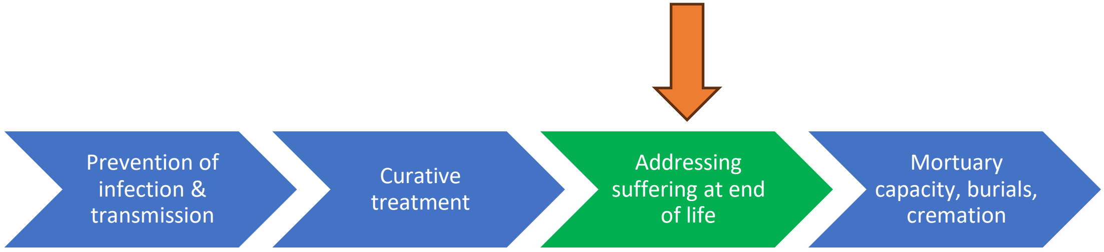
Scottish
Partnership
for Palliative Care

Palliative and End of Life Care and the COVID-19 Pandemic



A submission to the Scottish COVID-19 Inquiry by the Scottish Partnership for Palliative Care

About SPPC

SPPC brings together health and social care professionals from hospitals, social care services, primary care, hospices and other charities, to find ways of improving people's experiences of declining health, death, dying and bereavement. SPPC provides a voice for organisations and individuals working in this area, a means of staying informed and connected, and a vehicle for collaboration. SPPC also engages with the public and communities through our Good Life, Good Death, Good Grief alliance.

SPPC was founded 30 years ago and has grown to be a collaboration of over 100 organisations involved in providing care towards the end of life. SPPC's membership includes all the territorial NHS Boards, IJBs, local authorities, the hospices, Third Sector organisations and a range of professional associations. In 2022 SPPC won a Scottish Public Service Award for its portfolio of work.

About this submission

This submission is based on engagement with stakeholders in 2021 during the production of SPPC's report *Every Story's Ending*[i]. This work has been complemented by a stakeholder workshop held in December 2023. The submission draws on the experiences and views of people undertaking a wide range of different roles, with the majority being health and social care practitioners providing palliative and end of life care during the pandemic. Palliative and end of life care is provided across different settings. This submission includes perspectives on care in hospitals, in people's homes, in care homes and in hospices.

This submission aims to reflect some common themes but it will not reflect everyone's experiences or views: people had varying professional and personal circumstances during the pandemic, and sometimes the same experience impacts differently on different individuals.

What do we mean by palliative care and end of life care?

Though more specific definitions can be helpful (see Glossary), one way of thinking about 'palliative care' is to talk in terms of providing 'good care' to people whose health is in irreversible decline or whose lives are coming to an inevitable close. Perhaps what differentiates 'palliative care' from 'just good care' is the awareness that a person's mortality has started to influence clinical and/or personal decision-making. However, palliative care is not synonymous with death – it is about life, about the care of someone who is alive, someone who still has hours, days, months, or years remaining in their life, and about optimising wellbeing in those circumstances.

End of life care is a core part of palliative care which should follow from the diagnosis of someone entering the process of dying, whether or not they are already in receipt of palliative care. This phase could vary between months, weeks, days or hours in the context of different disease trajectories. There can be uncertainty involved in identifying when someone might be expected to die – illness can be unpredictable, and changes can occur suddenly and unexpectedly.

Who provides palliative care?

In Scotland most of the care that people receive when their health is deteriorating could be termed **general palliative care**, being provided by health and social care professionals to people living in the community, in care homes and in hospitals.

It is palliative care regardless of whether someone has cancer, organ failure (including neurological conditions) or 'old age', or whether they are living at home, in a hospice, in a care home, in prison or in a medical ward, in ICU or a homeless shelter, or in a neonatal ward.

Specialist palliative care can help people with more complex palliative care needs and is provided by specially trained multi-professional specialist palliative care teams who are generally based in a hospice, an NHS specialist palliative care unit or an acute hospital, but whose expertise should be accessible from any care setting and at any time. Services labelled 'palliative' are usually specialist palliative care.

The role of palliative care in a pandemic

The role of palliative care within a pandemic is to address suffering in all settings both for those who are dying and for those receiving disease modifying interventions. In addition to those people dying of COVID-19 there was a continuing need to provide palliative and end of life care for people with other conditions.

KEY CHALLENGES

Limited Knowledge Base

Prior to the first wave of the pandemic there was little published evidence about the trajectories of decline and symptoms to be expected amongst people dying with COVID-19. There was also limited evidence about how to adapt existing strategies for managing symptoms such as breathlessness amongst people with COVID-19.

Sudden Increased Need for Palliative and End of Life Care

By 28th [6] March 2021 there had been 9,958 deaths registered in Scotland where COVID-19 was mentioned on the death certificate. During the calendar year 2020 there were 6,324 excess deaths, 11% higher than the five-year average[ii].

Procurement and Supply Chains

The infectious nature of COVID-19 and the sudden increase in dying led to concerns and difficulties relating to the availability of PPE, equipment and medicines for palliative care. There were particular difficulties for care homes and hospices in being able to access PPE.

Rapid Change in Place of Death

The pandemic led to a major shift in the place of death. From the beginning of 2020 until mid-March 2021 the total number of all deaths at home increased by 36% compared to the average number of people who died at home in the equivalent period in 2015-2019[iii]. The vast majority of these deaths at home (especially outwith the COVID-19 waves) were from causes other than COVID-19. There was also an increase in the complexity of needs of people dying at home creating challenges for GPs, district nurses and other community staff[iv].

Pre-Existing Weaknesses

In addition to the challenges identified above which are specific to COVID-19 the pandemic highlighted pre-existing weakness. Key deficiencies have included:

- Many people who would benefit from an anticipatory care plan do not have one.

- Anticipatory care planning and Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) decisions are widely unknown, misunderstood and/or often negatively viewed by the public.
- Clinical decision-making intended to avoid burdensome and non-beneficial treatments are sometimes perceived as denying access to life-saving treatment for old people, especially those in care homes.
- Many care homes for older people are under-resourced and insufficiently supported by and integrated with health services.

RESPONDING TO THE PANDEMIC

> *"We experienced change in a myriad of ways. Some were challenging but equally some of the pace of change allowed important things to be done quickly and purposefully."*
>
> Workshop Participant

A number of developments helped to build and spread capacity to provide palliative care and end of life care:

Guidance, Information and Education

- a rapid systematic review and evidence summary[v] of the symptom burden and clinical profile of COVID-19 deaths which was used to inform clinical practice and guideline development (see below).
- the rapid development of two national COVID-specific clinical guidelines; *Guidance for when a person is imminently dying from COVID-19 lung disease*; and *Guidance for supporting end of life care when alternatives to medication normally given through syringe pumps are required*
- large scale education events via Zoom to inform and teach about these guidelines within primary and secondary care, supported across Scotland by palliative medicine consultants and other contributors
- practical resources for professionals (and carers) administering medication
- COVID-19:palliative care toolkit - a resource for health board planners aiming to identify key risks and ensure continuing access to and delivery of palliative care medicines, produced with major input from the Scottish Palliative Care Pharmacists Association
- local frameworks and guidelines

- guidance for GPs on rapid anticipatory care planning
- ethical framework and guidance from the Scottish Academy of Medical Royal Colleges and Faculties on visiting in hospitals and care homes which addressed 'end of life' situations
- palliative and end of life care components of the Chief Medical Officer's national COVID-19: Clinical Advice and other guidance
- resources to support effective communication with people and their families about anticipatory care planning including DNACPR
- comprehensive public facing information specifically for people and/ or their loved ones at increased risk of getting seriously ill and potentially dying from COVID-19
- palliative care education for staff unaccustomed to or needing more help dealing with mortality
- online education and confidence-building module for informal carers
- specialist palliative care support to clinical areas facing higher than usual rates of dying
- specialist palliative care support to HDU and ICU teams with complex palliative and end of life care in ventilation and respiratory support situations
- proving palliative care input to Scottish Government Advisory Groups on topics including: care homes; provision of oxygen; and primary care assessment and treatment of COVID-19
- whilst inputting to policy development and local practice palliative care specialists often championed the importance of access to life sustaining treatments *alongside* measures to reduce suffering. The intent was to avoiding overly-simplistic binary responses when there was no certainty about whether someone would recover or die (this context of uncertainty is common in end of life care)
- palliative care practitioners championed the use of person centred language.

Reconfiguration of Resources and Services

Specialist palliative care services and practitioners had a key role in change, usually in collaborative partnership with other parts of the health and care system. This included whole system design to address suffering and irreversible dying in amongst COVID-19 care and “normal care”. There was a wide range of rapid innovation by many services. Changes which took place included:

- new community-based models (community teams, hospice at home, rapid response services)
- establishment of Hubs to support inter-agency & multi-disciplinary team (MDT) communication and collaboration, and to provide information and support to people and their families

- early and rapid reconfiguration of palliative care units to provide end of life care to those dying from or with covid
- rapid access to end of life care from GP assessment hubs where acute, irreversible dying was occurring
- redeployment/refocussing of specialist palliative care staff from hospices and NHS specialist units to support care in other settings (acute hospital, care homes and community)
- establishment of virtual services (day services, outpatients, consultations, bereavement support, virtual ward rounds)
- repurposing of buildings and reallocation of space for other forms of care where needed
- development/extension of staff welfare services
- establishment of 24/7 single points of easy access
- acute hospital palliative care teams working in new ways across covid and non-covid care in hospital settings delivering and supporting end of life care[vi]
- establishment of rapid response integrated teams.

Other Responses

- informal but effective collaborative leadership arrangements
- use of ECHO and other approaches to virtual learning
- leadership of and participation in research projects seeking to understand COVID-19 and palliative care
- making connections with and sharing learning across the Four Nations

Scottish Partnership for Palliative Care Contributions

- Rapid establishment of multiple virtual national networks which underpinned much collaboration, flow of intelligence and mutual support within and between settings, and between geographical locations, including linkage with Scottish Government
- Translating early emerging research from Italy and Spain
- Proving a platform for clinical experts to update teams across Scotland on clinical features of COVID-19, and treatment updates
- Offering a safe place for teams to share worries, issues and ask for help from colleagues
- Project management support to informal collaborative leadership

- Public facing information specifically for people and/ or their loved ones at increased risk of getting seriously ill and potentially dying from COVID-19

IMPACTS OF THE PANDEMIC

> *"Grief - the experience and lack of available support is having longer term impacts on how people are managing and coping with grief."*
>
> Workshop participant

Loss of Human Contact

Measures to control infection had a huge impact on the experiences of dying people and their loved ones, and on the provision of end of life care. Visitor restrictions meant many people died without desired contact with loved ones.

> *"Visiting - different places had different guidelines and this was not fair for families.*
>
> *Reflection - one person per visit [allowed] whilst patient alive yet after death number of people who could attend was not capped.*
>
> *Unfair to patients who were asked to choose who should be their assigned visitor. Put people in a really difficult position with one examples of one person not picking anyone to be with them so not to let anyone down resulting in them dying alone.*
>
> *Communication to public was not enough. New rules usually came in on a Friday with the ward staff being left to share this with patients and families."*

> *“care home staff had to enact guidance given and were doing their best [there is a] sense of injustice - they were following guidance and at the time received abuse and currently feel blamed.”*
>
> Workshop participant

Staff’s ability to connect and communicate with dying people they were caring for was made much more difficult by masks, visitor restrictions and restrictions on touch. Families (and some staff) experienced bereavement in traumatic circumstances, at a time when funerals and other usual sources of solace such as the support of friends, family and community was restricted. Many individuals experienced multiple losses.

Impacts on Family Carers

Unpaid carers experienced increased isolation and loneliness during the pandemic. The strain on these unpaid care during the pandemic was even more acute because of stretched health and social care services.

> *“Carers had limited practical and emotional support which was lonely and exhausting, considerably impacting their physical and mental health.”*
>
> Workshop participant

Impacts on Staff Wellbeing

> *“Not being able to deliver usual gold standard of support was really challenging professionally and personally.”*
>
> Workshop participant

Caring for people who are dying can often be psychologically, spiritually and emotionally challenging. During the pandemic these challenges were compounded by specific circumstances: dying tended to be concentrated temporally during the waves of the pandemic; much dying with COVID was concentrated within the care home sector where many staff experienced, at least initially, inadequate support from the wider healthcare system[1]; some staff who previously had little experience of end of life care were deployed in areas with high levels of dying; enforcing restrictions on visiting towards end of life was often traumatic for staff, as was facilitating final goodbyes via phone or video; there were relentless periods of intense and distressing work, when staff were already deeply fatigued; those providing care and those being cared for shared a reciprocal risk of infection; staff had to deal with concern and fear about becoming infected and also infecting their own loved ones; usual coping strategies were limited by restrictions on aspects such as social contacts and holidays. Some staff had roles which meant a sudden switch to home working with a range of challenges: loss of usual social contact with colleagues; loss of boundaries between "work" and "home"; lack of suitable workspaces; tech issues; working in the midst of whatever else was going on at home, including home schooling.

As the pandemic evolved staff were required to manage and deliver a return to the "new normal", whilst still trying to cope with the personal and professional impacts of what had taken place in the early waves of the pandemic.

Staff experienced trauma, mental health issues and burnout. Amongst staff who previously had little experience of end of life care there was a large volume of distress, which hospital palliative care teams, palliative care clinical nurse specialists and spiritual care teams identified and sought to address.

These remains a continuing legacy of impact on staff wellbeing.

> *"We as staff members would appreciate recognition that the trauma part is ongoing"*
>
> Workshop participant

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[1] This statement is not intended to attribute criticism to particular parts of or roles within a system which spans NHS, IJBs and Scottish Government but rather to note that the outcomes experienced by staff and residents in care homes was sometimes not what anyone involved in the system would have wished for.

Leadership

Those in leadership and management roles were faced with high volumes of decision-making, the need to keep up with and implement the relentless flow of fast-changing guidance, to make choices where there were no “good” options, to attend to the needs of staff, to manage shifting team dynamics, and to innovate and redesign responses.

> *“[It was] challenging to work across different levels of demand, at pace whilst also having your own personal experience. Emotional work expanded for leaders as they led change with teams who faced fear, uncertainty, family impact, personal impact, pace and also had to make change”*
>
> Workshop participant

Widening of Inequalities

Existing inequalities were exacerbated by the pandemic. Differentials in the receipt of palliative care and social determinants of outcome worsened.

Positive Experiences

People’s experiences of the pandemic were not entirely negative. The unprecedented circumstances made it possible to effect the major changes necessary more quickly and more easily than would ordinarily have been possible.

> *“From a positive perspective, there was permission to do things quickly without the usual need to take new processes through the usual multiple governance processes.”*
>
> Workshop participant
>
> *“camaraderie was incredible”*
>
> Workshop participant

There was also great satisfaction in seeing how new ways of working had a positive impact.

> *"We were able to reach families in ways we hadn't done before and this has remained transformational - from intimate conversations about death and dying to medical assessments to art, music etc - all possible online or on a phone - so powerful"*
>
> Workshop participant

LESSONS WHICH SHOULD BE LEARNED

- Palliative care should be included and fully integrated into planning for future pandemics where death is a likely or possible outcome of the disease. This should encompass not just support for people dying from the agent causing the pandemic, but also the need to sustain palliative and end of life care for people with other conditions. Support for people approaching the end of life is a major core activity of the health and social care system at all times.
- The public should be made more aware of, better informed about and fully engaged in anticipatory (future) care planning, including DNACPR decision-making.
- Temporary changes to the law during the pandemic which improved timely access to end of life medications for people in care homes should be reintroduced on a permanent basis.
- The significant and long term harms of people dying whilst separated from loved ones should be considered explicitly as part of pandemic planning. A range of scenarios (covering for example different case fatality rates and levels of infectivity) should be developed (and planned for) which explore and reflect the acknowledged complexity of balancing risks, interests and outcomes.
- People and their families should be better supported to maintain communication, including saying final goodbyes, in the context of a highly infectious pandemic.

- Care homes should be better resourced, equipped and supported/integrated as key settings providing palliative and end of life care.
- Third Sector providers of palliative care need a model of sustainable funding which reflects their very significant contribution to the provision of palliative care.
- Hospices should be better engaged and integrated from the outset in the strategic planning and delivery of services in the context of a pandemic. This should start by improving integration and engagement in normal times. Hospices were important leaders and rapid innovators in the early responses to the pandemic but experienced difficulties due to a lack of integration with the wider system (for example difficulties accessing PPE).
- Current and future provision of health and care services should reflect: increased need for bereavement support; increased need for palliative care following late presentation/diagnosis of serious illness; planning and preparation to meet needs in event of major outbreaks; the important role which improving palliative care can play in delivering outcomes identified in the NHS Recovery Plan.
- Further research should be commissioned to fully understand the increase in people dying at home during the pandemic. This should include exploration of the preferences and experiences of people and their families; the experiences of health and social care professionals; service responses and sustainability.
- Drawing on learning from other jurisdictions a national system should be put in place to measure and understand the experiences and outcomes of the Scottish public at the end of life.
- People who were bereaved during the pandemic should get the bereavement support which is right for them.
- Services to support staff experiencing burnout and trauma (including the impact and consequences of moral harm[2]) should be adequately resourced and sustained for as long as needed.
- Given the long term impacts of the pandemic on staff, and current service pressures (which are having their own impact on staff) it is unhelpful to pretend that things have returned to a state of normality.
- Where service innovations which took place in response to COVID-19 are evaluated positively (e.g. rapid adoption of remote consultation, greater integration and collaborative working between primary care, social care,

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[2] Moral injury is understood to be the strong cognitive and emotional response that can occur following events that violate a person's moral or ethical code. Potentially morally injurious events include a person's own or other people's acts of omission or commission, or betrayal by a trusted person in a high-stakes situation. For example, health-care staff working during the COVID-19 pandemic might experience moral injury because they perceive that they received inadequate protective equipment, or when their workload is such that they deliver care of a standard that falls well below what they would usually consider to be good enough.

secondary care and hospices) planners and commissioners should seek to ensure that these are resourced on a sustainable basis and embedded as business as usual.

- Approaches which facilitated rapid pandemic responses (eg collaborative working, realism/flexibility around risk and governance, resource pooling) and which now deliver improved care (as opposed to just reducing deficits in pandemic conditions) should be sustained in order to respond to the post-pandemic crises currently impacting the health and social care system.
- A nimble trusted national network such as SPPC, with established relationships spanning all sectors and able to bridge between policy and delivery, is valuable infrastructure both during and outwith a pandemic and should be sustained.
- In addition to these specific recommendations the full suite of recommendations set out in Every Story's Ending would improve and strengthen palliative and end of life care in Scotland, which is a key part of preparedness for a future pandemic.

GLOSSARY

World Health Organization Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient’s illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

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[i] *Every Story’s Ending - proposals to improve people’s experiences of living with serious illness, dying and bereavement in Scotland* Scottish Partnership for Palliative Care (2021). https://www.palliativecarescotland.org.uk/content/everystorysending/

[ii] *Covid in Scotland: Peacetime excess deaths highest since 1891. BBC News* https://www.bbc.co.uk/news/uk-scotland-52214177

[iii] *Dramatic increase in deaths at home during the pandemic - No.2* – Blog series. Jan Savinc. Scottish Centre for Administrative Data Research. March 2021 https://www.scadr.ac.uk/blog-series-dramatic-increase-deaths-home-during-pandemic-no2

[iv] *Community end of life care during the COVID-19 pandemic: Initial findings of a UK primary care survey*. Sarah Mitchell et al. MedRxiv. Feb 2021 https://www.medrxiv.org/content/10.1101/2021.02.15.21251756v1.full-text

[v] *Symptom burden and clinical profile of COVID-19 deaths: a rapid systematic review and evidence summary.* Keeley P, Buchanan D, Carolan C, Pivodic L, Tavabie S, Noble S. BMJ Support Palliat Care. 2020 Dec;10(4):381-384. doi: 10.1136/bmjspcare-2020-002368. Epub 2020 May 28. PMID: 32467101. https://pubmed.ncbi.nlm.nih.gov/32467101/

[vi] *Hospital Specialist Palliative Care Team Influence on End-of-Life Care in Coronavirus Disease 2019? A Retrospective Observational Cohort Study*. Duffy T, Seaton RA, McKeown A, Keeley P,

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Sanzone N, Quate L, Farmer E, Stubbs H. Palliat Med Rep. 2022 Oct 21;3(1):235-243. doi: 10.1089/pmr.2022.0041. PMID: 36341471; PMCID: PMC9629908. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9629908/