



The Future of Hospice Care in Scotland

Summary report
August 2021



The COVID-19 pandemic has brought the importance of end of life care into sharp focus. Hospices have been at the forefront of Scotland's response to the pandemic, rapidly adapting their services to continue to provide expert, high quality care when their communities needed them most.

Up to 10,000 more people are predicted to need palliative care by 2040, with more people expected to die at home or in a care home and the complexity of the care they need set to increase. This will put more strain on stretched services, and on the families and carers of loved ones, at a time when the wider health and social care system is already under huge pressure and major new reforms are on the horizon.

The Future of Hospice Care in Scotland is a collaborative report between Hospice UK and the Scottish Hospice Leadership Group designed to stimulate further discussion and collaboration, and drive forward change. The report sets out:

- The role and contribution of hospice care
- The hospice sector's response to the COVID-19 pandemic
- How hospices are adapting to meet future challenges
- What is needed to enable change

For more information please contact policy@hospiceuk.org

The project has been informed by:



An online survey of hospice and palliative care staff in Scotland (74 responses)



Five focus groups with hospice and palliative care staff



Polling of 510 members of the Scottish public



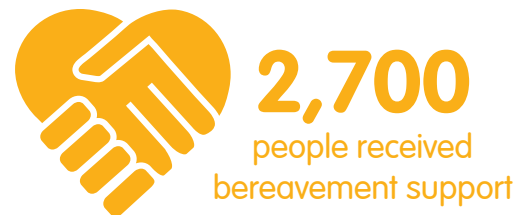
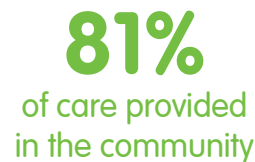
An evidence review and collection of case studies



Interviews with key stakeholders across palliative and health and social care

What is hospice care?

Care and support provided by Scottish hospices



Hospice care aims to affirm life and death. It means working with and within local communities to tailor palliative care around the needs of each adult and child with a terminal or life-shortening condition, whatever that may be, and extends to supporting their carers, friends and family before and after bereavement. Hospice care is provided by multi-disciplinary teams of staff and volunteers who offer expert support that places equal emphasis on someone's clinical, physical, emotional, social and spiritual needs with the understanding that everyone will be different.



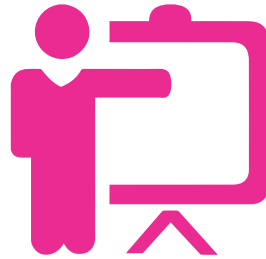
Data is from 2018-19 as this represents the last full year of hospice activity data available prior to the COVID-19 pandemic

Support Scottish hospices provide to other settings



4/5

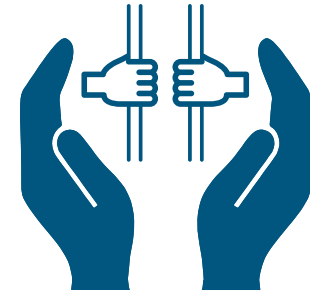
hospices have an out of hours/crisis service for other clinicians



Over

2/3

provide education and training to other settings



2/3

provide support to staff in prisons



Over

1/2

provide support to learning disability services



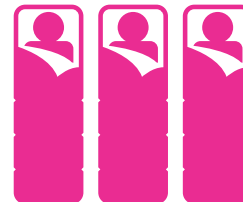
4/5

provide services or support to hospitals



3/4

provide services or support to care homes

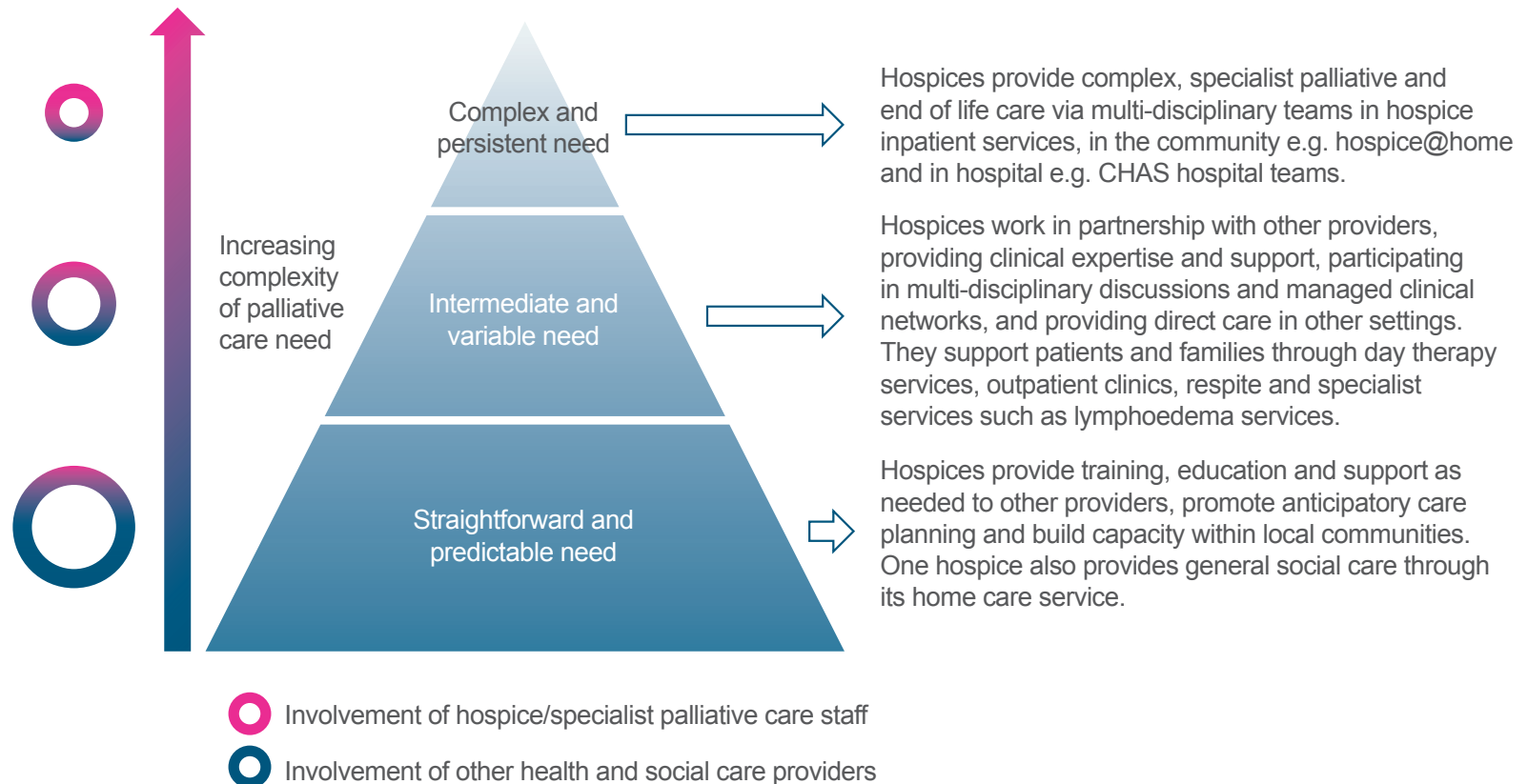


Over

1/3

provide services or support to homelessness services

Hospices support people at all levels of palliative care need across all settings



Adapted from Palliative Care Australia's figure on alignment of need for palliative care against workforce capability, in its Palliative Care Australia (2018) Palliative Care Service Development Guidelines.

How have hospices responded to COVID-19?

Hospices rapidly adapted their services to continue to provide vital palliative and end of life care and bereavement support in their communities by:



Increasing care in the community

With more people dying at home and in care homes during the pandemic, hospices expanded the support they provided in the community through community hubs, hospice@home and rapid response services and offered more support to care homes and community teams.



Providing more support virtually

Hospices quickly shifted to using virtual technology where face to face support was not possible, providing virtual consultations, online wellbeing hubs and counselling and bereavement support via phone and video consultation, expanding the reach of their services.



Strengthening partnership working

Hospices worked closely with care homes, community/primary care services and acute care, and increased the support and training they provided to staff in other settings.



Increasing bereavement support

Hospices expanded and adapted their bereavement services as the need for bereavement support increased throughout the pandemic, using their strong community links to recruit and train additional volunteers.



Supporting local and national planning

Hospices provided clinical leadership around national COVID-19 guidelines and local protocols, such as symptom control, access to medication and visiting restrictions, as well as participating in local and national planning, and contributing to the research community's rapid response to the pandemic.



Supporting staff

Hospices supported their own staff and staff in other health and social care settings to cope with the challenges of the pandemic and traumatic experiences of death.

Beyond the pandemic - how are hospices adapting to meet future challenges?

Increasing support and partnership working across sectors

Hospices are collaborating and working with other providers, particularly district nursing, GPs, social care, out of hours services, acute care and care homes, and increasing the training and support they provide to help meet the rising number of people with palliative care needs across all settings.

Reducing pressure on statutory services

Hospice care lessens demand on NHS services by reducing emergency admissions, reducing length of stay in hospital and facilitating discharges. Hospice care provides significant value for money, with children's hospice care generating £6.24 in public return for every £1 of statutory funding spent and adult hospice care generating £3.96 for each £1 of public funding.

Increasing care in the community

Hospices are responding to the growing number of people dying at home and in care homes by increasing their community capacity and reviewing their models of care and workforce in the community. The sector is looking at how to sustain successful community models that have been introduced during the pandemic as well as identifying further priorities, such as increasing out of hours support.

Hospital-Based Children's Supportive and Palliative Care Team

Around a third of the 16,700 children across Scotland with life-shortening conditions have one or more inpatient stays in hospital during a year. Since 2019, CHAS has funded Glasgow's Royal Hospital for Children to establish Scotland's first hospital-based Children's Supportive and Palliative Care team. The team consists of a consultant in paediatric palliative medicine, two clinical nurse specialists and an administrator, who work closely with other professionals within the hospital. The team aims to provide families with seamless and integrated care, and in its first 12 months 86 referrals (Sept 2019-20) were accepted by the team. The parent of a 1-year-old fed back that the team "have completely transformed our experience of the NHS's involvement in our son's life".

Strathcarron Hospice@Home Service

Strathcarron Hospice's Hospice@Home service in Forth Valley provides high quality personal care to patients at home, as well as practical and emotional support to the patient and their family. It is delivered by a small team of health care assistants with specific experience and training in palliative and end of life care. An independent evaluation showed that patients being cared for by the Hospice@Home service experienced half the number of hospital episodes and on average nine bed days less than those who were not supported by the service – reducing pressure on acute services. The evaluation also showed very high levels of carer/relative satisfaction and that the service was well integrated into wider health and social care services.

Beyond the pandemic - how are hospices adapting to meet future challenges? (continued)

Tackling inequalities

Addressing the deep-seated inequalities in the care that people experience at the end of their lives is a key priority for the hospice sector. Hospices' links with their local communities and strengths in partnership working are helping them improve how they reach and support people across all parts of society.

Developing inpatient services to meet needs

Hospices are reviewing their inpatient capacity and services in response to local need. They are developing inpatient services to better support people with diagnoses other than cancer and are developing more rehabilitation and respite services to support patients for short periods of time.

Supporting families and carers and empowering communities

Hospices have been expanding services such as bereavement support, respite and out of hours care to provide more support to carers and families. They have also been building resilience and empowering communities to find their own solutions to supporting people at the end of life, as well as addressing issues such as social isolation and loneliness.

Homelessness and Palliative Care ECHO Network

Milestone House in Edinburgh recently began providing stepdown beds for people experiencing homelessness who have been discharged from hospital. Managers felt it would be beneficial for staff to have space to discuss issues around death and dying. St Columba's Hospice Care established an education network through Project ECHO which included staff from Cyrenians and Milestone House, a GP from Edinburgh Access Practice, and staff from Marie Curie and Strathcarron Hospice. The ECHO network provided palliative and end of life care education relevant to homelessness settings, offered advice and support from peers and hospice colleagues, and is beginning to bring services that support people experiencing homelessness together to improve access to palliative care.

Helping Hands

Highland Hospice's partnership project 'Helping Hands' is a befriending service to help address isolation and loneliness. The service has four objectives: build community capacity to deal with death and dying; support carers to sustain their caring roles; mitigate impacts of social isolation for clients; support wider health and social care system to cope with increasing demand. The project uses an innovative partnership approach with local communities and in order to extend the service across the whole Highland region it deliberately sought partnerships with small, locally run organisations with a close connection to their community. Local knowledge and contacts support the recruitment of volunteers and helps people feel more comfortable referring to the service.

What support is needed to enable change?



Create the conditions for partnership working

Strong relationships and good communication is key to successful collaboration, with people needing time and capacity to understand each other's roles and develop common goals across sectors.



Effective use and sharing of data

Integrated IT systems are needed to share information quickly between hospices, NHS and other services, to improve patient care. In addition, robust local data about population need and unmet need has to inform strategic planning decisions and the design of services across all partners.



Maximise digital solutions

To sustain the use of virtual services, alongside face to face support, there needs to be good IT infrastructure, support for staff and volunteers, and support and access to equipment for patients and families to ensure it is an equitable choice for people.



Sustainable funding

There needs to be long-term sustainable funding to meet the population need for palliative and end of life care across all settings, including within the hospice sector, with investment to support increased need in the community a priority.



Prioritise palliative care and value hospices as equal partners

Palliative care needs to be prioritised within local population needs assessments and strategic commissioning plans, with hospices an equal partner in the planning, design and delivery of services and supported by strong local and national leadership for palliative care.



Sustainable workforce

There needs to be a supported and sustainable workforce of specialist and generalist staff to meet palliative care need across all settings. The top three challenges relating to the hospice workforce are matching NHS pay and benefits, attracting and recruiting sufficient staff to meet future demand, and retaining current talent.

Action to take at a national level

The Scottish Government, the new national clinical lead for palliative care, hospice and specialist palliative care leaders, integration authorities, health boards and other partners should work together to ensure:

- the areas highlighted in this report inform the development and implementation of the **new national strategy for palliative care** in Scotland
- there is **strategic leadership** and a unified voice between hospice and NHS specialist palliative care services across the whole of Scotland
- there is a **sustainable funding** solution for the hospice sector that recognises the increased need for palliative care, changing models of care and parity with NHS salaries, as part of wider funding to meet population need for palliative care across all settings
- there is appropriate **workforce planning**, education and investment, and strategies to support and retain current staff, to ensure we have the right staff with the right skills to meet people's palliative care needs in the future, including within children's palliative care
- there is a greater focus within **strategic commissioning plans** on the strategic planning of palliative care services to meet population need
- the **evidence base** for hospice and palliative care, service evaluations and improved patient care is further developed and used
- hospices are fully involved in developments around the **National Digital Platform** and reforms to **social care**, to ensure they work for people with palliative care needs

Action to take at a local level

Integration authorities, health boards, hospices, local health and social care services across all settings, and community groups should work together as equal partners, to discuss and address the areas in this report they identify as particularly relevant to them, such as:

- Understanding each other's roles, developing shared goals for palliative care and **strengthening local partnership working**, particularly between hospices and district nursing, GPs, social care, out of hours care, acute care and care homes
- Assessing **local population need** for palliative care, particularly in the community and out of hours, and developing services and models of care that are sustainable and meet people's needs
- Understanding **unmet need and inequalities** in palliative care, prioritising this in needs assessments and strategic commissioning plans, and working jointly to reduce barriers and inequalities in palliative care
- Building **resilience and capacity within local communities** to support people with palliative care needs, their families and carers
- Reviewing local **IT systems** and working towards integrated systems that allow information to be shared and accessed between hospices, NHS systems and social care
- Expanding the palliative care **education and support** that hospices deliver to other providers, and ensuring this is resourced and joined up strategically at a local level
- Reviewing local palliative care **workforce models** to foster more flexible and integrated working both within hospice care and across other settings