought she needed to "keep the blinds and windows drawn to prevent the virus from getting in".[19] St Michael's Hospice described how the "destructive cycle of deconditioning" was exacerbated by COVID-19.[20]



*activities of daily living

[21]

A series of surveys by the Disabled Children's Partnership (DCP) to track the experiences of disabled children, including those with life limiting illnesses and their families, revealed the impact of a reduction in access to services during the pandemic. The third survey, No End in Sight, conducted in April 2021, found that over 50% of families could not access therapies that were vital for their child's development. This resulted in children falling behind in terms of speech, communication, social, motor skills and being in pain.[22] In response, Together for Short Lives has called for "a therapies catch-up plan to address where children have regressed or plateaued in their speech, communication, physical development, or social skills".[23] More joined up services that are accessible via a single point of access could also help make services more visible and available.

Visitation

Services had to restrict visitation of patients to prevent the spread of infection. The Department of Health and Social Care produced regularly updated guidance on visitation policies and health and care staff had to continuously review their guidance around visitation to ensure they had the balance right between patient liberty and infection risk.[24] East Suffolk and North Essex NHS Foundation Trust's full service review after the first wave of the pandemic found that restricted visitation was "very difficult for patients, their loved ones and staff and allowing compassionate visiting is key and providing supportive care alongside active management is important".[25]

There was, however, an initial lack of sector specific guidance on infection-control for hospices. St Catherine's Hospice in Crawley said that it was not clear whether they had to follow guidance for care homes and adult social care settings or guidance for acute hospital wards, community hospitals or community providers.[26] After hospices were not referred to in initial guidance, Hospice UK was invited to take part in the development of further guidance. As a result, hospices were included in later national guidance on visitation and infection control. It is vital that, in the case of future pandemics, hospices are viewed as a key part of the health and social care system and are included in pandemic preparation and given appropriate infection control guidance from the offset in order to protect and assist patients and staff.

> *"We continue to fall between the gap of being classified as a hospital [or] as a care home for [infection prevention control]."*[27]
>
> *Submission by the Hospice of the Good Shepherd*

Hospices "regularly reviewed and adjusted" visiting restrictions in order to "balance risk with patient liberty".[28] Many were able to offer compassionate visits when a patient was determined to be in the last days or hours of their life. While welcomed, this was often difficult to manage for staff and could be traumatic for visiting loved ones. Sue Ryder shared in their evidence a quote from an IPU nurse who felt visiting restrictions had "ripped the heart out of palliative care".[29] The impact on staff and visitors will be explored later in this report.

Sarah Clayton, District Nurse Clinical Lead at South Doncaster District Nursing, commented that patients have been guided to choose to receive care at home and often "put off" in-patient care due to visitation policies.[30] St Catherine's Hospice stated in their evidence that visiting restrictions also had a particular impact on certain communities.[31]

> *"People from cultures where decisions tend to be made as part of a family unit were particularly disadvantaged by visiting restrictions, as were people from cultures where family involvement in post death rituals such as washing bodies is particularly important."*[32]
>
> *Submission by St Catherine's Hospice*

Visitation restrictions and infection prevention control measures also prevented people in care homes, particularly those with dementia, from taking part in effective advance care planning (ACP) as they could not access their relatives or surrogate decision makers.[33] Advance care planning is a key component of palliative and end of life care, which allows people to have more choice and control over their death. Advance care planning is particularly important to LGBT people to ensure their relationship with their loved one(s) is recognised and their identities and wishes are respected.[34]

Furthermore, as a result of the pandemic, advance care planning often had to happen very quickly, despite health and care workers and the people they cared for not knowing how to have these conversations or not trusting ACP.[35]

> *"… the community matrons came in around the entire home with residents with DNRs which I didn't really agree with but – and then they obviously had emergency healthcare plans put in place as well … They spoke to families, spoke to residents as well that have their capacity and that was all agreed. At the time it seemed … that they weren't going to go to hospital, if you know what I mean? They were just going to get left to die type of thing …"*[36]
>
> *Interview with care home manager included in the submission by the International Observatory on End of Life Care at Lancaster University.*

However, poor advance care planning during the pandemic did lead to renewed efforts to improve its use. For example, in London, the EARLY Identification and Personalised Care Planning Toolkit was developed to support GP practices to identify patients at end of life who might benefit from discussing and developing a personalised care plan.[37] A new Planning Ahead Coordinator was also introduced in Leeds, working across a primary care network to support adults with frailty to make their future care plans.[38]

Visitation restrictions and restrictions on who could be present on a ward also caused significant barriers for those with additional communication needs. Neurodivergent people who may be non-verbal or have additional communication needs faced barriers as they were unable to have someone to advocate for them or help them to understand and communicate in a healthcare setting.

> *"An autistic man with a terminal illness was taken into hospital; he was scared and anxious, unable to communicate and became aggressive. His family were not with him to explain his needs. After he died, the family wanted information. The social worker concerned found it incredibly difficult telling the family that he had been so agitated he needed to be sedated prior to his death."*[39]
>
> *Submission by the Association of Palliative Care Social Workers*

PPE

The need for health and care workers to wear personal protective equipment (PPE) also created significant operational challenges. There was unprecedented global demand for PPE and numerous submissions of evidence described the challenges that palliative and end of life care services had accessing this equipment.[40] The Care Workers' Charity described how care workers had to improvise when unable to access PPE, using bin bags and masks meant for builders.[41]

> *"The COVID-19 pandemic shook the very foundations of Dr Kershaw's Hospice. Visiting restrictions, access to PPE and COVID testing made business-as-usual more or less impossible."*[42]
>
> *Submission by Dr Kershaw's Hospice*

PPE shortages were experienced by over a third of UK palliative care services between April and July 2020.[43] Evidence submitted by Marie Curie said that this initial lack of access was due to the UK healthcare system not recognising palliative care as an essential part of the COVID-19 response, creating a perception that it was not a 'frontline NHS' service.[44] Sarah Clayton, District Nurse Clinical Lead at South Doncaster District Nursing, said that nurses were not completing face-to-face visits during the early days of the pandemic, partly due to issues accessing PPE.[45]

In response to this crisis, the Department of Health and Social Care worked closely with NHS England (then NHS England and Improvement) and Hospice UK to explore ways to provide continuous supply of PPE to the hospice sector.[46] This led to the establishment of 19 regional PPE hubs, centrally coordinated by Hospice UK, which divided up and delivered PPE to all the hospices in their region.[47]

The PPE hub system enabled hospices across the UK to access free PPE for the duration of the pandemic. This was cited in evidence the APPG received, with the Hospice of the Good Shepherd mentioning how linking into the regional hub system improved its supply of PPE.[48] At the height of the pandemic, the hospice sector was collectively ordering over 1 million items of PPE per week (1,053,126 items, January 2021) demonstrating the significant need for this service.[49]

There was a wealth of evidence submitted to the APPG on the impact that wearing PPE had on interactions between patients and health and care workers. On a practical level, submissions described difficulty reading and writing and the discomfort of wearing PPE as well as the time taken to drive to pick up PPE stock.[50] PPE also made "effective and sensitive communication" with patients at end of life and their families very difficult, with masks making it impossible to lip read or understand facial expressions.[51]

> *"Finally, we found it has also been challenging for staff to make clinical judgements regarding when a patient is in their last 24-48 hours of life, when communicating remotely or through PPE and screens."*[52]
>
> *Submission by John MacArtney, Marie Curie Senior Research Fellow and sociologist of dying and palliative care at the University of Warwick*

Submissions of evidence raised the lack of training to support health and care workers with these challenges. Interviews with adult nursing students recruited by Health Education England to support the NHS during the pandemic by Jane Crussell revealed how previously "offered training in the principles of palliative and end of life care" had "not prepared them for real life experiences of COVID-19", including supporting and communicating with patients and families whilst wearing PPE.[53] Specialist palliative care professionals in County Durham and Darlington argued that the negative impact of PPE on communication skills and how to combat this should be "woven into training".[54]

As well as hindering effective communication, PPE also made it more difficult to empathise with and offer comfort to patients. The Association of Ambulance Chief Executives said this difficulty "was acutely felt by ambulance clinicians when a patient was dying, during a resuscitation attempt or verification of death situation."[55] Evidence submitted by Dr Kerry Jones reported that care workers faced ethical dilemmas around whether to wear PPE which "increased a sense of loneliness" among people under their care who were used to a reassuring hug or hand hold and did not understand why PPE was being worn due to their cognitive impairment.[56] The impact of such ethical dilemmas on the mental health of the workforce will be explored later in this report.

It was clear that not being able to reassure and comfort patients effectively had a particularly big impact on the mental health and wellbeing of the palliative and end of life care workforce in part due to their perception of palliative and end of life care as holistic, personalised and encompassing spiritual and emotional care. St Michael's Hospice in Hastings and Rother described PPE as disruptive to the "intimacy of dying" in this most "privileged of times to care for patients and their families".[57]

> *" We had to put our red PPE on, which is like FFP3 masks and our overalls...at the back of the car to protect ourselves and our patients...having to go into someone's home and you're dressed in all of this, you know, the face masks and the visors and things and you've got this poor patient whose laid in the bed...trying to reassure them when normally they could look at your facial expression, they can't see your face under your face mask... we're a very compassionate team and a very tactile team so we were having to just put our hands on their shoulder just to try and give them some reassurance. Also, with the FFP3 masks they can't hear your voice very well, it's quite muffly, so just trying to reassure them the best we can, just to try and make them as comfortable as we can coming into their home dressed like that, it must be quite terrifying for them."*[58]
>
> *Submission of evidence by Selina Rogers, Healthcare Assistant in St Luke's Hospice Plymouth's urgent care service*

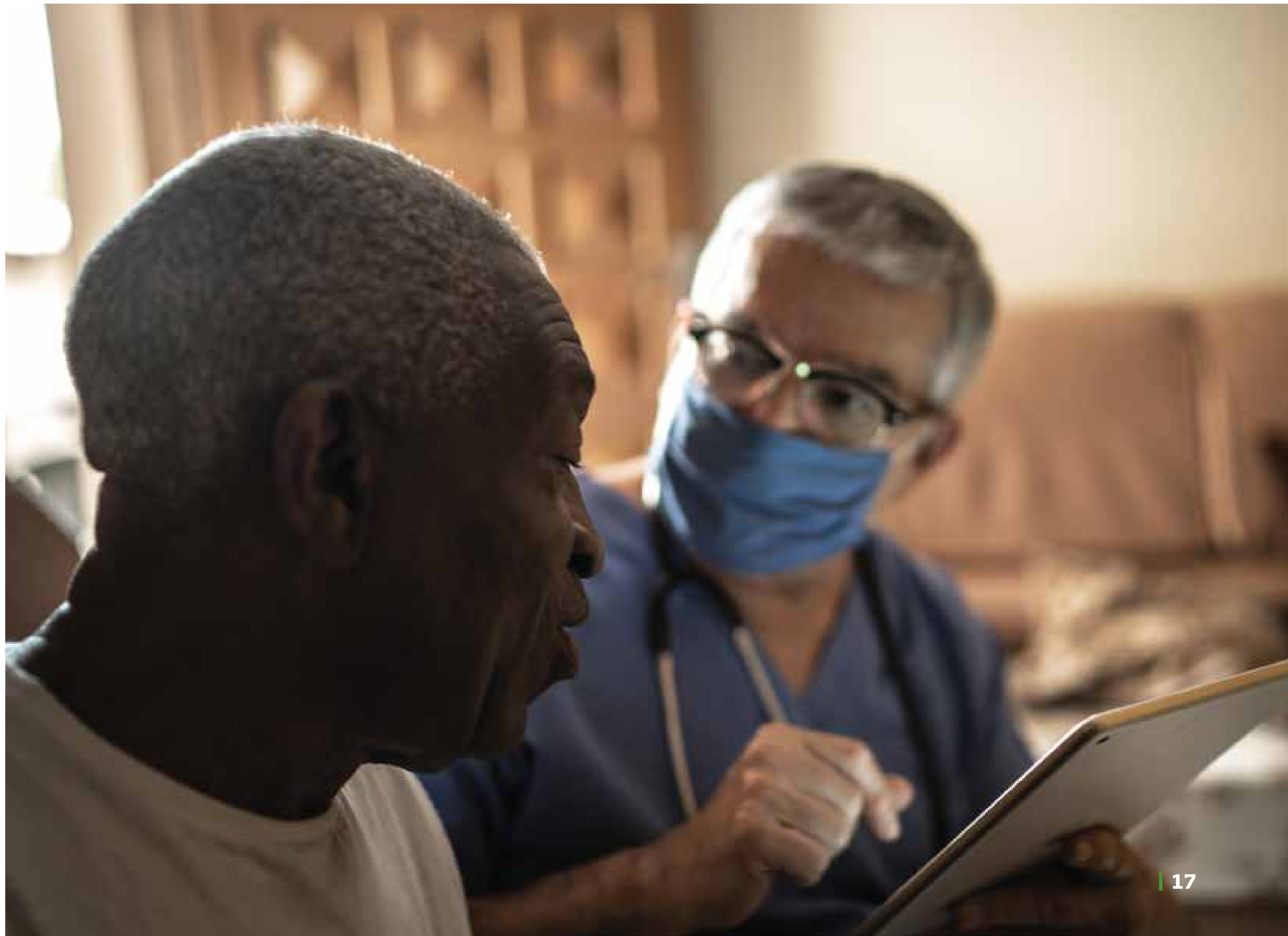
PPE also caused acute distress and fear for some patients at end of life. Masks meant that some frail and elderly patients might not hear comforting words and the sight of gowned and masked health and care workers could increase agitation.[59]

> *" [The wife of a patient whose treatment has been stopped] starts to cry and asks me to go and speak with him, to try to make him understand what is happening. I put on my mask, goggles, apron and gloves and enter his room, He looks scared at the sight approaching his bed, I say his name and tell him what we are doing. All he says is 'Oh Jesus' over and over. I have no idea if he has understood anything I have said."*[60]
>
> *Submission by Jan Bolton, Macmillan social care co-ordinator, Northamptonshire Centre for Oncology*

Recommendations

Integrated Care Systems and Higher Education Institutions training health and social care professionals must cover the challenges of communicating whilst wearing PPE, particularly when caring for patients at end of life and those who might be agitated or confused, in training on communication with patients.

National Government must ensure that future pandemic planning accounts for those providing care to seriously ill people and people at the end of their life, particularly in a domiciliary setting, and includes specific guidance for hospices from the offset.



1.3: Increased complexity of symptoms resulting from restrictions

Late referrals and diagnoses due to pandemic restrictions have resulted in further changes to the end of life care landscape that will have lasting consequences. Many individuals did not attend appointments or refused home visits during the pandemic because they were shielding or worried about contracting COVID-19 or putting pressure on the NHS.[61] Others had difficulty accessing healthcare or did not receive a diagnosis or referral due to the appointment taking place virtually, with some patients feeling as though they were not properly assessed.[62]

As a result, many people were, and continue to be, referred to palliative and end of life care services later in their condition. This places further demands on the workforce as patients referred to services later in their disease tend to have "higher symptom burdens and advance care planning… needs to happen more rapidly".[63] The Association of Physiotherapists in Oncology and Palliative Care explained that as more people were cared for in the community, patients were getting input from physiotherapists much later. As a result, patients became "de-conditioned" earlier and struggled more with symptoms such as fatigue and breathlessness. This put more pressure on therapy teams when patients were referred.[64]

Delays in examining palliative patients prevented health and care workers from providing high-quality care. University Hospitals Dorset specialist palliative care service outlined how families who were adhering to strict shielding measures declined visits from care providers, only allowing health and care staff into their home once they were in "considerable discomfort" which was "too difficult for the families to deal with". As a result, patients could not benefit from early interventions and experienced increased symptoms and pain.[65]

Finally, Sue Ryder mentioned how delays in diagnoses sadly led to some patients dying when their condition could have been cured were it identified earlier.

> *"There have been delays in patients seeking help when they develop symptoms, and then further delays in their diagnostic and treatment pathways during the pandemic. This has, unfortunately, led to potentially curable patients becoming palliative."*[66]
>
> *Submission by Sue Ryder*

This trend is expected to continue in the coming months and years as missed diagnoses and conditions continue to be picked up. The Hospice Charity Partnership's hospice team anticipate "an additional surge in demand" due to "delayed and undiagnosed cancer, as well as deteriorating, heart and lung disease and other sub-optimally managed degenerative conditions" and are seeing young people in their 40s and 50s require specialist intervention and end of life care.[67]

1.4: Increase in deaths at home

Another significant change in the palliative and end of life care landscape, driven by the pandemic, is the surge in deaths at home. Since the beginning of the pandemic, nearly 120,000 more people have died at home across the UK, compared to long-term rates.[68] Between January 2020 and September 2021, there were 57,000 more home deaths than expected (based on the 2015-2019) and almost 8,000 fewer hospice in-patient deaths in the same period as care moved into the community.[69] Even outside of the peaks in COVID-19 infection, around 30% more people were dying at home compared to the 2015-2019 average.[70]

These deaths are not just driven by COVID-19 infection but are, in fact, primarily due to non-COVID conditions such as cancer, heart disease and dementia. During one of the APPG's oral evidence sessions, Professor Julia Verne from UK Health Security Agency (formerly Public Health England) said that her team had seen an increase in the proportion of people dying at home from cancer increase from 31% in 2019 to 41% in 2020.[71]

> *"What we had to contend with was a huge surge in rapid dying at home from COVID. Our hospice at home team, who particularly support people in the last few days or short weeks of life, were absolutely frontline in care and support here and often alone because of the reduction in district nurse and GP visibility."*[72]
>
> *Oral submission of evidence by Dr Corinna Midgley, Medical Director of Saint Francis Hospice in Essex*

This rapid increase in deaths at home resulted in greater demand for community palliative and end of life care services, which is reflected in the evidence the APPG received. Sue Ryder shared that, prior to the pandemic, it was beginning to see an increase in referrals to support patients dying at home but that referrals increased by nearly 29% across its services between April 2019 and April 2021.[73] St Michael's Hospice in Hastings referred to a reduction in demand for its inpatient unit alongside increased demand for community palliative care support.[74]

It is not entirely clear what has driven this increase in need in the community but the evidence submitted suggests that patient choice, due to fear of COVID-19 infection or not being permitted visitors in an inpatient setting, was a significant factor. Coventry Integrated Palliative Care Team, The Royal College of Nursing and palliative care clinicians across South Tyneside and Sunderland all highlighted how visiting restrictions prevented patients from wanting to be admitted to secondary care.[75]

> *"For some other bereaved carers, they made the difficult choice to have the person they care for die at home, so there would be no restrictions on visiting, this led for some to stressful and traumatic experiences of end-of-life care taking place in the carer's home, when under non covid conditions they would have opted for end of life and death being in a medical or care home setting."*[76]
>
> *Submission by Leeds Palliative Care Network*

Some hospices found they had to close inpatient wards in response to this change in need.

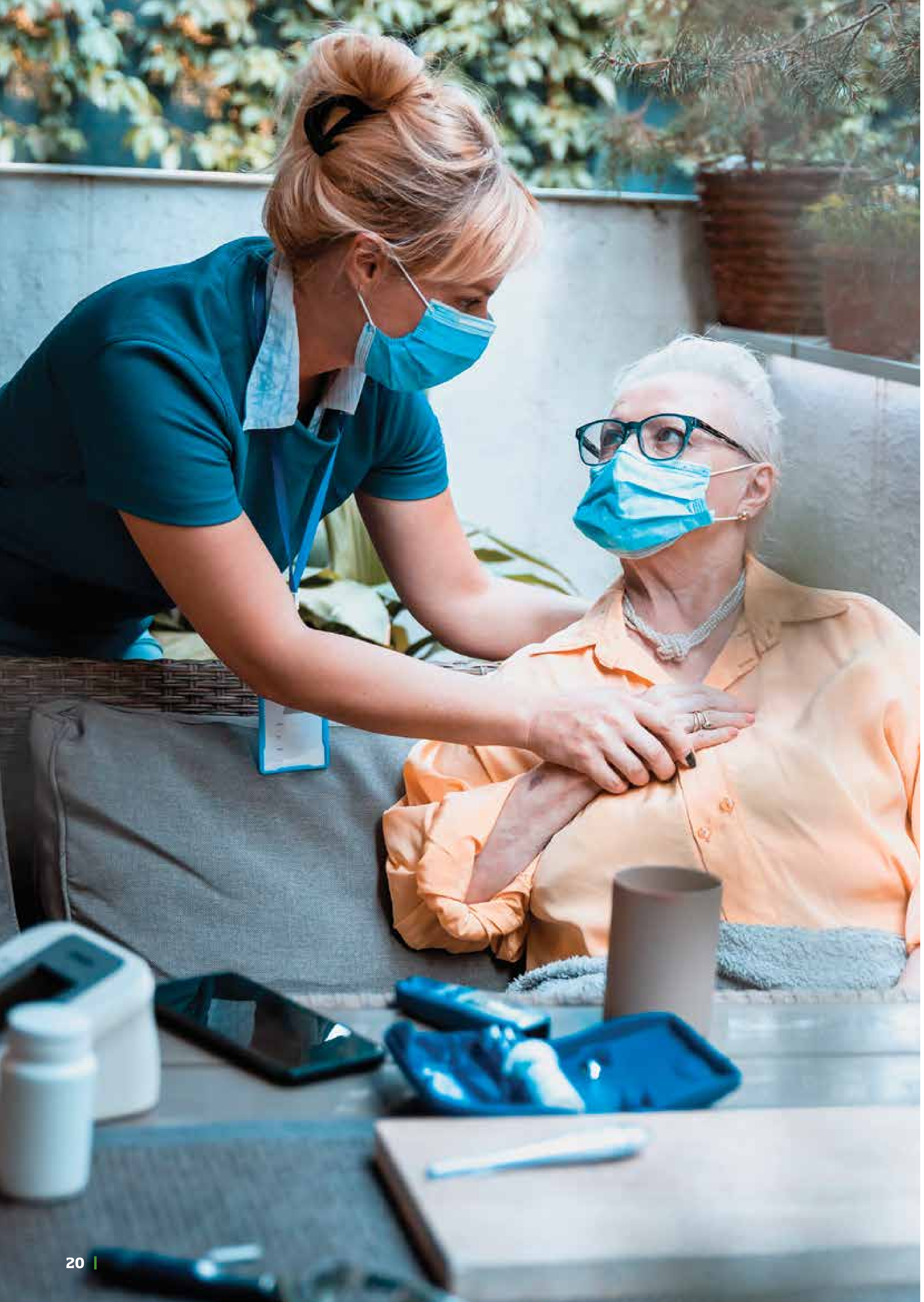
> *"There was a temporary reduction in demand for inpatient hospice beds as a result of visiting restrictions and desire to avoid infection risk. Many people wanted to stay at home and to avoid any institutional setting. Like many other hospices, we closed beds for both financial and infection prevention and control reasons."*[77]
>
> *Submission by St Catherine's Hospice in Crawley*

Much like the broader increase in death across the UK, the rise in deaths at home and increase in the need for community care is not a short-term impact of the pandemic but the beginning of a long-term trend. High numbers of deaths at home have continued outside of periods of high COVID-19 infection with more than 600 excess deaths at home a week in 2022 across the UK.[78] It is vital that the UK COVID-19 Inquiry investigates the rise in deaths at home since the beginning of the pandemic and listens to the voices of the loved ones and health and care staff who cared for those dying at home during the pandemic.

People should be able to choose where they die, providing it is appropriate to their needs. In its evidence, Marie Curie argues that the long-term change in palliative care need towards the community will necessitate "a sustained shift in palliative and end of life care resources into community services and appropriate funding being made available to support these services in the community in the coming years".[79]

Recommendation

The COVID-19 Inquiry must examine the surge in deaths in people's own homes since the beginning of the pandemic.



2. Resulting changes and long-term impact on delivery of care and patient experience

The health and social care sector had to respond to the changing palliative and end of life care landscape by adapting its ways of working. Health and care workers addressed new challenges in innovative ways, which many providers are keen to see continue. However, despite examples of increased collaboration and innovation, patient experience was still negatively impacted by the pandemic. It is crucial that decision makers and services harness learning from these experiences and ensure it informs future provision.

2.1: Impact on collaboration

Increased need for palliative and end of life care, both in the community and more broadly, and the operational challenges associated with the pandemic drove improved collaboration between end of life care providers and with the wider system. In his evidence, Professor Stephen Barclay, the lead of the Palliative and End of Life Care Group at the University of Cambridge, described how the pandemic has "forced forward" multidisciplinary and more effective working between local authorities, practitioners and those working in health and care policy.[80] Macmillan Cancer Support also reported that community and primary care professionals took a "more active role" in palliative and end of life care in response to the pandemic.[81] Ashtons Hospital Pharmacy Services appointed a palliative care ambassador to improve the organisation's engagement with hospices.[82]

Notably, public and third sector organisations, including hospices, worked much more closely together to make more effective use of resources. Hospice of the Good Shepherd, for example, provided step up and step down beds, for people who could not be cared for at home but did not need to be cared for on an acute hospital ward.[83]

Evidence provided by Together for Short Lives described how hospices formed and improved relationships with other local health and social care providers through local resilience forums and how this has the potential to expand the reach of hospices and improve care and staff skillset.[84]

> *"Opportunities are opening up. We've been providing step down from hospital and some from children's social care and we're now picking up calls from CCNs & providing complex needs packages & end of life care at home. We're also working with SCBU. Barriers are being broken down."*[85]
>
> *Quote from a children's hospice cited in the submission by Together for Short Lives*

One example of increased collaboration during the pandemic is between St Joseph's Hospice in Hackney and the Physicians Response Unit (PRU), which supports patients with emergency care needs in Tower Hamlets, Newham and Waltham Forest. At the beginning of the pandemic, St Joseph's Hospice agreed a joint Standard Operating Policy with the Physicians Response Unit to support its work responding to palliative and end of life care emergencies in the community. The aim of this collaboration was to bridge the gap between primary and secondary care for patients at end of life and enable high-quality care in the home.[86]

PRU clinicians were trained in prescribing end-of-life care anticipatory medication, writing community medicine administration charts as well as having sensitive conversations about planning for end of life and updating Treatment Escalation Plans. PRU clinicians also have access to an end of life care folder with locally relevant information to coordinate care and support patients at home, including community prescribing guidance from the hospice and booklets on bereavements. The team have access to patients' advance care plans through 'Coordinate My Care' and the Standard Operating Policy enables St Joseph's to refer patients with emergency needs to the PRU and the PRU to refer people to the hospice's in-patient or community services.[87]

Together for Short Lives shared an example of collaboration by Acorns Children's Hospice. During the pandemic, an Outreach Nurse Lead at Acorns was seconded to the Palliative Care Team at Birmingham Women's and Children's NHS Foundation Trust. During their time there, they were able to support children and families on a palliative pathway, and those that had been bereaved. Having an Acorns nurse at the hospital provided opportunities to "support families moving towards palliation and ensur[e] Acorns is discussed with the relevant medical teams at the early stages of parallel planning".[88]

East Suffolk and North Essex NHS Foundation Trust also improved collaborative working in the community during the pandemic by developing guidance on prescribing, verification of expected deaths, policies for family giving just in case medication and DNACPR communication.[89]

> *"Our regions developed end of life hubs for coordination that are still functioning well and our collaborative working with continuing health care, hospices and discharge teams has led to improved timely discharge or transfer."*
>
> *Submission by East Suffolk and North Essex NHS Foundation Trust*

In addition to formal and informal collaboration at a local level, the palliative and end of life care workforce also collaborated at a national level to share knowledge and expertise and support one another during the pandemic, for example, through ECHO networks. Project ECHO (Extension for Community Healthcare Outcomes) is a methodology designed to provide education and enhance confidence virtually through knowledge sharing and peer support.[90]

In March 2020, Hospice UK set up two ECHO networks in response to the pandemic focused on Clinical Practice and Business Continuity and ran sessions on a weekly or bi-weekly basis. These sessions included presentations from experts in the palliative care community, intelligence distribution and the sharing of challenges individuals were facing in a safe and supportive environment. Approximately 300 people joined each of these sessions in the first few months, demonstrating the degree to which the palliative care community used the networks to raise issues they were facing and support one another.[91]

To maximise the learning from these ECHO networks, Hospice UK produced The Conversation, an evolving document that compiled learning, resources and information shared in the ECHO sessions.[92] In October 2022, the networks continue to meet monthly at the request of their members and the Business Continuity ECHO has been transformed into a new Innovation ECHO.

Submissions to the APPG emphasised how much of the collaboration developed during the pandemic has remained in place and continues to have a positive impact on the delivery of care at end of life. For example, Sue Ryder worked with ambulance service trusts in some areas to enable their hospices to accept 999 patients without the patient being sent to the acute trust first. This practice has continued and Sue Ryder now has even closer working relationships with acute trusts than before the pandemic and holds day-to-day discussions on bed availability and hospice at home capacity for care packages.[93]

Some submissions of evidence expressed a desire to see collaboration between services go further. Hospice of the Good Shepherd said that patients would be even better supported if health and care services, including care homes, linked up with their local hospices earlier so they could support and co-ordinate palliative care journeys and support packages.[94]

Despite promising news of increased collaboration, in some areas, the pandemic reduced collaboration between services and increased tensions between different parts of the health and care system. In particular, individuals and organisations who submitted evidence to the APPG described how pressures on GP services resulted in less collaboration and co-ordination between palliative care services and primary care. Macmillan Cancer Support shared how these pressures led to the suspension of multidisciplinary Gold Standard Framework (GSF) meetings used to coordinate patient care.[95] Specialist palliative care clinicians in South Tyneside and Sunderland also described how multidisciplinary team meetings were cancelled due to COVID-19, however, these meetings were revived with the help of technology after the first wave of infection.[96]

St Gemma's Hospice raised that it was challenging seeing some professionals "stepping back" from face-to-face care, whilst their hospice prioritised this and witnessed the impact that the lack of face-to-face care from others had on the quality of care.[97] Sarah Clayton, District Nurse Clinical Lead at South Doncaster District Nursing, also described how district nurses felt "unsupported by GPs" who reduced face-to-face contact and experienced an increased level of stress as a result.[98] Specialist palliative care clinicians working across South Tyneside and Sunderland described the deterioration in relationships between GPs and community teams during the pandemic, with community nursing staff still not allowed on the premises of some GP practices.[99]

> *"There has been a breakdown in working relationships between GP's and community nursing teams due to a feeling of resentment caused by GP's essentially 'closing their doors' to patients and health care professionals to the detriment of a coordinated approach to PEOLC."*[100]
>
> *Submission by specialist palliative care clinicians working across South Tyneside and Sunderland*

It is important to note that the APPG did not receive sufficient evidence from general practice or representatives of this sector and therefore is missing information on their perspective on the challenges to collaboration with other services during the pandemic. However, it is clear that the pressures of the pandemic led to some GP practices not being able to provide the support to palliative care colleagues that was expected of them.

2.2: Increased innovation

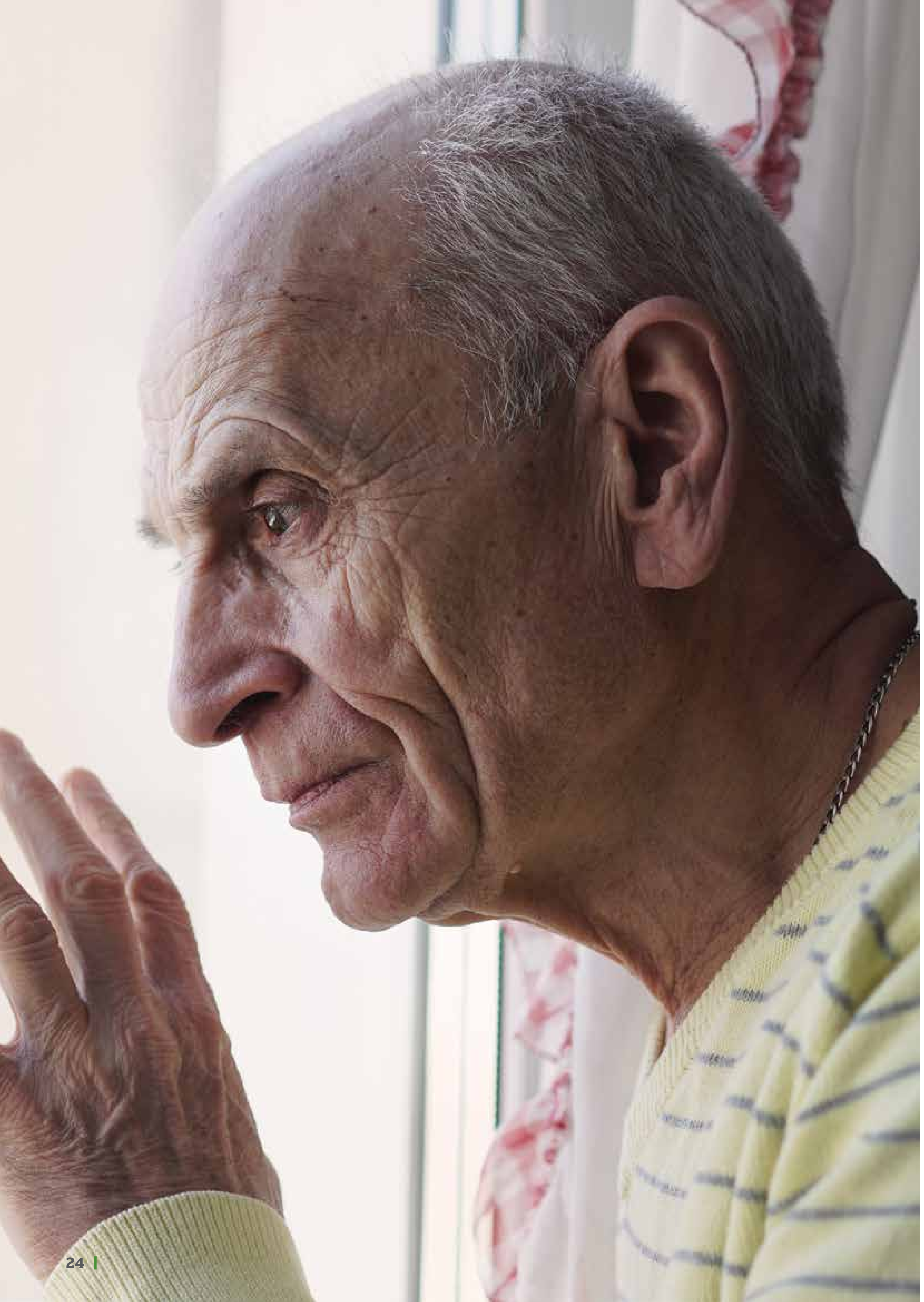
The changes in palliative and end of life care need and operational challenges created by the pandemic also led to innovative new approaches to delivering care and support. Evidence submitted to the APPG made it clear that many clinicians are proud of what was achieved during this time and are keen to sure that lessons are learned from what was accomplished. Three key areas of innovation in palliative and end of life care that emerged in the evidence were:

- rapid adoption of new guidelines and approaches to working.
- changes around prescriptions and the administration of medicines.
- an expansion in out-of-hours services to meet growing community demand.

Rapid adoption of new guidelines and approaches to working

Submissions described the speed at which new technology, policies, procedures and guidelines were adopted and the benefits that this had, such as enabling more efficient training.[101] Garden House Hospice Care said that the "increased efficiency" in adopting new policies and guidelines "should and could be possible outside of the pandemic".[102]

Margaret Gibbs, Lead Palliative Care Pharmacist at Ashtons Hospital Pharmacy Services, also outlined the value of the rapidly available expert guidance, with an increased focus on symptoms more prevalent in COVID-19 patients, provided by the Association for Palliative Medicine in the early weeks of the pandemic. She explained that the speed at which guidance was made available allowed them to support healthcare professionals in a timely way, and hoped that this experience would influence "work on creating guidance from experts without the protracted timescales involved".[103]



> *"The rapid implementation of technology and acceleration of policy development (e.g. family carers being able to administer subcutaneous medication for symptom control at end of life) has demonstrated that change can be instigated quickly and effectively when required. This is encouraging and reminds us to challenge the status quo within clinical practice."*[104]
>
> *Submission by University Hospitals Dorset NHS Foundation Trust*

Prescriptions and the administration of medicines.

Innovation in anticipatory prescribing during the pandemic made it easier for palliative care medication to be delivered flexibly, outside of acute settings and by a variety of professionals. Anticipatory prescribing is when injectable medicine is prescribed or dispensed prior to clinical need to enable visiting medical professionals to administer the medicine when it is required.[105]

In April 2020, the Department for Health and Care and NHS England (then NHS England and Improvement) temporarily permitted medicines prescribed for one patient to be used for another in care homes and hospices and introduced guidance to support providers with implementing this.[106] Margaret Gibbs, Lead Palliative Care Pharmacist at Ashtons Hospital Pharmacy Services, explained in her evidence how, normally, many doses for medication may be dispensed in case a patient needs them at end of life and, if they are not needed, are generally destroyed.[107]

> *"The Royal Pharmaceutical Society took the unusual step of advising pharmacists that during the pandemic, they could consider solutions that may be outside the usual regulatory structures…to be able to use our expertise in dealing with urgent situations in patients best interests was genuinely one of the highlights of my career."*[108]
>
> *Submission by Margaret Gibbs, Lead Palliative Care Pharmacist at Ashtons Hospital Pharmacy Services,*

Essex Partnership University Foundation Trust developed an anticipatory formulary of medications in line with national guidance, which was reviewed weekly, and held anticipatory medications as stock within the ward to ensure patients had quick and effective access to drugs.[109] In their evidence, Gibbs also called for the permanent relaxation of Home Office licensing regulations to enable nursing and care homes to keep a minimal stock of drugs that might be needed at end of life.[110] Practitioners who participated in a 2020 survey of clinicians across the UK and Ireland also called for a centralised stock of anticipatory medication to ensure people can access drugs when they need them.[111]

> *"In Southampton we worked closely with a Primary Care Network to devise emergency drug grab packs that could be prescribed and given by GP's and other non-medical prescribers assessing patients dying at home from COVID. GP's assessed patients remotely and anticipated Just in Case medication that might be required; drugs were immediately available in patients' homes preventing delays and the need for families to go to pharmacies."*[112]
>
> *Submission by the Mountbatten Group*[113]

Another impact of the pandemic on prescription and administration of medication was the increased flexibility with regards to who delivered medication. The Mountbatten Group described the introduction of a Patient Group Directive to allow nurses and paramedics to administer symptom control medication at end of life, including in people's own homes or care homes, without requiring a patient-specific prescription. This led to a reduction in calls to General Practice, 111 and 999 as well as admissions to the hospice for symptoms control, enabling more people to die in the community.[114]

NICE Guidance on managing COVID-19 released during the pandemic also suggested that "family members be considered as an alternative option to administer medications if they so wish and have been provided with appropriate training"[115] It is more common for family caregivers to administer anticipatory medication in rural Australia but rare in many other countries. It has been argued that there is a risk that family caregivers may feel "under pressure to undertake tasks for which they do not feel prepared or confident" and "may feel a tension between their emotional involvement and this clinical task".[116]

In her oral evidence, Michelle Denyer, who works in health and care, lives in Derbyshire and cared for her husband Trevor at end of life during the pandemic, explained how she requested that she be able to administer medication to Trevor after experiencing delays in district nursing arriving to administer his morphine.

> *"One time we were waiting like four hours for someone to give him some medication. I know in the great grand scheme of everyday life…if someone said I could see you in four hours' time you'd think wow, amazing, but if your husband was, you know, on his hands and knees with his head on the bed, not really, not being able to breathe, not knowing what to do with himself and someone said I'd come in four hours you wouldn't think that was ok."*
>
> *Oral evidence submitted by Michelle Denyer*[117]

However, Michelle also said she felt a lot of pressure because, whilst the hospice supporting Trevor had a policy in place to enable family to administer medication, they had not used this policy before. Every time she rang the hospice before administering medication, the professionals answering the phone expressed concern and surprise that that she was administering Trevor's medication.[118]

> *"I felt very much like I was…this trial really and that felt really onerous on me that, you know, they hadn't done it with anyone before and I kind of thought, I don't want to mess this up for other carers who might want this opportunity."*[119]
>
> *Submission by Michelle Denyer*

Michelle described how once, after calling the hospice at 4am, they said Trevor needed some haloperidol but there was none available in her box of medication. She asked the hospice if she could take an ampoule from the nurse's box, which was also kept at their house, and the nurse was "absolutely horrified". Michelle found this upsetting as she knew how to administer this medication but wasn't allowed to. She was further distressed when four different healthcare professionals said to her the next day that they would have just used the haloperidol from the nurses box.[120] Michelle also raised how she was left with all of Trevor's medication after his death and that none of it was ever collected.[121] The Medicines & Healthcare products Regulatory Agency should explore how end of life care medication prescribed to someone who has died might be recycled to avoid waste.

Mary Hopper, who cared for her mum as she was dying in 2020, explained how the District Nursing team got angry at her father, after he gave pain medication to her mother, despite him following guidance and recording what he did. He was told that he had done the wrong thing and he could no longer be trusted. Every day after that nurses would come in to count the medication which caused distress for herself and her father.[122]

Innovation in administration of medication over the pandemic was vital in ensuring that those at end of life had their symptoms managed when access to providers was limited. However, Michelle and Mary's experiences demonstrate that it is essential that these reforms are implemented well, regularly assessed, and that families and unpaid carers are well supported. It is also important that providers ensure clear internal communication between staff on changes and guidance, to ensure that staff can properly support families and unpaid carers.

Expansion in out-of-hours services

The Royal College of Nursing described how a huge increase in the need for out of hours care resulted in a 30% increase in evening and weekend staffing levels in a large hospice in South London.[123] In one of the APPG's oral evidence sessions, Dr Matt Sweeting, Director of Care at Farleigh Hospice, shared how the hospice re-organised its clinical services at the beginning of the pandemic and:

- closed all of its in-patient beds and deployed all of its staff as community facing.
- retrained some fundraising and retail staff to do patient-facing work.
- created a telephone advice line managed by shielding staff and an overnight clinical advice line run by specialist nurses.
- started an education programme to train new care staff in the community across mid-Essex.
- created a virtual ward to support people during the second COVID-19 wave.[124]

Dr Kershaw's Hospice also immediately closed its in-patient unit to increase care in the community, extended the hours of its medical advice line from 9-5pm on weekdays to 24/7 and moved from a five-day working week to a seven-day rota.[125] The Mountbatten group said the pandemic accelerated plans to implement a 24/7 coordinating centre in Hampshire, with the hospice's new community model including a rapid 24/7 response service seven days a week with advice and support both over the phone and through home visits if required.[126]

> *"Our new model has reduced pressures in district nursing, primary care and out of hours/111 services; there has been a 53% increase in activity within Hampshire's Community team; 40% of contacts being received at the weekend or overnight."*[127]
>
> *Submission by the Mountbatten Group*

Andrew Randall, Chief Executive of Hospiscare, outlined the importance of out-of-hours and community services from a service user perspective in evidence he submitted in a personal capacity about the death of his foster child.

> *"We have nothing but praise for the hospice, who were supportive of us before our child was admitted and it was vital to have that out of hours lifeline to call when needed. Things always happen in the middle of the night."*[128]
>
> *Submission by Andrew Randall Chief Executive of Hospiscare*

Services have continued to flex and adapt in response to changes in need or available resource or funding during the pandemic. For example, hospices in Birmingham set up a 24-hour face-to-face urgent response service during the first wave of COVID-19. This was later commissioned as an 8am- 8pm face-to-face service, seven days a week, but with 24/7 access to specialist palliative care advice on the phone.[129]

Submissions to the APPG praised the benefits of out-of-hours services but also expressed concerns over the high level of demand for their support and their financial sustainability. St Helena Hospice received 11,326 calls to their 24/7 advice line in three months (April-June 2020).[130] Palliative care clinicians across South Tyneside and Sunderland said that the "out of hours palliative care team have struggled to meet the demand" as unpaid carers need support with caring for people with palliative and end of life care needs, which goes beyond the specific need of the patient. In their evidence, these clinicians advocated for a team of support workers to work alongside qualified staff in the community.[131]

The need for funding for out of hours services was recognised by NHS England (formerly NHS England and Improvement), which announced £5 million in short term funding to enable access to a single point of contact for palliative care, 24/7 specialist palliative care advice and palliative care hubs in December 2021.[132] This funding was managed by Hospice UK.

Furthermore, the experience of out-of-hours care for patients and their families was not always seamless. Michelle Denyer said in her written evidence that out-of-hours district nursing care felt "frustrating and clanky; not individualized, but protocol driven. It may look on paper like the service between day and night is continuous, but it's not there is a gap".[133] It is clear that there is a need for further improvement in this area and scaling up of the models that have proven to be successful.

Recommendations

NHS England should assess and roll-out innovations in the administration of palliative care medication developed during the pandemic and ensure providers are well trained and knowledgeable on any changes.

NHS England must ensure that every unpaid carer administering medication to seriously ill patients at home feels confident, supported and well-informed on procedure.

Integrated Care Boards must prioritise access to high-quality out of hours community services for people with palliative and end of life care needs, for example, by ensuring the services they commission include both a specialist out of hours advice line for professionals and a single point of access for those caring for someone at the end of their life, in line with the new statutory guidance on palliative care.

National organisations should share examples of good practice, innovation and collaboration in providing end of life care with their networks in order to inform others in the sector.

2.3: Adoption of technology

The pandemic had a transformational impact on the delivery of palliative and end of life care and this is particularly evident in the adoption of technological solutions. Technology enabled health and care providers to continue their existing support, led to positive changes in care and facilitated individualised care and collaboration.

The adoption of technology allowed many health and care services to continue their support for people with palliative and end of life care needs in spite of operational challenges. At the beginning of the pandemic, Dr Chris Ainsworth described frequent hospice zoom meetings several times a week to dynamically shape the response to COVID-19.[134] Also in the early days, Hounslow and Richmond Community Healthcare NHS Trust used video calling to support people with palliative and end of life care needs, and those important to them, who did not want health and care workers to visit them at home.[135]

> *"Like many Trusts we purchased iPads to facilitate conversations between patients and their loved ones and encouraged wards to contact family members proactively to ensure they were kept updated."*[136]
>
> *Submission by East Suffolk and North Essex NHS Foundation Trust*

Many service providers, such as St Luke's Hospice in Harrow, used technology to offer many of their services virtually, such as arts and crafts sessions, appointments, physiotherapy assessments, bereavement support and support services to reduce isolation.[137] Garden House Hospice Care commented on the significant uptake of virtual outpatient appointments and how these have become accepted as normal and welcomed by patients who struggle with mobility.[138]

Many submissions commented on how the adoption of technology has led to positive changes in care. Dr Lucy Selman from University of Bristol and Dr Emily Harrop from Cardiff University said it has allowed bereavement services to increase their reach and reach those who cannot attend face-

to-face support or prefer accessing their support online, like young people.[139] St Gemma's Hospice and Garden House Hospice Care said that the development of virtual wards helped to prevent unnecessary hospital admissions and support early discharge from acute settings.[140] Ann Fox, Senior Nurse for Continuing Healthcare in Leeds, said that sometimes virtual appointments can resolve issues more quickly and easily and free up time for face-to-face appointments for those who need it.[141]

Eden Valley Hospice explained how the increased use of technology actually enabled better and more personalised care.

> *"One example was of a patient who was too ill to go home and dearly wanted to see her home for the last time. The social worker went to the patient's home and took her on a live tour of the patient's house. Another family wanted to be able to see their mother as much as possible but due to the pandemic there was restricted visiting. So, with the patients consent a camera was placed so that the family could link in at any time of the day or night to see their mother."*[142]
>
> *Submission by Eden Valley Hospice*

Lewis-Manning Hospice Care used virtual services to connect with patients and address isolation. They were able to secure funding for a virtual service "offering mindfulness, exercise and art sessions, quizzes / coffee mornings, bereavement support and the opportunity for one to one conversations with a nurse". They received "fantastic" feedback from patients for this service. The team also made regular phone calls to patients "with many calls lasting a couple of hours each". While this was often "exhausting" for staff, for patients "this contact was a lifeline".[143]

Other submissions discussed how technology increased collaboration between services. For example, the Leeds Citywide Bereavement Services Forum met more frequently as a result of zoom, which facilitated the sharing of good practice, partnership working and identifying gaps in provision.[144] Garden House Hospice Care found that switching to virtual meetings for their regional multidisciplinary team meetings enabled better attendance.[145] Virtual meetings for service users in Greater Manchester also made it possible to bring together different people, save service users time and increase their engagement.[146] Fully integrated IT systems rolled out across Greater Manchester during the pandemic also meant that prescribing, dispensing and administering medicines was seamless.[147]

Many submissions of evidence highlighted the importance of investment in staff training and infrastructure to sustain and build upon the value of technology and ensure online services are sustainable.[148] In particular, the CovPall study team mentioned the need for investment in technological infrastructure that supports the hospice sector to facilitate remote working and services.[149]

Concerns over the use of technology

In addition to citing the benefits of palliative and end of life care embracing technological solutions, many submissions also expressed concerns over the use of technology and its negative impacts. City Hospice in Cardiff emphasised how important it is that "the use of digital technologies and telephone reviews is proportional to the patient and patient's complaint and that medical care is not negatively impacted".[150]

Several submissions indicated that virtual appointments could lead to poor quality care or patient experience, such as health and care professionals missing signs of a diagnosis. Dr Nadia Khan, of the British Islamic Medical Association, said she felt that relationship building was often more difficult when "across a screen".[151]

> *"Much of my outpatient work is still virtual and this is much less satisfying than seeing patients face to face. I also worry about what I might miss through this one dimensional form of consultation."*[152]
>
> *Submission by Dr Sarah Cox, Consultant in Palliative Medicine, Chelsea and Westminster Hospital NHS Foundation Trust*

George Plumptre, CEO of the National Garden Scheme, provided evidence to the APPG in both a professional and personal capacity, sharing his experience of the death of his mother-in-law Judy Williams. Plumptre called for a "better balance" between telephone and face-to-face appointments and argued that some symptoms like Judy's were "immediately apparent" in-person but "hard to detect by phone".[153] John MacArtney, Marie Curie Senior Research Fellow and sociologist of dying and palliative care at the University of Warwick, also commented that clinicians found it challenging to assess a patient's condition during a phone call and that it was not always possible to switch to video call due to "variations in digital literacy".

A survey of over 2,000 people across the UK with a previous cancer diagnosis, between February and March 2021, by Macmillan Cancer Support and YouGov found that most people with cancer near the end of life (or living with treatable but not curable cancer) conducted consultations with their cancer healthcare team by phone. Although 79% of this group were 'satisfied', 43% would have preferred face to face appointments.[154]

The APPG also received evidence on patients either disengaging from services when they were delivered virtually or by phone or considering these services insufficient. Independent Age's survey of supporters about bereavement support during the pandemic revealed a reluctance among some respondents "to seek support that would be delivered remotely".[155]

Joh Winter, an unpaid family carer of parents with complicated degenerative conditions, who provided oral evidence to the APPG said weekly phone calls in lieu of her father's in-person hospice support and her mother's dementia club, "though appreciated, were no substitute for the in-person services that had been vital to my parents' wellbeing".[156] As a result of a lack of in-person services, Joh "saw an immediate decline in [her parents'] mental health and their actual ability to do the simple tasks they used to do".[157]

In his evidence, John MacArtney made the case for further research into the impact of the shift towards digital and remote services on people with a terminal illness. He called, in particular, for research into "inequalities that may have been created for those without access to computers or those whose first language is not English".[158] The APPG supports this call.

Recommendations

The research community should examine inequalities that may have been created through the shift to remote health and social care services, particularly for those without access to computers or whose first language is not English.

NHS England and Integrated Care Boards should support providers to upgrade their technology and train their staff and volunteers in how to use it, in order to provide accessible virtual services.

3. Long-term impact on the workforce

The health and social care sector had to respond to the changing palliative and end of life care landscape by adapting its ways of working. Health and care workers addressed new challenges in innovative ways, which many providers are keen to see continue. However, despite examples of increased collaboration and innovation, patient experience was still negatively impacted by the pandemic. It is crucial that decision makers and services harness learning from these experiences and ensure it informs future provision.

3.1: Mental health

The APPG received a high volume of evidence demonstrating the impact the COVID-19 pandemic had on the mental health and wellbeing of the health and social care workforce. Reports of trauma among all manner of frontline staff were widespread with some sharing that they felt "permanently scarred" by their experiences.[159] Ambulance staff struggled with witnessing the last contact between patients and their relatives before transportation to hospital, where the patient then died.[160]

Despite being experienced in witnessing death and caring for people at end of life, specialist end of life care providers faced unique and traumatic experiences during the pandemic.[161] St Barnabas House Hospice explained that both the "sheer numbers" of patients dying and the decreasing age of the patients compounded the "emotional work" involved in end of life care. For their hospice, the average time from referral to death of a patient reduced to just 52 days.[162]

Selina Rogers shared that pre-pandemic, patients would be under the care of St Luke's Hospice Plymouth for 19-20 days before death, however following lockdown, it became closer to 5 days, and at times the team lost 2 or 3 patients in a single day.[163] A palliative care CNS shared on behalf of the Palliative Care Team at Barking, Havering and Redbridge Community Trust that the number of withdrawals of ventilation on the respiratory wards was "very hard emotionally to deal with" and had a significant impact on many in the team.[164]

As stated in evidence shared by the Hospice Charity Partnership, the end of life care workforce has "had to absorb all of the additional burdens created by the pandemic and many feel they are part of an unseen group" as their trauma has not been addressed or received public attention.[165]

As discussed in section 1.2, during the pandemic, health and social care providers suddenly had to take on new roles managing operational challenges around infection control, including use of PPE and visitation restrictions. Care staff faced "ethical dilemmas" around social distancing, staff that refused to work with infected patients and having to physically isolate infected patients and residents.[166] Dr Chris Ainsworth shared that hospice staff had to take on a "policing role" around visitation which at times was met with hostility from patients and families.[167]

> *"Throughout this whole Covid experience, what stays with me the most are those conversations with loved ones and family members to say: 'I am really sorry, we can't enable a visit', or if you do it is a one-off kind of hour visit… they have been some of the hardest conversations that I have had in my whole nursing career … you can't help but feel that you have not done enough, even though I know that we have … it just goes against the grain of everything we do."*[168]
>
> *A nurse quoted in research led by the International Observatory on End of Care at Lancaster University and part of the CovPall study.*

This prompted feelings of guilt, moral distress, and even PTSD and other psychiatric symptoms across the workforce.[169] The trauma experienced by health and care workers had a lasting impact on their mental health and ability to continue working, with many experiencing Post-Traumatic Fatigue and struggling with resilience.[170] For many, this is compounded by ongoing struggles to provide care to dying patients while understaffed and under-resourced, and with the continual presence of COVID-19. There is an urgent need for more mental health support for the workforce and recognition of what they have experienced.

Recommendation

National Government should ensure that mental health support is made available to the entire health and care workforce, including non-NHS staff, at a time and place that enables them to access this support. Line managers should also be trained to identity when a staff member or volunteer requires support and signpost them to support services.

3.2: Understaffing and the impact on staff and patients

Due to ongoing understaffing, increased need, and the widespread trauma associated with the pandemic, there are now significant levels of burnout across the workforce. Evidence from hospices details how the workforce has been under “immense pressure” throughout the pandemic.[171] Selina Rogers explained how many staff members at St Luke’s Hospice in Plymouth had to pick up extra shifts to account for shortages and Rowcroft Hospice mentioned the “mental exhaustion” amongst its workforce.[172] Evidence submitted by Lancaster University on experiences of moral distress during COVID-19, found that some specialist palliative care staff turned to potentially concerning habits, such as alcohol consumption, to try to cope.[173]

As the number of COVID-19 cases and hospitalisations reduced, the toll on the mental health of the workforce continued. Hospiscare in Devon shared that this was not only affecting frontline workers but support workers as well, who were having to manage working from home and working virtually, which for some was “immensely difficult”.[174] Leeds Teaching Hospital stated in their evidence that this is a reflection of “the continuous and cumulative burden of uncertainty, unpredictability and clinical challenge over the last 18 months”.[175]

> *“Front line workers are exhausted and cannot see any light at the end of the tunnel.”*[176]
>
> *Submission by the Hospice Charity Partnership*

Burnout, exhaustion and mental ill-health prompted or worsened by the pandemic are driving health and social care staff to leave the workforce and worsening the understaffing of some services.[177] In Greater Manchester, staff absence has been driven more by burned out staff than COVID-19 isolation or sickness.[178] Some hospices are also struggling with retention after an extended period of such extreme working conditions.[179]

Understaffing and burnout are perhaps at their worst for services providing care in the community, where demand has risen steeply. The number of district nurses has declined by nearly 50% in the last ten years and there are now significant delays in the provision of care due to these unfilled roles.[180]

Health and social care staff submitting evidence to this review shared their increasing concerns about the care they are able to provide to patients with such severe understaffing. Some have experienced “moral injury” from knowing they do not have the capacity to address patients’ needs as individuals or provide all of the care they would like to.[181] For some this is triggering them to exit the workforce, as they “don’t want to keep working knowing they are not providing the best care to patients”.[182]

In some areas, due to shortages in community care teams, providers have felt the need to “inform people of the risks of remaining at home and accessing care” and encourage them to access in-patient services instead.[183] Social care staff have also experienced extreme staff shortages and in one case a care home was unable to spare a member of staff to accompany an end of life patient to the hospital. This resulted in poor handover and the patient’s family not being contacted about their loved one’s condition.[184]

Due to the pressures on health and social care staff, they often have not had the capacity to build relationships and shared trust with patients and communities. Dr Nadia Khan spoke on behalf of the British Islamic Medical about the need for health professionals to build trust with patients from the Muslim community, but that this requires time. It was particularly difficult to build trust when the end of life trajectory with COVID-19 was often very sudden, and so staff found it difficult to keep loved ones up to date and news of death often came as a shock.[185]

GP services were also under significant pressure during the pandemic. In July 2021, Professor Martin Marshall, Chair of the Royal College of GPs stated “Even before the pandemic, millions of patients a week were seen in general practice and GPs were already under immense workload and workforce pressures. But these pressures are now unsustainable…We simply do not have enough GPs”.[186] More recently, in July 2022, Professor Marshall shared that the service remains overstretched, saying “GPs don’t have the time or resources to deliver the type of care they want to deliver for their patients”.[187]

This pressure on general practice is reflected in accounts of care submitted to this review. The Queen’s Nursing Institute reported difficulty in getting in contact with GPs via phone lines and St Luke’s Hospice in Harrow found shortfalls in some GP services, citing a lack of knowledge or willingness to engage.[188] Debbie Martin, who cared for her husband Rich who died of Motor Neurone Disease in 2020, shared that she was never contacted by her GP during the time that Rich was under her care, which was a particular point of pain for her. The GP only contacted Debbie, 6 days after Rich had died, to ask if she was happy with the wording on the death certificate.[189]

Understaffing in hospices

The workforce crisis has hit hospices hard. A Hospice UK survey conducted during the pandemic found an average 11% vacancy rate in community nursing roles for adult hospices and an average 7% vacancy rate in adult hospice based nursing roles. These vacancies are representative of what is affordable within current hospice funding rather than the level of staffing required to meet population need. Hospice UK has also said that the sense on the ground is that workforce shortages have worsened since the survey was undertaken.[190]

Evidence submitted to the APPG outlines how shortages have been exacerbated by the pandemic. Hospice of the Good Shepherd shared that long term nursing shortages worsened and at times it has been impossible to find agency staff to fill roles.[191] Hospice wards were “decimated” by staff sickness. One hospice had 50 staff members that had to shield and so could not be patient facing.[192]

There has also been a shortage of volunteers, as many hospices struggled to balance their need for volunteers with the risk of COVID-19 infection.[193] The Mountbatten group shared that the most significant impact of COVID-19 on their workforce was the loss of volunteers supporting clinical areas, as many of their volunteers were aged 70 or over, and/or had underlying health conditions.[194]

While some hospices attempted to involve volunteers in other ways, such as remote befriending or delivering shopping, it likely negatively impacted the volunteers themselves not being able to undertake their normal role.[195] This reduction in attending volunteers put additional pressure on paid staff.[196] The Mountbatten group shared that, at the time of submitting evidence, only some of its volunteer workforce was returning; “on the Isle of Wight c33% of volunteers have come back and in Hampshire c65% have returned”.[197] Volunteers play an important role in making hospice care possible, and the impact of the pandemic highlights the fragility of the hospice workforce.

This evidence shows it is vital that understaffing in the health and social care workforce, particularly those specialising in palliative and end of life care, is addressed. The Hospice Charity Partnership highlighted that newly qualified staff are unlikely to move into palliative care early in their career, making it particularly difficult to address staffing in the sector.[198] Currently, there are not adequate numbers of training posts in palliative medicine to fill current vacancies at a time when the workforce needs to grow to meet demand.[199]

A sustainable funding solution for hospices is necessary to address workforce shortages in end of life care. Hospice of the Good Shepherd shared that following the 3% pay increase announced for NHS staff, hospices are facing staffing issues, as they do not have the funding to offer the same pay. Hospices fear they are unable to compete with the NHS for staff, and therefore the situation in end of life care could "very quickly turn bleak".[200] Hospices must be supported and funded sufficiently to meet the pay, terms and conditions offered in the NHS in order for them to continue to fill their role in the health and care system post-pandemic.[201] This support could be offered through uplifts to ICB contracts to hospices.

3.3: Quality of care

Since the beginning of the pandemic, palliative and end of life care patients and those close to them have noticed how increasingly stretched services have been and how this has impacted the quality of care. Ann Fox explained that when her Mum received end of life care in 2019, the District Nurses service seemed "stretched and under supported" but when her Dad was at end of life in 2020, it was almost non-existent.[202]

Others witnessed a change in the behaviour of staff, describing them as stressed, angry, "harassed and pressured" or "hyper", and noted that stress was negatively impacting their conduct as they were burnt out and overworked.[203]

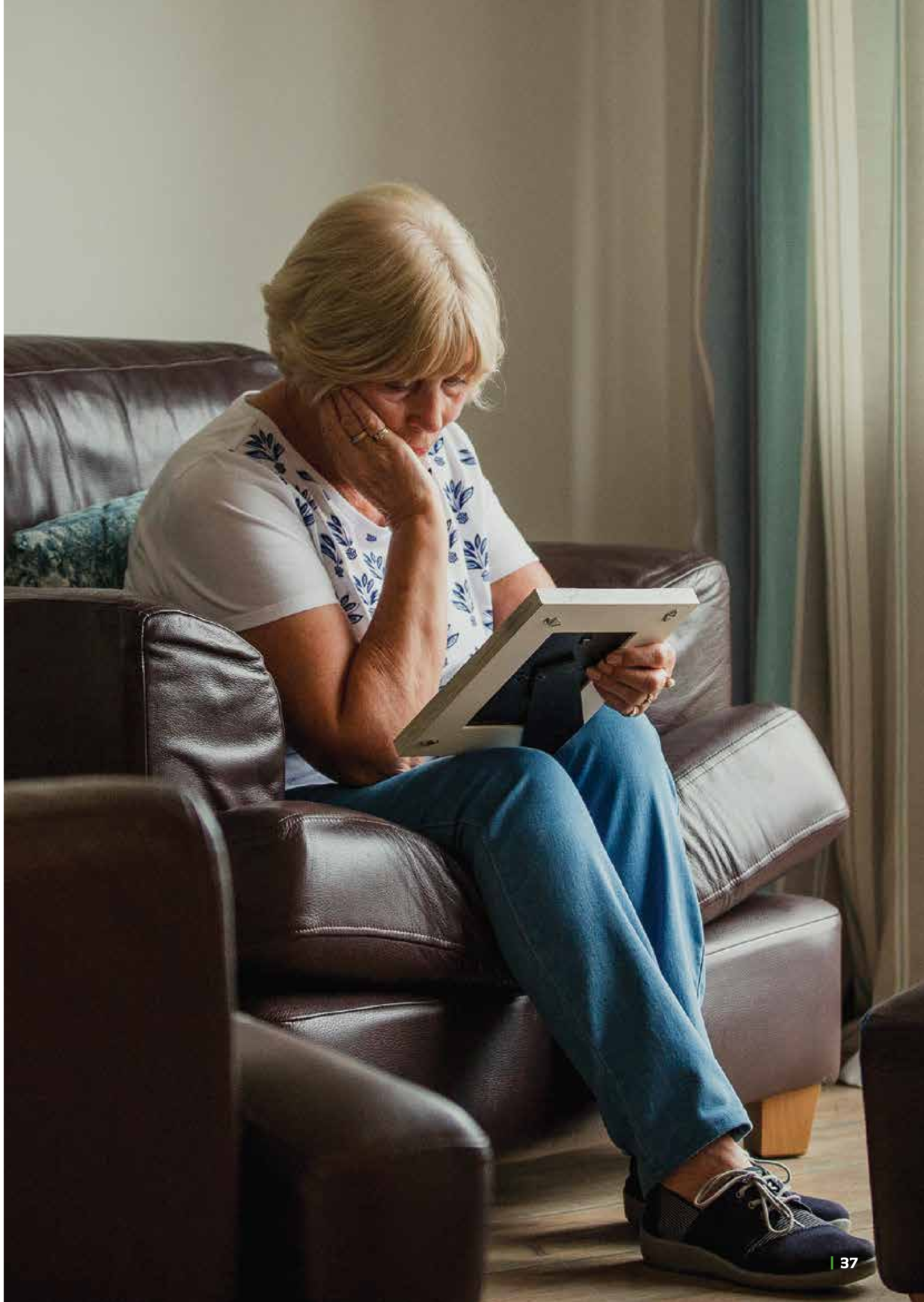
In some instances patients have been put in danger. St Christopher's Hospice's submission included evidence gathered during workshops with current and former unpaid carers in 2021. Carers reported that professionals who came into their home to care for someone at end of life "seemed anxious and rushing to leave, and on occasion did a poor job as a result". In one example, paramedics informed an unpaid carer that the way an oxygen tank had been set up by another professional was a safety hazard.[204]

The APPG also received several examples of poor pain management at end of life. A bereaved woman quoted in Professor Lynn Sudbury-Riley's submission, described how she had to fight for medication to keep her loved one calm, with end of life care medication not arriving until after they had died.[205] Simon Fuller shared that, after his father contracted COVID-19 in hospital, he was discharged home unsafely, while suffering from confusion and "terminal agitation" and had to be readmitted just 6 hours later.[206]

Joh Winter explained in her oral evidence that after signing her very ill parents up to a social care agency, they were sent "a 19 year old with no experience of dementia care" despite the agency being aware of Joh's parents' high-level needs.[207] It is clear that this care worker was not sufficiently trained or experienced enough to support Joh's parents effectively.

Evidence submitted to the APPG suggests that incidences of poor quality care are becoming more widespread. Marie Curie found that three quarters of bereaved unpaid carers felt that end of life care needs for their loved ones were not being met, and in two thirds of cases their pain was not managed.[208] In a survey of 493 UK adults bereaved by COVID-19, COVID-19 Bereaved Families for Justice found that 36% of respondents experienced issues with the standard of care received by their loved one, and 13% had no access to palliative and/or end of life care.[209]

Alzheimer's Society's evidence showed how being under resourced led to inappropriate or insensitive uses of do not attempt resuscitation (DNAR) orders and blanket DNAR decisions.[210] In evidence submitted to the APPG, The Royal College of Nursing referenced the Care Quality Commission's thematic review into the use of Do Not Attempt Cardiopulmonary resuscitation notices, which highlighted shortfalls in how these notices were "introduced and discussed with people, especially those people who may lack capacity, or who are from a Black and Minority Ethnic (BAME) background".[211]



3.4: Changing role of generalist workforce

The increase in death since the beginning of the pandemic, including in the community, has led to the generalist health and social care workforce taking on increased responsibilities in providing end of life care with little preparation.

> *"Ambulance service had to absorb the increase in calls for deceased patients as no other services are commissioned to verify deaths in their area. With such calls taking in excess of an hour to conclude this depleted the resources available to respond to 999 calls."[212]*
>
> *Submission by the Association of Ambulance Chief Executives*

Community nurses have had to take on additional responsibilities such as completing do-not-resuscitate forms and verifying death certificates.[213] The Queen's Nursing Institute explained how end of life care has been delegated to staff in a way that felt "inappropriate and unsafe for the job", which felt like a "big red flag for safety of patients and staff".[214]

Many staff had to be redeployed during the pandemic and were thrust into roles in which they did not have experience. Year 2 and 3 Adult Nursing students were asked to undertake extended clinical placements to help meet increasing demand on health care services. Before the pandemic, nursing students had expressed that they did not feel prepared to provide end of life care as part of their clinical placements.[215]

> *"I'm operating outside of my comfort zone and I'm always worried I'm not getting things right."*
>
> *A redeployed consultant Physician quoted in Care of the dying person before and during the COVID-19 pandemic: A quality improvement project.[216]*

Individuals bereaved during the pandemic noted a lack of sufficient training in end of life care among generalists supporting people close to them. Mary Hopper, who cared for her mum who died of cancer in 2020, told the APPG that her mother's GP seemed "so uneducated about palliative care symptom control" and had no specialist palliative care providers to contact for help.[217] Debbie Martin, who cared for her husband Rich who died of Motor Neurone Disease in 2020, shared with the APPG that her husband's care was at times delivered by generalist carers who simply washed and dressed him and did not care for him as an end of life patient.[218] Evidence submitted by St Christopher's Hospice from their workshops with unpaid carers detailed an incident in which healthcare staff seemed unable to recognise or accept signs of dying processes, attempting resuscitation on a patient that the unpaid carer had perceived to have died ten minutes before, with the carer having to intervene, asking them to stop.[219]

The APPG also received evidence of a lack of understanding of advance care planning. When Simon Fuller repeatedly called the hospital where his father was being cared for to discuss transfer to a hospice, he was asked why he thought his father was at end of life. An end of life care plan had been put in place after a previous hospital admission and he died four days after this conversation. Simon said that there was a breakdown in communication between teams in the hospital and a resistance to accepting that his father was at end of life.[220]

Residential care home staff in particular have had to deal with a sharp increase in their involvement with end of life care due to a spike in deaths among residents.[221] One care home staff member recalled being asked if the home had a "cold room to keep the bodies in".[222] Care workers felt a lack of preparedness as guidance provided over the pandemic did not always include information on providing palliative and end of life care.[223] At times, care workers moved into the residential home in order to best manage the care of dying patients.

> *"In every case, recounting the impact of the pandemic on themselves, their staff, their families and their residents reduced the care home managers to tears."[224]*
>
> *Submission by Professor Stephen Barclay, Palliative and End of Life Care Group at the University of Cambridge*

The APPG received evidence that care home staff often did not have the confidence to use palliative drugs on their residents, Professor Lynn Sudbury-Riley provided an account of a woman trying to get her loved one, who was in a care home, correct end of life care, where staff were not aware of the need for anticipatory medication and were not able to take extra measures to keep her comfortable and calm.[225] As highlighted in section 2.2, use of anticipatory prescribing was expanded during the pandemic and there was significant innovation in this space. There remains a need to ensure this is understood throughout health and social care.

This influx of death in the pandemic has exacerbated historic challenges for care home staff, including inadequate staffing and a lack of access to end of life care training.[226] Evidence submitted to this review details support and training that hospices and other specialist end of life care providers have been providing to the generalist workforce in order to ensure they are able to provide care to dying patients to the best of their ability, and are able to cope personally. There is a clear opportunity to build upon innovation in this area to upskill the generalist workforce in end of life care.

Lesley Spencer, Palliative Care Ambassador at Ashtons Hospital Pharmacy Services responded to the need for additional support and training in generic care settings by encouraging experienced visiting pharmacists to take the European Certificate in Essential Palliative Care. This upskilling has allowed some pharmacists to "take a more proactive role in supporting medicines management within the Hospice sector".[227]

Hospice of the Good Shepherd set up webinar sessions to support nursing homes and saw good attendance, while Farleigh Hospice started an education programme to train new care staff working in the community.[228] At King's College Hospital NHS Trust the palliative care team developed clinical guidelines for the care of people with COVID-19, and supported this by delivering teaching delivered "to over 500 nurses and junior doctors over a 6-week period during March-April 2020".[229] South West London CCG highlighted how valuable the support of hospices has been to other care providers, which included a swabbing training video and training on the verification of expected death for care home staff.[230]

The evidence suggests that training like this has been well received and of benefit to care providers. A study by Lancaster University found that care home staff who completed training in advance care planning felt more skilled and able to carry out their role.[231]

In particular, the training and support offered by hospices has been incredibly valuable and facilitated collaborative working between specialist and generalist health and care staff. Many hospices are looking to continue to offer this support, however, with limited resources and insecure funding there is concern over how sustainable this may be. Saint Francis Hospice in Essex has been providing guidance, equipment and support to generalist care staff but has found the demand hard to meet.[232] Hospices need to be supported to continue, and expand, the support and training they offer based on their specialist palliative and end of life care experience.

It is clear from the evidence that generalist health and social care staff at all levels need basic training in how to support people who are dying. As set out above, the number of deaths in 2020 is set to be normal in 2031. As the need for end of life care increases, the generalist workforce will need to play a more significant role in palliative and end of life care and must be supported to be able to do so in a way that is safe and positive for patients and staff.[233] As more and more people die, specialist palliative care services will need to be reserved for those with the most complex symptoms.

Recommendation

National Government and NHSE should ensure that all health and care staff have the training they need to support people who are dying, and their loved ones. All health and care staff training programmes should prioritise palliative and end of life care and palliative and end of life care training within courses needs to be delivered consistently across different providers.

3.5: Sustainability of palliative and end of life care funding

End of life care in the UK is currently delivered by a patchwork of public, private and not-for-profit services. Funding for end of life care in England is also heavily dependent on where you are based and who cares for you at end of life. For example, if you die in a hospital, your care is fully funded by the NHS. If you die under the care of a hospice, your care is free but largely charitably funded. If you are supported by social care, you either have to pay or, if you are eligible, your care is funded by your local authority. The pandemic exposed the cracks in this system and led to hospices requiring further Government support to survive and significant financial pressure on unpaid careers.

Providers

Prior to the pandemic, an average of 34% of adults' hospice funding and 18% of children's hospice funding came from the Government, with hospices across the UK having to raise £3.1m of charitable income every single day.[234] As most hospices have to raise the majority of their funding from charitable donations, they have to be increasingly concerned about fundraising and staying afloat financially, which can be a distraction from priorities in the provision of care.[235]

Evidence submitted to this review detailed how the COVID-19 pandemic made fundraising even more challenging for hospices. As charity shops had to close during lockdown and in-person fundraising events had to be cancelled, hospices experienced a massive decrease in their income whilst facing unprecedented demand for their services.[236] One hospice's overnight sitting service had to end due to lack of funding to sustain it, highlighting how dependent these services are on charitable donations.[237]

Over the pandemic, NHSE (formerly NHS England and Improvement), supported by Hospice UK, distributed £390 million in grant funding to hospices across the UK to buy extra capacity from the hospice sector and prevent the NHS being overwhelmed.[238] An assessment of the first tranche of COVID-19 funding provided to hospices in England between April and July 2020, found that, in return for the initial grant of £155 million, the NHS received the benefit of £323 million in capacity.[239] This demonstrates how hospices can alleviate pressure on the NHS and add value to the wider health and care system.

Hospices said this funding was "very welcome", and things could have been "bleak" without it.[240] Now that this emergency funding has stopped, hospices once again struggle to raise sufficient funds to provide care for the growing number of people who need palliative and end of life care, including those whose more complex symptoms are a result of missed diagnoses during the pandemic. Hospices are also facing additional costs recovering from COVID-19 and using IT to provide modern, accessible care.[241]

Unpaid carers

Joh Winter had to give up her job to provide care and support to both her parents for 24 hours a day, seven days a week. She only received £67.60 in Carer's Allowance per week, which was then stopped within two weeks of her being unable to continue providing care due to the mental health crisis she was experiencing.

> *"I am now struggling to pay my bills after depleting my savings following two years of attempting to survive on the equivalent of 40 pence per hour for a 24/7 job for which I was given an 'allowance' of £67.60 a week. Carers Allowance was stopped within two weeks of me no longer being able to care for my parents and I have had no income since."*[242]
>
> *Oral evidence submission by Joh Winter*

Recommendations

Integrated Care Boards should review how specialist palliative and end of life care services in their area can alleviate pressure on the NHS.

Employers should implement measures that support staff who also work as unpaid carers and increase their likelihood of remaining in the workforce, such as becoming a Compassionate Employer. Employee support programmes such as this should work together in collaboration.

The Government should conduct a review of hospice funding in England, akin to that conducted in Wales, and work with hospices and Hospice UK to devise a sustainable funding solution for the hospice sector in England.

4. Long-term impact on families and unpaid carers

4.1: Experiences of unpaid carers

Families and unpaid carers took on significant additional caring responsibilities over the pandemic. Evidence from providers of end of life care noted that delays in the provision of care across the system resulted in an increased reliance on unpaid carers, which has had a massive impact on their lives.[243] Carers UK reported that 74% of carers are "exhausted" as a result of their caring responsibilities.[244] Following their workshops with unpaid carers, St Christopher's Hospice found that many were experiencing a drop in motivation, felt isolated and had taken on poor eating habits due to the stress. Former carers also expressed guilt at not being fully equipped to navigate the changing environment or meet their loved ones' high-level care needs.[245]

Many services that provide support, information and respite for unpaid carers closed during the pandemic due to infection control restrictions and a lack, or reallocation, of resources. Evidence submitted to this review suggested that by the end of 2021, many services still had not been able to resume.[246] Some attempted to take their support services online but found that unpaid carers struggled to access this and lost out on the value of leaving the house to attend in-person services.[247] This meant that the responsibilities for those caring for someone at home with end of life or palliative care needs became "more than a full time role", with unpaid carers having to take on clinical tasks, social care needs, navigate the changing system and access food and medication within restrictions.[248] Mary Hopper explained that when caring for her mother, she "wasn't able to be her daughter" due to having to take on much of her care.[249]

In evidence submitted to this review, Together for Short Lives explained how, despite being exhausted, many unpaid carers for children with terminal or life-limiting conditions felt they had to carry on shielding even after restrictions ended to protect the vulnerable child or young person. This suggests that many unpaid carers may have continued to face the same burden of care for much longer than expected.[250]

Joh Winter explained how, after the pandemic began, and the hospice and dementia club that supported her parents both closed, she had to take on "every single aspect" of her parents care, being "on duty" 24 hours a day, seven days a week. This added pressure took a significant toll on Joh's wellbeing, causing a "spiral of bad mental health" in which she struggled to sleep, eat and take care of herself and her parents.[251] Despite receiving respite from her caring responsibilities, Joh's mental health has not recovered and she continues to be impacted by what she experienced during the pandemic.

Debbie Martin had to take on the majority of her husband's care, and expressed how isolating this was. Debbie also expressed concern to the APPG that many people far older than herself would likely be having to deal with similar responsibilities, and wondered how they would cope.[252]

In some cases, specialist clinical expectations were placed on unpaid carers, such as sharing information on specific prescriptions between the hospital and GP.[253] Those with experience in health and social care also found they were given additional responsibilities and expected to understand and take on vital aspects of care with no communication from staff.[254]

A particular point of trauma for many unpaid carers was how little information they were given about the process of dying, despite it being known to health and care staff that they would be caring for the patient throughout. Ann Ashworth, who was bereaved when her mother died of COVID-19 in 2021, shared that herself and her brother were not informed of symptoms that were likely to occur as their mother declined, and therefore had to manage her night time agitation and attempts to climb out of bed with no warning, information or support.[255]

Maureen Anderson, carer of her Mum and Dad, who died at home in summer 2020, also expressed that she felt there had been an assumption that her family had knowledge about death that they did not have, and therefore they were not told anything about the dying process and what this might look like when caring for their parents. Reflecting on her experiences, Maureen felt there were things she would not have done, or would have done differently to manage her mother's symptoms if she had the appropriate information at the time.[256]

Some unpaid carers and family members were not given sufficient information on their loved ones prognosis or how long they may have left to live. Ann Ashworth explained how her mother's discharge letter said she had "weeks or months left to live", therefore when she died three days after discharge this came as a "terrible shock".

> *"Although he knew her death was inevitable when it came it was a huge shock with profound and lasting consequences for him."*
>
> *George Plumptre, on the impact the lack of information about his mother's prognosis had on his father.*[257]

Some providers produced resources on specific procedures, such as giving subcutaneous injections, to support unpaid carers with their increased clinical burden.[258] However, for the most part unpaid carers were left alone with no way to reliably access support or information on their loved one's condition and how to care for them.

Recommendation

Integrated Care Boards must assess the post-pandemic need for, and availability of, services, which provide respite for unpaid carers and reinstate services closed due to COVID-19.

Furthermore, as recommended in section 3.4, National Government and NHSE should ensure that all health and care staff have the training they need to support people who are dying, and their loved ones. This should include training to ensure, those closest to an end of life care patient are properly informed of the patient's prognosis, common symptoms experienced when a patient is actively dying, how to manage this and where they are able to access help and support.

4.2: Traumatic bereavement

During the pandemic, many were bereaved under traumatic circumstances. Bereaved carers expressed an "intensified sense of guilt", anger, as well as complicated or traumatic grief. For many, their grief was magnified as they could not access their support networks and many were already experiencing isolation and loneliness.[259] Some have also questioned whether, if the circumstances had been different and the pandemic had not been a factor, their loved one would have died at that time or in the way that they did, which has also impacted their grief.[260]

For those whose loved one died in a hospice, hospital or other facility that was restricting visits, many did not get the opportunity to say goodbye to their loved one.[261] The National Bereavement Alliance and Childhood Bereavement Network found that among those bereaved by COVID-19, 85% were unable to say goodbye to their loved one as they would have liked.[262] Healthwatch Suffolk used a survey and telephone interviews to gather the experiences of people who had been bereaved during the pandemic. One bereaved person explained "My mother is now wracked with guilt that she wasn't present at my father's death".[263]

> *"The fact that we couldn't see her all of this time in my mind was what caused her death, she just gave up as she couldn't understand why my sister and I couldn't see her every day like before."*[264]
>
> *Bereaved person quoted in Healthwatch Suffolk's submission*

When loved ones were given an opportunity to say goodbye this was particularly shocking and traumatic as they had not been able to witness their deterioration due to having little contact with their loved one.[265] Furthermore, the lack of visits and strained communication from health and social care staff meant that some bereaved individuals feel they lack information on what medically happened to their loved one. Linda's husband died in hospital of COVID-19. Her first contact with the palliative care nurse was late the day before her husband died and while she was told he was going to die, she had no knowledge of how things would happen or how long it would take. Linda expressed that this lack of information on the medical detail and order of events of her husband's death is interrupting her grieving process.[266]

Evidence submitted to this review by Sands detailed the experiences of bereaved parents who experienced stillbirth or neonatal death during the pandemic. Due to restrictions, partners were excluded from appointments and scans, meaning mothers were left to receive bad news about the death of a baby, or make difficult decisions, alone. This led to increased feelings of isolation for the bereaved parents.[267]

Following a bereavement, pandemic restrictions caused further trauma.[268] Dr Chris Ainsworth explained that there was "no official guidance on how to reliably contact a registrar over the weekend to allow a funeral to take place in a timely fashion" which was particularly problematic for Muslim communities.[269] Normal practice changed, including care after death, which was distressing for many as their contact with the deceased was restricted. Nurses had to advocate for deceased people and their families when they needed timely access to religious rituals and specific aftercare of the body.[270] Despite their best efforts, normal grieving processes for many cultures were often impacted.[271] Alzheimer's Society found that unpaid carers and people living with dementia from south Asian and Afro-Caribbean backgrounds found COVID-19 "heavily impacted funeral arrangements".[272] The impersonal nature of remote funerals and the restrictions on attendance made it difficult for many to process their grief and also limited opportunities for face-to-face support.[273]

> *"These have not been normal deaths and the grieving process isn't 'normal'."*
>
> *Submission by Linda L, whose husband died of COVID-19.*[274]

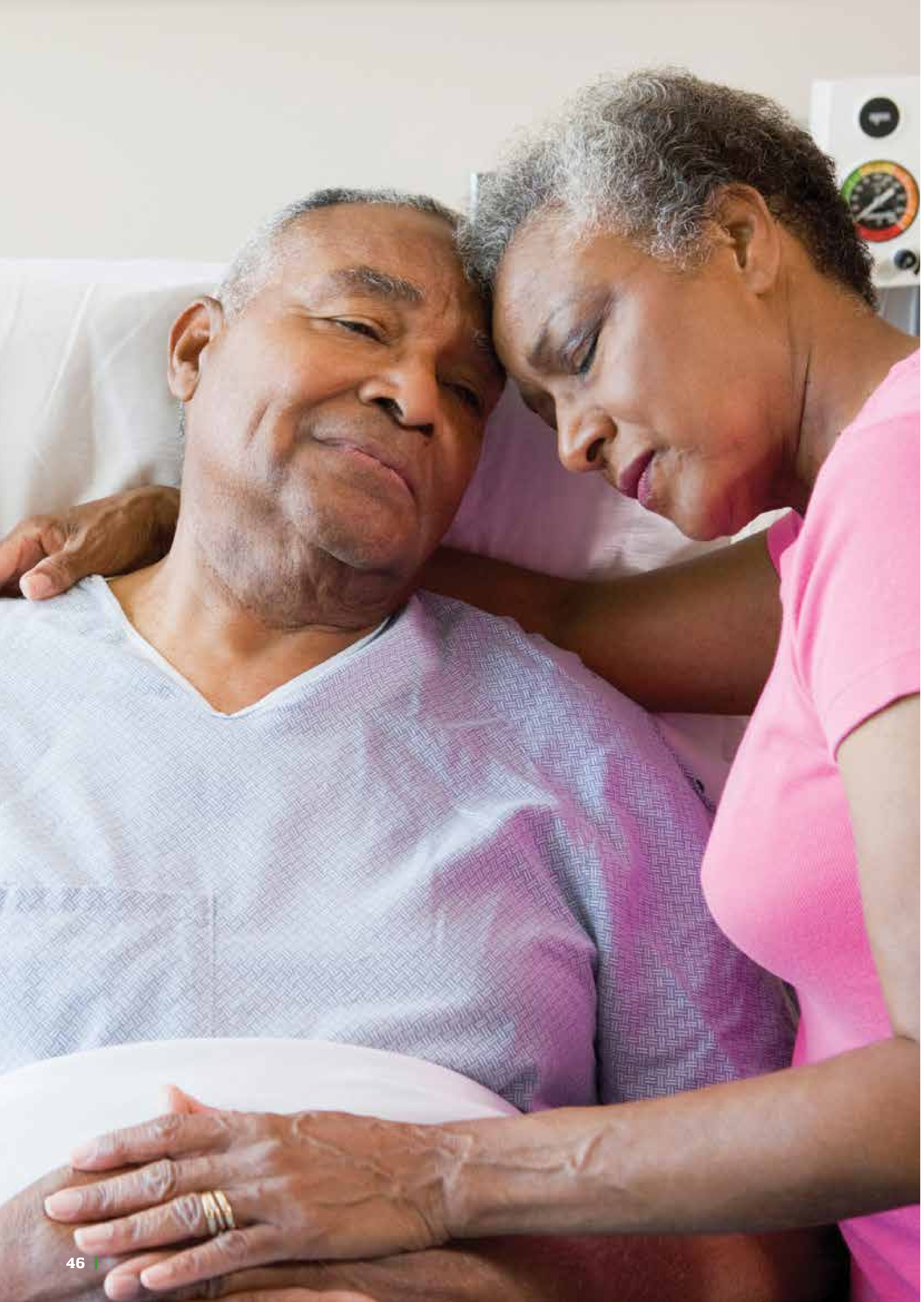
The trauma involved in pandemic bereavements has resulted in an increase in complex grief disorder, with more and more people being vulnerable to PTSD and other complications.[275] Professor Lynn Sudbury-Riley's research found that many bereaved respondents required medical intervention due to their bereavement, suffering flashbacks, "brain fog" and symptoms of prolonged grief disorder.[276] The effects of this will be serious and long-lasting.[277]

Despite this significant increase in complicated and traumatic grief, the APPG received evidence that there were insufficient services to support people. Ann Ashworth explained that neither herself, nor her brother, were offered any information on accessing counselling or support after their mother died.[278] Professor Lynn Sudbury-Riley and COVID-19 Bereaved Families for Justice both said that some who attempted to access bereavement support were met with inadequate or inappropriate services for the complexity of their grief.[279]

Recommendations

Health and social care staff must receive culturally-informed training in bereavement, particularly how to identify those at risk of complex grief disorder, PTSD and others in need of additional support. They must also be able to signpost those individuals to appropriate support and services.

Integrated Care Boards must commission and fund bereavement support services specifically to support those experiencing complex and traumatic grief and take action to ensure there is wider bereavement support in their areas.



5. Long-term impact on communities

5.1: Large scale bereavement

The pandemic saw a rise in deaths and, as a result, a significant increase in the scale of bereavement, as well as its complexity.

> *"Across England and Wales, 614,000 people died during 2020 and 2021, leaving an estimated three million people facing bereavement. This is 75,000 more deaths than the average across the previous five years - with an estimated additional 375,000 people left bereaved as a result of the pandemic."*[280]
>
> *Submission by Marie Curie*

Bereavement rates were particularly high in certain demographics, for example, up to 318,000 people aged 65+ were bereaved in the period between March 2020 and May 2021, with this bereavement more likely to have been traumatic.[281]

The sheer size of this wave of bereavement and the way society reacted to it had an impact on the bereavement of individuals. For many, their processing of their grief was complicated by the wider conversation around the pandemic and the prevalence of insensitive conspiracy theories.[282] In 2021, a poll by Sue Ryder found that 59% of people who were bereaved during the pandemic felt as though their grief had been forgotten amidst the global crisis.[283]

The evidence submitted by the LGBT Foundation provided information on how the pandemic uniquely affected LGBTQ+ communities. For many, trauma from the HIV/AIDS pandemic resurfaced during COVID-19, as well as feelings of grief from bereavements of that time. Many also found it particularly difficult to think about how differently this pandemic was treated in comparison to the HIV/AIDS pandemic and what that meant for their communities.[284]

Services have had to adapt to this changing need and address a "Tsunami of grief".[285]

Dr Lucy Selman and Dr Emily Harrop found in a survey conducted March-May 2021 that referrals for bereavement support increased for 46% of organisations, with 40% reporting a waiting list of over 3 weeks. This limited availability of services provided a barrier to bereaved individuals getting the support they need.[286]

Throughout the pandemic, voluntary and community bereavement services were developed or expanded to try to meet this need. According to the National Bereavement Alliance and Childhood Bereavement Network, in September 2020, "41% of voluntary sector bereavement service managers were already reporting an increase in the number of people seeking their help".[287] In response to the increased demand for bereavement support, St Barnabas Hospice developed a self-referral telephone bereavement support service, which was made available to the public in Lincolnshire.[288]

Aside from expanding their reach, 78.2% of bereavement services changed their services due to COVID-19 and 51.7% introduced new services, such as walking groups and bereavement cafes.[289] This also applied to Wales, where City Hospice expanded their number of counsellors and diversified their services, including music and art therapy, to meet the needs of the population.[290]

Despite the hugely positive work done by hospices and other community organisations, they cannot address the huge growth in need for bereavement support alone. If not addressed, this wave of bereavement "may lead to significant physical and mental health morbidity and create a further burden on health and social care services".[291] Dr Lucy Selman and Dr Emily Harrop found that more than two thirds of UK voluntary or community bereavement services are aware of inequities relating to who is accessing their support.[292]

A 2022 survey in Sue Ryder's 'A better route through grief' report found that 70% of respondents reported they could not access the support they would have liked after experiencing a close bereavement. Furthermore, almost 1 in 5 people cited that the barriers preventing them from accessing formal support were a lack of culturally-relevant services and because the service could not be provided in their language.[293]

"The pandemic has highlighted the need for bereavement care to be considered an integral part of health and social care provision".[294]

Independent Age argues that there is currently "no clear responsibility" for the provision and commissioning of bereavement support services.[295] There is now an opportunity to take a system based approach to these services and so provide more consistent coverage and meet demand.[296]

The UK Commission on Bereavement was launched in response to the increased bereavement during the pandemic and released a report in October 2022. The commission found that over 40% of those who wanted formal bereavement support did not receive it. The report highlighted the wide-ranging impacts of grief and how this this was affected by the pandemic. It set out recommendations to improve experiences of bereavement and this APPG supports and echoes these recommendations.[297]

5.2: Public conversation around death

One aspect of the pandemic noted in much of the evidence submitted to this review is the increased openness around death, dying and bereavement due to the pandemic and the positive and negative impacts this has had throughout society. Evidence submitted to this review noted an "increased openness" to talk about death and dying.[298]

> *"During Covid people had to face death as a daily reality, in the media, in their locality and in their own homes. As a nation we have been forced into talking about death and facing up to it in a way that has not happened in my lifetime."*[299]
>
> *Submission by Lesley Spencer, Palliative Care Ambassador at Ashtons Hospital Pharmacy Services.*

As such, there have been increased opportunities for dialogue around living with death and loss, and this has helped achieve greater understanding of grief and bereavement.[300] For example, due to increased need and visibility, conversations around bereavement and mental health have opened up in Muslim communities in a way that was not there before the pandemic and Muslim organisations such as the British Islamic Medical Association, and faith leaders have facilitated this.[301]

This increased awareness and openness around death has also led to practical improvements in access and care. The pandemic made many feel vulnerable, and there is evidence to suggest this was linked with an increase in thinking about death and advance care planning.[302] The Association of Palliative Care Social Workers included the experience of a social worker, serving a community where the discussion of death was "traditionally avoided". They reported that people became more willing to engage in planning for end of life.[303]

Evidence submitted to the APPG by Greater Manchester's Palliative and End of Life Care Strategic Clinical Networks, cancer services and hospices argued that society's understanding of what a "good death" is has developed, and more people have begun interrogating what this would mean for them.[304] The pandemic has also brought about a recognition of the need for advance care plans and access to palliative care for non-cancer patients, shifting perspectives on who end of life care is for.[305] Some hospices have also reported greater recognition and uptake of their community care services.[306]

The British Geriatrics Society noted that there has been more discussion of how older people want to spend their last days, and the "benefits and burdens of aggressive hospital treatment" and felt this had a positive impact on planning for better, individualised end of life care for older people.[307]

While the majority of evidence submitted on this topic discussed the positive community support that came out of the pandemic, some also found that the prevalence of discussions about death was difficult to manage and at times handled with insensitivity. COVID-19 Bereaved Families for Justice reported that increased conversations around COVID-19 and death often included conspiracy theories, which was difficult for some to deal with.[308] Participants in Professor Lynn Sudbury-Riley's study also commented on how social media amplified negative feelings.[309]

In later stages of the pandemic, discourse around the "new normal" and "freedom day" increased, and many people affected particularly negatively by the pandemic "for whom life does not feel to be normal" found this particularly difficult.[310]

It is vital that we seize the opportunity presented by increased awareness of death, dying and bereavement to ensure that the conversation is positive and leads to more people being able to seek support in bereavement or prepare appropriately for end of life.

Recommendation

The Government should fund a national public information campaign on bereavement and breaking down taboos around talking about death and dying. This campaign should take a cross-sector approach and unite all the groups and organisations that have a role to play in bereavement support.

Conclusion

This APPG received evidence from across the health and social care sector demonstrating the vast and varied impact of COVID-19 on death, dying and bereavement.

This review has found that the COVID-19 pandemic reshaped the palliative and end of life care landscape, accelerating the increasing mortality in the UK and the shift towards death in the community, as well as introducing new challenges around infection control.

As a result, health and social care providers adapted, and collaboration and innovation in the sector sky-rocketed. It is important that we recognise that this capability to innovate remains and collectively work to ensure that progress made is continued.

Despite the positive work in the sector, and the best efforts of the workforce, the pandemic had a significant and persisting negative impact on death, dying and bereavement. The evidence presented in this review shows a workforce at breaking point, coping with trauma and burnout with increasingly dwindling numbers. Hospices in particular are struggling to find the resource they need to provide care to their population.

In some instances patients are not receiving the care they deserve at end of life, and this has had, and continues to have, a huge impact on their loved ones, carers and wider community.

The pandemic had a significant impact on death and dying, but this evidence makes it clear that a lot of what made death during the pandemic so traumatic and unmanageable will continue without intervention. It is essential that National government and NHS England recognises the current situation as it is laid out in this review and undertakes this APPG's recommendations to begin to address this.

References

1. Office for National Statistics, Excess deaths in England and Wales: March 2020 to June 2022, 20 September 2022 [last accessed February 2023].
2. Polly M Edmonds, Katherine E Sleeman, Natasha Lovell, Rosemary Chester, Richard P Towers, Stephen A Marshall, Irene J Higginson, Sabrina Bajwah, Wendy Prentice, The impact of and response to the COVID-19 pandemic on a hospital palliative care team, Future Healthcare Journal, March 2021, 8 (1) 62-64.
3. Ibid.
4. Evidence submitted to the APPG by Marie Curie & The Hospice Charity Partnership.
5. Chris Thomas, The state of end of life care: Building back better after Covid-19, The Progressive Policy Think Tank (IPPR), April 2021.
6. Evidence submitted to the APPG by The Queen's Nursing Institute.
7. Evidence submitted to the APPG by The National Bereavement Alliance and The Childhood Bereavement Network.
8. Evidence submitted to the APPG by Alzheimer's Society.
9. Evidence submitted to the APPG by NHS England.
10 Evidence submitted to the APPG by Greater Manchester's Palliative and End of Life Care Strategic Clinical Networks, cancer services and hospices.
11. Eilís Keeble, Sarah Scobie and Rachel Hutchings, Support at the end of life: The role of hospice services across the UK, Nuffield Trust in association with Hospice UK, May 2022.
12. Evidence submitted to the APPG by St Catherine's Hospice in Crawley, Dr Alex Nicholson, Consultant in Palliative Medicine at County Durham and Darlington Foundation Trust, Saint Francis Hospice and the Mountbatten group.
13. Evidence submitted to the APPG by Together for Short Lives.
14. Evidence submitted to the APPG by Dr Matt Sweeting, former Director of Care at Farleigh Hospice in Essex.
15. Evidence submitted to the APPG by Multiple System Atrophy Trust.
16. Ibid.
17. Evidence submitted to the APPG by The Association of Ambulance Chief Executives.
18. Evidence submitted to the APPG by The Hospice of St Francis.
19. Evidence submitted to the APPG by Joh Winter.
20. Evidence submitted to the APPG by St Michael's Hospice.
21. Ibid.
22. Evidence submitted to the APPG by Together for Short Lives citing The Disabled Children's Partnership, No End In Sight, May 2021.
23. Evidence submitted to the APPG by Together for Short Lives.
24. Evidence submitted to the APPG by Eden Valley Hospice.
25. Evidence submitted to the APPG by East Suffolk and North Essex NHS Foundation Trust.
26. Evidence submitted to the APPG by St Catherine's Hospice in Crawley.
27. Evidence submitted to the APPG by Hospice of the Good Shepherd.
28. Evidence submitted to the APPG by Eden Valley Hospice.
29. Evidence submitted to the APPG by Sue Ryder.
30. Evidence submitted to the APPG by Sarah Clayton, District Nurse Clinical Lead, South Doncaster District Nursing.
31. Evidence submitted to the APPG by St Catherine's Hospice.
32. Ibid.
33. Evidence submitted to the APPG by Alzheimer's Society.
34. Evidence submitted to the APPG by LGBT Foundation.
35. Evidence submitted to the APPG by Alzheimer's Society.
36. Evidence submitted to the APPG by the International Observatory on End of Life Care at Lancaster University.
37. Evidence submitted to the APPG by the London Palliative and End of Life care Strategic Clinical Network.
38. Evidence submitted to the APPG by Jo Joy-Jones, Leeds LS25/26 PCN Planning Ahead Coordinator.
39. Evidence submitted by the Association of Palliative Care Social Workers.
40. Evidence submitted to the APPG by the Department of Health and Social Care.
41. Evidence submitted to the APPG by The Care Workers' Charity.
42. Evidence submitted to the APPG by Dr Kershaw's Hospice.
43. Evidence submitted to the APPG by Macmillan Cancer Support citing Marie Curie, Better End of Life 2021, April 2021.
44. Evidence submitted to the APPG by Marie Curie.
45. Evidence submitted to the APPG by Sarah Clayton.
46. Evidence submitted to the APPG by the Department of Health and Social Care.
47. Hospice UK, Hospice UK's response to the Department of Health and Social Care's consultation on extending free PPE to the health and care sector, October 2021.
48. Evidence submitted to the APPG by Hospice of the Good Shepherd.
49. Hospice UK, Hospice UK's response to the Department of Health and Social Care's consultation on extending free PPE to the health and care sector, October 2021.
50. Evidence submitted to the APPG by Hospice of the Good Shepherd, Dr Alex Nicholson and Sarah Clayton.
51. Evidence submitted to the APPG by Sheila and Sarah Clayton.
52. Evidence submitted to the APPG by John MacArtney, Marie Curie Senior Research Fellow.
53. Evidence submitted to the APPG by Jane Crussell, Senior Lecturer (Adult Nursing), London South Bank University.
54. Evidence submitted to the APPG by Dr Alex Nicholson.
55. Evidence submitted to the APPG by The Association of Ambulance Chief Executives.
56. Evidence submitted to the APPG by Dr Kerry Jones, Lecturer (End of Life Care), The Open University.
57. Evidence submitted to the APPG by St Michael's Hospice.
58. Evidence submitted to the APPG by Selina Rogers, Healthcare Assistant at St Luke's Hospice Plymouth.
59. Evidence submitted to the APPG by Margaret Gibbs, Lead Palliative Care Pharmacist, Ashtons Hospital Pharmacy Services.
60. Evidence submitted to the APPG by Jan Bolton, Macmillan social care co-ordinator, Northamptonshire Centre for Oncology, Northampton General Hospital.
61. Evidence submitted to the APPG by Hospice of the Good Shepherd, Macmillan Cancer Support, Hounslow and Richmond Community Healthcare NHS Trust and City Hospice.

62. Evidence submitted to the APPG by George Plumptre, CEO of the National Garden Scheme, John MacArtney and Sarah Clayton.
63. Evidence submitted to the APPG by City Hospice.
64. Evidence submitted to the APPG by The Association of Physiotherapists in Oncology and Palliative Care.
65. Evidence submitted to the APPG by University Hospitals Dorset NHS Foundation Trust.
66. Evidence submitted to the APPG by Sue Ryder.
67. Evidence submitted to the APPG by The Hospice Charity Partnership.
68. Data from Office of National Statistics, Northern Ireland Statistics and Research Agency and National Records of Scotland [last accessed in November 2023].
69. Evidence submitted to the APPG by The Nuffield Trust.
70. Ibid.
71. APPG on Hospice and End of Life Care, Oral evidence session on the rise in deaths at home during the pandemic: minutes, December 2021.
72. Evidence submitted to the APPG by Dr Corinna Midgley, Medical Director and Consultant in Palliative Medicine, Saint Francis Hospice.
73. Evidence submitted to the APPG by Sue Ryder.
74. Evidence submitted to the APPG by St Michael's Hospice.
75. Evidence submitted to the APPG by Coventry Integrated Palliative Care Team, The Royal College of Nursing and Specialist Palliative Care Clinicians across South Tyneside and Sunderland.
76. Evidence submitted to the APPG by Leeds Palliative Care Network.
77. Evidence submitted to the APPG by St Catherine's Hospice.
78. Data from Office of National Statistics, Northern Ireland Statistics and Research Agency and National Records of Scotland [last accessed in November 2023].
79. Evidence submitted to the APPG by Marie Curie.
80. Evidence submitted to the APPG by Professor Stephen Barclay, Lead for the Palliative and End of Life Care Group at the University of Cambridge.
81. Evidence submitted to the APPG by Macmillan Cancer Support.
82. Evidence submitted to the APPG by Lesley Spencer, Palliative Care Ambassador, Ashtons Hospital Pharmacy Services.
83. Evidence submitted to the APPG by Hospice of the Good Shepherd.
84. Evidence submitted to the APPG by Together for Short Lives.
85. Ibid.
86. Evidence submitted to the APPG by The Physicians Response Unit.
87. Ibid.
88. Evidence submitted to the APPG by Together for Short Lives.
89. Evidence submitted to the APPG by East Suffolk and North Essex NHS Foundation Trust.
90. Evidence submitted to the APPG by Hospice UK's Project ECHO team.
91. Ibid.
92. Ibid.
93. Evidence submitted to the APPG by Sue Ryder.
94. Evidence submitted to the APPG by Hospice of the Good Shepherd.
95. Evidence submitted to the APPG by Macmillan Cancer Support.
96. Evidence submitted to the APPG by Specialist Palliative Care Clinicians across South Tyneside and Sunderland.
97. Evidence submitted to the APPG by St Gemma's Hospice.
98. Evidence submitted to the APPG by Sarah Clayton.
99. Evidence submitted to the APPG by Specialist Palliative Care Clinicians across South Tyneside and Sunderland.
100. Ibid.
101. Evidence submitted to the APPG by Garden House Hospice Care, University Hospitals Dorset NHS Foundation Trust and Fylde Coast Palliative and End of Life Care Partnership.
102. Evidence submitted to the APPG by Garden House Hospice Care.
103. Evidence submitted to the APPG by Margaret Gibbs.
104. Evidence submitted by University Hospitals Dorset NHS Foundation Trust.
105. Bárbara Antunes, Ben Bowers, Isaac Winterburn, Michael P Kelly, Robert Brodrick, Kristian Pollock, Megha Majumder, Anna Spathis, Iain Lawrie, Rob George, Richella Ryan, Stephen Barclay, Anticipatory prescribing in community end-of-life care in the UK and Ireland during the COVID-19 pandemic: online survey, BMJ Supportive & Palliative Care, June 2020, 10, 343–349.
106. Department for Health and Social Care, Coronavirus (COVID-19): reuse of medicines in a care home or hospice, last updated September 2020 [last accessed February 2023].
107. Evidence submitted to the APPG by Margaret Gibbs.
108. Ibid.
109. Evidence submitted to the APPG by Essex Partnership University NHS Foundation Trust.
110. Evidence submitted to the APPG by Margaret Gibbs.
111. Bárbara Antunes, Ben Bowers, Isaac Winterburn, Michael P Kelly, Robert Brodrick, Kristian Pollock, Megha Majumder, Anna Spathis, Iain Lawrie, Rob George, Richella Ryan, Stephen Barclay, Anticipatory prescribing in community end-of-life care in the UK and Ireland during the COVID-19 pandemic: online survey, BMJ Supportive & Palliative Care, June 2020, 10, 343–349.
112. Evidence submitted to the APPG by the Mountbatten Group.
113. Ibid.
114. Ibid.
115. National Institute for Health and Care Excellence, COVID-19 rapid guideline: managing COVID-19, last updated July 2022 [last accessed February 2023]
116. Ben Bowers, Kristian Pollock, Stephen Barclay, Administration of end-of-life drugs by family caregivers during covid-19 pandemic, BMJ, April 2020, 369 [last accessed February 2023]
117. Evidence submitted to the APPG by Michelle Denyer.
118. Ibid.
119. Ibid.
120. Ibid.
121. Ibid.
122. Evidence submitted to the APPG by Mary Hopper.
123. Evidence submitted to the APPG by The Royal College of Nursing.
124. Evidence submitted to the APPG by Dr Matt Sweeting.
125. Evidence submitted to the APPG by Dr Kershaw's Hospice.
126. Evidence submitted to the APPG the Mountbatten group.
127. Ibid.

128. Evidence submitted to the APPG by Andrew Randall, Chief Executive, Hospiscare.

129. Evidence submitted to the APPG by The Hospice Charity Partnership.

130. Evidence submitted to the APPG by St Helena Hospice.

131. Evidence submitted to the APPG by Specialist Palliative Care Clinicians across South Tyneside and Sunderland.

132. NHS England, COVID-19 Response: Palliative and end of life care advice and coordination, January 2022.

133. Evidence submitted to the APPG by Michelle Denyer.

134. Evidence submitted to the APPG by Dr Chris Ainsworth.

135. Evidence submitted to the APPG by Hounslow and Richmond Community Healthcare NHS Trust.

136. Evidence submitted to the APPG by East Suffolk and North Essex NHS Foundation Trust

137. Evidence submitted to the APPG by St Luke's Hospice.

138. Evidence submitted to the APPG by Garden House Hospice Care.

139. Evidence submitted to the APPG by Dr Lucy Selman, University of Bristol, and Dr Emily Harrop, Cardiff University.

140. Evidence submitted to the APPG by St Gemma's Hospice and Garden House Hospice Care.

141. Evidence submitted to the APPG by Ann Fox.

142. Evidence submitted to the APPG by Eden Valley Hospice.

143. Evidence submitted to the APPG by Lewis-Manning Hospice Care.

144. Evidence submitted to the APPG by Leeds Bereavement Forum.

145. Evidence submitted to the APPG by Garden House Hospice Care.

146. Evidence submitted to the APPG by Greater Manchester's Palliative and End of Life Care Strategic Clinical Networks, cancer services and hospices.

147. Ibid.

148. Evidence submitted to the APPG by Dr Lucy Selman and Dr Emily Harrop and data collected as part of the CovPall study shared with the APPG by the International Observatory on End of Care at Lancaster University.

149. Data collected as part of the CovPall study shared with the APPG by the International Observatory on End of Care at Lancaster University.

150. Evidence submitted to the APPG by City Hospice.

151. Evidence submitted to the APPG by Dr Nadia Khan on behalf of The British Islamic Medical Association.

152. Evidence submitted to the APPG by Dr Sarah Cox, Consultant in Palliative Medicine.

153. Evidence submitted to the APPG by George Plumptre.

154. Evidence submitted to the APPG by Macmillan Cancer Support.

155. Evidence submitted to the APPG by Independent Age.

156. Evidence submitted to the APPG by Joh Winter.

157. Ibid.

158. Evidence submitted to the APPG by John MacArtney.

159. Evidence submitted to the APPG by Dr Sarah Cox.

160. Evidence submitted to the APPG by The Association of Ambulance Chief Executives.

161. Evidence submitted to the APPG by Greater Manchester's Palliative and End of Life Care Strategic Clinical Networks, cancer services and hospices.

162. Evidence submitted to the APPG by St Barnabas House Hospice.

163. Evidence submitted to the APPG by Selina Rogers.

164. Evidence submitted to the APPG by the Palliative Care Team at Barking, Havering and Redbridge Community Trust.

165. Evidence submitted to the APPG by The Hospice Charity Partnership.

166. Evidence submitted to the APPG by Dr Kerry Jones.

167. Evidence submitted to the APPG by Dr Chris Ainsworth.

168. Data collected as part of the CovPall study shared with the APPG by the International Observatory on End of Care at Lancaster University.

169. Evidence submitted to the APPG by Dr Kerry Jones and by the International Observatory on End of Life Care at Lancaster University.

170. Evidence submitted to the APPG by Fylde Coast Palliative and End of Life Care Partnership.

171. Evidence submitted to the APPG by Sue Ryder.

172. Evidence submitted to the APPG by Selina Rogers and Rowcroft Hospice.

173. Data collected as part of the CovPall study shared with the APPG by the International Observatory on End of Care at Lancaster University.

174. Evidence submitted to the APPG by Andrew Randall, Chief Executive, Hospiscare.

175. Evidence submitted to the APPG by Leeds Teaching Hospitals NHS Trust Specialist Palliative Care Team.

176. Evidence submitted to the APPG by The Hospice Charity Partnership.

177. Evidence submitted to the APPG by The Queen's Nursing Institute.

178. Evidence submitted to the APPG by Greater Manchester's Palliative and End of Life Care Strategic Clinical Networks, cancer services and hospices.

179. Evidence submitted to the APPG by the Mountbatten group.

180. Evidence submitted to the APPG by The National Garden Scheme and City Hospice.

181. Evidence submitted to the APPG by St Michael's Hospice.

182. Evidence submitted to the APPG by The Queen's Nursing Institute.

183. Evidence submitted to the APPG by St Barnabas Hospice.

184. Evidence submitted to the APPG by Sarah Clayton.

185. Evidence submitted to the APPG by Dr Nadia Khan on behalf of The British Islamic Medical Association.

186. Royal College of GPs, College sounds SOS for general practice – and calls for rescue plan, July 2021 [last accessed February 2023].

187. Royal College of GPs, GP patient survey reflects 'overstretched' service working under intense and unsustainable pressure, July 2021 [last accessed July 2022].

188. Evidence submitted to the APPG by The Queen's Nursing Institute.

189. Evidence submitted to the APPG by Debbie Martin.

190. Health and Social Care Select Committee Committee, Written evidence submitted by Hospice UK (RTR0118), January 2022 [last accessed February 2023].

191. Evidence submitted to the APPG by Hospice of the Good Shepherd.

192. Evidence submitted to the APPG by Dr Matt Sweeting.

193. Evidence submitted to the APPG by John I MacArtney.

194. Evidence submitted to the APPG by the Mountbatten group.

195. Evidence submitted to the APPG by John I MacArtney and Lesley Spencer.

196. Evidence submitted to the APPG by Lesley Spencer.

197. Evidence submitted to the APPG by the Mountbatten group.

198. Evidence submitted to the APPG by The Hospice Charity Partnership.

199. Evidence submitted to the APPG by Dr Sarah Cox.

200. Evidence submitted to the APPG by Hospice of the Good Shepherd.

201. Evidence submitted to the APPG by the Hospice Charity Partnership and Dr Corinna Midgley

202. Evidence submitted to the APPG by Ann Fox.

203. Evidence submitted to the APPG by Professor Lynn Sudbury-Riley and St Christopher's Hospice.

204. Evidence submitted to the APPG by St Christopher's Hospice.

205. Evidence submitted to the APPG by Professor Lynn Sudbury-Riley, Professor of Marketing & Director of Education for Marketing, University of Liverpool Management School.

206. Evidence submitted to the APPG by Simon Fuller.

207. Evidence submitted to the APPG by Joh Winter.

208. Evidence submitted to the APPG by the Queen's Nursing Institute citing Marie Curie, Charity warns three out of four home deaths during pandemic did not get the care they needed, April 2021 [last accessed February 2023].

209. Evidence submitted to the APPG by the COVID Bereaved Families for Justice

210. Evidence submitted to the APPG by the Alzheimer's Society

211. Evidence submitted to the APPG by the Royal College of Nursing.

212. Evidence submitted to the APPG by the Association of Ambulance Chief Executives.

213. Evidence submitted to the APPG by John I MacArtney.

214. Evidence submitted to the APPG by The Queen's Nursing Institute.

215. Evidence submitted to the APPG by Jane Crussell.

216. Simon Tavabie, Steve Bass, Eleanor Stewart, Ethan Redmore and Ollie Minton, Care of the dying person before and during the COVID-19 pandemic: A quality improvement project, Future Healthcare Journal 2020 Vol 7, No 3, e50-e53.

217. Evidence submitted to the APPG by Mary Hopper.

218. Evidence submitted to the APPG by Debbie Martin.

219. Evidence submitted to the APPG by St Christopher's Hospice.

220. Evidence submitted to the APPG by Simon Fuller.

221. Evidence submitted to the APPG by the International Observatory on End of Life Care at Lancaster University.

222. Ibid.

223. Evidence submitted to the APPG by Dr Kerry Jones.

224. Evidence submitted to the APPG by Professor Stephen Barclay.

225. Evidence submitted to the APPG by the Alzheimer's Society and Professor Lynn Sudbury-Riley.

226. Evidence submitted to the APPG by Macmillan Cancer Support.

227. Evidence submitted to the APPG by Lesley Spencer.

228. Evidence submitted to the APPG by Hospice of the Good Shepherd and Dr Matt Sweeting.

229. Evidence submitted to the APPG by the Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, King's College London.

230. Evidence submitted to the APPG by NHS South West London CCG.

231. Evidence submitted to the APPG by the International Observatory on End of Life Care at Lancaster University.

232. Evidence submitted to the APPG by Dr Corinna Midgley.

233. Evidence submitted to the APPG by Marie Curie.

234. Health and Care Select Committee, Written evidence submitted by Hospice UK (EPW0053), May 2022 [last accessed February 2023].

235. Evidence submitted to the APPG by George Plumptre.

236. Evidence submitted to the APPG by John I MacArtney.

237. Evidence submitted to the APPG by Dr Alex Nicholson.

238. Evidence submitted to the APPG by NHS England.

239. Department for Digital, Culture, Media & Sport, Evaluation of the VCSE Funding Package – Scoping Report, January 2022.

240. Evidence submitted to the APPG by St Catherine's Hospice and Hospice of the Good Shepherd.

241. Evidence submitted to the APPG by Dr Kershaw's Hospice.

242. Evidence submitted to the APPG by Joh Winter.

243. Evidence submitted to the APPG by City Hospice.

244. Evidence submitted to the APPG by Macmillan Cancer Support citing Carers UK, Breaks or breakdown: Carers Week 2021 report, June 2021.

245. Evidence submitted to the APPG by City Hospice and St Christopher's Hospice.

246. Evidence submitted to the APPG by the Multiple System Atrophy Trust.

247. Evidence submitted to the APPG by Dr Alex Nicholson.

248. Evidence submitted to the APPG by the Hospice of St Francis and St Christopher's Hospice.

249. Evidence submitted to the APPG by Mary Hopper.

250. Evidence submitted to the APPG by Together for Short Lives.

251. Evidence submitted to the APPG by Joh Winter.

252. Evidence submitted to the APPG by Debbie Martin.

253. Evidence submitted to the APPG by St Christopher's Hospice.

254. Evidence submitted to the APPG by the COVID Bereaved Families for Justice

255. Evidence submitted to the APPG by Ann Ashworth.

256. Evidence submitted to the APPG by Maureen Anderson.

257. Evidence submitted to the APPG by George Plumptre.

258. Evidence submitted to the APPG by Garden House Hospice Care.

259. Evidence submitted to the APPG by Leeds Palliative Care Network.

260. Evidence submitted to the APPG by St Christopher's Hospice.

261. Evidence submitted to the APPG by the COVID Bereaved Families for Justice.

262. Evidence submitted to the APPG by the National Bereavement Alliance and the Childhood Bereavement Network.

263. Evidence submitted to the APPG by Healthwatch Suffolk.

264. Ibid.
265. Evidence submitted to the APPG by Dr Alex Nicholson.
266. Evidence submitted to the APPG by Linda L.
267. Evidence submitted to the APPG by Sands.
268. Evidence submitted to the APPG by The Association of Ambulance Chief Executives.
269. Evidence submitted to the APPG by Dr Chris Ainsworth.
270. Evidence submitted to the APPG by the Royal College of Nursing.
271. Evidence submitted to the APPG by the COVID Bereaved Families for Justice.
272. Evidence submitted to the APPG by Alzheimer's Society.
273. Evidence submitted to the APPG by Independent Age and Marie Curie.
274. Evidence submitted to the APPG by Linda L.
275. Evidence submitted to the APPG by Fran Hall
276. Evidence submitted to the APPG by Professor Lynn Sudbury-Riley.
277. Evidence submitted to the APPG by Marie Curie.
278. Evidence submitted to the APPG by Ann Ashworth.
279. Evidence submitted to the APPG by Professor Lynn Sudbury-Riley and COVID Bereaved Families for Justice.
280. Evidence submitted to the APPG by Marie Curie.
281. Evidence submitted to the APPG by Independent Age.
282. Evidence submitted to the APPG by COVID Bereaved Families for Justice.
283. Evidence submitted to the APPG by Sue Ryder.
284. Evidence submitted to the APPG by LGBT Foundation.
285. Caroline Pearce, Jonathan R Honey, Roberta Lovick, Nicola Zapiain Creamer, Claire Henry, Andy Langford, Mark Stobert, Stephen Barclay, A silent epidemic of grief': a survey of bereavement care provision in the UK and Ireland during the COVID-19 pandemic, BMJ Open 2021: 11:e046872.
286. Evidence submitted to the APPG by Dr Lucy Selman and Dr Emily Harrop.
287. Evidence submitted to the APPG by The National Bereavement Alliance and The Childhood Bereavement Network.
288. Evidence submitted to the APPG by St Barnabas Hospice.
289. Evidence submitted to the APPG by Dr Lucy Selman and Dr Emily Harrop.
290. Evidence submitted to the APPG by City Hospice.
291. Evidence submitted to the APPG by Professor Stephen Barclay.
292. Evidence submitted to the APPG by Dr Lucy Selman and Dr Emily Harrop.
293. Sue Ryder, A better route through grief: Support for people facing grief across the UK, June 2022.
294. Caroline Pearce, Jonathan R Honey, Roberta Lovick, Nicola Zapiain Creamer, Claire Henry, Andy Langford, Mark Stobert, Stephen Barclay, A silent epidemic of grief': a survey of bereavement care provision in the UK and Ireland during the COVID-19 pandemic, BMJ Open 2021: 11:e046872.
295. Evidence submitted to the APPG by Independent Age.
296. Evidence submitted to the APPG by NHS South West London CCG.
297. The UK Commission on Bereavement, Bereavement is everyone's business, October 2022.
298. Evidence submitted to the APPG by City Hospice.
299. Evidence submitted to the APPG by Lesley Spencer.
300. Evidence submitted to the APPG by St Michael's Hospice and the National Bereavement Alliance and the Childhood Bereavement Network.
301. Evidence submitted to the APPG by Dr Nadia Khan on behalf of The British Islamic Medical Association.
302. Evidence submitted to the APPG by Compassion in Dying and Dignity in Dying and Hospice UK's Dying Matters Campaign.
303. Evidence submitted to the APPG by The Association of Palliative Care Social Workers.
304. Evidence submitted to the APPG by Greater Manchester's Palliative and End of Life Care Strategic Clinical Networks, cancer services and hospices.
305. Evidence submitted to the APPG by Dr Alex Nicholson.
306. Evidence submitted to the APPG by St Barnabas House Hospice.
307. Evidence submitted to the APPG by the British Geriatrics Society.
308. Evidence submitted to the APPG by COVID Bereaved Families for Justice.
309. Evidence submitted to the APPG by Professor Lynn Sudbury-Riley.
310. Evidence submitted to the APPG by St Christopher's Hospice.

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