Age-attuned Hospice care
An opportunity to better end of life care for older people

Caroline Nicholson
Heather Richardson
Foreword

Healthcare has to balance good and bad, but it’s ugly when people are treated as pathologies, denied the chance to contribute to decisions about their care, and doing the things that matter to them are subjugated instead to having things done to them by well-meaning but misguided clinicians.

50 years ago, Cicely Saunders responded to this scourge in cancer with what is now the Hospice Movement. We have come a long way, but are back at square one, although this time it is the frail and elderly whose care and experiences as they die are poor, and a blight on our society.

But there are differences between then and now: this population is very large and growing – in 20 years the people with four or more diseases will double in older people. It doesn’t stop there: social and clinical care is so entwined as to be indistinguishable: being lonely means you will probably die sooner. Hospices can no longer bask in the complacency of rescuing selected people with defined diseases cared for by our expert teams. Yet we have other strengths: we are embedded in our communities with armies of volunteers who could offer care and support at scale, our charitable income makes us nimble, innovative and focused; we are willing to go the extra mile and there is passion to make a difference to the lived experiences of our neighbours. We can and must be out there as collaborators and co-workers with other clinicians, social care and sister charities.

Older people facing death from cumulative diseases and disabilities may seem uncomfortable for us to engage, although we have so much to bring to the table in support of existing services. This population is today’s challenge for hospice and palliative care services to grasp, for if ignored, frail older people will be our nemesis and it will have been we who are culpable.

Professor Rob George
Medical Director St Christopher’s Hospice, Professor of Palliative Care Cicely Saunders Institute King’s College London
Foreword

Despite the evidence (from the work of the Gold Standards Framework group) that more people will die of frailty and multiple long-term conditions than of cancer, our services for those moving towards the end of their life remain focussed on the needs of the latter group.

The needs of frail older people are frequently met poorly, with a reactive health service which responds to acute frailty syndromes such as a fall or an episode of confusion with an acute general hospital admission. Frequently the opportunity to reflect with the older person and their family on where they are in their life course is missed, with a consequent failure to offer the right care at the right time.

This document is a “call to arms” to the Hospice movement to recognise that there are a large group of people who currently are denied palliative care. Recent discussions between geriatricians and palliative care physicians have found encouraging common ground, as well as a recognition that we can learn from one another. Clinicians often cite uncertainty about prognosis as a barrier to accessing palliative care, and trajectories of decline can be difficult to predict for this group of people. However, advances in our understanding of frailty offers better opportunities to identify people who are likely to be nearer the end of their lives. It’s also often the case that older people are more comfortable with acceptance of some degree of uncertainty- frequently more so than those caring for them.

This is a very timely publication. The challenge to us all is to reflect and then act to improve care for our frail older patients.

Dr Eileen Burns
President of the British Geriatric Society, Consultant in Older People’s Medicine
Our starting point

Modern hospice care was established in the 1960s in response to unacceptable deficits in care. The success of hospices in improving the experiences of people facing the end of life is recognised within and beyond the sector – reflective of both their compassion, tenacity and creativity, and the sustained support of their communities.

Even so, many people in the UK continue to die without access to the right care for themselves, their families and carers, not least people who survive into late old age. Our premise in writing this publication is that hospices have a real opportunity to attend to the needs of survivors into late old age, their families and carers, and are uniquely placed to do so. We argue for change at clinical, service and societal levels with input from a range of partners. We invite hospices to respond with urgency, generosity and optimism, all characteristics of the sector that we have seen drive change so effectively in the past.

Living into late old age is already a reality for many people and is likely to become increasingly common. Assumptions about people in late old age and intentions for their care are often ill-considered; they result in relatively poor quality of life and equally poor experience of end of life care. We, at St Christopher’s and King’s College London, want to change that and invite you to join us and others, in trying to think and do something different. We believe that this requires us to see the world quite differently.

This publication is just the start of seeing the world differently. We have tried to draw together a mix of evidence, experience and aspiration to inspire practitioners, leaders, academics and others with a stake in the care of older people to establish new approaches to care, different relationships and changes in our society that acknowledge and embrace the challenges and opportunities of late old age. The approach we propose is intended to inform thinking and give meaning and direction for the changes hospices may want to make.

Caroline is a clinical academic working across the interface of older people and end of life care. She, like older people themselves, straddles the worlds of palliative care and aged care. Attuning professionals and services to the voices, capabilities and needs of older people and their families is a central pillar of her work. Heather, as one of the chief executives of St Christopher’s hospice, brings working knowledge of the capabilities of hospices, whilst also recognising the real pressure and challenges they face, within finite resources, to meet the needs of new groups.

We hope that this publication will serve as the start of new thinking, conversations and exploration. It is work in progress – to be refined and developed in the future. We hope also that you will be inspired to join us on this journey.

Of course, this is much more than our work and thinking. We would like to acknowledge in particular the thinking of Jane Seymour, Rob George, Mary Pennell and the staff and patients of St Christopher’s who have influenced and guided us both.

Caroline Nicholson and Heather Richardson
Introduction to the publication

The approach of this publication reflects our own exploration of the question: ‘How should organisations like St Christopher’s amend its provision to make it accessible, appropriate and effective for older people who, because of their age, are likely to be coming to the end of their life?’

We begin by making a case for why hospices should bother – particularly at a time when there is no shortage of individuals seeking our help, for whom we offer well evaluated models of care. The lived experience of older people confirms that they have a need for the kind of care – personalised and holistic in nature, encompassing the needs of families and carers – that has become our hallmark. The lives, experiences, aspirations and concerns of people we have known – depicted in the stories of Bill, George and Precious (described on page 9) – is the basis of this claim.

Then we propose a new approach; age-attuned hospice care that balances continuity with ongoing adaptation to loss. We highlight three levels of intervention within that approach – clinical interactions and support for people in our care, their families and carers; work with other providers to improve the system of care and efforts to provoke societal change.

What those interventions would look like in practice, their outcomes and the evidence supporting them, are described in more detail. We finish by suggesting resources for hospices interested to explore the detail of what we have summarised in top-level information.

A glossary is included to enable readers to be confident that they understand to what we refer.

“It is cause for celebration that people are living longer but our health and social care services must be age-attuned.”

Paul Knight 2013, Past British Geriatric Society President
## Contents

**Section 1**  
Why bother with age-attuned hospice care? ........................................ 6

**Section 2**  
What does age-attuned hospice care look like? ................................ 10

**Section 3**  
What would enacting age-attuned hospice care mean for hospices? ................................................................. 12  
Working differently with older people, their families and carers................................................................. 12  
Working in partnership across the system........................................................................................................ 15  
Supporting Societal Change..................................................................................................................... 17

**Section 4**  
Next steps................................................................................................................................. 20

**Section 5**  
Resources........................................................................................................................................ 21

**Section 6**  
Glossary of Terms ..................................................................................................................... 23

**Section 7**  
References......................................................................................................................................... 25
Section 1: Why bother with age-attuned hospice care?

WHY? Because the needs of older people coming to the end of life present growing challenges for everyone

- The number of older people living and dying with progressive long-term conditions is growing\(^1\), and their complex needs span health and social care. These include palliative care to improve quality of life\(^3\), to address symptoms and concerns when cure is not possible, and to make people more comfortable.

- Older people will be the main recipients of palliative care in coming decades\(^4\). However, currently they do not routinely receive specialist palliative care\(^5\), people in late old age very rarely access hospice care, despite fitting many of the necessary criteria\(^6\) and their experiences at end of life are often poor\(^7,8\).

- To date, specialist palliative care has often focused its attention on people either with dominating single diseases, like cancer, or giving care at the very end of life\(^9\). Dying in old age, often linked to multiple conditions, can be slow and unpredictable, so its onset may pass unrecognized\(^10\).

- Whilst older people often prioritise quality over quantity of life\(^11\), the current inequity they experience in accessing specialist palliative care services and the under-recognition and limited resource to support general palliative care, may mean they receive inappropriately aggressive, and costly\(^12\), treatments that produce unnecessary suffering and indignity for older people as they die.

- Increasing numbers of older people will live and die in the community; indeed, projections to 2040 suggest that community care needs to double and care homes will be the most common place of death\(^13\).

- Paid domiciliary carers, family members and other personal carers provide the majority of domiciliary and end of life care for older people, often over long periods, with little recognition or resource and support\(^14\).

- Proximity to death, rather than age alone, is the strongest driver of health care costs, which are linked to increasing health conditions and age-related impairments\(^15\).

Key facts

- The number of people over 85 will more than double to 3.4 million\(^72\)
- Over one third of all deaths are people aged 85 and over\(^72\)
- End of life care provision in care homes and the community needs to double by 2040\(^50\)

“We emerge deserving of little credit; we who are capable of ignoring the conditions which make muted people suffer. The dissatisfied dead cannot noise abroad the negligence they have experienced.”

J Hinton
WHY? Because older people are calling for something different

- They do not want to be treated as “old” but rather as an individual with their own views and preferences\textsuperscript{15}, – one size does not fit all

- They often want to be active participants in their care, supported to make decisions and recognised for what they can do, rather assuming what they cannot accomplish\textsuperscript{16}. Responsive and skilled care sustains dignity and identity\textsuperscript{17}

- Care continuity and help to navigate services are priorities for older people and their family\textsuperscript{18,19}

- They want to remain active and connected to people and places that are important to them because these connections are central to retaining their quality of life\textsuperscript{16}. Enabling this calls for changes in the way care is shaped and delivered, the role of professionals in someone’s life and their wider social network, and how society embraces and supports someone growing older\textsuperscript{14}

- Older people are often at ease talking about death, but are seldom given such an opportunity\textsuperscript{20}. Concerns of older people around dying focus on increasing dependence, being a burden and the impact of their own death on those left behind\textsuperscript{21}

- Those with dementia generally want to be included in decisions about their care for as long as possible\textsuperscript{22}, and for their “family” to be supported to be partners in care at the end of life and then supported into bereavement\textsuperscript{23}.

National Voices- coalition of health and social charities – person-centred narratives

WHY? Because hospices are well placed to respond

- Our history is one in which we have listened and responded to the voices of individuals ignored or unheard by other parts of the health and social care system. It is important that we listen now and respond to the voices of older people in the development of services fit for the future.

- Hospices are often pioneering and innovative, positioning us well to respond to a new and growing group of people who need a new kind of care and help as they approach the end of life.

- Our philosophy is about helping people to live well even when their condition(s) is advancing and cannot be cured. We are keen to be led by people’s needs, recognising that these will vary from individual to individual, and also over time. These principles will be key to high quality care of older people facing the end of life.

- Hospice care is expert in nature, aspiring to deliver care that makes a real difference in health status, as well as improving experience. The needs of older people are often complex, demanding careful diagnosis and treatment.

- Hospices have a history of influencing the care of other professionals and organisations committed to delivering high quality experience to individuals at the end of life. They could work with other providers in their local area to improve the quality of their care and that of others, tailored to the needs of older people whose life is coming to an end.

- Hospice care does not shy away from the realities of death, dying and loss. Its workforce is prepared to have important conversations about these realities of life, enabling older people to explore and confirm goals that are important to guide their care plans and related decisions.

- Hospice care seeks to be integrated, and to work in partnership. High quality care for people who are older, their families and carers will need to draw on a wide range of services cutting across health, social care and the voluntary sector.

- Hospices usually have good engagement with their local communities. We can draw on their resources and skills whilst simultaneously working together to change societal views around end of life. This is important to ensure older people continue to feel valued and remain part of society, regardless of growing dependency and other challenges arising from ill health.

Key facts

- Hospices are seen as the gold standard of end of life care.

- Access to hospice care reduces with age and a non-cancer diagnosis.

- The numbers of people they reach is increasing but remains a relatively small proportion of everyone who dies.

“You matter because you are you, and you matter until the last moment of your life. We will do all we can not only to help you die peacefully, but also to live until you die.”

Dame Cicely Saunders, Founder of St Christopher’s and the modern hospice movement.
Insights into living in late old age

Bill is 89 years old and lives with Joan, his wife of 65 years. They live in their London house where they raised their two children. They describe life as “just the two of us”. Bill and Joan met in their early twenties having both worked in the local munitions factory. Bill has macular degeneration, heart failure and osteoporosis. His symptoms are getting worse, he is tired and falling more. Joan sometimes finds it hard to pick Bill up off the floor and they have had to call the ambulance on a few occasions. This has knocked Bill’s confidence and he’s finding it hard to leave the house. Bill has said he has had enough now and has taken to his bed more and is eating less.

Precious is 86 years old and came over from the Caribbean 20 years ago with her husband James to live with their daughter Martha. At the time Martha had two young children and was a single parent. Now Precious has heart failure and gets increasingly breathless and tired. She also has long standing diabetes and recently Martha has had to help with the injections. Precious is requiring a lot more care, which Martha finds tiring. She wants more help but doesn’t know where to get it from. Precious would like things to continue as they are, doesn’t like the thought of people coming into her home to help and refuses to talk about the future.

George is 92 and originally from Ireland. He was employed in an enamel factory and attributes his long-standing lung disease to the fumes and poor working environment. George lives in a council flat on the eighth floor having moved there with his wife Dorothy in the 1970s. They never had children, and Dorothy died of a stroke 15 years ago. George has early Alzheimer’s disease, prostate cancer and depression. His neighbours are concerned that he’s increasingly forgetful. George wants to be in his own home and has turned down his GPs suggestion of a short stay in a local care home.
Section 2: What does age-attuned hospice care look like?

Age-attuned hospice care has an underpinning aim – to help people maintain some continuity in the life they lead, whilst simultaneously adapting to loss and mortality. This balance is a fine one, calling for input that enables continuity of relationships, activity, interests and wellbeing on the part of the older person whilst also addressing their ongoing losses related to bereavements, growing dependence, increasing ill health and related preoccupations with care. It demands care with a dual focus – enabling people to both live and die well as their conditions progress, with flexibility, given that such progression is unpredictable in this group of people¹⁰.

Adapting and fine-tuning hospice care to reflect this balance, and re-orientating it towards older people is, arguably, relatively easy for hospices. Their challenge is to achieve high quality transformation and roll it out at scale and in a sustainable way. To that end, we propose:

- A systemic approach drawing on activities that support prevention and proactivity, re-enablement and community integration²⁵-²⁷

- A multi levelled approach to the challenge:
  - Working differently with older people, their families and carers as part of a clinical response
  - Working in partnership to improve services and the system more generally
  - Supporting Societal Change

- Close attention to the nature of care on offer, driving improvements to ensure care is:
  - **Relational** – attending to the dynamic between the person, their family and care providers. This interdependence enables and values the time, resource and skill required to deliver quality care²⁸
  - **Inclusive**, allowing meaningful involvement of the older person and their family, to determine, plan and co-design their care. The intention is to promote agency in older people, enabling them to draw on their capabilities and relationships. This can be developed and enhanced if recognized and valued²⁹-³¹
  - **Integrated** – reflective of someone’s health and social needs, reducing fragmentation, increasing consistency³² and sharing responsibility across the relevant agencies
  - **Individualised and wrapped around the person**, with the aim of engendering a sense of security on the part of the older person and their family. Such care will be focused on their concerns and needs, delivered in partnership with the older person and their family³³-³⁵. Families are valued and provided with help that enables them to attend to their needs beyond day to day caring³⁶

- A collegiate approach to design and delivery of new services, in which hospices see themselves as one element of a wider system of care. The approach invites hospices to identify, prioritise and develop key external relationships that support transformation of local systems and wider society within which older people live as well as their own clinical and organisational processes. In particular, hospices are encouraged proactively to strengthen relationships with primary care, geriatric services, mental health and social care, in order to share and build on mutually advantageous strengths and expertise³⁷³⁸.
Balancing continuity and adaptation to loss

Clinical response
- Optimising care and journeying together
- Connection and assessment
- Proactive care to reduce distress
- Building confidence to talk sensitively about death, dying & loss
- Developing the right philosophy of care and workforce

Service or system response
- Valuing older people
- Promoting different places of care
- Embracing the ageing process and its opportunities
- Working in partnerships across sectors and specialities
- Providing resources for both patients & staff to enable quality care
- Appreciating different places of care

Societal response
- Older person and/or “family”
- Appreciating different places of care
- Optimising care and journeying together
- Connecting and assessment
- Proactive care to reduce distress
- Building confidence to talk sensitively about death, dying & loss
- Developing the right philosophy of care and workforce
- Providing resources for both patients & staff to enable quality care
- Appreciating different places of care
- Optimising care and journeying together
- Connection and assessment
- Proactive care to reduce distress
- Building confidence to talk sensitively about death, dying & loss
- Developing the right philosophy of care and workforce
- Providing resources for both patients & staff to enable quality care
Section 3: What would enactment of age-attuned hospice care mean for hospices?

Level 1
A clinical response: working differently with older people their families and carers

Some top tips to deliver optimal care

- Use assessment tools specific to older people with frailty/multiple morbidities
- Prioritise use of advance care plans, that capture both current goals and future wishes. Review regularly and amend to reflect small incremental changes
- Adopt practices that recognise “family” carers as experts and partners in care as well as recipients needing support
- Provide education and training for staff that attend to the challenges of frailty and multimorbidity to promote further confidence and competence.

An optimal clinical response

- Negotiating and learning the best way to be involved
- Watchful waiting
- Individualised assessment
- Negotiating plans for care

- Optimising care and journeying together
- Connection and assessment
- Older person and/or “family”
- Proactive care to reduce distress
- Enhancing capacity and confidence
- Advanced symptom control
- Advice about when and where to seek help

- Rehabilitative palliative care
- Giving options and ways to best manage change
What does optimal care look like?

- Systematic and comprehensive assessment, focused on what matters to the person, their goals and preferences for care. Assessment tools will reflect the specific needs of people who are older, including those that focus on frailty, presence of comorbidities and common conditions of old age.

- A focus on parallel planning – where there are a number of possible outcomes, some becoming more obvious over time and some less likely.

- Sensitive discussions about the future and what someone can expect in the light of their health conditions and age. Attention is required to the personal realities of living and dying and someone’s sense of their own mortality, so that advance care planning has context and meaning.

- Ongoing commitment on the part of professionals to get to know the individual their family and carers, and also their strengths and concerns so that plans and the level of engagement are negotiated and become increasingly individualised.

- Access to advanced symptom management skills, with knowledge and confidence to stop treatments as well as start them.

- Access to rehabilitative palliative care – to maintain or improve functionality. Exercise programmes that maximize strength and balance and functional rehabilitation enable older people to preserve their personhood.

- A care trajectory and commitment that includes the process of “Watchful Waiting” – a term to describe a long-term relationship with people and their families in which engagement is purposeful and proactive, as a basis for identifying and responding to incremental change over time.

- Extension of care into bereavement for people left behind after a death. This support may need to be practical as well as emotional in nature.

What impact would this approach have if enacted by hospices and others?

Older people, and their families, will:

- Have a greater sense of wellbeing, linked to the achievement of realistic goals that are important to them.

- Feel secure about the future, confident that distressing symptoms will be managed wherever possible.

- Feel empowered. They will be confident that they are centre stage in decisions made about their care and understand how their care and treatment plans align to their needs and goals.

- Enjoy some sense of control despite a changing condition. They will be able to identify and understand changes that suggest their illness is advancing and know who to contact for further help if necessary.

What do hospices already do well that they can build on?

- Looking at people holistically.

- “Family” involvement that is intentional and sustained.

- Meticulous symptom assessment and treatment, often reasons for acute admission in old age.

- Care that helps people maintain their dignity and is compassionate in nature.

- A focus and commitment to good quality of life, even when someone’s condition is deteriorating.

- Engaging with loss and dying and working with uncomfortable emotions.

- Bereavement Care. There is little evidence that this has developed sufficiently in mainstream service provision.
What new skills do hospices need in order to do this well?

• A more consistent and systematic focus on function and rehabilitation

• Competencies that focus on recognising and managing the consequences of frailty; including the complexities of managing comorbidities

• A working knowledge of the process of ageing, common geriatric syndromes\textsuperscript{51}, and potentially reversible conditions\textsuperscript{52}

• The confidence to identify short and long-term goals alongside needs, in order to manage uncertainty and unpredictability both in people who seek help, and the other professionals involved in their care.

Which are the key relationships to invest in and develop?

• The Primary Care Team

• Community Pharmacists

• Geriatric services - acute, intermediate and community based

• Social Care Agencies

• Mental Health Services

• Care homes and residential facilities for older people

• Older People’s and Carers interest groups.

Insight from the literature

This population of people seem to have the same symptomatic problems as those conventionally seen by hospices but they underreport them\textsuperscript{63}. The accumulated losses of old age can be as, or more distressing, than the person recognising that their life is drawing to a close\textsuperscript{64}. Conversely older people often have much more capability and resilience than health and social care providers recognize\textsuperscript{65}.

“People need recognition of their capability and strengths over a life long lived – this may help ease a conversation about their current or future vulnerabilities.”

Caroline Nicholson 2017

“In the last few days of life people age 85 or over experienced less emotional and spiritual support and were more likely to have had unwanted treatment decisions made.”

Hunt et al 2014\textsuperscript{71}
Level 2
Working in partnership across the system

Some Top Tips to Drive Appropriate Services

- Learn about the population you serve and those likely to die in the next few years
- Proactively develop new relationships with other care providers involved in older people
- Jointly develop referral triggers and pathways
- Think about your USP and where you can most make a difference
- Work together across professional and service boundaries including co-location, to engage with older people to explore their needs and requirements for care.

Improving services and the system of care

- Utilise tools that support decision making for older people
- Find opportunities for shared learning between organisations and professionals
- Appreciate, collaborate with, and learn from local residential and social care agencies
- Develop patient related outcome measures across organisational boundaries that foster, and embed relational and effective care
- Appreciate, collaborate with, and learn from local residential and social care agencies
- Develop patient related outcome measures across organisational boundaries that foster, and embed relational and effective care

- Find opportunities to engage in trans-organisation and trans professional patient reviews
- Create relationships with commissioners and providers that help integrate the hospice into system wide networks and plans
- Listen to stories about the lives of older people in order to better understand their values, aspirations and priorities for care
- Draw on the expertise and feedback from older people and their families to develop and improve services
- Engage in collaborative research projects that facilitate shared vision for future care

- Providing resources for both patients & staff to enable quality care
- Working in partnerships across sectors and specialities
- Older person and/or “family”
What does optimal provision look like?

- Early identification of palliative care needs in older people across the system
- Active patient and family involvement that is enabled and supported by multiple providers across the system. Shared structures and processes such as advance care plans, patient held records and other forms of patient activation that will support this.
- Tailored, responsive and flexible care that accommodates unpredictable and changing need across an extended trajectory, differing social support structures on the part of older people, their families and care settings and the introduction of new technologies to increase clinical responsiveness.
- Integrated and seamless provision between services engaged in care for older people, reflected in clear referral criteria, cross-organisational pathways and clarification regarding roles and responsibilities. Shared Information systems and infrastructures that support continuity of care, including Electronic Palliative Care Coordination Systems.
- Collaborations between services that can jointly deliver periods of care and interventions at home to those who want to remain in this context, avoiding unplanned hospital admissions.
- Care around the clock with access to support and advice for carers at all times.
- Patient reported outcome measures that enable providers to measure and demonstrate effectiveness.

What outcomes could we expect if older people had access to such provision all of the time?

- Any older person who could benefit from palliative care could expect to gain access to the services they require.
- Referral for such provision would be timely, regardless of the entry point into the system of health or social care on the part of the older person.
- Care for older people at end of life will be well co-ordinated and experienced as seamless, even when provided by multiple professionals and agencies.
- People at home or in care homes who wish to remain in this context for the duration of their illness(s) could expect to do so, subject to adequate planning and consideration of the risks of refusing hospital admission or similar.

How could hospices build on what they do well already?

- We offer high quality care, albeit for a relative few.
- We have experience of working with other agencies across health and social care.
- We are proactive in responding to unmet need.
- We often educate and train others in palliative care, including care homes.

What key relationships will foster innovation and developments across the system?

- Closer work with geriatric services, primary, secondary care and social services.
- Work with care homes including understanding their care context.
- Sheltered housing and social care agencies.

Insight from the literature

Assumptions about home as the most desired place to die are unfounded and hospital can be an appropriate place for end of life care in some cases and in response to some needs on the part of the older person. However, people living on their own are less likely to access palliative care and more likely to die in hospital. Supporting their particular needs at end of life requires special consideration.
Level 3
Supporting societal change

Some top tips to drive societal change

- Seek opportunities to confirm the value of older people within the service you provide. Use images, stories and quotations that reinforce their central place in your care on offer and plans for the future.

- Encourage people to tell stories about their life and their legacy; encourage others simultaneously to listen and reflect on what they hear with the intention of amending and expanding their life view.

- Find opportunities for intergenerational activity and care. Focus on those in which there is strong reciprocal learning or attachment.

- Encourage community participation in care. Provide training and support to ensure people feel confident in their roles and know where to go if they face something they feel unprepared for. Create networks for this learning.

Shaping society’s response

- Encourage individuals, groups and communities to learn skills and engage in the care and support of others important to them who are approaching the end of life.

- Recognise what older people bring to society, relationships, conversations and decisions.

- Identify and promote opportunities in which the state of dependency can enhance lives of people who are more independent.

- Encourage conversations on the part of citizens about legacy.

- Promote discussions related to plans regarding older life and its end.
**What does strong contemporary society look like?**

It will be a society in which:

- Older people are revered in recognition of all that they have achieved in their lives; also the experience and views they bring to conversations, relationships and decisions on the part of others today and in the future.

- Conversations about death, dying and loss are initiated by citizens as a basis for making plans and decisions about the rest of their life and its end, engaging professionals as necessary to support their choices.

- The state of dependency is valued alongside independence, with due recognition of the opportunities afforded by this state, as well as its challenges.

- Individuals, groups of people and communities participate in the care of their families, neighbours and friends to enable them to live and die well, simultaneously building networks with others also involved in their care.

**What outcomes could we expect if society operated like this all of the time?**

- Older people will continue to enjoy the experience of social connectivity and the opportunity to contribute to the lives of others.

- Care, help and support available to older people will be considered worthy of investment – and those employed to provide this are trained and remunerated accordingly.

- Older people will consider how they want to live and die in advance of being unwell. They will have rehearsed their intentions with families and professionals involved in their care and will be confident about reviewing and revising them to reflect changing preferences and needs.

- People with different levels of dependence connect formally and informally, confident that they have something valuable to offer to each other.

- Older people receive care and support from people with whom they already have a relationship, or from individuals interested to engage in a new relationship of value that is carefully and jointly negotiated.

- Individuals providing care and support to neighbours and friends become connected to others, to whom or from whom they might receive support in the future.

**What does the evidence tell us about where to focus our efforts?**

- Quality of life on the part of older people is enhanced when they remain socially connected and continue to contribute to society as well as good health and some financial security.

- When people make overt plans for the end of their life, their wishes around where and how they die are much more likely to be respected.

- High quality relationships can be relatively easily established between people who are diverse in age, (dis)ability, culture and experience when there is a shared awareness of mortality. Increased wellbeing is one outcome of such relationships.

- When the public is supported to act with reciprocity and agency in a compassionate response to someone seriously ill or dying, the impact of their contribution is enhanced.

- The public wants to be involved in end of life care. People are dissatisfied with care currently provided by professionals and do not feel it is the responsibility of professionals alone.
What do we already do well as hospices or palliative care services that we can build on?

- Years of experience of working with volunteers
- Strong community support and relationships
- A philosophy that sees patients in the context of their families and other social networks
- Early work on encouraging community participation in care
- Work with carers as partners in care
- Having conversations about death, dying and loss – either as part of clinical interactions, through Dying Matters or similar.

What new approaches do we need to learn and adopt to maximize our impact on society?

- Public health approaches to end of life
- Death cafe culture
- Models of shared risk
- Story telling – in order that people can identify and share their legacy
- Cross generational work.

What are the key relationships to invest in and develop?

- Other voluntary sector organisations like Age UK and Independent Age.

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**Insight from the literature**

Communities can play an increasingly significant role in their own health and social care, and evidence demonstrates the positive impact of this work on a range of health outcomes and at a number of levels – advantageous to those involved in supporting others, those affected by poor health, including carers, and the communities themselves. Community engagement in end of life can influence complex issues such as wellbeing and social isolation – key challenges for people in late older age.
Section 4: Next steps

This publication offers some headlines about age-attuned palliative care. We hope that it will engage hospices and encourage discussion on their part about the contribution that they could make to the care and wellbeing of older people who are coming to the end of their lives. We are in no doubt that there is much more to do – in terms of building the evidence base, establishing best practice and confirming the best way to upscale provision so that everyone who needs such care is in receipt of it.

Some of the most notable areas that call out for urgent attention are:

• Authority given to the voices of older people and their families
• What society considers important and where it is willing to take responsibility
• How we equip lay people to respond to the changing landscape of care
• Validated assessment tools and measures of outcome specific to people who are frail
• Exploration of new technologies and support care of older people and evaluation of their acceptability and effectiveness
• Policy and regulatory implications associated with the particular care needs of much older people.

Even so, we are clear that age-attuned palliative care is a real opportunity for hospices. It is in keeping with national intentions for hospice care and supports international and national policy to make palliative care an essential service for older people. As importantly, the proposals in this publication are consistent with the calls for action on the part of hospices made by the Commission into the future of hospice care, namely responding to the changing needs in the context of palliative and of life care, establishing hospice care as a solution to them and strengthening the connection between hospices and their local care systems and communities.

Whilst hospices face particular challenges currently around access to funding and staff in particular, there is consistent evidence suggesting that extending access to palliative care is likely, on balance, to be cost-effective, reducing demand for acute and emergency care and delivering better outcomes for patients and their families. Our challenge and our opportunity as hospices are to find ways to be part of the system through which these benefits are realised and in which we can be both contributor and beneficiary.

“In its first flourishing 50 years ago, hospice care brought creativity, confidence and compassion to new services that transformed the lives and the deaths of many. Hospices should again work to put right an absence of care and an ignorance of need”

Professor Dame Barbara Monroe,
Vice Chair, Commission into the future of hospice care
Section 5: Resources

Working differently with older people, their families and carers

- BGS website- Fit for Frailty 1 and 2, and Comprehensive Geriatric Assessment http://www.bgs.org.uk/fit-for-frailty/resources/campaigns/fit-for-frailty/fff-headlines
- Nice Guideline NG56 on Multimorbidity ; clinical assessment and management https://www.nice.org.uk/guidance/ng56
- Palliative Care Outcome Scale https://pos-pal.org/ and OACC suite of patient reported palliative outcome measures

Working in partnership across the system

Primary care

- Palliative care Tool Kit –http://www.eapcnet.eu/LinkClick.aspx?fileticket=PXIX1RoSrXU%3D

Care home

- MY Home Life- promoting quality of life in care homes http://myhomelife.org.uk/
- Healthcare support for older people in care homes- A Quest for Quality http://www.bgs.org.uk/carehomes/campaigns/carehomes/questforquality

Social Care

- SCIE website a range of resources and links to support people at the end of their life https://www.scie.org.uk/adults/endoflifecare/

Across care contexts

- Coordinate my care http://coordinatemycare.co.uk/
- EACPC Core competencies in Palliative care http://www.eapcnet.eu/LinkClick.aspx?fileticket=getYk7bkp0%3D

- Scottish Partnership for Palliative Care https://www.palliativecarescotland.org.uk
- Gold Standard Framework http://www.goldstandardsframework.org.uk/
Supporting societal change

- Dying Matters https://www.dyingmatters.org/
- Posh club http://theposhclub.co.uk

General Resources

- Better Endings, Innovation Unit https://www.innovationunit.org/projects/better-endings/
- Compassionate Neighbours https://www.stjh.org.uk/neighbours
- NIHR Themes reviews: On care homes, older people with frailty in hospital and end of life and palliative care services https://www.dc.nihr.ac.uk/themed-reviews/
Section 6: Glossary of Terms

**Family** may or may not be a person’s biological family members: they are socially connected people in a close supportive role who share in the illness experience and may undertake vital care work and emotion management.

**Frailty** is a distinct health state, related to biological ageing, in which body systems gradually lose their in-built reserves; this increases older people’s risks of poor health outcomes, potentially reversible disability, institutionalization and death⁶².

**Geriatric Services specialise in the care of older people** addressing clinical, preventative, remedial and social aspects of illness in old age to ensure that people receive the highest possible levels of care. They are inter-disciplinary services comprising geriatricians, specialist nurses, rehabilitative therapists, pharmacists, dieticians, social and mental health workers. Geriatric services work across primary and secondary care and their interface, sometimes called intermediate care, in close collaboration with other specialties, e.g. psychiatry/community medicine and specialist palliative care.

**Hospice Care** in partnership so that high quality palliative and end of life care might be provided to all, across the many different settings where it is needed. They are intimately connected to people with palliative and end of life care needs and their communities who can offer support. They are advocates for those who may be less visible in society. Hospice care helps people cope with the reality of dying, death and bereavement, and always does so with confident expertise.

**Late Old Age** is when people are 85 years old or over. Whilst care should always be based on need not age, 40% of all deaths are in people over 85. They are more likely to live with multiple morbidities, less likely to be known to specialist palliative care or have their preferences for end of life care to be known or recorded.

**Multimorbidity** is the coexistence of two or more long-term conditions. These can be specific physical or mental health diagnoses, such as diabetes or dementia, or symptom or functional complexes such as frailty. Managing multimorbidity is complicated because different conditions and their treatments often interact in complex way.

**Palliative Care** is concerned with the expert management of people with advanced, progressive or life-threatening disease, including co-existing chronic conditions, to live as well and as long as possible until the end of their natural lives. Some palliative care services include in their name subsets such as supportive, rehabilitative, or end of life care. It should be available to someone experiencing distress associated with serious illness for which there is no potential cure. Palliative care is associated with a range of principles including the view of dying as a natural process, while at the same time affirming life, and of acting neither to hasten nor postpone death. We have delineated palliative care into the definitions that are often used in evidence and policy, whilst simultaneously acknowledging that many of these terms are inconsistent with delineations in practice.

**General Palliative Care** is provided by the patient’s usual professional carers who have routine responsibility for people with advanced illness, including those at the end of their lives. These include GPs, district nurses, hospital doctors, ward nurses, allied health professionals, staff in care homes, social care staff, social workers and chaplains.
Specialist Palliative Care is an accredited specialty in medicine and in other disciplines specialism is recognised by agreed accredited levels of competence. It is provided by multi-disciplinary teams that include consultants in palliative medicine and nursing, advanced nurse practitioners, specialist social workers and allied health professionals, experts in psychological, psychiatric and pastoral care and complementary therapies. Specialist palliative care services, like geriatric services, cross all care settings. They include inpatient units, either in the voluntary sector or NHS; hospital-based services including hospital support and outpatients, day care services, community services and bereavement support.

Supportive Care is the subset of specialist palliative care that is applicable early in the course of illness, in conjunction with other disciplines such as cardiology, oncology and respiratory medicine and therapies intended to prolong life, such as chemotherapy, active cardiac and respiratory support and include those investigations needed to understand and manage distressing clinical complications better. In such situations it may be time-limited with people entering and leaving specialist services as necessary until they die.

End of Life Care is a subset of Palliative Care that refers specifically to care provided in the last phase of life. The phrase is ambiguous but used in this publication to define when someone is expected to be in their last year(s) of life.

Rehabilitative Palliative Care centres on patients’ personal goals and provides a culture of enablement, through which the multidisciplinary hospice team supports patients to achieve their priorities. It optimises choice, independence, autonomy and dignity.

Social Care offers help, care and support to people with a wide range of needs arising from disability, illness or other life situations. It helps people to live as independently as possible, protects people from harm in vulnerable situations, balances risks with rights and offers essential help at times of crisis. Support is offered in people’s own homes, residential and nursing homes or other community settings. Unlike NHS care, which is free to all at the point of contact, individuals may be assessed for eligibility based on needs and their financial resources.
Section 7: References

36. Public Perceptions and Experiences of Community-Based End of Life Care Initiatives: Research Report pfPHEbSRJ.
52. Hibbard JH, Gilbert H. Supporting people to manage their health: an introduction to patient activation: King’s Fund. 2014.
At St Christopher’s Hospice our vision is of a world in which all dying people and those close to them have access to care and support, whenever and wherever they need it.

Each person is unique and we tailor our care to meet social, emotional and spiritual needs, as well as manage physical symptoms. Our goal is to help people live well until they die and support those affected by the loss of a loved one. Every year we provide care and support to nearly 6,500 people across South East London, both at home and in the hospice.

We passionately believe that everyone should have access to the best care at the end of their lives and have an extensive education programme, working with people across the world, to improve and develop hospice care.

We were founded in 1967 by Dame Cicely Saunders and, over 50 years later, her words still remain at the heart of everything we do: “You matter because you are you and you matter until the last moment of your life.”

As a registered charity we need to raise £15 million every year to continue to care for people when it matters most. Without the support of our local communities this wouldn’t be possible. Thank you from us all for your support.

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“The Wives’ Fellowship is an organisation of Christian women founded in 1916. Today we number approximately 3000 members and we have branches throughout England. Our association with St Christopher’s Hospice began in 1975 and although fundraising is not in our remit any surplus monies (£1.3 million to-date) are donated to St Christopher’s to be used solely for education and research. We are proud to fund St Christopher’s work in the field of frailty and trust that this work will help you to understand and respond appropriately to the increasing number of elderly men and women living with co-morbidities and frailty at end of life.”

Sarah O’Boyle, Wives’ Fellowship Chair