University of Glasgow

Marie Curie
Care and support through terminal illness

Past, present and future

Caring for those approaching the end of life in Scottish Hospitals

Supported by

PATCH

Scottish Partnership for Palliative Care

MACMILLAN CANCER SUPPORT

ESRC 1965 - 2015 50 YEARS SHAPING SOCIETY

Contents

Executive summary

Ben Gold/Marie Curie

Over half a million Scots will die in Scottish acute hospitals in the next twenty years, and millions of people with palliative care needs and approaching the end of life will be cared for in a hospital in the years and months before their death.

Public policy approaches in recent years emphasising care in community settings have led to a mistaken perception by some that any palliative and end of life care provided in a hospital setting represents a failure of the system or a 'problem'[1]. Good care for people needing palliative and end of life services takes place in hospitals daily, where people need and often choose to be. The problem with much palliative and end of life care in hospitals is not that it is taking place, but that it needs to be better supported and resourced.

There is a recognition and understanding from Scottish Government to hospital wards that more needs to be done to support palliative care in acute settings.

Marie Curie and the University of Glasgow brought together a range of interested stakeholders from across Scotland to discuss and consider how palliative care in acute settings can be improved, what changes need to be made, and how we can share good practice.

This report brings together the findings of that work and highlights a range of challenges facing acute hospitals in ensuring good palliative care and recommendations to address them including:

- The need for a much greater **commitment at national and local policy** level for supporting palliative care in acute settings.
- Challenges in **identifying patients with palliative needs** following their admission or when approaching end of life. There needs to be greater awareness of existing data and better use of tools, training and support to help more people get identified.
- **Support to make change in acute services** to help those with palliative care needs. There are lots of examples of successful change and innovation that could be shared and replicated.
- **IT challenges** including the sharing of current clinical information and electronic anticipatory care plans are a problem and can lead to unwanted and inappropriate treatments being given to patients. The roll out of the National Digital Platform must work to support all health and social care professionals and patients so they can access health information safely to support patient centred integrated care.
- Scotland is **failing to meet the staffing levels** for specialist palliative care recommended by the Association of Palliative Medicine. This can mean many acute settings not having sufficient staff to support patient needs. There needs to be a palliative care workforce plan developed to support Scotland to meet these recommendations.
- Many of those working in acute hospitals do not have the **training and education** they need to support people with palliative care needs, including communication training.
- Many hospitals do not have the **environment** to support people coming to the end of life, with some spending the final hours on busy and noisy wards with little space for family and friends.
- The **evidence base** to show the true value of palliative care in acute settings needs to be strengthened. There is emerging evidence that there is value to be gained through focused approaches to acute based palliative and end of life care, as well as the impact that it has on the wider health and social care system including any financial efficiencies. To further understand and strengthen this there needs to be greater investment in research and service evaluation.
- For many hospitals there is still a culture of 'treat and cure', which can mean patients with palliative care needs do not always get the care and support they would prefer or need. Lack of resource, understanding and consideration of employing palliative approaches leads to a greater risk of non-beneficial overtreatments being used at cost to both individuals and the system. **The Realistic Medicine approach** introduced by the Chief Medical Officers must be adopted and embraced in all settings and by all professionals including all those that work in acute settings.

31,000

deaths will be in hospital by 2040 if community-based services don't get the support they need.

Recommendations

Reflecting on recent palliative care policy and acute hospitals

National and local policy should actively support palliative care in acute settings for all people with palliative care needs. This should be part of a whole system approach.

- Scottish Government should establish a new palliative and end of life care strategy or framework to succeed the Strategic Framework for Action on Palliative and End of Life Care (SFA) in 2021 including:
    - A commitment to palliative care in all settings, including acute hospitals, acknowledging the recommendations in this report and setting out how to achieve them.
    - It should cross reference the Realistic Medicine agenda.
    - It should be supported with robust data and evaluation.
- Appointment of a national clinical lead for palliative and end of life care covering all settings to act as a link between policy and practice, between settings and specialties, and between commissioners and those that deliver services.

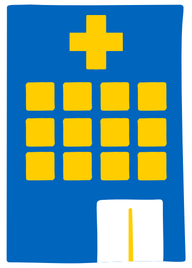
The establishment of a national group for palliative care in acute settings. The group should:

- promote palliative care in acute settings
- support the sharing of good practice
- develop benchmarking of services through the establishment of a national minimum dataset
- feed into Scottish Government and other key decision-making bodies.

An appropriate place to be cared for and die

Scotland should ensure that hospitals are supported to provide consistently high-quality care that improves patient outcomes and experience for someone who has palliative care needs and/or is at the end of life. Measures should include:

- Appointment of clinical and executive leads in each NHS Board for palliative and end of life care. This role would work across the system, including linking with the Integration Joint Boards (IJB) in the area, as well as ensuring a link-up between all specialities and palliative care teams where appropriate and with services across other settings. These appointments must come with funded time.
- Appointment of Allied Health Professional leads for palliative and end of life care in each NHS Board in Scotland.
- NHS Boards and Health and Social Care Partnerships should jointly identify money to fund collaborations between specialities and palliative care, such as the Tayside renal programme and the Caring Together Programme.



47%

of people who died 2017/18 in Scotland died in a hospital

Identifying palliative patients in hospital settings

Everyone with a palliative care need should be identified if admitted to hospital or attending an outpatient appointment.

- Training and support, as well as tools for identifying patients with palliative care needs, should be provided to all clinical staff working in hospital settings.
- There should be an emphasis placed on those patients at the front door of the hospital to support early identification. This could follow the Frailty at the Front Door Collaborative model developed by Healthcare Improvement Scotland.
- Information materials and resources on identifying palliative patients should be shared widely with hospital staff.
- Hospitals should be encouraged to use monitoring systems which improve patient safety for example, National Early Warning Score (NEWS) 2, which determines the degree of illness of a patient and prompts critical care intervention.
- Hospitals should endeavour to recognise patients beginning to die with sufficient time to allow a discharge to the community (home) for end of life care, if it is safe to do so and is the patient's preference. This will require an integrated health and social care response that can work at pace.

Changing models of care

Scotland should ensure that its hospitals are best placed to support people to receive care when they are terminally ill, approaching the end of life and dying, through joined-up services supporting multi-disciplinary teams.

- NHS Boards and Health and Social Care Partnerships should jointly identify money to fund collaborations between specialities and palliative care, such as the Tayside renal programme and the Caring Together Programme. This should work across those functions delegated to the IJBs and NHS Board's.
- The role of chaplaincy and support services in hospitals should be explored and support offered to develop these functions further.
- The Scottish Government should support and fund the development of volunteer-led services to support families and people dying in all Scottish hospitals, exploring the Marie Curie Companion service and Compassionate Inverclyde as examples of good practice. An initial fund could be established centrally to prove value with local Boards taking forward through mainstream funding in subsequent years following successful evaluation.

By 2040 **45% of all deaths (29,590) are projected to be in people aged over 85**.

Improved research, quality improvement activity, support innovation and change

- The Scottish Government should set aside £15million for a nationwide Change and Innovation Fund to test new models of integrated care in acute settings to support palliative patients to achieve better outcomes, but also to support the rollout of proven models of care to other areas.
- Encourage and share good practice, for example the Tayside Renal project.
- There needs to be more research and quality improvement carried out into acute palliative care to develop and build the evidence base.

IT

IT and technology should support patient centred care and enable those working with patients to have the most up-to-date information about that care and be able to provide appropriate input.

- Support the roll-out of the National Digital Platform and ReSPECT as an early adopter.
- All those delivering care and support to a patient with a terminal illness, and the patient themselves, should be able to access the patient record and be able to update it regardless of care setting.

Workforce

Scotland should increase the number of palliative care consultants, doctors and specialist nurses, and others working in acute and other settings to support people living with palliative care needs and approaching the end of life.

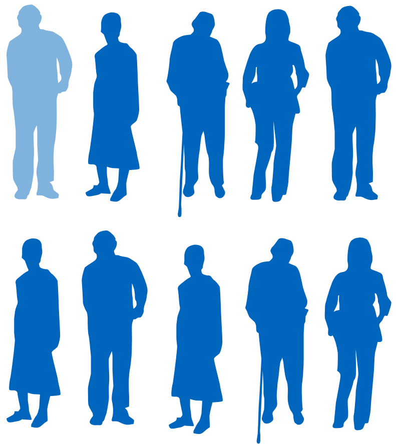
- A workforce plan following the Association of Palliative Medicine (APM) recommendations for palliative medicine should be established covering the next 20 years. This should also include recognition and need of other roles that form part of the multi-disciplinary team including Allied Health Professionals (AHP), pharmacists and chaplains. This should consider the development of commissioning guidance to support Integration Authorities, NHS Boards, hospitals, hospices and other providers.
- The Scottish Government should ensure that Scotland is working toward achieving the recommendations on palliative medicine staffing levels set out by the APM.

At any one time
in Scottish hospitals,
one third
of patients will be in
their last year of life

Volunteers and non-statutory support

Scotland should draw upon its strength in communities, the third sector and the power of volunteers to respond to the needs of their community and empower them to support those with palliative needs and approaching the end of life in acute settings.

- The development of national and local volunteer-led services to support families and people with palliative care needs and those approaching end of life in all Scottish hospitals, exploring the Marie Curie Companion service and Compassionate Inverclyde as examples of good practice.
- Support start-up funding to prove value with the option for local Boards to take forward through mainstream funding in subsequent years following successful evaluation.



One tenth
will go on to die
on that admission

Education and training

All acute staff should be given training to provide care and support for those living with a terminal condition, coming to the end of life and dying in hospitals, as well their families, friends and carers. This should include communication training.

- Additional Commitment to Teach (ACT) funding should be targeted to support medical education for students and to increase teaching capacity of future doctors, which was highlighted as a priority for the long term.
- Dedicated resource should be made available to palliative care specialists to provide training and support to other clinicians in acute settings.
- Support should be provided to nursing staff working across a wide range of clinical settings in hospital to develop their knowledge and skills in palliative care.
- A suite of e-learning tools to support acute staff should be developed. This could be delivered by Healthcare Improvement Scotland or NHS Education Scotland.
- Training should also include risk management and align to the Realistic Medicine agenda.
- Consideration should be given to providing training to support staff including cleaners, porters, catering staff and administration staff who work on ward areas and have considerable interactions with patients and families.

Communication

All acute staff should have training and support in communication skills to support them in speaking with people with palliative care needs and their families.

- Each NHS Board should produce a communications strategy to ensure all staff have the communications skills they needed depending on their role from basic communication skills right through to advanced conversations in highly distressing and end life care situations.
- Continued support for Building on the Best and other initiatives aimed at supporting early conversations around dying, death and bereavement, as well as care, taking a person-centred approach.

Acute palliative care beds in Scotland

Each NHS Board and Acute Hospital should review the palliative care support available in their area/hospital.

- The proposed NHS Board leads for palliative care (see above) should carry out a review of palliative care beds in their areas. This review should be carried out in conjunction with local Integration Joint Boards (IJB), independent and third sector providers of palliative and end of life care services, such as care homes and hospices.

Environment

All Scottish hospitals should review their environment to determine their suitability for those with palliative care needs and those approaching the end of life.

- Hospitals should consider how to better support patients at end of life and their family, friends and visitors.
- Any capital projects around hospitals should be required to consider how the hospital environment impacts on those at end of life.
- The Scottish Government should consider supporting something similar to or aspects of the Hospice Friendly Hospital Design and Dignity programme.

Half

of people aged over 85 in hospital were in the **last year of life**

Building an evidence-base and improving regulation and standards

Scotland should collect robust data and evidence to show that Scottish hospitals are providing the best care for those with a terminal illness and approaching the end of life. This should also include a measure of patient and carer experience.

- Hospitals should conduct regular audits of end of life care, this should include patient and carer feedback to capture patient experience.
- The Scottish Government should consider joining England, Wales and Northern Ireland in the National Audit for End of Life Care in hospitals (NACEL) or develop minimum data sets to identify:
  - hospital outputs/measures
  - recognition of unmet need/ demonstration of meeting needs across localities
  - access to care
  - quality/experience of care
  - health economics of palliative care provision in acute settings
  - acute staff confidence in supporting people with palliative care needs and at the end of life.
- There needs to be greater investment in research into palliative and end of life care and this should include research around acute settings.

There needs to be greater scrutiny of care standards for end of life care in hospital and acute settings.

- Healthcare Improvement Scotland (HIS) should draft specific standards for end of life care in acute and hospital settings and review all hospitals in Scotland against them in the next five years.
- HIS should focus on the palliative care aspects of its Care of Older People in Hospital standards when carrying out future inspections of acute settings.
- Audit Scotland published a report on palliative care in 2008, which has not been repeated since. Audit Scotland should consider repeating this review.

Three weeks

People in the last six months of life will spend on average **three weeks in hospital** before they die.

Introduction

Every year tens of thousands of people with palliative care needs will be cared for in a Scottish hospital, including over 27,000 who will die there. Being able to access palliative care is something everyone should be able to do from the point they need it and, in any setting, whether in their own home, a care home, a hospice or a hospital.

With a national and local focus on shifting people's care from acute to community settings, and with the general perception (based on opinion polls/research) that most people would prefer to be at and to ultimately die at home there has been an emerging narrative that care and dying in a hospital is seen as a 'problem' and that care and support in a community setting should be where efforts are focused.

Marie Curie and the University of Glasgow's End of Life Care Studies team, with the support of the Scottish Partnership for Palliative Care (SPPC), Macmillan Cancer Support and Palliation and the Caring Hospital (PATCH), set out to review palliative care in Scottish acute hospitals. Through three seminars and a consultative exercise with a range of experts the project examined a range of issues including public policy, culture, practice, barriers and challenges, examples of good practice, as well as innovation, and looked across the recent past, the present and exploring future trends.

The aims of this project are:

- to identify the challenges facing palliative care provision in hospitals and how they can be overcome
- to inform current and future national and local policy in palliative care
- to support key commitments for change.

This report is a summary of the work of the seminars and incorporates additional feedback from a range of people interested in palliative care in acute settings. This report will be of interest to:

- Scottish Ministers
- civil servants
- NHS Boards
- local authorities
- Scottish hospitals
- palliative care teams
- health and social care partnerships
- the general public, including patients and families.

The Project

Marie Curie and the End of Life Studies Group at the University of Glasgow have done a range of joint work exploring issues surrounding palliative and end of life care in Scottish Hospitals since 2015. To further develop this work the two organisations, with the support of the Scottish Partnership for Palliative Care (SPPC), Macmillan Cancer Support, and PATCH, held a series of three interactive workshops with key stakeholders between autumn 2018-spring 2019. As leading organisations in palliative care that recognises the role in delivering palliative care it was felt that a collaborative approach was necessary and also reflected the importance of the issue.

This work was partly funded by an Impact and Acceleration Award given by The Economic and Social Research Council (ESRC), and from resources within Marie Curie.

Each workshop was designed to support a group inquiry and took an investigative approach to the provision of palliative care in acute settings in Scotland. Workshops used key policy documents, research and good practice examples as a basis for discussion. Each workshop also included a number of presentations from various experts.

The first workshop focused on historical aspects of palliative and end of life care in Scottish hospitals, the second addressed contemporary issues and looked at examples of good practice in Scotland, and the third looked at future projections, and explored examples of good practice from elsewhere that might inform future hospital-based palliative care in Scotland.

A range of participants were invited to take part in the workshops to share expertise and discuss key questions. A full list of all those who took part is set out in Annex A. These people were invited in a consultative capacity and were not there as specific representatives of their organisations.

Notes were taken and recorded, at times verbatim, and proformas were used to capture key points. Those who attended also provided further commentary via email, this also included suggested research and articles.

Following the seminar, initial findings were presented to a range of groups interested in palliative care in acute settings and feedback was invited and incorporated into the final report.

In a letter to the Scottish Parliament's Cross-Party Group on Palliative Care, the Cabinet Secretary for Health and Sport, Jeane Freeman MSP, expressed support for this work and government has committed to reviewing its findings and recommendations of this report.

The focus of this work referred largely to adults (those over the age of 16) with palliative care needs and not children and young people. Some of the points raised and discussed will be relevant to children and young people, but this age group also has very specific needs and settings that should be considered separately.

The project also refers primarily to acute hospitals and largely excludes community and cottage hospitals.

Objectives

Ahead of three workshops the following objectives were identified by the partner and supportive organisations:

- creation of a recent timeline/overview of the landscape of hospital palliative care provision since it first became a policy concern – this includes both specialist and non-specialist palliative care
- better 'on-the-ground' understanding of how policy and other drivers is shaping practice
- a 'snapshot' of current successes and issues
- the need to identify opportunities for improvement and change both for now and to meet the challenges of the future (the next twenty years).

The following is a report of the work of those three seminars setting out key issues by theme, as identified by the participants.

Quotes from participants have been anonymised and set out in italics throughout the report.

A number of case studies were presented or discussed at the seminars and these have been highlighted throughout the report in boxes.

The recommendations that were discussed and identified by participants are set out throughout the report and summarised above.

Palliative care in acute settings in Scotland

Layton Thomas/Marie Curie

26,917
people in Scotland died in a hospital in 2017/18

In 2017/18, 26,917 people in Scotland died in a hospital, that's 47% of all people who died that year. This is far more than the numbers of people dying at home, in a care home or a hospice. Despite the overall percentage of people dying in hospital having steadily declined from 60% in the last 15 years, the actual numbers of hospital deaths are increasing, including a 5% increase in 2017/18.

At any one time in Scottish hospitals, one third of patients will be in their last year of life and one tenth will go on to die on that admission[2]. For those aged over 85[3] nearly half of them were found to be in the last year of life. People in the last six months of life will spend on average three weeks in hospital before they die[4].

Excellent care is being given in hospitals across Scotland to people with palliative care needs from their diagnosis to death. This can include those admitted for treatment and support and then later discharged home through to those admitted at end of life and cared for in their last days and hours. It can also include those attending outpatient appointments for treatment, scans and investigations, or consultations. People with palliative care needs may be using acute hospital services for years, months, days, weeks or hours depending on their terminal disease(s) or conditions. Acute hospitals may provide pivotal interventions that enable the person to spend more time at home in the last period of life.

The role of hospital specialist palliative care teams in acute settings has been shown to be an effective means of managing patients affected by severe illness, reducing the number of deaths that occur within the hospital, long periods of hospitalisation and instances of readmission[5]. Inpatient palliative care consultations have also been proven to have a positive impact on patient outcomes and transitions to the community, demonstrating the potential to improve patient quality of life and relieve overburdened acute care[6].

However, this care is not universal in hospitals across Scotland, with many patients not being identified as being palliative and missing out on potential palliative consultations. Research has suggested that there are currently numerous barriers to palliative care for older people in acute settings[7]. Those with organ failures including advanced liver disease and needing palliative care are among those most likely to have frequent unplanned hospital admissions and often die in hospital with an acute complication[8].

Staff in acute hospitals need to have the skills to identify patients who are approaching the end of life and who would benefit from improved care coordination and advance planning, including an exploration of their wishes around future treatment and attention paid to their carer's needs. Hospital staff also need to recognise the patient who is approaching the end of life and either coordinate a timely discharge to a community setting or provide excellent care in the hospital.

The unique challenge for hospitals however is that the expectation of both staff and patients (and their families) is that hospitals are a place where a person goes to get better. This often leads to a culture within hospitals of active disease-focused treatment being the accepted norm and a move to palliative and end of life care being viewed as 'giving up'. Many people don't realise that palliative care can be concurrent with other treatments, which can further this problem. There is also a growing challenge as more and more patients present with multi-morbidity and an unclear prognosis. This also means that patients may perceive mixed messages from their healthcare providers, with community teams recognising deterioration and beginning conversations about the future but secondary care teams addressing acute deteriorations without referring to the 'bigger picture'.

There is evidence that many families do want more information about possible outcomes of care, including knowledge that the person is "sick enough to die[9]". However, evidence also suggests that patients expect their healthcare teams to initiate conversations around future deterioration and if the subject is not raised by the professional, the patient will not initiate it[10]. Professionals may also find it difficult to raise such discussions, especially if they do not feel there is a credible, positive alternative approach to guide patients towards.

The Scottish Government is committed through its Strategic Framework for Action (SFA) to ensuring that everyone who needs palliative and end of life care has access to it by 2021. The SFA specifically states that this must be in all settings, including hospitals, which is a welcome commitment. However, palliative care policy, the SFA included, has mainly focused on community settings, with little attention or resources being given to acute hospitals.

Wider Scottish Government policy in health and social care has for the last decade been about supporting a shift in care from acute settings to home or care in the community. This has followed both the preferences of people and their families, but also because it is can lead to resource efficiencies in the health and social care system. Over the years there has been a suggestion through some research and public opinion polls that most people would prefer to die at home, which has led to an emphasis on enabling deaths in community settings. This has had an unfortunate consequence of creating a paradigm of 'home care/death equals good, hospital care/death equals bad'. This has led to hospitals being seen as a 'problem' in terms of receiving palliative care and as a place of death, as well as leading to a lack of a positive role in Government policy for hospitals in palliative care provision[11].

Recent research suggests that even with national policy efforts to shift care from acute to community settings, a significant number of people will still be dying in a hospital in Scotland by 2040 with around 22,500 deaths. Although this would be a reduction in both the total number of hospital deaths and a reduction in the overall percentage (34% of all deaths in 2040), the research found that this will only be possible with increased support in care at home and community-based services to support dying people.

Scotland's population is also ageing. By 2040 45% of all deaths (29,590) are projected to be in people aged over 85. There will be a substantial increase in the number of people living with multi-health conditions including frailty, cancer and dementia. This will lead to a change and increase in the complexity of both hospital admissions and community care.

29,590

of all deaths in Scotland are projected to be in people aged over 85 by 2040.

If community-based services do not get the additional support they need then this is likely to lead to more deaths in hospital in the years to come, with the numbers potentially increasing to over 31,000 by 2040[12].

In-patient capacity in hospices is unlikely to increase in Scotland over the next twenty years and is more likely to decrease with a number of Scottish hospices recently reducing their inpatient hospice beds. Charities like Marie Curie and independent hospices are developing more community-based services or 'hospice at home' models of care, which will help increase reach, but also need further investment and support. Care homes are at capacity and without significant investment then it is unlikely that more people will be able to die in care homes with the support they need.

To ensure people receive the care they need, hospitals must be given the support and resources they need to deliver that care in a way that is person-centred with compassion and dignity to all those involved.

Workshop Findings

The following section captures the findings across the three workshops set out according to themes and including quotes from sessions and feedback forms highlighted in boxes. Where examples of good practice were discussed or presented on during the workshops these have also been included as case studies. Recommendations under each theme are included at the end of each section. The quotes we've included are all from seminar participants.

I. Reflecting on recent palliative care policy and acute hospitals

Since 2008 there have been two major palliative care policy documents published in Scotland, Living and Dying Well, and the Strategic Framework for Action on Palliative and End of Life Care.

Living and Dying Well, published in 2008, was recognised as a significant document not least for its recognition of palliative care in acute settings. In particular, it led to a short life working group looking at acute settings, which outlined a range of actions in a report.

"(Living and Dying Well) was important as a driver for change and encouraged joint working."

Despite this work it was agreed that there is still considerable progress that needs to be made in providing palliative care in acute settings. It was noted that a number of recommendations that came out of the Living and Dying Well work were not completed or deserve further reconsideration.

"Some national working group is important with all the local innovation. We lost a group advocating for hospital care generally and palliative care specifically after L&DW ended. Some policies and practices worked, such as national guidelines, some worked a bit to drive change, DNACPR, and some were harmful [like the] Liverpool Care Pathway".

The establishment of a national group for palliative care in acute settings was a recommendation in Living and Dying Well that was not delivered on and it was agreed that this would still be useful to establish a national group to have to monitor the progress of palliative care in acute settings.

"There is a need for strong clinical leadership. The need for proper implementation of policy."

In 2015 the Scottish Government published its Strategic Framework for Action (SFA) on Palliative and End of Life Care, with an ambitious vision of making sure everyone who needs palliative care can access it by 2021. The framework makes an important and clear commitment to palliative care in all settings, including hospitals, which is welcome. However, it was noted that there is a lack of meaningful inclusion in the framework of acute care settings beyond this commitment and any detail to support its development. This leaves the space open to interpretation, which it is hoped that this report will help fill.

The recently published commissioning guidelines to support Integration Joint Boards (IJBs) in developing their palliative care services does include a section referencing hospital and acknowledges that end of life care there can be appropriate. However, the focus is very much on transition and returning people to a community setting. Hospitals may provide specific interventions that are pivotal for improving quality of life and death (for example, surgical treatment of cancer related bowel obstruction or radiotherapy for spinal cord compression) and may help increase the time a person can spend in the community. Such treatments will not

13%

Deaths in hospitals have fallen as a percentage from nearly 60% in 2004 to 47% last year.

be possible for every patient in a hospital setting and nor will it be every patient's preference to die in a community setting, they may want to die in a hospital. For those patients in an acute care setting, where sudden change and uncertainty are real risks, which would not allow for discharge or for those who might be of risk of death during the discharge then hospital is the safe and essential place for their end of life care.

Overall, despite being acknowledged in national palliative care policy, hospital and acute settings have largely been overlooked in the last ten years. Where it has been referenced it has often been seen as primarily an 'inappropriate' place of care for those with palliative care needs and approaching the end of life.

"Many stakeholders see hospitals as a 'big problem' with regards to a place for people to be cared for as they die. Hospitals are often seen as somewhere to go as a last resort. This has partly been as a result of a range of public policy, which has committed to a shift in providing health and social care in community and homely settings rather than the acute. This combined with a perception that the majority of people would prefer to die at home rather than hospital. However, evidence increasingly shows that people change their minds the nearer to death they are, and hospitals become a more acceptable place for someone to die." (A range of research has shown a change in preferences in where people die, for example, Agar et al in 2008[13])

The 'problematisation' of palliative care in hospital has also been highlighted in research across multiple countries, suggesting that palliative care policy tends to focus on solving the 'problems' of hospital as a place of palliative and end of life care, and that the hospital does not have a positive role in palliative care provision[14].

It is worth highlighting that during the lifespan of the government's two policy documents, as well as other Scottish Government policy and national strategies, which have seen a focus on shifting care from the acute setting to the community, that deaths in hospitals have fallen as a percentage from nearly 60% in 2004 to 47% last year. This represents a drop from over 33,700 to nearly 27,000. There has been a corresponding increase in the percentage of deaths occurring in community settings. In just the last four years the number of deaths at home or in a care home have increased by 2,623 from 23,109 to 25,732 deaths last year (46% of all deaths). It is worth noting that despite the decline in the proportion of total deaths which take place in hospital, because of the rising numbers of total deaths the absolute numbers of deaths in hospital have increased in recent years.

There is no analysis or evaluation to show to what extent policy led to this change. There is also little or no evidence to highlight that any shift in care to other settings away from hospital has improved patient experience.

It is also worth highlighting that research shows that when asked, people do not have a high preference to die in a care home, even when compared to hospital[15], but this is considered an acceptable place for people to die in policy terms, as it is in a community setting.

However, it does highlight some of the potential strength national policy can have in shaping national and local action, which is why a national policy/strategy around palliative care in hospitals would be welcome by many in this sector.

There was a strong consensus there is a *"need for national policy"* for palliative and end of life care in acute hospital settings.

It was recognised that this should be described in the context of a whole system approach to integrated palliative and end of life care.

National policy "forces health boards and partnerships, and providers of care to review their compliance with policy or the opportunity a policy provides to improve service [or] acquire funding to test new approaches."

Throughout the discussions in the seminars the Chief Medical Officer's Realistic Medicine agenda was raised. It was highlighted that the Realistic Medicine approach can play a key role in supporting people with palliative and end of life care needs in hospital, especially with a focus on the better involvement of patients in shared decision-making. This should include recognising the role of place in someone's care.

"Realistic medicine has a key role in complementing policy, especially for patients in the last year of life. Better involvement of patients with shared decision making. Working with and advising on over-treatment and over-investigation at the end of life."

However, despite this support for the policy it was raised that this is yet to be realised in practice in a lot of settings, including hospitals, and especially for those approaching the end of life.

Recommendations:

National and local policy should actively support palliative care in acute settings for all people with palliative care needs. This should be part of a whole system approach.

- Scottish Government should establish a new palliative and end of life care strategy or framework to succeed the SFA in 2021 including:
    - A commitment to palliative care in all settings, including acute hospitals, acknowledging the recommendations in this report and setting out how to achieve them.
    - It should cross reference the Realistic Medicine agenda.
    - It should be supported with robust data and evaluation.
- Appointment of a National Clinical Lead for palliative and end of life care covering all settings to act as a link between policy and practice, between settings and specialties, and between commissioners and those that deliver services.

The establishment of a national group for palliative care in acute settings. The group should:

- promote palliative care in acute settings
- support the sharing of good practice
- development of benchmarking of services through the establishment of a national minimum dataset
- feed into Scottish Government and other key decision-making bodies.

Since the conclusion of the seminars and before this report was published the Scottish Partnership for Palliative Care (SPPC) has facilitated the establishment of the Scottish Network for Acute Palliative Care (SNAPC), which offers the opportunity to fulfil the recommendations set out above.

II. An appropriate place to be cared for and die

It was agreed and strongly stated by those attending the seminars that hospitals are an appropriate place for people to be cared for with palliative care needs and approaching the end of life, as well as dying there.

Even the most optimistic research still leaves around a third of people choosing not to die at home or a care home. A considerable number of these people would prefer to die in hospital, and it is important that hospitals are able to support them effectively.

The possibility of a home death depends on various factors, such as the progression of the illness, the need for symptom control, whether there are complications, the family support available, access to community based palliative care services, and whether necessary equipment and other services are available[16]. Having an advanced care plan like the Key Information Summary (KIS) also increases the chance of a home death[17]. Having a carer has been identified as the single most important factor associated with a home death, whereas living alone or being unmarried increased the likelihood of a hospital death[18]. This means for some, despite their best wishes, they will be in hospital at the time of their death.

It is also important to recognise that the moment and mode of all deaths cannot be reliably predicted and uncertainty is an increasing feature of multi-morbidity. As such, death may occur in acute settings after rapid deterioration or following an unsuccessful planned treatment in hospital.

“(Hospital is) essential for many people and their families. It is necessary we continue to strive to make this a good place to die as in the near future there is unlikely to be a major (reduction) in the numbers dying in hospital.”

It was also noted that the right care can be delivered in hospital at any point during a person’s terminal illness and not just at the very end of life, so this could be years and months before a person dies. ISD figures show that across Scotland, on average, a person will spend at least 3 weeks in an acute setting in their last 6 months of life[19].

“It is inevitable that some patients with a terminal illness and approaching the end of life will need an acute hospital admission. This cannot be avoided.”

Building on the recognition in the Strategic Framework that palliative care should be available in all settings, there needs to be a commitment by everyone from Scottish Government, to NHS Boards, health and social care partnerships, hospitals, commissioners, planners, practitioners and the general public that hospitals are a legitimate choice for people to choose to die and a place that can improve the quality and care, as well as the experience for someone who is terminally ill and at the end of life.

Palliative care is a delegated function to Integration Authorities, and they have responsibility for palliative care services in the community and in the acute setting. However, this relates only to some services in acute settings, so those in other specialities such as cardiology, are still the responsibility of the NHS Boards and these specialities may be dealing with patients who may have palliative care needs. Delegated specialist palliative care services continue to support hospital-based teams and work with all hospital staff to deliver palliative and end of life care. This means that palliative care in hospitals is under the shared responsibility of NHS Boards and IJBs. This further underlines the need for collaboration and to work on the basis that hospitals serve the communities they belong too.

There is a need to ensure that these services all work in partnership with palliative and end of life care services and specialties within the acute setting, as well as with community services.

This needs to be reflected in local commissioning and planning of palliative care services by Integrated Joint Boards (IJB), NHS Boards, local hospital policy and operating plans, and in the ongoing design, development and re-organisations of the Scottish hospitals estate. A purposeful commitment to palliative and supportive care as core business in hospitals is required to unlock the benefits for individuals and the whole system that could be realised. This should be both general approaches and attendance to specialist needs.

Recommendation

Scotland should ensure that hospitals are supported to provide consistently high-quality care that improves patient outcomes and experience for someone who has palliative care needs and/or at the end of life.

- Appointment of clinical and executive leads in each NHS Board for palliative and end of life care. This role would work across the system, including linking with the IJBs in the area, as well as ensure link up between all specialities and palliative care teams where appropriate and link in with services across other settings. These appointments must come with funded time.
- Appointment of Allied Health Professional leads for palliative and end of life care in each NHS Board in Scotland.
- NHS Boards and Health and Social Care Partnerships should jointly identify money to fund collaborations between specialities and palliative care, such as the Tayside renal programme and the Caring Together Programme.

III. Identifying palliative patients in hospital settings

Research has stated that one in ten patients will die on their current hospital admission and three in ten are in the last year of life, and this rises to nearly half of all those over 85[20]. This suggests that a significant proportion of those in acute beds would benefit from a palliative care approach or at end of life and that hospitals should be geared up for responding to that. Following a presentation of this research, the group highlighted that this information should be used to consider how better to support identification in hospitals.

“Many are identified, but many are discharged without prognosticating what may happen. Risk of readmission and missed opportunity for conversations .”

The consensus from the workshops was that some, but not all, people in hospitals were being identified with palliative care needs. It was also clear that many people are identified late in their disease trajectory having not been picked up in other settings, and so do not get the level of support that they should have had from the point they would have likely needed it.

It was reported that patients in hospital settings that might benefit from a palliative approach are often not identified due to the prognostic uncertainty.

“The identification of ‘dying people’ is massively complex.”

“Those with a malignant diagnosis (are identified), but I still feel that those with organ failures and deteriorating frailty are missing out.”

It was also reported that patients with completed, up-to-date and good quality anticipatory care plans, such as the Key Information Summary (KIS) , which have

ONE IN TEN

patients will die on their current hospital admission and

THREE IN TEN

are in the last year of life

come from primary care are invaluable for emergency departments and assessment units in making decisions early to support the patient in terms of next steps, such as planning for admission and discharge. However, it was reported that far too often this information is not available and patients with palliative care needs are not identified, leading to missed opportunities to support the patient.

For those approaching the end of their lives Scottish Government has guidance to support clinicians, Caring for people in the last days and hours of life, which was published in 2014. This guidance recognises the uncertainty in accurately predicting when a person is dying. It states that this uncertainty should be recognised by staff and should inform how care is provided[21].

It was reported that many hospitals use this guidance as a framework for identifying those patients who are dying. Many hospitals also have in place systems to facilitate a rapid discharge into the community (such as home) for end of life care.

This guidance has not been evaluated against or reviewed and so it is unclear as to how well it is informing practice across Scotland, including in acute settings.

Ensuring better identification of those patients in hospital who have palliative care needs was strongly supported by the seminars. It was also suggested that in uncertain situations, a parallel planning approach might be best for the patient, where rescue therapies can be pursued, but concurrently a palliative care approach introduced.

"People can have a good death in hospitals. Needs much more work on identifying patients in the last year of life and having palliative or patient wishes discussed earlier."

It was recognised that identifying patients who have palliative needs is something that must be better in all settings, as well as capturing patient information and using anticipatory care planning tools. This would mean that, when patients are admitted to hospital, there would be a better chance of their prognosis being recognised by those delivering their care and a discussion could take place about realistic preferences for care.

A number of tools to support practitioners to identify people who are palliative were highlighted in the seminars which could be used by those working in all settings, including hospitals, to support better identification, including SPAR, SPICT, SPICT4ALL, ReSPECT. There are also a range of additional electronic tools such as the e-frailty tool, which can help identify severe frailty in a person. This is currently used in primary care settings.

It was also highlighted that identifying a person much earlier in the progression of their terminal disease can allow for more meaningful conversations, engagement and planning. It was reported that often discussions happen at the point of crisis or where death is close, where help and support can be lacking.

"Having earlier conversations about anticipatory care planning, that's the important bit."

It was noted that a person's admission to hospital should be seen as a potential trigger for assessment for palliative care needs, with anticipatory care planning and input from specialist palliative care staff being brought in as and when appropriate. This has been recognised in research too, with a recent study recommending that a good palliative care assessment is needed in all wards because of the number of complex patients, comorbidities, and polypharmacy[22].

The important role that outpatient services in hospital could be playing in identifying patients with palliative care needs was also raised. It was shown that where outpatient services, which work across specialities including palliative care, such as in the Renal Service and Caring Together case studies highlighted in this report show the potential for outpatient care to identify and provide support to those with palliative care needs. However, it was suggested that there are missed opportunities in outpatient services too with people not being identified.

Supporting the identification of patients with palliative care needs can take place in any setting and a patient could be using multiple settings at any one time to manage their illness. Good co-ordination between all settings to support the identification and care of a patient with palliative care needs is essential. The next section discusses improving care co-ordination and integrated care to improve identification and support of patients.

Recommendation:

Everyone with a palliative care need should be identified if admitted to hospital or attending an outpatient appointment.

- Training and support, as well as tools for identifying patients with palliative care needs, should be provided to all clinical staff working in hospital settings.
- There should be an emphasis placed on those patients at the front door of the hospital to support early identification. This could follow the Frailty at the Front Door Collaborative model developed by Healthcare Improvement Scotland.
- Information materials and resources on identifying palliative patients should be shared widely with hospital staff.
- Hospitals should be encouraged to use monitoring systems which improve patient safety for example, National Early Warning Score (NEWS) 2, which determines the degree of illness of a patient and prompts critical care intervention.
- Hospitals should endeavour to recognise patients beginning to die with sufficient time to allow a discharge to the community (home) for end of life care, if it is safe to do so and is the patient's preference. This will require an integrated health and social care response that can work at pace.

The Deteriorating Patient workstream; Scottish Patient Safety Programme (SPSP)

The Deteriorating Patient workstream aims to ensure appropriate treatment and care in the event of a sudden change in a person's condition and reduce the level of harm and mortality experienced by those using healthcare services. This is achieved by reliable recognition and response to acutely unwell patients. Applying the IHI's Model for Improvement the workstream focusses on:

- early recognition of acute physiological deterioration through the National Early Warning Score (NEWS)
- implementation of a process for structured response and treatment for sepsis
- avoidance of acute kidney injury
- person-centred care planning based on an individual's clinical condition and goals of care
- effective communication of people at risk and their treatment plan.

SPSP worked with Scottish Partnership for Palliative Care (SPPC) to ensure that the Scottish Structured Response to the Deteriorating Patient I Acute Hospitals reflected the circumstance of patients who may be approaching the irreversible end of their natural lives alongside other patients for whom "rescue" is the priority.

IIV. Changing models of care

It was recognised that there needs to be different ways of working with a stronger integrated approach within hospitals between palliative care specialists and others, as well as better links between hospitals, the community and primary care settings, specifically out of hours services.

"Often little join up from acute to the community."

It was accepted that different hospital departments and specialties have their own unique challenges, for example the needs of intensive treatment units are very different to hospices.

All at the seminars agreed that more needs to be done to make it clear and understandable how palliative care adds value to the care of other departments/specialties' patients and helps their staff look after the most seriously ill. This would be supported by the recommendation outlined above that there should be designated palliative care lead in every hospital, which could work with all specialties within the hospital and across other health and social care settings.

Regarding end of life care, it is important to recognise that throughout hospitals the needs of different wards will vary depending on the number of deaths they have to deal with. It was reported that in Fife, the Board looked at the number of deaths per ward, finding that some have just as many deaths a year as the hospice unit in Fife. Other wards have very few deaths, less than one a month. This means that the expectation around care provided in these areas could be quite different – the skills, knowledge and experience could differ considerably.

The areas with high numbers of expected deaths are more likely to have the skill set to manage end of life care and have had greater opportunity to work with palliative care specialists. Those wards with far fewer deaths may need more support on a case-to-case basis, with a greater need for specialist palliative care input.

The role of outpatient services in supporting terminally ill people was highlighted, and often shown to be an example of good practice of palliative care services delivered in partnerships across specialties. A number of case studies set out below demonstrate the success that some outpatient services have had in improving outcomes for terminally ill patients. The important role of outpatient care provided in acute settings was observed to often be overlooked and the discussion largely confined to in-patient hospital users.

A number of examples of good practice around changing models of care and better joint working were explored through the seminar series and mentioned subsequently by participants, which suggest that new models of care can support patients both in acute settings, as well avoid unnecessary admissions and realise efficiency savings.

NHS Tayside Renal Service

The provision of palliative care for patients with advanced chronic kidney disease (CKD) varies considerably across the UK due to lack of resources and palliative care not being viewed as a priority. A recent redesign of the renal supportive care (RSC) service in NHS Tayside, which ran out of Ninewells Hospital, for patients with CKD managed without dialysis, but with palliative care input, was to enable consultants to cover a wider geographical area and communities. The redesign was made possible out of existing acute budgets.

Evaluation of the service showed that:

- most RSC patients had a full assessment of symptoms and recorded improvements between their first and most recent consultation
- significantly more RSC patients received anticipatory care planning (ACP), and had their preferred place of care (PPC) and cardiopulmonary resuscitation documented
- all patients chose the community as their PPC
- more patients without ACP and PPC documentation died in an acute hospital setting, as opposed to the community
- significant savings were achieved following this change
- NHS Tayside is the only board with a reducing number of dialysis sessions in Scotland (1,500 less per year) but has similar rates of survival.

These programmes can also help avoid non-beneficial over-treatment and other unnecessary investigations.

The issue of finance to support change and remodel services was expressed as a concern in how to take this forward. It was highlighted that managers of acute budgets, both those in Integration Authorities and those in NHS Boards, need to work together to realise how resource can be released to improve outcomes for palliative patients in all acute settings.

"[We need] more core funding!"

However, it was also agreed changes could be made that were not driven by additional funding or other resources. There are a number of examples of where integrated models of care have achieved better outcomes for patients and realised resource savings for boards (see below).

There was support for hospitals across Scotland to share examples of good practice and explore different models of care that can provide better support to patients across settings including the hospital, as well as bringing together palliative care specialists and other specialists.

It was suggested that the government should consider setting up a 'Change Fund' to support and develop innovative ways of delivering palliative care including testing and designing new integrated care models across acute specialties and with links to the community, as well as using the fund to roll out good practice and proven models of care. This fund could be open to bids from Scottish hospitals with a view to delivering change that could be absorbed into mainstream funding after a period of time and successful evaluation. Similar funds have proven to be very successful in the past including the Reshaping Care for Older People Fund and the Integrated Care Fund.

Effective, early discharge planning and engagement with community services – including palliative care teams should be encouraged to avoid/reduce issues at interface.

The importance of multi-disciplinary teams (MDTs) was highlighted as an important forum for influencing care. There have been some examples of specialist palliative care teams from acute settings involved in disease specific and primary care MDTs and it was indicated that this has been successful and should be explored further with more opportunities for palliative care specialists to be core members of MDTs.

It was also highlighted the important role that integrated joint boards (IJBs) play, as they are responsible for commissioning of all palliative care services in their areas and across all settings, including the acute. It was suggested that IJBs need to be aware of the palliative care services available in the acute settings in their areas, but also that some functions not delegated to them will be caring for palliative patients. IJBs need to effectively plan for palliative care services in hospitals, which they are responsible for, and work in partnership with those functions not delegated to them but support and care for palliative patients.

There needs to be greater involvement with the third sector working in the community, but also involving them in acute care settings too. It was reported that in some areas links between acute settings and third sector palliative care services, including hospices can be a challenge.

"Care needs to be co-ordinated across all sectors – acute, community, primary, ambulance."

The Caring Together Programme

Marie Curie, British Heart Foundation Scotland and NHS Greater Glasgow and Clyde.

Caring Together was designed to improve the quality of palliative and end of life care for patients in Greater Glasgow and Clyde with advanced heart failure. The programme covered a population of 1.2 million, and patients benefited from:

- improved access to palliative care services in hospitals, hospices, care homes and at home
- better coordination and provision of care among stakeholders enabling preferred place of care (PPC) choice
- increased support on heart failure for families and carers.

This approach enabled most patients to remain in their PPC through integrated care models. Key components which were instrumental in achieving this included:

- clear and concise referral criteria and pathways
- comprehensive assessment of identified patients
- care manager to coordinate care
- individualised anticipatory care management plan
- multidisciplinary working and joint learning.

There is also a significant role for NHS boards who are responsible for the general capacity of hospitals, training and education of the clinical teams, as well as care standards, all of these areas will involve palliative care and are at the end of life. This may also include the emerging concept of enhanced supportive care approach, which will include seriously ill people, who will possibly be terminally ill and at risk of death.

Taking an integrated approach to working between settings and specialties could lead to improved outcomes for patients and families, as well as to efficiencies in the use of resources, such as hospital beds. The case studies above demonstrate what is possible.

Recommendation

Scotland should ensure that its hospitals are best placed to support people to receive care when they are terminally ill, approaching the end of life and dying, through joined-up services supporting multi-disciplinary teams.

- NHS Boards and Health and Social Care Partnerships should jointly identify money to fund collaborations between specialities and palliative care, such as the Tayside renal programme and the Caring Together Programme. This should work across those functions delegated to the IJBs and NHS boards.
- The role of chaplaincy and support services in hospitals should be explored and support offered to develop these

functions further.

- The Scottish Government should support and fund the development of volunteer-led services to support families and people dying in all Scottish hospitals, exploring the Marie Curie Companion service and Compassionate Inverclyde as examples of good practice. An initial fund could be established centrally to prove value with local Boards taking forward through mainstream funding in subsequent years following successful evaluation.

Improved research, quality improvement activity, support innovation and change

- The Scottish Government should set aside £15million for a nationwide Change and Innovation Fund to test new models of integrated care in acute settings to support palliative patients to achieve better outcomes, but also to support the roll out of proven models of care to other areas.
- Encourage and share good practice, for example the Tayside Renal project.
- There needs to be more research and quality improvement carried out into acute palliative care to develop and build the evidence base.

IV. IT

Challenges with IT were also raised by participants, in particular regarding the sharing of patient and anticipatory care planning (ACP) information between care settings. The Key Information Summary (KIS) was recognised as a valuable tool, and one that is being increasingly used in acute settings. However, the fact that only GPs can access the KIS to make changes was cited as a problem for those working in acute settings, as they cannot update them, but need to contact GPs and GP practices directly to request that changes be made, which are not always made leaving records not up-to-date. This can present additional problems including patient safety if there are any subsequent readmissions of the patient.

"ACP = KIS – good to see it on many patient's electronic records but often not up to date and recent hospital admissions changes made by patients/family/medical teams are not included, which can lead to repeated conversations or inappropriate treatments in emergencies."

The Scottish Government is currently in the process of developing a National Digital Platform, which will have at its core, a patient-centred record, a single source of 'truth'. This record will be accessible across all health and social care systems and at all times with data being portable between systems.

The first of the applications that Scottish Government is incorporating into the system is the 'ReSPECT' form/process, which is to help people communicate how they wish to be treated if they are unable to communicate in an emergency. This is an important process for supporting people close to end of life in acute settings and the group expressed its support for this work and its proposed outcomes. This process is currently being piloted through a collaboration between the Scottish Government and NHS Forth Valley.

Recommendation

IT and technology should support patient centred care and enable those working with patients to have the most up-to-date information about that care and be able to provide appropriate input.

- Support the role out of the National Digital Platform and RESPECT as an early adopter.
- All those delivering care and support to patients with a terminal illness, and the patient themselves should be able to access their patient record and be able to update it regardless of care setting.

V. Workforce

Hospital support teams are professional teams that provide specialist palliative care advice and support to other clinical staff, patients and their families and carers in the hospital environment. They offer formal and informal education and liaise with other services in and out of the hospital. Hospital palliative care support teams, in the first instance, offer support to healthcare professionals in hospital units and other settings not specialised in palliative care. The Scottish Atlas for Palliative Care reported that there were 27 Hospital Support teams across Scotland in 2015[23].

The issue of palliative care specialists in acute settings was raised throughout the workshops. Overwhelmingly there was a belief among those attending that there needs to be a greater number of specialist palliative care staff, but that also those specialists working in other areas that need training and support in palliative care.

"We need more specialists in palliative care to continue to embed joint decision making, realistic medicine and anticipatory care planning."

"More palliative care specialists working in general acute wards. Working together rather than in different parts of the systems."

Many reported that time for staff in hospitals to spend with terminally ill and dying patients was seriously limited. It was also noted that with increased pressures on acute settings staff stress levels were increasing and were not sustainable long term.

"We need to behave in a way that encourages patient's engagement with the conversation. At the moment we almost do the opposite – time limitations, staff not feeling confident/ skilled to have the conversation etc."

"We need more specialist nurses, who deliver the bulk of care in hospital."

"Need increased capacity in specialist palliative care (in acute settings)."

"Every acute receiving ward should have specialist palliative care as part of the extended team."

In its report on workforce published in August 2019, Association for Palliative Medicine (APM) there were 39.7 Whole Time Equivalent (WTE) palliative medicine consultants working in Scotland (49 consultants)[24].

The majority of Scotland's palliative consultants were in the South and West of Scotland (28.7 WTE) with the East and North having only just over a quarter (10.2 WTE).

There were 14 WTE specialty registrar doctors (SRT) in palliative medicine in Scotland. This was the lowest per head of population in the UK.

There is currently limited data to show the number of specialist palliative care nurses working in Scotland in acute hospitals. It was reported that it is common in Scotland for a single Clinical Nurse Specialist to be the sole specialist non-medical specialist resource for an entire 500 bed hospital operating 24/7.

The APM believes that current recommendations regarding palliative care workforces such as those set out in the Commissioning Guidance for SPC (published by the National Council for Palliative Care (NCPC) in 2012) do not address the growing complexity of conditions and increasing patient need, as well as not reflecting the future way in which consultants in palliative medicine will be trained, through the Shape of Training (see below). The APM has suggested that a population-based figure be used to calculate the level of palliative medicine consultants and speciality doctors working in palliative care needed to effectively support patients and families in all settings. Based on work in Ireland and Australia the recommendation for the combined number should now be 2.2 WTEs to every 100,000 of the population[25].

Current figures make it unclear if Scotland is meeting this target, but the UK average is 0.8 WTEs per 100,000 and there is no suggestion that Scotland would be significantly different to this level.

To support terminally ill people receiving palliative care in hospitals requires a multi-disciplinary approach with support from allied health professionals, pharmacists, chaplaincy services and others. Ensuring that there is the right mix of practitioners in place to fully support patients and their family's needs to be included in workforce plans.

We recognise the recent announcement by the Scottish Government in November 2019 that funding has been made available for two additional trainee doctors in palliative medicine[26]. However, this is still not enough to meet the recommendations set out in the APM report.

There are also a range of other professionals working, often in multi-disciplinary teams to support terminally ill people in acute settings, who need further support including physiotherapists, pharmacists, and other allied health professionals. A workforce plan for palliative medicine should include all members of the teams responsible for delivering palliative care. There is very little data available regarding the number of allied health professionals and other members of the multi-disciplinary teams working in palliative care in acute settings. Such information would be important to help assess current workforce levels, as well as support future workforce planning.

Recommendation

Scotland should increase the number of palliative care consultants, doctors and specialist nurses, and others working in acute and other settings to support people living with palliative care needs and approaching the end of life.

- A workforce plan following the Association of Palliative Medicine (APM) recommendations for palliative medicine should be established covering the next 20 years. This should also include recognition and need of other roles that form part of the multi-disciplinary team including allied healthcare professionals (AHPs), pharmacists and chaplains. This should consider the development of commissioning guidance to support Integration Authorities, NHS boards, hospitals, hospices and other providers.
- The Scottish Government should ensure that Scotland is working toward achieving the recommendations on palliative medicine staffing levels set out by the APM.

VII. Volunteers and non-statutory support

The group discussed the important role that volunteers can play in supporting hospitals and staff looking after people approaching the end of life. It was recognised that statutory services cannot meet all the gaps in support, and that by 'harnessing' the power of volunteers could help acute wards.

"More people living well and health for longer – keen to volunteer, share skills – could harness this resource to support care in hospitals."

A number of examples of where this was happening in the UK already were discussed and a presentation from the Marie Curie Companion service was given at the third workshop.

Marie Curie Companion Volunteer Service

Marie Curie and Taunton and Somerset NHS Foundation Trust.

Marie Curie's Companion Volunteer Service partnered with Musgrove Park Hospital to provide one-to-one emotional support for people who are dying and their families.

Musgrove Park Hospital identified a need to spend more time with dying patients and their families but didn't have capacity to do so. Since 2014, more than 350 patients have been supported by 30 volunteers, who provide emotional support for patients and their loved ones, as well as respite for families.

Marie Curie Companions offer a same-day response from specially trained volunteers available from 9am-9pm seven days a week. A quick phone-call is all it takes to refer someone, and a local volunteer can usually be with a patient within one hour to provide the right support for their needs.

Hospital staff reported a reduction in stress, and the service allowed medical staff to focus on clinical priorities.

Those at the seminar suggested that the Scottish Government and others should support and fund the development of volunteer-led services to support families and people dying in all Scottish hospitals, exploring the Marie Curie Companion service and Compassionate Inverclyde as examples of good practice. An initial fund could be established centrally to prove value with local Boards taking forward through mainstream funding in subsequent years following successful evaluation.

Recommendation

Scotland should draw upon its strength in communities, the third sector and the power of volunteers to respond to the needs of their community and empower them to support those with palliative needs and approaching the end of life in acute settings.

- Support the development of national and local volunteer-led services to support families and people with palliative care needs and those approaching end of life in all Scottish hospitals, exploring the Marie Curie Companion service and Compassionate Inverclyde as examples of good practice.

- Support start-up funding to prove value with the option for local boards to take forward through mainstream funding in subsequent years following successful evaluation.

VIII. Education and training

It was strongly agreed that palliative care must be woven into medical training as a "key skill".

"Education still ineffective – not followed up – has an impact on care delivery."

Postgraduate speciality training in palliative medicine is currently a minimum of four years in duration and this will remain following a Shape of Training review, but it will include the equivalent of 12 months Internal Medicine training, which will effectively reduce the time that trainees spend in palliative medicine to three years from four.

There is general support that this model will enhance the training in internal medicine and will prepare doctors for the management of acutely unwell patients, with an increased focus on chronic disease management, comorbidity and complexity.

It was suggested that specialists working in a range of settings including emergency medicine, geriatrics and medicine for the elderly would benefit from greater collaboration with and training in specialist palliative care. There were calls for closer networks at a senior level to develop new integrated models of care and shared training. A number of examples of where this had worked to the benefit of palliative patients were discussed and these have been highlighted in case studies throughout this report.

"Good general training on recognising dying and death within it, for generalists so that everyone gets a good death. Not everyone needs a specialist."

"Non-palliative care specialists in acute settings need to become palliative care generalists."

It was highlighted that experiential learning based on the ward might help ensure that staff get the training they need in palliative and end of life care but avoid the problem of having to release staff for education. Experiential learning is the process of learning through experience and is more specifically defined as "learning through reflection on doing" [27]. This could be carried out in acute palliative care units.

The seminars also talked about the need to consider support for all hospital staff around dealing with dying, death and bereavement. The role of the healthcare assistants on wards was highlighted as an important group of staff, as they often have significant contact with patients and families, requiring them to have difficult conversations, as well as provide emotional and spiritual support. Other staff roles that need supporting include porters, catering staff, administrators and others. This support, training and education would help with identifying patients, supporting families and also support staff through grief and bereavement.

Recommendation:

All acute staff should be given training to provide care and support for those living with a terminal condition, coming to the end of life and dying in hospitals, as well their families, friends and carers. This should include communication training.

- Additional Commitment to Teach (ACT) funding should be targeted to support medical education for students and to increase teaching capacity of future doctors, which was highlighted as a priority for the long term.
- Dedicated resource should be made available to palliative care specialists to provide training and support to other clinicians in acute settings.
- Support should be provided to nursing staff working across a wide range of clinical settings in hospital to develop their knowledge and skills in palliative care.
- A suite of e-learning tools to support acute staff should be developed. This could be delivered by Healthcare Improvement Scotland or NHS Education Scotland.
- Training should also include risk management and align to the Realistic Medicine agenda.
- Consideration should be given to providing training to support staff including cleaners, porters, catering staff and administration staff who work on ward areas and have considerable interactions with patients and families.

IX. Communication

Good communication was highlighted as being key to supporting people in hospital who have palliative care needs and may be approaching the end of life. However, it was noted that there were often difficulties with such communication from both the professional side and patients and families.

"People don't want to think about or talk about dying."

"Palliative care and communication in acute hospitals need to ensure that staff have the skills and expertise."

It was suggested by some in the group that staff in hospitals were uncomfortable talking about dying and death, sometimes more than the patients and families are, and one group member suggested that staff were reluctant to hand out any information to patients and families on end of life. This was tied into the broader concern that there is still a very public taboo around dying, death and bereavement that needs to be challenged.

"Do we need more public engagement? Stories and narratives are not being looked at. How do we get people campaigning for good/more resources in hospital? Hospital is seen as a place that makes you better, not a place that you are cared for well."

Tackling this taboo through public education and engagement would make a significant difference in how conversations in hospitals between staff and patients and families could go, and the group believe would help lead to significant improvements.

The importance of good communication was emphasised in helping patients and families achieve outcomes that were important to them around the care they received and how they received it. This was particularly highlighted for those who needed to have conversations about anticipatory/advance care planning, resuscitation status and other personal goals.

"Encouraging the conversation about the end of life, before the end of life. Valuing the opportunities of life rather than fixating on the end – death."

It was also suggested that communication with the patient and family at transitions in care, for example, discharge home or to another care setting is incredibly important but is not as seamless as it should be. Talking to patients about their illness and health problems, and how to manage them, as well as supporting them with information materials and signposting to relevant services in the community was highlighted as good practice, but not

Building on the Best

Scottish Partnership for Palliative Care, NHS Boards and Macmillan Cancer Support.

Building on the Best is a programme which brings together health and care professionals, patients, carers and families to improve how hospitals support people who may be approaching the end of their life.

In the first phase of the programme general wards were supported to identify and implement changes. These included: a conversation guide to support staff and families to engage in shared decision making; redesign of ward processes to improve communication; education to build staff skills and confidence.

The second phase of the project started in August 2019, focusing on establishing a Scottish hospital palliative care network, support of local ward-based improvements and public engagement.

Building on the Best in Scotland is funded by Macmillan Cancer Support.

something that was not always done.

The group particularly highlighted the challenges around do not attempt resuscitation conversations, including the role of clinical decision-making and patient/family choice. It was agreed that these conversations should be wrapped in anticipatory and advanced care planning discussions, and as part of an overall treatment plan.

Recommendation:

All acute staff should have training and support in communication skills to support them in speaking with people with palliative care needs and their families.

- Each NHS Board should produce a communications strategy to ensure all staff have the communications skills they needed depending on their role from basic communication skills right through to advanced conversations in highly distressing and end life care situations.
- Continued support for Building on the Best and other initiatives aimed at supporting early conversations around dying, death and bereavement, as well as care, taking a person-centred approach.

X. Acute Palliative Care beds in Scotland

It was suggested by some in the group discussions that having acute palliative care beds in the hospital “makes all the difference.” It was noted that, “the biggest positive change in engagement with our team is having beds.”

The average available staffed beds for the palliative medicine specialty reported for acute NHS hospitals during the period 2013-14 – 2017-18 is presented in Annex C.

In-patient palliative care units are increasingly seeing non-cancer admissions, but the inherent uncertainty of these conditions poses a challenge of when a person should be admitted to hospital or not, and when another off-site facility (palliative or otherwise) would be more appropriate.

For in-patient palliative care beds to work effectively within a hospital there must be effective shared care between the palliative care team and the speciality team or a clear ‘lead team’ approach taken by the palliative care service with another team advising on the management of the person’s underlying illness and disease focused treatment.

Some in the group suggested that hospitals across Scotland should consider increasing or introducing (or reallocating existing hospital beds) acute palliative care beds to better support palliative patients in acute settings. However, it was recognised that this would also present challenges and that any discussions around increasing acute beds should be considered alongside future palliative care workforce issues, as well as within the wider context of the shifting balance of care from acute to community settings. These discussions should be held between all key stakeholders working to support people with palliative care needs and at the end of life and be part of wider commissioning conversations to develop services responses to meet the needs of local communities.

It was also highlighted that where patients require the skills/expertise of an index speciality/multidisciplinary team, for example, gynaecology, cardiology, respiratory, moving patients to designated palliative care beds may not be the best option for them. However, in these circumstances those specialists which have greater experience and are equipped to care for patients should consider requesting input from the specialist palliative care team, but not always do this.

However, for many wards the environment is not conducive for those patients who are coming to the end of their lives, often large, noisy wards with lots of beds. (See section on Environment below)

Recommendation

Each NHS Board and Acute Hospital should review the palliative care support available in their area/hospital.

- The proposed NHS Board leads for palliative care (see above) should carry out a review of palliative care beds in their areas. This review should be carried out in conjunction with local IJBs, independent and third sector providers of palliative and end of life care services, such as care homes and hospices.

XI. Environment

The seminars raised the issue of the hospital environment and how often it was not appropriate for people who are approaching the end of life, as well as for family, friends and loved ones. It was noted that many teams in these settings work hard to make sure wards and the environment people are as in are as sensitive and caring as possible but are restrained by the physical environment.

It was highlighted by the group to be as one of the more important issues that needed to be addressed in order to improve the experience of patients approaching the end of their lives and their families in hospitals.

“Environment often not good.”

It was agreed that there is a need for a good environment for people to die in, as well as allow their family, friends and loved ones to be there.

“Essential for many people and their families. It is necessary we continue to strive to make this a good place to die, as in the near future there is unlikely to be a major shift in the numbers dying in hospital.”

“Can be lack of single rooms and facilities for families, and a lack of privacy can be a barrier. There is a risk of medical interventions and the medicalisation of death.”

"Restricted movements of patient once admitted to allow for patient, family and ward staff team to develop relationship and understanding."

"A good death is possible in hospital with the right environment, care and support for patients and their families."

"Quiet, restful area."

"People are being told that dying at home is better, but often it's not. We need the public to recognise that dying in hospital is good too."

Ninewells Accident and Emergency department currently has a designated area to deal with imminent deaths. This area is currently being redeveloped in collaboration with specialist palliative care services.

It was suggested that specialty wards/ units can be very "busy and noisy". The aim should be single rooms within the host speciality.

Hospice Friendly Hospitals Programme

The Hospice Friendly Hospitals Programme is an initiative of the Irish Hospice Foundation, in partnership with the Health Service Executive. The Programme was established in 2007 seeks to ensure end-of-life, palliative and bereavement care are central to the everyday business of hospitals.

The HFH Hub:

- Coordinates and hosts three national networks open to all hospital staff to promote improvements in end-of-life care:
    - The Acute Hospital Network
    - Children and Maternity Network
    - The End-of-Life Care Coordinator Network
- Develops and promotes ceremonial resources such as the end of life symbol, family handover bags, drapes and ward altars.
- Develops and promotes education supports for all hospital staff like:
    - Final Journeys and Dealing with Bad News training programmes
    - 'Just in time' education tools
    - animations and video clips
    - individual education and professional development grants.
- Operates the Design & Dignity Programme, in partnership with the HSE, which aims to transform the way hospital spaces are designed for people at the end of life.
- Advocates for investment in specialist palliative care, end of life care and bereavement services at hospital, hospital group and national level.
- Provides expert advice and guidance directly to hospital staff to support them implement the HFH Programme in their hospital.

Recommendations

All Scottish hospitals should review their environment to determine their suitability for those with palliative care needs and those approaching the end of life.

- Hospitals should consider how to better support patients at end of life and their family, friends and visitors.
- Any capital projects around hospitals should be required to consider how the hospital environment impacts on those at end of life.
- The Scottish Government should consider supporting something similar to or aspects of the Hospice Friendly Hospital Design and Dignity programme.

XII. Building an evidence-base and improving regulation and standards

The need for improved regulation and standards for end of life care in Scottish hospitals was raised by the group.

There was also widespread agreement that there need to be a stronger evidence base for palliative care generally, but also specifically in acute settings. This should include:

1. the need to develop measure of quality of care, care experience and outcomes
2. evidence for the effectiveness/value of specialist and generalist palliative care interventions
3. evidence and data about what is taking place with people in hospital towards the end of life (including how hospital sits within wider patterns of service use across the system).

"Boards need to agree to have mandatory feedback every six months about quality of dying and management of very ill patients in their hospitals."

Need to consider "how to measure core outcomes across Scotland for deteriorating and dying patients in hospitals".

It was reported that some Boards were doing audit work including the Care Assurance Scheme (CAS), which includes an End of Life Care Standard. However, not all Boards are doing audit work and there is no national overview and data is not comparable or consistent.

It was also noted that there "has been a lot of information around for a long time", but nothing done with them to improve practice.

"If we could possibly have some kind of standards that were based on patient, family, staff, hospital, and broad measurable outcomes of these areas regarding communication, care planning and bereavement. Something manageable to get a baseline."

"There's lots of really good stuff being led on at a local level, but the bit we lack is that wider systematic context and a profile and people in really senior leadership positions to talk about this stuff."

Significant data gaps around palliative care admissions and patients in hospitals who are palliative was also highlighted as a concern and something that needed to be addressed.

"We do need some national data re: some of the arguments we need to make at the policy level, as well as improvement…"

"We need an action plan for collecting data."

"Why is The National Audit of Care at the End of Life (NACEL) not here?"

It was highlighted that a better evidence-base would increase the case for investment in the palliative care specialty.

"Need more evidence-based documents and policies."

It was also noted by many that there is a lack of significant qualitive data to measure patient experience either nationally or locally.

"Anecdotally many people die well in hospital in Scotland. Anecdotally many people don't, therefore we need some data on this."

"Outcome data, we lack that."

Care Opinion, the online resource which allows people to share stories of the care they have received can play a role in highlighting patient and family experience of care for someone who is terminally ill and approaching the end of life. This can be used to support improvement and learning across health and social care. However, it was noted that despite this, Care Opinion did not provide a reflective sample of the whole population and would not show local or nationwide trends

The also pointed out that previous policies and practice had not been properly evaluated and learned from and cited the example of the Liverpool Care Pathway. It was agreed that more evaluation of practice should be carried out, particularly before new approaches are adopted in other areas.

Recommendations

Scotland should collect robust data and evidence to show that Scottish Hospitals are providing the best care for those with a terminal illness and approaching the end of life. This should also include a measure of patient and carer experience.

- Hospitals should conduct regular audits of end of life care, this should include patient and carer feedback to capture patient experience.
- The Scottish Government should consider joining England, Wales and Northern Ireland in the National Audit for End of Life Care in hospitals (NACEL) or develop minimum data sets to identify:
    - hospital outputs/measures
    - ecognition of unmet need/ demonstration of meeting needs across localities
    - access to care
    - quality/experience of care
    - health economics of palliative care provision in acute settings
    - acute staff confidence in supporting people with palliative care needs and at the end of life.
- There needs to be greater investment in research into palliative and end of life care and this should include research around acute settings.

There needs to be greater scrutiny of care standards for end of life care in hospital and acute settings.

- HIS should draft specific standards for end of life care in acute and hospital settings and review all hospitals in Scotland against them in the next five years.
- HIS should focus on the palliative care aspects of its Care of Older People in Hospital standards when carrying out future inspections of acute settings.
- Audit Scotland published a report on palliative care in 2008, which has not been repeated since. Audit Scotland should consider repeating this review.

XIII. A Realistic Medicine Approach

Scotland is well placed to tackle the culture of indiscriminate active treatment at the end of life, through the Chief Medical Officer's Realistic Medicine agenda. Each hospital has a Realistic Medicine lead who could link in with the proposed palliative care NHS Board leads mentioned above.

Hospitals should be encouraged to celebrate the end of life care they deliver and foster aspirations to aim for 'a good death' for patients dying from long-term conditions or frailty. Participation in events such as Dying Matters Week would encourage more open conversations about death and dying in hospital staff, patients and their visitors.

XIV. Other factors

A number of external issues that can have an impact on hospitals and care provided there for people approaching the end of life were raised during the course of the seminars that it was considered important to reflect on when looking at how to improve care of terminally ill and dying people in Scottish hospitals.

It was highlighted throughout the seminars that the health and social care workforce as a whole and not just in the acute setting was the biggest challenge facing the provision of appropriate care for people with palliative care needs and approaching the end of life. It was noted that if the balance of support by professionals in all settings was not addressed long term, then it would make it very difficult to get care for terminally ill people and those at the end of life right when they are admitted to hospital.

It was noted that there is a need for more support for GPs and primary care through collaborative initiatives and multi-disciplinary working with those in acute and other settings to care for patients with higher levels of needs. For example, at the Acute Medical Unit (AMU) in Tayside there is a consultant with planned time available to speak with the referring doctor and can offer a range of options rather than admitting for assessment.

The capacity of social care settings to support people approaching the end of life was also cited as a problem, without investment and support then more and more people will be admitted to hospital at end of life or be unable to be discharged to die in the community if that is their preference.

"Heard a lot about realistic medicine, need to look at realistic policy as well. That palliative care in the community will double by 2021 (Scottish Government's Health and Social Care Delivery Plan), is not going to happen. The resources aren't there. Across all sites we're feeling the pinch of financial climate, hard when trying to improve quality of care with shrinking resources."

It was highlighted that care homes need lots more interventions of care for their residents than they are currently equipped for. Those that cannot get the care they need in a care home, an example cited related to a resident not being able to have a syringe driver in a care home, as it was decided to be too complex, meant that the resident had to be admitted to hospital as no other option available.

Delays in care at home packages to support people to stay at home or to get home from hospital following an admission were also cited as a growing concern.

Out of hours support was also highlighted as a concern with terminally ill people at end of life often having needs out of hours and not always being able to get the support they need in the community resulting in an unnecessary hospital admission.

"Out of hours remains a concern, as not joined up and disjointed."

"There is a cohort of patients who do not need to come to hospital, but this group also needs out of hours specialist support."

It was suggested that an increase in support for rapid response services in the community would help reduce the number of unnecessary hospital admissions.

The group also suggested that there needs to be better communication between primary care, social care and acute settings, as well as out of hours services to ensure greater continuity of care. This would take a number of stakeholders across multiple settings to achieve this. Local leadership would be key to achieving this and should be explored.

Taking the work forward

The Scottish Government's Strategic Framework for Action is due to finish in 2021. Through the process of discussion at the three seminars there was a clear expression of a need for a future policy direction to be given by Scottish Government to cover the period following the next Scottish Parliament election in 2021.

With the growing demand on health and social care services by those living with a terminal illness and approaching the end of life, the need for a plan to ensure that the needs of this population are met in any setting, including hospitals, will be vital.

We believe that the work of these three seminars and the recommendations set out this report should be included in any new strategy or policy document with clear plan and timeline for implementing the recommendations.

We would also urge all NHS Boards and Integration Authorities to review the recommendations set out in the document and to consider incorporating into existing strategies and action plans or developing bespoke palliative care plans for acute settings.

Annex A

List of Participants invited to participate in seminars

Those invited to take part were not as representatives of their organisation, but as individual experts

Name	Title	Organisation
Alistair McKeown	Palliative Consultant	Queen Elizabeth University Hospital
Amy McCreadie	Administrator	University of Glasgow
Anne Scott	Advanced Nurse Practitioner, Medicine of the Elderly	Royal Infirmary of Edinburgh
Bridget Johnston	Florence Nightingale Foundation Chair in Clinical Nursing Practice Research	University of Glasgow
Calvin Lightbody	Consultant	NHS Lanarkshire
Christopher McNally	Acute and General Medicine	NHS Greater Glasgow & Clyde
Claire O'Neil	Macmillan Lead Nurse Palliative Care	NHS Greater Glasgow & Clyde
David Clark	Professor	University of Glasgow
Deans Buchanan	Consultant in Palliative Medicine	NHS Tayside
Dr Anne Finucane	Lead Researcher, Marie Curie Hospice Edinburgh	Marie Curie
Dr Euan Patterson	RCGP Rep	Royal College of General Practitioners (RCGP) Scotland
Dr Jane Edgecombe	Co-chair, palliative care acute group	NHS Greater Glasgow & Clyde
Dr Kirsty Boyd	Macmillan Reader in Palliative Care	University of Edinburgh
Dr Lucy Martin	Acute Medical Registrar	NHS Forth Valley
Eileen Wallace	Lay Representative	Scottish Older People's Assembly
Jen Pennycook	Improvement Advisor, Patient Safety Programme	Healthcare Improvement Scotland
Judy Glossop	Volunteer	Marie Curie
Julia Bearne	Service Manager	Marie Curie
Libby Ferguson	Consultant	Marie Curie Hospice, Glasgow
Mairi McGuire	Consultant Acute Physician	NHS Lanarkshire

Name	Title	Organisation
Marian Krawczyk	Program Convenor, End of Life Studies	University of Glasgow
Mark Hazelwood	Chief Executive	Scottish Partnership for Palliative Care (SPPC)
Nicola Robertson	Head of Nursing, Planned Care	NHS Fife
Norma Beveridge	Head of Nursing, Emergency Care	NHS Fife
Pam Levack	Medical Director	PATCH (Palliation and the Caring Hospital)
Paul Adams	Head of Service and Palliative Care Lead for Glasgow HSCP	Glasgow Health and Social Care Partnership
Richard Meade	Head of Policy and Public Affairs, Scotland	Marie Curie
Robin Taylor	Consultant	NHS Lanarkshire
Sandra Campbell	National Clinical Lead for Palliative and End of Life Care/ Nursing	Healthcare Improvement Scotland (HIS)
Sharon Foley	Chief Executive Officer	Irish Hospice Foundation
Susan Brown	Policy and Public Affairs Manager, Scotland	Marie Curie
Tim Warren	Head of Palliative Care Policy	Scottish Government
Tricia Hatt	Strategic Partnership Manager	Macmillan Cancer Support

*This project was also supported by submissions and discussions with the following:

- Colette Reid, Clinical Director, NHS Lothian
- Patricia Brooks-Young, Nurse Consultant, NHS Tayside

Annex B

Terminology

Terminal illness

A terminal illness is a disease or condition which can't be cured and is likely to lead to someone's death. It's sometimes called a life-limiting illness.

People with a terminal illness may live for days, weeks, months or sometimes years. It can be difficult for doctors to predict how long someone will live for. This can depend on their diagnosis and any treatments they may be receiving[28].

Palliative Care

Palliative care is treatment, care and support for people with a life-limiting illness, and their family and friends. It's sometimes called 'supportive care'.

The aim of palliative care is to help you to have a good quality of life – this includes being as well and active as possible in the time you have left. It can involve:

- managing physical symptoms such as pain
- emotional, spiritual and psychological support
- social care, including help with things like washing, dressing or eating
- support for your family and friends.

A life-limiting illness is an illness that can't be cured and that you're likely to die from. You might hear this type of illness called 'life-threatening' or 'terminal'. People might also use the terms 'progressive' (gets worse over time) or 'advanced' (is at a serious stage) to describe these illnesses. Examples of life-limiting illnesses include advanced cancer, motor neurone disease (MND) and dementia.

You can receive palliative care at any stage in your illness. Having palliative care doesn't necessarily mean that you're likely to die soon – some people receive palliative care for years. You can also have palliative care alongside treatments, therapies and medicines aimed at controlling your illness, such as chemotherapy or radiotherapy.

However, palliative care does include caring for people who are nearing the end of life – this is sometimes called end of life care[29].

End of Life Care

End of life care involves treatment, care and support for people who are nearing the end of their life. It's an important part of palliative care.

It's for people who are thought to be in the last year of life, but this timeframe can be difficult to predict. Some people might only receive end of life care in their last weeks or days.

End of life care aims to help you to live as comfortably as possible in the time you have left. It involves managing physical symptoms and getting emotional support for you and your family and friends. You might need more of this type of care towards the end of your life.

End of life care also involves talking to you and your family and friends about what to expect towards the end of your life. The people looking after you will talk to you about your needs and wishes, and make sure they consider what you want in the care they provide[30].

Annex C

Palliative Care Hospital Beds in Scotland

The average available staffed beds for the palliative medicine specialty reported for acute NHS hospitals during the period 2013-14 – 2017-18 is presented in the following table.

	2013-14	2014-15	2015-16	2016-17	2017-18p
Aberdeen Royal Infirmary	-	0	0	0	0
Arran War Memorial Hospital	-	-	-	-	-
Balfour Hospital	-	-	-	-	-
Belford Hospital	-	-	-	-	-
Borders General Hospital	6	7	7	7	8
Caithness General Hospital	-	-	-	0	0
Dr Gray's Hospital	-	-	-	-	-
Dumfries & Galloway Royal Infirmary	8	8	8	8	9
Forth Valley Royal Hospital	-	-	-	-	-
Galloway Community Hospital	0	0	0	0	0
Gilbert Bain Hospital	-	-	-	-	-
Glasgow Royal Infirmary	0	0	-	-	-
Golden Jubilee National Hospital	-	-	-	-	-
Inverclyde Royal Hospital	0	-	-	-	0
Lorn and Islands Hospital	-	-	-	-	-
New Victoria Hospital	-	-	-	-	-
Ninewells Hospital	2	2	2	2	3
Perth Royal Infirmary	10	10	10	10	10
Queen Elizabeth University Hospital	-	-	-	-	-
Queen Margaret Hospital	9	9	9	9	9
Raigmore Hospital	-	-	-	0	-
Royal Alexandra Hospital	0	-	-	-	-
Royal Infirmary of Edinburgh at Little France	-	-	-	-	-
St John's Hospital	-	-	-	-	-
Stobhill Hospital	-	-	-	-	-
Stracathro Hospital	-	-	-	-	-
University Hospital Ayr	-	-	-	-	-
University Hospital Crosshouse	-	-	-	-	-
University Hospital Hairmyres	-	-	-	-	-
University Hospital Monklands	-	-	-	-	-
University Hospital Wishaw	-	-	-	-	-
Vale of Leven General Hospital	-	-	-	-	-
Victoria Hospital	-	-	-	-	-
West Glasgow	0	0	0	-	-
Western General Hospital	-	-	-	-	-
Western Isles Hospital	-	-	-	-	-

p Provisional
‘-’ denotes no data

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