

Scottish Hospices:

Working to address the challenges
facing health and social care
in Scotland



Full Report

Hospice care reaches
far beyond the walls of
the hospice building.

A purple flower graphic with five petals, used as a background for the first statistic.

46300

family and friends
supported each year

A green flower graphic with five petals, used as a background for the second statistic.

15200

patients directly
supported each year

A blue flower graphic with five petals, used as a background for the third statistic.

3700

inpatients
each year

A purple flower graphic with five petals, used as a background for the fourth statistic.

253

hospice beds

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What is a hospice?

Hospices are renowned for the individualised care and support they provide for people towards the end of life. However, inpatient care is the tip of the iceberg when it comes to the impact of hospices. Hospice care reaches far beyond the walls of the hospice building...

Hospices provide palliative and end of life care to individuals with life-limiting illnesses. They support patients, their families and others close to them, throughout illness and bereavement.

Hospices provide support in people's homes, inpatient beds, outpatient clinics, support groups, befriending and remote support like telecare. Hospices provide excellent quality facilities and employ multi-professional teams of highly-skilled staff. Hospice teams, which include many volunteers, have undergone extensive training and education to equip them to support and care for those dependent on their knowledge and care.

Hospices provide personalised care based around the needs of an individual and their family, aiming to optimise aspects of life which bring meaning, joy and hope. As well as managing symptoms, hospices help people with their psychological, social and spiritual needs.

In this report we use the term 'hospice' to refer to Scottish Independent Voluntary Hospices¹ all of which are charities - owned, governed and financially supported by the communities they serve. Hospices work with a range of partners to meet the ever-changing needs of communities. Hospices nurture innovation, and because of their size and structure can often explore new ways of working more easily and quickly than larger organisations.

Hospice staff work alongside NHS and social care staff to deliver core services. They also provide education, advice and support to professionals working in hospitals, communities and care homes. Hospices support and develop their community's capacity to care, for example outreach work with schools, befrienders and other community-engagement activities.



¹ Some NHS specialist palliative care units also have 'hospice' in their title, or are informally referred to as a 'hospice'. NHS units are not covered in this report.

Who benefits from hospices?

Hospices are for people approaching the end of their life...

...with any life-limiting illness

Hospices actively support people with any life-limiting, terminal illness that can benefit from their services. This includes (but is not limited to) people with cancer, heart failure, chronic obstructive pulmonary disease, dementia, end-stage liver disease, motor neurone disease, multiple sclerosis, Parkinson's Disease and stroke.

...from any background

Generally, people are referred to a hospice by a health and social care professional. Hospices strive to provide equity of access to people on the basis of clinical need, from all socioeconomic, cultural and minority groups.

...of any age

Adult hospices and the Children's Hospice Association Scotland (CHAS) work collaboratively to support people of all ages. CHAS is the sole provider of children's hospice services in Scotland and delivers care to babies, children, young people and their families up to the age of 21. Adult hospices provide services for people over 16 or 18 depending on the hospice.

...living at home...

Hospice specialists visit and provide care for people who live at home but who need support with pain, other symptom management or psychosocial issues. This care is available to people whether they live at home, in a care home or in another residential setting. People can also receive holistic care and symptom management by attending a hospice outpatient clinic. Hospice staff also give advice and support to NHS and social care professionals providing care in community settings.

...or in the hospice

Scottish voluntary hospices provide a total of 253 beds, where patients can be admitted for management of specific symptoms and the assessment of complex needs and care at any stage of their illness and at the end of life. Some people have highly complex palliative care needs that can only be addressed within a specialist palliative care unit such as a hospice. Hospices have facilities and highly skilled staff on site which enable them to diagnose, assess and treat people who might otherwise experience unnecessary distress. Approximately a third of people admitted to a hospice return home after a period of assessment, treatment or symptom control.

...and their family and friends,

As well as caring for an individual with an illness hospices support a person's family and those close to them. It is estimated that for every patient, the hospice supports an additional three family members, for example through drop-in information, support groups, complementary therapy and bereavement support.

...and community.

Hospices help to foster resilient and compassionate communities, and offer a safe and supported place for people to ask questions or have open conversations about death, dying and bereavement. Hospices shape and support their local community's capacity to care in many ways, for example by establishing peer support groups; employing outreach workers; developing public-facing resources and education; co-ordinating befriending services; working with schools; and training volunteers.

What services do hospices provide?

Each independent voluntary hospice has developed its services in response to the needs of the local population. This means that every hospice is different. For example, a hospice serving Glasgow's urban population is likely to be quite different from a hospice serving a rural island community. The following list gives an overview of the kinds of services that many hospices offer (though not every hospice offers every service on this list):

Community Clinical Nurse Specialists

Many hospices employ community Clinical Nurse Specialists who provide expert symptom management advice, emotional and psychological support to patients and families in their home, working closely with NHS primary care teams.

Outpatient clinics

Aimed at providing specialist palliative care support closer to people in their communities, people can be referred to outpatient clinics which take place in the hospice.

Hospice at Home

Some hospices have Hospice at Home services which provide specialist palliative nursing and psychosocial support to patients who expressly wish to remain in their own home or be discharged home at the end of life.

Inpatient units

An inpatient unit houses beds where patients can be admitted for management of specific symptoms, the assessment of complex needs, and care at the end of life.

Day Hospice/Centre

Hospices provide holistic care and symptom management for patients who live at home, but who need support with pain, other symptom management and psychosocial issues.

Outpatient therapy groups

A range of outpatient therapy groups can be provided, for example on topics such as fatigue, breathlessness and exercise led by allied health professionals, and therapeutic interventions for children and young people facing loss and bereavement.

Bereavement support

Hospices have bereavement services which offer psychological and emotional support to patients, families and carers.

Family support

Most hospices have Patient and Family Support Teams which include social workers, chaplains, counsellors and volunteers. They can provide financial advice, spiritual support, counselling and bereavement support, not just for a patient, but for their whole family and others close to them.

Drop-in information centre

Many hospices have drop-in information services where people can ask questions and seek information on relevant topics.

Complementary therapies

Hospices may offer a range of therapies such as massage, reflexology and reiki - to relieve stress, aid relaxation, promote a sense of wellbeing and help develop coping skills.

Lymphoedema service

Some hospices provide a service for patients who have developed secondary lymphoedema as a consequence of treatment.

Education and support

Hospices provide education and support to a range of professionals, including staff working in a variety of hospital, community and care home locations.

Volunteer support/befriending services

Hospices co-ordinate volunteer support and befriending services which provide practical and social support to people with palliative care needs in their own homes or place of care.

Remote help and support

Remote help can include telecare services such as telephone advice, web-based support and Skype consultations.

Transition support

Hospices provide support to enable young people to transition smoothly from children's to adult's services.

Patient transport services

Hospices co-ordinate patient transport services, allowing volunteer drivers to deliver the important service of transporting patients to and from hospital/hospice appointments.

Support to take part in activities

Many hospices provide support to allow people and their families to have special experiences together.

How do hospices support the wider health and social care system in Scotland?

Hospices deliver core services

Hospices provide support in people's homes, inpatient beds, outpatient clinics, befriending and remote support like telecare. Hospice staff serve alongside NHS colleagues as part of formal palliative medicine on-call rotas, both in core hours and out-of-hours. Hospices provide expert telephone advice to health and social care professionals working in a variety of hospital, community and care home locations. This support is often available 24/7, and whether or not a patient has had previous contact with the hospice. Hospice staff work in partnership with colleagues working in other parts of the health and social care system, and are active in local professional networks.

Hospices are major funders

Last year, hospices raised over £50 million from the public, without which vital services would not exist. This funding was harnessed through fundraising and charitable donations, and reflects the importance Scotland's people place on the availability of quality specialist palliative care. Together with a further £23million from statutory sources hospices were able to spend nearly £74 million. This represents 18% of the Third Sector's total contribution to Scotland's health economy[†].

Hospices are innovators

Hospices nurture innovation, and because of their size and structure can often explore new ways of working more easily than larger public sector organisations. Hospices recognise the need to continue to develop and adapt services, working with a range of partners to meet the ever-changing needs of communities. The Hospice Movement has been instrumental in ensuring palliative care in the UK is ranked best in the world.

Hospices build caring communities

By taking their expertise, resources and understanding beyond the walls of the hospice building, hospices support individuals, communities and other organisations to better care for each other. Hospices provide a hub around which supportive communities are built, and currently around 7000 people in Scotland are active volunteers in support of their local hospice.

Hospices are at the forefront of work to build open and supportive attitudes to death, dying and bereavement in Scottish society (sometimes known as 'health promoting' or 'public health' approaches to palliative care), with the aim of equipping people and communities to deal with the consequences of loss, death, dying and bereavement. This encompasses all kinds of activity, from informal involvement in local community events, to the establishment of ambitious community engagement projects.

Hospices provide education

Most hospices have education departments, and provide education and training on a range of topics including holistic assessment and symptom management; communication skills; anticipatory care planning; breaking bad news; loss, grief and bereavement; family support and spirituality in healthcare. Hospices are a main provider of palliative care education and training to the NHS, including GPs, district nurses and other NHS staff. In addition to formally structured training and education activities, hospices support learning and development by other health and care professionals through routine joint working and the provision of advice and information.

Hospices build relationships with local care homes and provide education, training and advice to support to their staff. Hospices provide education for undergraduate and postgraduate students in a range of health and social care-related subjects. Hospices undertake outreach work within their local communities, including work with school students and teachers, and use these opportunities to provide education and information to the general public.

Hospices support research

Hospices are actively involved in leading and supporting palliative and end of life care research, for example undertaking research alongside practice, contributing to research conferences and journals, reviewing research evidence, contributing to the development of national practice guidelines, and providing funding for academic posts. Many hospices have close working relationships with local universities and colleges, enabling a variety of formal collaborations including shared educator/lecturer posts, delivery of palliative care education, collaborative research studies, commissioning of research, provision of student placements, and hospice participation in clinical research and trials.

Hospices are leaders and advocates

Hospices have relationships with their communities that give them a good understanding of what people and families can need and want. They work to use this understanding to influence policy, practice and service development.

All hospices have local mechanisms for gathering feedback and views of people and families who use the hospice, for example through focus groups, community representatives, consultation, patient participation groups or through chatting to service-users.

Listening to these views, and augmenting them with the professional experience of staff, hospices work actively to influence local, regional and national decision-making processes. This includes being active contributors to clinical networks, planning processes and policy-development groups, responding to consultations, and proactively exploring how hospices can be helpfully involved as new processes emerge.



How do hospices help address current challenges facing health and social care in Scotland?

The challenges

We are fortunate in Scotland to have well-trained and dedicated staff, access to advanced medical technologies, an excellent network of hospitals, care homes and community services, Third Sector organisations that provide good generalist and specialist support, dedicated informal carers, and a strong hospice movement.

However, it is important to recognise that many areas of our health and social care system are under significant pressure.

The population of Scotland is ageing, and many have complex needs – care is increasingly being defined by multi-morbidities and frailty rather than single diseases. By 2039 it is expected that there will be a 85% rise in the number of people aged over 75[♦]. Around 57,500 people die each year, and it is estimated that 43,000 of them will need some form of palliative care[▲].

More people are living and dying with dementia. Informal carers provide the bulk of support, yet are often unsupported and undervalued themselves. The NHS workforce is overstretched, both in the community and in hospitals. Care homes are undervalued and under-resourced. Young adults can face difficulties in transitioning from children's services to adult's services. There is a need to improve equity of care provision.

Money is limited, yet there is a need to deliver excellent services. There is a need to reduce inappropriate hospital admissions, and ensure that people don't stay in hospital longer than they need or want to. Better advance/anticipatory care planning can support this.

Policy context

National policies have been developed which aim to address these challenges, and the diversity of hospice activity means that they contribute to delivering many of these national policies and priorities. Hospices help to deliver all of the National Health and Wellbeing Outcomes. The work of hospices is reflected in all but one of the Core Suite of Integration Indicators, especially those relating to emergency admission, discharge from hospital, carer support, quality of care experience and the two indicators explicitly linked to end of life care. Other policies whose implementation is supported by hospices include; the forthcoming Dementia Strategy with its enhanced focus on advanced dementia; the *Strategic Framework for Action on Palliative and End of Life Care*; *Beating Cancer: ambition and action* Scotland's cancer strategy; Getting it Right for Every Child; the cancer plan for children and young people in Scotland 2016-19 *Right Diagnosis, Right Treatment, Right Place*; the Chief Medical Officer's annual report *Realistic Medicine*; A National Clinical Strategy; recommendations of the taskforce on The Future of Residential Care; recommendations from the Independent Review of Primary Care Out of Hours Services; and the Carer's Act. The later section entitled *How do hospices help?* provides specific examples of how hospices are responding to some of the challenges these policies aim to address.

Integration Authorities

Integration authorities are responsible for strategic commissioning, including palliative care. Integrated Joint Boards (IJBs) are responsible for planning and delivering palliative care in their area². This should include undertaking local needs assessments and planning, taking into account the need to provide co-ordinated care across organisational boundaries and out of hours, and the need to educate and train the health and social care workforce.

² This is the case for all areas apart from in Highland, where the 'lead agency' model is followed, and planning and delivery of palliative care is the responsibility of NHS Highland. Throughout this report we use the term IJB to refer to IJBs and NHS Highland in its capacity as a lead agency.

Specialist palliative care is delivered by Independent Voluntary Hospices and by NHS specialist palliative care units and teams. This means that hospices are key to IJBs' delivery of objectives.

As non-commercial healthcare providers, hospices have expertise, experience and understanding of palliative care and the needs of local communities, and an enthusiasm to share this to improve local services. Some hospices are already leading service re-design and chairing local quality improvement networks. Some Integration Authorities have ensured that hospices have representation on strategic planning groups. When involved in planning with statutory partners, hospices have proven to be a huge asset, leading and supporting the design and delivery of services that meet local needs.

In Scotland there are 14 independent voluntary hospices for adults, and two hospices for babies, children and young people run by the Children's Hospices Association Scotland (CHAS). Not all areas have an Independent Voluntary Hospice. The table below indicates which IJB areas are covered by each hospice.

Accord Hospice	Serves the population of Renfrewshire IJB and parts of East Renfrewshire IJB.
Ardgowan Hospice	Serves the population of Inverclyde IJB.
Ayrshire Hospice	Serves the population of South Ayrshire IJB, East Ayrshire IJB and North Ayrshire IJB.
Bethesda Hospice	Serves the population of NHS Western Isles/Eilean Siar IJB.
CHAS	Serves the population of all IJBs.
Highland Hospice	Serves the population of NHS Highland.
Kilbryde Hospice	Serves the population of South Lanarkshire IJB.
Marie Curie Hospice, Edinburgh	Serves the population of Edinburgh City IJB, Mid Lothian IJB and West Lothian IJB
Marie Curie Hospice, Glasgow	Serves the population of Glasgow City IJB and East Dunbartonshire IJB.
The Prince and Princess of Wales Hospice	Serves the population of Glasgow City IJB, South Lanarkshire IJB and East Renfrewshire IJB.
St Andrew's Hospice	Serves the population of North Lanarkshire IJB and South Lanarkshire IJB.
St Columba's Hospice	Serves the population of City of Edinburgh IJB and East Lothian IJB.
St Margaret of Scotland Hospice	Serves the population of Glasgow City IJB, East Dunbartonshire IJB and West Dunbartonshire IJB.
St Vincent's Hospice	Serves the population of Renfrewshire IJB and parts of North Ayrshire IJB.
Strathcarron Hospice	Serves the population of Falkirk IJB, Stirling & Clackmannanshire IJB and North Lanarkshire IJB.

How do hospices help?

Hospices have a wealth of expertise and experience in palliative care, and as relatively small, streamlined organisations they are less hampered by bureaucracy than larger organisations. Hospices are able to respond quickly, flexibly and innovatively to challenges as they arise...

Supporting an ageing population with increasingly complex needs

By addressing physical, spiritual and psychosocial needs and the needs of families, the hospice approach to care is well suited to supporting a population living longer with multi-morbidities.

Hospice services are community-based, and after holistic assessment hospices can provide various different services. Respite at home, rapid access to allied healthcare professionals (at home or in the hospice), outpatient services, befriending and outreach to community day centres are examples of direct service responses supporting our aging population. Hospices have also been responsive to the increasing number of people living and dying with dementia, as described later.

Hospices typically link with other agencies and specialities. For example, hospices can work with community hospitals to provide step-down two-tier services, and many hospices support rehabilitation and enablement approaches. Care homes play a key role in caring for Scotland's ageing population, and hospices work to support this by providing education, advice and support for care home staff.

Reducing inappropriate hospital admissions.

Support to patients and carers at home can reduce the anxiety and crises which often trigger admission and good care in the community will prevent many inappropriate admissions to hospital.

Most hospice care is provided to patients and families at home. Hospice clinical teams work alongside district nurses, social care services and GPs to provide support. Hospices provide 24/7 advice to other community services and care homes when decisions are being made about the need for admission. Some hospices provide 24/7 medical on call services and tele-mentoring to support other services out of hours, while others input to hospital emergency assessment units.

Many patients are able to have symptom assessment and management at hospice outpatient clinics. Hospices sometimes provide inpatient care as an alternative to hospital admission. Hospices work with patients and families to explore and document preferences for future care. Known as 'anticipatory care planning', this can also reduce unwanted admissions to hospital.

Ensuring people don't stay in hospital longer than they need or want to.

Many of the services mentioned above which prevent inappropriate admission also support rapid discharge, by providing adequate support at home. Community nurse specialists, counsellors, social workers, complementary therapists and volunteer befrienders are all part of the mix of support which hospices can provide. Hospices have links with local discharge liaison teams. Some provide step-down care when someone doesn't need to be in hospital but is not ready to return home (for example where a family is learning a new intervention to care for their child).

Supporting people to live well and die well with dementia.

Hospices are developing and delivering a range of responses to support people to live and die well with dementia, working in partnership with other services. Hospices provide training and education for health and care staff who are supporting people with dementia and their families, whether in care homes, specialist dementia units or at home.

Volunteer-led befriending services work to address the isolation often experienced by family carers of people with dementia, providing home respite and complementary therapy. Day hospice services also support carers, and in some instances groups of people with dementia.

Increasing numbers of hospice patients have dementia alongside other conditions, and hospice staff have developed the skills to provide appropriate support. Hospices are adapting their services to address the needs of people with dementia.

Improving advance/anticipatory care planning.

Hospice staff have significant expertise in having conversations with people about what matters to them as they're approaching the end of life, their priorities and their preferences for future care. Hospices often support staff in other settings to have these conversations, and provide education to support people to build their skills and confidence to have these difficult conversations. Hospices' skills and expertise in this area are also being fed into national work to improve anticipatory care planning.

Supporting and valuing carers

Hospices assess the needs of carers and provide direct support, which can include counselling, spiritual care, therapeutic arts and complementary therapies. Hospices also provide information for carers on everything from financial matters to moving and handling to the administration of medicines. Support can be provided one-to-one in person or on the phone, through peer support groups/networks, carers' cafes, day units or short break befrienders. Hospices work with local carer centres and also signpost and cross refer to other services. Childrens' hospices have facilities so the whole family can stay, and support of siblings and parents is integral to the ethos of CHAS.

Delivering high quality services when money is limited

The risk of being admitted to hospital increases very significantly towards the end of life. Hospices enable many people to be cared for in their homes or other community settings services who would otherwise be cared for in acute hospital settings.

Hospices receive around £22million from NHS Boards/Scottish Government. However, through their engagement with local communities , they raise an additional £50million from other sources to fund services.

Hospices have a practical understanding of how to achieve value for money through efficiency, good configuration of services and working co-operatively with other service providers. The way hospices develop and deliver services is innovative, flexible and collaborative. Appropriately vetted and skilled volunteers contribute to delivering certain hospice services.

Educating and training the health and social care workforce.

As outlined earlier, hospices are a main provider of palliative care education and training to care homes and the NHS.

Providing co-ordinated care across organisational boundaries and out of hours.

Hospices work in partnership with other organisations in many different ways to help ensure that patients and families get the right care in the right place at the right time. Hospices fund medical and nursing staff who work in NHS as well as hospice settings. For example, a hospice consultant may do ward rounds in the local hospital, join the team meeting of other acute specialties and run outreach clinics. Hospice staff often provide input to review meetings in primary care. Hospices provide out of hours telephone support for patients and families, and to professionals from other areas of health and social care. Hospices sometimes provide space for the co-location of other services such as Macmillan and Marie Curie nurses.

Supporting an overstretched NHS workforce, both in the community and in hospitals.

Working in partnership to join up and integrate services can make tight NHS, social care and hospice resources go further, as well as offering a more seamless experience for patients and families. There are many good examples of this happening already. Hospices' extensive use of volunteers adds capacity to care and has potential to grow.

Improving equity of care provision

Hospices have staff and facilities dedicated to providing specialist palliative and end of life care. There are many challenges to providing this quality of care in busy hospital wards, or in minimally funded care homes. Hospices work to support improvements by providing advice and support to settings such as acute hospitals and care homes.

For historical reasons, while palliative care for people with cancer is well-established, palliative care for other conditions has been later to develop. Hospice services are open to people regardless of diagnosis, and hospices are developing links to a range of specialties treating people with serious heart, kidney, lung and neurological illness.

Hospices have done work to identify and address the barriers different minorities face that can prevent them from accessing hospice services, for example homeless people, some ethnic groups, asylum seekers, refugees and prisoners. Hospices provide education on how to address some of these barriers and provide palliative care that is 'culturally competent' for people from different cultural or religious backgrounds.

Building capacity in care homes

Hospices are major providers of education and support to care homes. In addition to traditional education approaches hospices have provided secondments, mentoring, and have established and facilitated peer learning groups. Hospices provide day to day advice and support to care home staff, and have also delivered their own services into a care home setting.

Supporting young adults to transition from children's services to adult's services.

Due to medical advances, many children who until recently would not have survived until adulthood are now doing so. The Children's Hospice Association Scotland have established a transition team and every young person over 18 in their care is allocated a transition worker who supports them to create an individual transition plan. The transition team supports young people to test out alternative care providers to supplement the care they receive.

The needs of young people are broader than palliative care and include education, housing and social opportunities. However, as part of this bigger picture, CHAS and adult hospices are increasingly working together to explore and develop the role of adult hospices. CHAS has supported young people get to know more about what an adult hospice can offer them and their family. Adult hospices are developing links with other relevant services and organisations,

including paediatric oncology and Together for Short Lives. Opportunities include transition beds in adult hospices, staff exchanges, recruitment of younger volunteers to support transition work and development of clearer transition pathways.

An invitation to get in touch

As independent organisations, hospices are often uniquely placed to deliver creative and quick responses to the changing needs and choices of people with life-limiting illness. By working closely with IJBs, hospices can bring leadership, expertise and patient-driven solutions to deliver greater value.

The integration of health and social care in Scotland creates new opportunities to improve care for individuals, families and communities. Scottish hospices have an essential role in this, and are ready to engage in discussions with partners about how to work together in new ways to improve local services.

Appendix 1: Addressing the myths

Hospices are often poorly understood, and there are many myths about hospices....

Myth	Fact
Hospices are for people with cancer.	Hospices actively support people with any life-limiting, terminal illness that can benefit from their services. This includes (but is not limited to) cancer, heart failure, chronic obstructive pulmonary disease, dementia, end-stage liver disease, motor neurone disease, multiple sclerosis, Parkinson's Disease and stroke.
The sole function of a hospice is to provide beds to look after people who are dying.	Though hospices do provide high-quality in-patient services for people approaching the end of their life, most people who benefit from hospice services will never use a hospice bed. Hospice services encompass community-based services, bereavement support, drop-in information, out-patient services, befriending, and remote help and support such as telecare and web-based support.
If you go to a hospice, you'll die there.	Approximately one third of people admitted to a hospice inpatient bed return home after a period of assessment, treatment or symptom control. People can also access support from hospice services without staying in a hospice overnight.
Hospices are just for ill people.	As well as caring for an individual with an illness, part of the hospice's role is to provide support to a person's family and those close to them. It is estimated that for every patient, a hospice supports an additional 3 family members.
Hospices are sad and sombre places.	Hospices are full of light, love and moments of joy, as well as times of deep sadness and loss. People often comment that they are surprised by the friendly and pleasant atmosphere they find. Hospices strive to bring joy and meaning into people's lives, supporting people to truly live until they die.
By using a hospice, a person is giving up on treatment aimed at cure.	Hospice staff recognise that there are times when it is appropriate for palliative care to be provided alongside other active treatment. Depending on the wishes and preferences of an individual, it may be appropriate to continue with some treatment interventions, whilst at the same time addressing any symptoms as well as psychological, spiritual and social needs.

Myth	Fact
Hospices are exclusive.	Hospices strive to provide equality of access to people based on their clinical need. This includes people with malignant and non-malignant conditions, and from all socioeconomic, cultural and minority groups.
Hospices are for old people.	Hospice care is provided for people of all ages. Adult hospices provide services for people over 16 or 18 depending on the hospice. The Children's Hospice Association Scotland (CHAS) works with babies, children and young people and their families. Services work together to ease transition from children's to adult services.
Hospices are like nursing homes.	Hospices are more specialist than nursing homes – they offer support for people with very complex needs. Nursing homes tend to support elderly people, where as hospices are for people of all ages. The average length of stay in a hospice is just one or two weeks - much shorter than the length of stay in a nursing home. In addition to in-patient beds, hospices provide a range of other services (as detailed elsewhere) not provided by nursing homes.

Appendix 2: Definition of palliative care

WHO 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 patients 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.

WHO Definition of Palliative Care for Children

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

<http://www.who.int/cancer/palliative/definition/en/>

Appendix 3: References

The figures, information and assertions presented in this report are the result of a survey and series of meetings undertaken by Scottish Independent Voluntary Hospices and the Scottish Partnership for Palliative Care from June – September 2016, which collated together information about the services, approach and resourcing of hospices in Scotland. Other main information sources are listed below.

† Scottish Council for Voluntary Organisations (April 2014) SCVO's State of the Sector Report. April 2014 <http://www.scvo.org.uk/wp-content/uploads/2014/04/SCVO-Sector-Stats-2014.pdf>

◆ National Records of Scotland (October 2015) Projected Population of Scotland (2014-based)

<http://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-projections/population-projections-scotland/2014-based>

▲ Estimate based on 75% of deaths likely to require palliative care input, as suggested on p.63 of: Funding the Right Care and Support for Everyone. Creating a Fair and Transparent Funding System; the Final Report of the Palliative Care Funding Review July 2011. Review team: Tom Hughes-Hallett, Professor Sir Alan Craft, Catherine Davies, Isla Mackay, Tilde Nielsson

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215107/dh_133105.pdf

Appendix 4: Credits

This report is collaboration by the Scottish Partnership for Palliative Care and all Scottish Independent Voluntary Hospices:

Accord Hospice

Ardgowan Hospice

Ayrshire Hospice

Bethesda Hospice

Children's Hospice Association Scotland (CHAS)

Highland Hospice

Kilbryde Hospice

Marie Curie Hospice, Edinburgh

Marie Curie Hospice, Glasgow

The Prince & Princess of Wales Hospice

St Andrew's Hospice

St Columba's Hospice

St Margaret of Scotland Hospice

St Vincent's Hospice

Strathcarron Hospice

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