Each Community is Prepared to Help:

Community Development in End of Life Care – Guidance on Ambition Six

THE NATIONAL COUNCIL FOR PALLIATIVE CARE

PHPC-UK

hospiceUK

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Foreword

Each community is prepared to help

"I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways."

Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020

Each year, about 500,000 people in England die. For each person, there are many around them who are affected by caring, grief and loss. The National End of Life Strategy 2008 set a determined path to improve the quality and experience of care for all. The Ambitions for Palliative and End of Life Care is a continuation of this work, building on the extensive national efforts made over the previous 7 years and broadening its reach and challenge to the whole community.

Public health approaches to palliative care are based on the recognition that dying, death and bereavement are inevitable parts of human experience. They are not primarily medical events in isolation. Professional support aims to help individuals who are approaching the end of their life, and those close to them, make the most of their remaining time, and to offer help and support in bereavement. The Ambitions Framework recognises the important role of the communities, within which the 'house of care' is situated. The inclusion of 'each community is prepared to help' is the desire to form new and improved partnerships between communities and professional services. By making the best use of both, together we can hope to achieve the eloquent aspiration of the National Voices narrative for end of life care:

"I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s)."[1]

Health and social care organisations are becoming increasingly familiar with public health approaches to community development. With the advent of Sustainability and Transformation Plans, as part of the NHS Five Year Forward View, localities are recognising more and more that many problems people face are not ones that can always be, or are best resolved, by individual organisations, but by partnerships across the whole of the community. This is particularly so in end of life care, where people want to feel safe, often in familiar surroundings, cared for by those they know and trust. The challenge is to find new ways of working where professional organisations can actively participate in helping to build supportive communities.

1 National Voices and The National Council for Palliative Care (NCPC) and NHS England (2015). Every Moment Counts: A narrative for person centred coordinated care for people near the end of life. London: National Voices. Available at: **www.nationalvoices.org.uk/node/563** (accessed June 7th, 2016)

This guidance has been developed by Dr Julian Abel and Dr Libby Sallnow, with support from Professor Scott Murray and Michael Kerin, on behalf of Public Health Palliative Care UK, the National Council for Palliative Care and Hospice UK. It provides advice and practical suggestions for organisations that are keen to stimulate and extend partnerships with communities. The guidance does not specify exactly what is needed for each area. Rather, it provides a series of interrelated recommendations that are suitable for local interpretation. This will require leadership, individual action and a preparedness to work together, across organisational boundaries and across professional and community roles. Together, we can build and enhance supportive networks at end of life in our homes, communities, educational institutions and workplaces.

To quote from The Compassionate City Charter, *'a Compassionate City is a community that recognises that care for one another at times of crisis and loss is not simply a task solely for health and social services but is everyone's responsibility.'*

Professor Bee Wee, National Clinical Director End of Life Care NHS England

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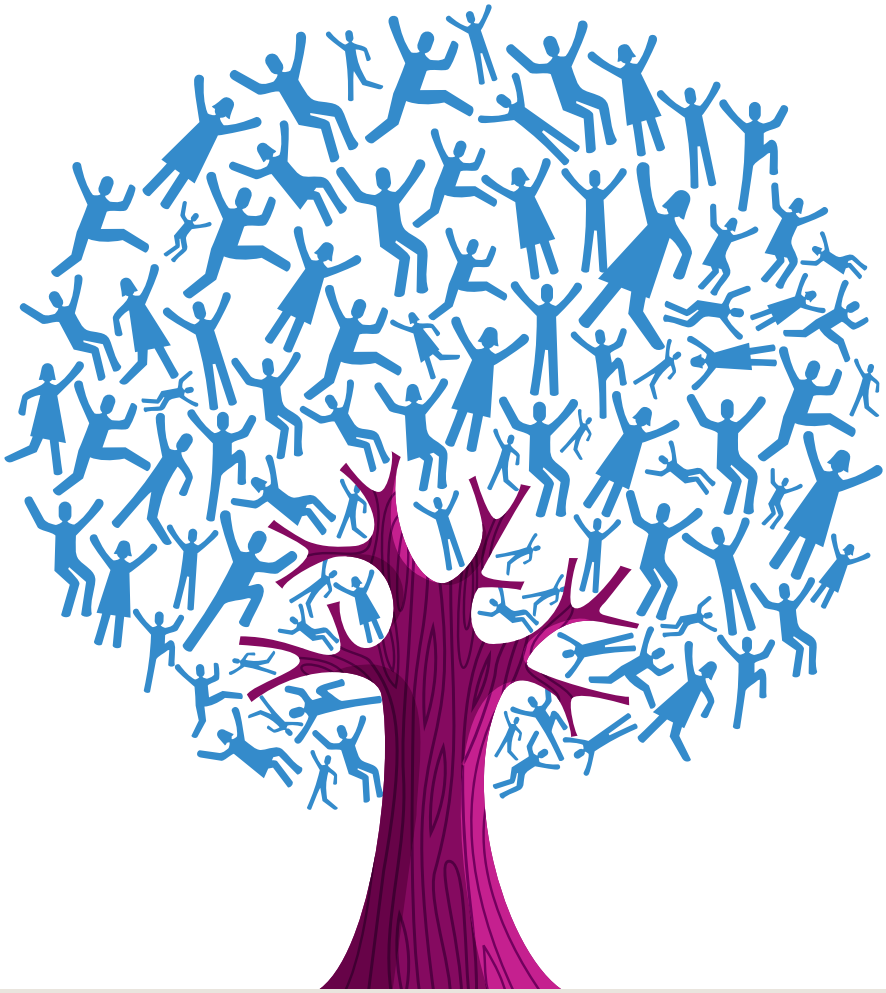


Executive Summary

Ambition six of the Ambitions for Palliative and End of Life Care is 'each community is prepared to help'. This guidance has been written as a summary of how organisations in particular and society as a whole can participate. Communities that are prepared to help falls into the category of Public Health Approaches to end of life care. Many will not be familiar with this field of work, which has been developing on an international basis for the last 20 years. Public health approaches aim to be inclusive for all people and for all ages. These approaches include community development to support the dying, those important to them, and those who are bereaved. Despite best efforts following publication of the National End of Life Strategy in 2008, the expected increase in the number of people accessing end of life care, particularly advance care planning, and people being supported to die at home has been relatively muted. Professional care is struggling to meet current demands. Using a public health approach to end of life care is a way of enhancing supportive networks other than the professional ones. Adding this to the overall picture of end of life, and bereavement, will hopefully make significant further improvements by building on the work and infrastructure that has already been done.

The guidance is primarily aimed at organisations and society as a whole but is inclusive of individuals. It aims to give practical examples of the varied and different public health practice examples. It is not a step by step guide, but rather a seeding of ideas. How it is introduced will be different for each area and each organisation. We have given a series of principles which will need local interpretation.

All of the examples given have already been put into practice, to greater or lesser extents. Organisations will need to select the recommendations they feel are the most appropriate for local areas. For some, programmes of public health which focus on community capacity and social capital may be in advanced stages. If this is the case, linking with existing projects and adding in end of life care is recommended. For others, these kinds of approaches will be new and unfamiliar.

The skills that are needed for community development are not necessarily familiar to health and social care professionals. Generally, professionals are proficient at engagement, which is based around having conversations about death and dying. Further skills are needed to build community capacity, whether this is in neighbourhoods or organisations. If there is a lack of familiarity and expertise with respect to these skills we recommend linking with bodies and organisations that have practical experience of running community development. A list of resources can be found at the end of the document, including organisations with this kind of expertise.

We hope that this guidance acts as a springboard for strategic projects which will run for a number of years. The aim should be to increase community capacity so that communities are more familiar with caring for the dying and the bereaved.

This capacity should not be built on dependencies with professional care. The challenge for professional care is to find ways of working with communities in mutually beneficial relationships (Abel and Kellehear 2016).

Julian Abel, Libby Sallnow June 2016

Introduction

Equity of care

Since the publication of the National End of Life Care Strategy in 2008, there has been significant effort and expenditure in England to try and improve end of life care for all. Despite the many gains, changes in place of death have been very modest, rising from a low of home death rates of 19% in 2006 to 23% in 2015 (National End of Life Care Intelligence Network). Whist this figure is not a measure of quality of death, we do know that there is inequity in provision of care between those people with cancer and those who have terminal illnesses other than cancer. Cancer hospital death rates are in the region of 30% with other diagnoses varying between 50 and 70%, dependent on condition (National End of Life Care Intelligence Network). There is significant inequality and variation in provision of end of life care services and quality of care, in addition to cancer and other terminal diagnoses. Studies have demonstrated inequity of access to services on the basis of culture, ethnicity, all ages, geography, deprivation, being homeless or imprisoned, sexuality, diagnosis and choice of place of care (Sleeman, Davies et al. 2016).

The challenge we now face is how to make significant impact to ensure that people, irrespective of diagnosis or any other factor, can make informed choices about where they die, what is important to them in their dying including place of care and that, should they choose to die at home, there is sufficient support available. Bereavement and loss are also experienced in relation to sudden and unexpected deaths including suicide, not solely expected deaths. We need to find ways of supporting those who are undergoing these experiences. We know that even with current resources our professional services are stretched. In addition, as a matter of preference, many people would like to be cared for by those who love them in their familiar surroundings. To this end, over the last 20 years there has been considerable international interest in how to enhance the naturally supportive networks that exist which would allow those people who choose to be cared for at home, and to die there should they choose to do so. Recognition of the importance of this approach has been its inclusion in the Ambitions for End of Life Care 2015 – 2020, Ambition Six being 'each community is prepared to help' (National End of Life Care Partnership 2015). The overall purpose of this guidance is a way of providing ideas and stimulating a variety of approaches which directly and indirectly helps to increase the community capacity to care.

Palliative and end of life services have traditionally enjoyed close relationships with their local communities, many owing their initiation to motivated groups of community members and still more remain financially dependent on funds raised through local giving. Since the early community based beginnings, palliative and end of life care have become increasingly specialised. Whilst huge strides have been made in service provision, quality of care and integration into mainstream healthcare, many significant

challenges remain. Increasing numbers of deaths year on year, increasing numbers of frail older people with multiple conditions and dementia, increasing number of babies surviving and children living longer with life-limiting often complex conditions with increasing technology dependence, high hospital death rates and low, although slowly increasing, home death rates and diminishing funding sources all add together to create a difficult terrain for services. Significant inequalities remain in the different levels of care and services to those historically focussed on terminally ill cancer patients and those with other life limiting illnesses.

The role of community development

The proliferation of professionals in end of life care over recent years has led to many achievements and improvements in symptom control or aspects of quality of life. However, increasing the numbers of professionals is simply not the answer to many of the social issues people face. There is increasing awareness that with the growing numbers of people dying and increasing demand for all aspects of health and care services, we need a different discussion from simply asking for more resources and more staff.

Recognition of the impact of loneliness on mental and physical wellbeing, the use of health services and mortality, (Smith, Holt-Lunstad et al. 2010, Reeves, Blickem et al. 2014) has led many across health and social care to reconsider which interventions may be appropriate to support people near the end of life and those caring for them. Examples underway include the Health Connections service in Somerset and the Living Well service in Cornwall. The focus of development in these areas has been to enhance community capacity by developing and supporting social networks. This includes peer and community support. This is seen as a sustainable social and financial model that does not depend on employing increasing numbers of professionals. In addition to the above examples, a number of hospices have started befriending and good neighbour schemes.

The Ambitions for Palliative and End of Life Care *'Each community is prepared to help' (Partnership 2015)* sets out clearly the role communities have to play in ensuring all those who need care and support are able to receive it. Four building blocks underpin the work: compassionate and resilient communities; public awareness; practical support; and the role of volunteers and many of the principles underpinning the ambitions as a whole, such as co-design, involving those important to the dying person and finding locally determined solutions are relevant. This guidance aims to give different communities and organisations, whether commissioners or service providers, some ideas about the initiatives they can set in place to try and develop community resource. This is not necessarily the domain of palliative care. The skills needed to be able to participate in these initiatives are those of community development, something which may not be familiar to many health professionals. Seeking expertise from those already knowledgeable is a great help, whether this is from community development projects in end of life care or projects in other areas such as mental health, maternity and more recently in addressing loneliness and social isolation in the frail elderly.

Engaging with communities can take on a range of shapes and sizes. This will depend on locally determined needs of the community, the degree to which strong and trusting relationships exist between professionals and the public. Skills, knowledge and resources are all part of what the community is able to offer. In addition, the degree to which professionals are open to working in partnership with communities has an impact. Whether the service engaging is a hospice, council or hospital, the availability of community development skills will directly impact on the success of working with communities. Additionally, this work cannot be seen as a stand-alone project. It depends engaging with communities consistently to develop trusting relationships built on over time.

The public health approach to end of life care, The Compassionate City Charter

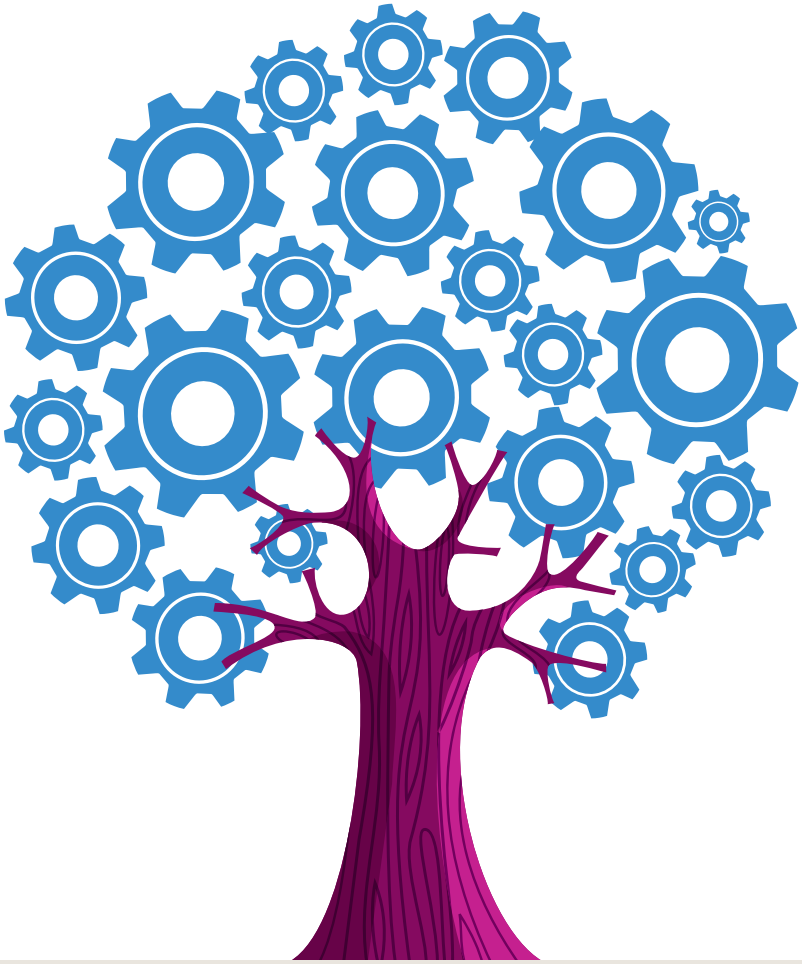
A range of terms have come into use to describe this approach, including compassionate communities, compassionate cities, (new) public health approaches, social network approaches or community development, engagement or participation. All are based on the principle that care at the end of life should be done *with* and not *to* people and that death, dying, loss and care are complex social events, of which the medical component is only one aspect (Karapliagkou and Kellehear 2014). Solutions to the problems facing people such as social isolation, carer fatigue, stigma and fear are not the sole responsibility of professionals. Everyone has a role to play and these issues will only be truly tackled if a whole-community approach is taken. Death, dying, loss and care are not experienced in a vacuum and neither, therefore, will the solutions be found at one person's door.

Central to community development in end of life care is implementation of the Compassionate City Charter. This is a checklist of public health approaches to end of life care. It can be fashioned to suit the needs of local communities and does not specify *how* implementation should take place (National Council for Palliative Care 2014). Rather, it gives guidance on *where* implementation should be focused. It is recommended that organisations turn themselves into compassionate ones. This can be done by adopting a compassionate workplace policy, giving recognition to those within any organisation who can provide emotional support. Training can be provided as further support. Workplaces can set up a 'bank' of volunteer help that can be given to people who have a terminal illness themselves, as well as those care giving or bereaved. Learning how to support those around us helps to develop understanding of what naturally occurring supportive networks can do at end of life. This will give insight into how networks can be developed and is an education on death literacy. This knowledge of how to look after and support the dying will be gained by practical experience. The charter is broad ranging in its approach and is more than community development alone. It covers policy, as well as societal engagement, looking to remind us that the experiences of the dying, those important to them, and those who are bereaved are common to all of us. These are not solely professional but experiences of society as a whole.

How to use the guide

This guidance covers a range of settings where community capacity at end of life can be increased. It gives a series of suggestions or recommendations regarding how to implement it in practice within the conclusion of each chapter, starting with the quick wins and progressing to more long term goals. Examples of where this has been done are present throughout. It is not meant as a document for people to read cover to cover. We expect readers will select their area of work and expertise and read the relevant sections. If they read other chapters, this may help to see the common ground and how it all can be linked together. We hope this serves as a useful tool in developing both a local and national response to the ambitions statement.

Experience of community development initiatives so far has shown a degree of uncertainty between community *engagement* and community *development*. By and large, health professionals and palliative care specialists in particular, are skilful and resourceful in talking about subjects relating to death and dying. The skills needed to develop community capacity are somewhat different. These are about finding ways of securing actions that will start increasing the capacity of communities to care for their dying. This might mean getting commitment to start a community group to support people affected by terminal illnesses. Equally, it can include getting businesses to become compassionate organisations and support local initiatives. These skills are closely related to social entrepreneurship, in which innovative solutions to social problems are sought from within communities.



Chapter 1

Public health approaches to end of life and palliative care – The Compassionate City Charter

The Compassionate City Charter

Compassionate Cities are communities that recognise that all natural cycles of sickness and health, birth and death, and love and loss occur every day within the orbits of its institutions and regular activities. A Compassionate City is a community that recognises that care for one another at times of crisis and loss is not simply a task solely for health and social services but is everyone's responsibility.

Compassionate Cities are communities that publicly encourage, facilitate, support and celebrate care for one another during life's most testing moments and experiences, especially those pertaining to life-threatening and life-limiting illness, chronic disability, frail, ageing and dementia, death in childhood, grief and bereavement, and the trials and burdens of long term care. Though local government strives to maintain and strengthen quality services for the most fragile and vulnerable in our midst, those persons are not the limits of our experience of fragility and vulnerability. Serious personal crises of illness, dying, death and loss may visit any us, at any time during the normal course of our lives. A compassionate city is a community that squarely recognises and addresses this social fact.

Through the auspices of the Mayor's office or equivalent body, a compassionate city will by public marketing and advertising, by use of the city's network and influences, by dint of collaboration and co-operation, in partnership with social media and its own offices – develop and support the following 13 social changes to the cities key institutions and activities.

- Our schools will have annually reviewed policies or guidance documents for dying, death, loss and care.
- Our workplaces will have annually reviewed policies or guidance documents for dying, death, loss and care.
- Our trade unions will have annually reviewed policies or guidance documents for dying, death, loss and care.
- Our places of worship will have at least one dedicated group for end of life care support.
- Our city's hospices and nursing homes will have a community development program involving local area citizens in end of life care activities and programmes.

- Our city's major museums and art galleries will hold annual exhibitions on the experiences of ageing, dying, death, loss or care.
- Our city will host an annual peacetime memorial parade representing the major sectors of human loss outside military campaigns – cancer, motor neuron disease, AIDS, child loss, suicide survivors, animal companion loss, widowhood, industrial and vehicle accidents, the loss of emergency workers and all end of life care personnel, etc.
- Our city will create an incentives scheme to celebrate and highlight the most creative compassionate organisation, event, and individual/s. The scheme will take the form of an annual award administered by a committee drawn from the end of life care sector. A 'Mayors Prize' will recognise individual/s for that year who most exemplify the city's values of compassionate care.
- Our city will publicly showcase, in print and in social media, our local government policies, services, funding opportunities, partnerships, and public events that address 'our compassionate concerns' with living with ageing, life-threatening and life-limiting illness, loss and bereavement, and long term caring. All end of life care-related services within the city limits will be encouraged to distribute this material or these web links including veterinarians and funeral organisations.
- Our city will work with local social or print media to encourage an annual city-wide short story or art competition that helps raise awareness of ageing, dying, death, loss, or caring.
- All our compassionate policies and services, and in the policies and practices of our official compassionate partners and alliances, will demonstrate an understanding of how diversity shapes the experience of ageing, dying, death, loss and care – through ethnic, religious, gendered, and sexual identity and through the social experiences of poverty, inequality, and disenfranchisement.
- We will seek to encourage and to invite evidence that institutions for the homeless and the imprisoned have support plans in place for end of life care and loss and bereavement.
- Our city will establish and review these targets and goals in the first two years and thereafter will add one more sector annually to our action plans for a compassionate city – e.g. hospitals, further and higher education, charities, community & voluntary organizations, police & emergency services, and so on (Kellehear 2015).

The role of the charter

This charter represents a commitment by the city and community to take a view of health and wellbeing which embraces social empathy, reminding its inhabitants and all who would view us from beyond its borders that 'compassion' means to embrace mutual sharing. Cities and communities are not merely places to work and access services but equally places to enjoy support in the safety and protection of each other's company, even to the end of our days.

The compassionate city and community charter is a condensed form of the variety of public health approaches to end of life care. The charter does not specify what should be done. Rather, it highlights areas for development. What this looks like in each area will be determined by the people involved.

The charter looks to join up top down policy support with bottom up community engagement and development. The core principle is how communities can support those living with advanced illness, those caring and important to them, and the bereaved. It points towards the variety of sectors where this can be done. It includes workplaces, educational institutions, public bodies, neighbourhoods, clubs, religious institutions and health and social care activity.

Model of implementation

The charter can be seen as describing a hub and spoke model of public health approaches. This guidance has been written in response Ambitions Six: Communities Are Prepared to Help. Many organisations will not be familiar with the principles of the public health approach and where their activities fit into the hub and spoke model. The charter is the bigger picture. Implementation involves health and social care organisations but goes much wider than this. It includes participation from all areas of society. The charter includes the term 'city' in the context of 'citizens' and this responsibility of civic care, rather than meaning a metropolis alone. Citizens are community members and the charter is therefore applicable for use in any community. Death, dying and loss is something that we will all experience and is everyone's business. We all have a civic responsibility to show kindness, consideration and support to all people who undergo these episodes in their life. We would want this for ourselves.

The charter is not fixed. It was developed outside the local government context in England, and is something that can be adapted for local use. It can be used flexibly so that local ownership becomes part of the method of adoption. Implementation involves bringing together interested parties who are committed to the principles. An organising committee needs to be set up and an implementation programme designed. The Charter was developed outside of local government context.
The key component for implementation of the charter is to build a coalition of support. The impetus to do this can come from a variety of sources, depending on interest. This might be palliative care providers but equally could be a civic decision led by the local council. A charter committee should include key players. Given the broad range

of activities, the makeup of this committee should be as wide as possible. At the very least, local council and palliative care providers should be involved, but others to include are community leaders, faith leaders, chamber of commerce representation, public health teams and political support.

This should be run like any other project. The organising committee will need to monitor progress, with regular reporting and evaluation on activity. The project is a long term one, which in some sense is ongoing. The formation of policies, events such as annual parades and prize giving competitions, should become part of the infrastructure of local government.

Implementation of the charter is a central way of building social capital to care for those in our communities who are dying. Combining the best use of professional care and community capacity is a new way of thinking about equity of end of life care irrespective of diagnosis. A challenge for professional organisations and individuals is to recognise and map social networks, whether these are in communities, in workplaces or educational institutions. Networks vary in strength. Personal networks may be small, particularly for the frail and socially isolated. Making best use of community support to build these networks, as in social prescribing schemes, will mean that innovative methods of support will be sought, rather than relying solely on professional care. (Abel, Walter et al. 2013)

In summary, this guidance document provides the rationale and examples of how individual institutions and localities can collaborate to provide widespread activity in a variety of sectors. Localities can commit to become compassionate cities or communities and the health and social care institutions should support this. Given that death is a social matter and not just a professional one, it is important for the professional organisations to work with communities by supporting them to care for dying and loss.

Bradford – England's first Compassionate City

The University of Bradford and the Bradford Municipal District Council (BMDC) which represents the City of Bradford enjoys a partnership around research into technology-enabled health care for people living with long-term health conditions. This partnership was sealed with a £12 million grant from the Department of Business, Innovation and Science to refurbish two buildings – one donated by the city and the other donated by the university – to provide infrastructure for a 'town and gown' set of relationships around regional health care needs. Out of that partnership and award scheme grew the DHEZ Health & Wellbeing Centre whose academic director is Professor Allan Kellehear.

Born from this relationship a first set of meetings were held with internal city/council departments in public health, and adult & social care services. After gaining in-principle support from these departments on the possible benefits of a

civic approach to end of life care (writ large in the Compassionate City Charter) further meetings were arranged with Council politicians to brief and lobby them about adoption of the Charter. After an in-principle agreement was reached with those politicians (specifically the Council Leader and Leader responsible for Health and Social Care) a further meeting was arranged with the CEO of the Council with members of these elected council members and the mentioned heads of department. After this meeting it was agreed that Council would commit to working towards the aims of the Charter by assembling a new Compassionate City Committee that would be charged with enacting the social actions described in the Charter. The Committee would be co-chaired by the Director of the DHEZ Health & Wellbeing Centre and the Elected Council member responsible for Health and Social Care. The Committee would be answerable to the CEO of Council and through her, the sitting council itself. Members of this new committee would be drawn from the key sectors of relevance to the Charter – schools and key educational institutions (HE and FE), workplaces, faith groups, health & social care services, cultural institutions, local media, etc.

The Council is at the preliminary stage of agreeing Committee membership although it has already been agreed that the organizers of the annual Bradford Literary Festival will take forward the organization of the Annual Peacetime Memorial Parade ("March of Memories"). This cultural recommendation with the Charter will take place every year at the end of the Bradford Literary Festival and its organisers will work with death, dying, end of life care, and human loss-related organisations, businesses, and services to design and implement the details of the parade. The Compassionate City Committee will work towards the parade date (in one year's time) to progress all the other action points within the Charter. The March of Memories parade itself will signal the end of the two-week long literary festival and be sown seamlessly into the marketing strategy of the existing literary festival preparations and delivery.

Professor Allan Kellehear, May 2016

Chapter 2
Hospices

Hospices that adopt a community development approach can enhance and enlarge what they do in ways that are beyond the impact of professional services alone. This can mean that specialist palliative care professionals can focus their efforts in a more efficient manner. This in turn offers the possibility of addressing issues of equity of care for people with all terminal illnesses and in all settings and allows social needs to have a specific means of addressing them.

Hospices are traditionally seen as having strong relationships with their local communities and the concept of working with communities is familiar, although often it is interpreted in a more limited manner as relating to fundraising or volunteering. Undertaking this work means hospices and all those who work within them will embark on a process of organisational culture change. Delivery of professional services is a support to people at end of life rather than the main component of care, The community can be seen as a resource of experts, as partners and leaders.

Challenges for hospices – cultural change

Inherent in the public health approach to end of life care, is the understanding that much of the work that has become the normal practice domain of professionals can potentially be done by the community or network of people who surround the patient. This naturally implies that the role of the professional may not be as central as professionals have traditionally thought. The challenge for health and social care professionals of all kinds, is to find new ways of working in harmony with community and their capacity to care of the dying. Typically, 80 to 95% of hospice patients have a diagnosis of cancer. The needs of people with other terminal diagnoses are no less than those with cancer. It is not possible to increase service size to create the same level of provision irrespective of diagnosis. The challenge for boards is to think about providing equity of care to the whole community who are in need. Finding new ways of working is a solution to this problem and thinking about making best use of community capacity is a way of doing this. For a board of trustees to endorse a community development approach, they need to develop the understanding that much of what is done by professionals, such as clinical interventions, beginning the process of advance care planning and hands on care, could be done by communities. In some ways, receiving care from people we know and trust can be thought of as being better. Community development involves the whole hospice, not just the clinical teams. Hospice staff who have contact with the public, all have a community development role. This includes fundraising teams, executives and board members. For example, many people's first contact with hospices is through hospice shops. The volunteers who work in the shops therefore have a role in taking a community development approach.

Professional and community partnerships

If the creation of compassionate communities is to be successfully adopted in a hospice, to be seen as a normal part of the range of care given to patients and interwoven into working practices, then effort is needed to educate and inform the board of trustees, executive teams and senior clinical leaders. Part of adopting a public health community development approach to end of life care in hospices therefore involves planning a programme of culture change throughout the organisation. Using a step by step approach of introducing ideas, creating practice examples and developing confidence through positive change amongst the staff are all ways of supporting this culture change.

There are a number of ways this can be used to help develop culture change within hospices to start to embed a public health approach.

- Presentation to the board on the Compassionate City Charter, the principles of a public health approach to end of life care and its practical uses (see chapter 1).
- Education session for the clinical teams and the senior management team on practice examples and benefits of using the public health approach to end of life care.
- Presentations from external speakers who work in hospices who have already started adopting the Compassionate City Charter or a community development approach.
- Inclusion of articles relating to public health approaches in journal club sessions.
- Attendance at relevant conferences to hear about practice examples and network.
- Linkage with and staff visits to other hospices that have already embedded this approach into their working practices.

Once it is felt that there is sufficient buy in from staff at all levels of the hospice, a strategic plan should be developed. We recommend starting with small scale practice changes using a stepwise model of change. Use of Institute for Healthcare Improvement quality improvement methodology is a safe way of doing this and is increasingly becoming part of change culture in the NHS, focussing on patient safety and quality of care. Its use in end of life care is also increasing (Institute of Healthcare Improvement 2015). Support and advice can be sought from Academic Health Science Networks and Health Education England (England).

Guidance on implementing a public health approach for end of life care in hospices

Top of the list is employing a community development worker or developing a partnership to access their skills. Experience from organisations that have started programmes is that community development workers, particularly those who have an intimate knowledge of the locality surrounding the hospice, make an enormous difference. Investment of time and money is critical for a successful project, as trying to fit the running of projects into existing busy jobs can be problematic.

Clinical initiatives

- Consider network mapping as a routine part of clinical care. This goes beyond the traditional genogram of simple family relationships to include all those important to the individual. Prompts should include asking about neighbours, friends, colleagues and others such as pharmacists, shop keepers or dog walkers. The emphasis is on gaining a picture of who forms the network, identifying roles and relationships. This is the foundation of enhancing the network to build a team around patient and carer(s). When this information is available to the professional team, integration of services with the caring network is much easier (Rempel, Neufeld et al. 2007).
- Think about how a social component of care can be included in existing services such as heart failure or neurological disease support groups. Include talks about health and wellbeing and help the group consider how they could become a supportive network. Look at how such groups could become peer-led and self supporting in the future.
- Compassionate neighbours or community companions can provide a lifeline of social support to many individuals and their families. Often these are people who have been through the experience of being a carer, although this is not necessarily the case. They can fulfil a variety of roles, giving emotional support and guidance to carers and families, sitting with the patient to give the carer a break, providing expertise on how to enhance naturally occurring supportive networks and how people can re-integrate back into their community after prolonged periods of social isolation. Patients and their carers report being able to communicate with companions in ways that are different from both family members and professionals. Include wide representation in the steering group when initiating this – GPs, commissioners and carers groups contribute valuable perspectives and support the project developing more widely, beyond the hospice.
- Include clinical staff members as trainers on community companion volunteer training. Clinical team members may at first be suspicious of volunteers who take on some of the roles of the professionals and may be concerned about the quality of the care they will provide. Observing the level of training they receive can help to develop a trusting relationship and provide a source of monitoring for new volunteers.

- Ensure that community development workers are part of the multidisciplinary team and present at multidisciplinary team meetings. This is immensely helpful in bringing about the cultural change and gaining confidence in community development approaches. Hearing stories of the support being given can break down barriers and embed community support in the standard care given to all patients.

Organisational initiatives

- Use hospice space for community events such as community meetings, and schools visits. The hospice should be seen as a welcoming community space, meaning those not directly involved in the care of dying people begin to pass through the doors.
- Develop a schools network. Peer support networks are effective for both children and staff. In addition to their development, consider training end of life champions within the staff group who can be trained on how to recognise and support children who are undergoing loss and bereavement.
- Support faith organisations in developing compassionate care networks for the dying and the bereaved. Faith groups can be a good source of support in homes and when people are admitted to healthcare institutions and often represent long established and well connected community networks. Providing guidance to faith groups on end of life issues and how they can be part of supportive networks is helpful. A challenge for faith organisations is ensuring that everyone who needs support is offered it. This may mean having policy and practice whereby all those who suffer bereavement are contacted to see if they want support.
- Make links with existing community groups and community centres to help them develop and support caring networks at end of life.
- The hospice should not be the only organisation engaged in the development of supportive networks at the end of life. Lunch clubs, community centres, carer's centres and community development projects in other fields should be brought in to share their expertise when applicable and develop their own responses, with the hospice offering specialist end of life care. Links should be established with the wider non-hospice bereavement voluntary sector, for example Cruse branches, local services such as the Dove Service, St Albans Bereavement Service and local suicide bereavement support. There are also opportunities to work in partnership with other (non-hospice) community based child bereavement services.
  See **www.childhoodbereavementnetwork.org.uk** for directory of organisations supporting children, whatever the cause of death.
- For those hospices that already have community development programmes, help mentor other organisations to become compassionate ones in the businesses and state sector. This can be done by providing guidance on policy for compassionate leave, setting up peer support networks within the organisation, starting conversations about death and dying and creating an informal structure so that staff can support each other.

- Run training programmes to continuously educate the caring networks of community companions, as new learning needs and competencies arise. This includes how to care for people with dementia, self care following a bereavement, moving and washing patients, how to give injections and how to think about advance care planning, depending on the confidence of the volunteers. Policies on safe administration of injections for those relatives, who may wish to do so, are available and may need to be adapted for local use.
- Develop a training programme open to professionals, community members and people who run existing community groups or programmes on network development. This can include how to say yes to support, explanations of the benefits of building a supportive network and advance care planning run by communities.
- Set up a bereavement support group run by people who have been bereaved. For example, this could have a focus on gardening, cooking or walking. After the initial support from the hospice in setting it up, the aim would be to gradually withdraw so the participants take over ownership and it becomes community run.

Fundraising and volunteer services involvement

- Consider how non-clinical teams, such as fundraising, shops and volunteers, can be seen as part of a compassionate communities programme as many people's first contact with hospices is via shops. Staff can be trained to give support, linking with community support groups. Shops are also a good place to provide information about the hospice activities. Fundraisers often visit schools, communities and businesses. Shifting their role slightly and forming partnerships with clinical team's means that these visits can be used to develop understanding about death, dying and bereavement and supportive networks in a variety of settings.

St Joseph's Hospice, London

St Joseph's Hospice is a large London hospice serving a diverse population in East London. It has adopted a community development approach for a number of years and through a range of channels.

One of the early triggers for looking for alternative models of care and support was the recognition that patients using the services within the hospice were not reflective of the demographic of the local population outside the hospice. A change in perspective from looking at those we were serving to those we were not was a first step in adopting a population level or public health approach.

Understanding that we were not community development experts and knowing that good community development projects existed in the local community in fields other than end of life care was a second step. We were lucky to have a

community development in health charity working close to us – Social Action for Health and we developed a partnership to take the work forward over a number of years. A long term view was important as we knew it would take more than one or two projects to change experiences of local people. We also started with small projects first, to understand the local community's interest, capacity and thoughts around death, dying and loss. We hosted some dialogue events with translators. Community leaders who had never been to the hospice could come and ask questions of the senior medical team and do a walk round with senior leaders. They commented on what environmental changes would make it easier for people to come and access our care. This led to small but significant changes such as jugs in the bathrooms for ablution before prayer and adding items to the prayer room. We built on these early projects to develop 'Bridge Builders'. These community members were who trained to take messages into the community about the support available for people at the end of life, how to develop community capacity and access services available.

We also worked hard to share the principles of a public health approach to end of life care with the wider hospice through educational events and attending the public health and palliative care conference series. As a result, many different departments such as physiotherapy, complementary therapies, bereavement and chaplaincy began to interpret the principles from their own perspective. This led to a series of different compassionate communities efforts throughout the hospice.

One of the interpretations has been 'Compassionate Neighbours' – a project which supports local people to be trained to care for those facing issues of death, dying and loss in their local communities. They are specifically called 'neighbours' as they are not taking on a professional volunteer role. They are matched with someone who lives nearby who is struggling due to end of life issues. They visit them at home or go for trips out in the community and aim to go beyond the traditional befriending model of visiting once a week. This supports them to be build new social networks. This is part of a social movement which changes the way local people perceive death, dying, long term care and the hospice locally. We have trained over 120 compassionate neighbours as of May 2016 and have further training running throughout the year. The training has been hugely popular and oversubscribed. We are beginning to see real personal and social change, both for the compassionate neighbours and the people they are visiting and more widely, through the energy which surrounds the project in the community, the local endorsement by GPs, the CCG and others who can see the difference and importance of such participatory work.

Libby Sallnow 2016

Chapter 3
Hospitals

Introduction

Hospitals have an important role to play in the broader context of supporting a compassionate communities programme for end of life care. In addition, ensuring that they are linked with community capacity to support people at end of life is a critical part of the routine discharge process for all patients, particularly the frail and vulnerable.

Patient flow and use of ecomaps

Patient flow is a major concern for hospitals. Increased length of stay as a consequence of lack of community resource results in increasing pressure on the bed availability. Support in the community is a critical factor in the discharge process. This begins at the time of admission. Good practice to improve patient flow is to set the expected date of discharge early on during the admission (Nesta and The Health Foundation 2015). To do this, it is necessary to map supportive social networks. Eco- Mapping, the process of mapping formal and informal social networks, has been used in the field of social care since the mid 1970s (Rempel, Neufeld et al. 2007). A variety of tools are available and in addition, ecomaps can be drawn freehand. After an acute admission, people will need the support of family, friends, neighbours and community to be able to manage at home. Simple pragmatic details will need to be resolved. This includes making sure the house is warm, ensuring that there is food available and assisting with the tasks of living such as cooking, washing, cleaning and shopping. The supportive network needs to be ready to perform these functions if discharge is going to be more patient centred and successful. It can take the supportive network a number of days to be organised and ready to support someone at home. The process of setting an expected date of discharge is dependent on ensuring the support network is available. Therefore network mapping should begin early in the admission. If this begins closer to discharge, the result may be several days' delay. It is therefore important and good practice to begin network mapping early and to set a date of discharge with the agreement of the supportive network.

Many hospitals understand the importance of social networks and have a variety of different ways of accessing support in the community. Hospitals should link together existing initiatives with the development of the routine use of ecomapping. This will mean the best use of community support can be made.

Linkage with commissioners, providers and communities

Most localities now have established end of life care groups which determine local strategy and oversee developments. These are usually led by Clinical Commissioning Groups (CCGs). They are a useful way of coordinating development and strategy for end of life care across organisational boundaries. Hospital representation at these groups is necessary. This guidance document recommends the initiation of community development projects across localities. As these grow, they are likely to find ways of linking with significant community resource to support the frail, elderly and the dying, including babies, children, young people as well as adults. Hospital end of life teams will need to link into these resources as a way of facilitating discharge. In addition, information gathered in hospital may well be useful for these projects. Secure ways of transferring this information will need to be resolved.

Bereavement

Bereavement support is an area that lends itself to community development approaches. The current model of bereavement support is that of a short therapeutic intervention for those suffering a severe bereavement reaction. However, bereavement is a normal reaction to death and loss. Normalising this experience and giving support can be done on a routine basis by setting up opportunities for bereaved people to meet and support each other. Supportive bereavement groups can be set up in hospital with the aim of them becoming peer-led and self supporting in the future. There are also existing peer support networks that can act as a resource, for example WAY (widowed and young) and Survivors of Bereavement by Suicide. These groups should aim to cater for the different needs and preferences that the bereaved may have and can include walking groups, groups who sit and talk, mediation or others. Ideally the groups would be designed with participation of those intended to use them.

Hospitals as compassionate organisations

Hospitals themselves can be turned into supportive communities. Each hospital employs many thousands of staff with relatively stable teams. Employees may spend the bulk of their working lives within a single organisation. Hospitals should become compassionate organisations, developing compassionate policies, setting up informal networks of support at both emotional and practical levels. Dying, death, loss and bereavement occur at all levels irrespective of hierarchies. Support is needed throughout the organisation.

Finally, hospitals often have a large number of volunteers working within them. Their roles can be redefined and extended to include a community companion type role (see Chapter 2 – Hospices) whereby the volunteer provides a social role, supporting the person and their family. If a local hospice or other group has initiated a community companions project, the hospital should link with this and either encourage the community volunteer to visit in the hospital, or offer one of the hospital's own volunteers to take on this role during the admission.

Recommendations

- Hospitals use social mapping as a matter of routine to enable discharge. These eco – maps should be used both for discharge and for teams to enable and encourage families to develop their own networks.
- Link with existing hospital initiatives for supporting people at home using community resource and volunteers. This will involve contacting the Clinical Commissioning Group and local council to see if they are running community development programmes. Local hospices may already have linked with community groups and the hospital should be part of an expanding network of care.
- Link with new and ongoing community development programmes within end of life care and in other fields. This should be done through representation at locality level end of life care groups.
- Support the development of the hospital volunteer role to include a social support role for patients and families. Encourage these volunteers to speak with any community companions who may be visiting the person at home.
- Use of Institute for Healthcare Improvement quality improvement methodology for development and implementation of change within the hospital (Institute of Healthcare Improvement 2015).
- Linkage to existing peer support groups and formation of supportive bereavement groups within the hospital which can continue in the community.
- The hospital should itself become a compassionate organisation, with adoption of compassionate policies for end of life care and formation of supportive networks within the hospital.

Evaluation

Evaluation is a critical part of embedding a community development approach for organisations. Demonstration of change must be part of investment and effort. There are a variety of uses of outcomes of evaluation.

- Provide supportive information for commissioners to demonstrate value for money and improved quality of experience.
- Run a modified VOICES survey of the bereaved for local use, on an annual basis. Use the information gathered to inform service development through the local CCG and through the hospital end of life group.
- Use quality improvement methodology in service development to demonstrate continuous improvement. The outcomes can be made available on the hospital website and should be presented at governance committees.
- Use outcomes of evaluation for hospital board presentations.

- Use daily diaries for feedback from patients and relatives for the final days of life (McEvoy, Pugh et al. 2011). Feed the output from these diaries into ward governance meetings.
- Use hospital complaints about end of life issues as a way of searching for areas of practice that need improvement.

Chapter 4
Primary Care

There is a great potential for members of primary care teams to support or even initiate community development projects. The teams are based in the community and know many of the resources within the community that support individuals and groups. The mind-set of primary care clinicians is often patient and person-centred and there is a long history of community development initiatives in primary care from 1926.

For example, in 1994 a rapid participatory appraisal was carried out by a GP, Health visitor, social worker and an OT in an inner city practice to identify broad health needs in a deprived area, together with community leaders. Lack of transport was identified as a major concern, and a bus was re-routed by the council in response to the community demand (Murray, Tapson et al. 1994). A similar approach seeking to identify community resources to improve the experience of people with serious health problems would be effective (Woolf, Zimmerman et al. 2016).

The main current barrier for this community orientation to develop as we approach 2020 is the lack of time and resource in primary care. Until recently, the percentage of the national health spend in primary care has been decreasing, while primary care doctors and nurses are dealing with more health promotion and chronic illness workloads. The payment structures of general practitioners also favour specific illnesses that can be measured for example diabetes, and increased management control makes it harder for individual practices to innovate in this area.

Palliative care and primary care are not strangers. Primary care and palliative care are specialties that have developed in parallel over the last 50 years and both value a wide ranging approach, continuity of care and caring for family carers as well. They both highlight existential issues and the promotion of resilience in individuals to help them cope and manage their illness. A needs-based public health approach can make both, primary care and palliative care; improve the health of a locality. The new public health approach to end of life care is increasingly being shown to give added value to both these specialties. Primary care is often the first source of support for the bereaved and use of the public health approach can make a significant impact on the morbidity of bereavement.

Recommendations

- Promote a discourse in the practice about death and dying and especially when doing activities such as advance care planning, identifying patients for palliative care and undertaking routine tasks. This can be done by practice staff training in a workshop, and afterwards they support each other to have such conversations with patients, carers and themselves.

- Make a number of resources available for patients, such as from "Good Life Good Death Good Grief" and Dying Matters information. Macmillan has a range of free booklets for the public on advance care planning and bereavement, which include the 10 Top Tips series.
- Organise meetings, either through patient groups or with local community centres to have an occasional death café, where people meet to discuss death, dying and loss. This can take place in a local coffee shop, building or the practice if thought appropriate.
- The practice includes on its website links to other sites, such as Dying Matters, Good Life Good Death Good Grief, Macmillan Cancer Support and the Final Fling. These should appear in prominent parts of the webpage, for example repeat prescribing. Similarly materials could be available electronically or to hand out.
- Work with local colleagues, such as pharmacists and undertakers on how to bring death and dying to patients they meet in their own places of work.
- Form clusters of general practitioners who work together to implement a public health approach to end of life care. In Scotland groups of around 8-10 practices will be used as the denominator for quality improvement initiatives. There are also localities and commissioning groups.
- Include initiatives as locally enhanced services which promote social wellbeing at end of life.
- Individual professionals take opportunities to speak at public meetings such as at the Fringe in Edinburgh.
- General practitioners become involved in on-going initiatives such as Compassionate Cities so there could be a compassionate practice approach taken with general practice integrated with other aspects.
- Link with social prescribing projects run by CCGs.

The Dying Well Community Charter and Pathfinder Project

Using a Charter as a core document can be a useful way to underpin local public health approaches to palliative and end of life care. It provides a vision, and identifies core principles and ways of working around which local organisations and individuals can gather, as well as a means to harness local energy and support.

About the Dying Well Community Charter

The Dying Well Community Charter was published by the National Council for Palliative Care in 2014, and commissioned by Public Health England. It was informed by a number of other Charter initiatives, including "What makes a good

death? A North East Charter" (NHS North East Strategic Health Authority , 2010), the Compassionate City Charter and the Royal College of Nursing and Royal College of General Practitioners' 2011 End of Life Care Patient Charter.

Whereas the Compassionate City Charter provides a list of possible capacity-building initiatives (the "what" to do), the Dying Well Community Charter sets out the principles which underpin the public health approach and in particular of relationship-building with individuals and communities (the "how" to go about it). The two charters can be seen as complementary. Both have at their heart the insight that death and dying do not happen in isolation from the rest of life and emphasise that "care for one another at times of crisis and loss is not simply a task for health and social care services but is everybody's responsibility."

The Pathfinder Project

In addition to developing the Dying Well Community Charter, NCPC was asked by Public Health England to find a number of areas to roll it out, although no funding was made available for localities to support any work they did. An invitation to send expressions of interest was published to which 23 consortia across England responded. 8 pathfinder localities were selected: Lancaster, Cheshire, North Somerset, Dorset, Hackney, Hull & the East Riding of Yorkshire, Birmingham and Liverpool. Each pathfinder consortium is different, most containing a mix of voluntary sector organisations and statutory bodies, although the make-up and leadership varies.

Launch events were held in each pathfinder locality during 2015, to raise awareness of the initiative and to enable local leaders and potential partners to be invited, informed, and discuss how to develop and progress local initiatives. Since the launches, pathfinders have been involved in capacity building projects. The initial work is being evaluated, and results will be published in 2016.

The language of "pathfinders" was chosen deliberately because this was the first time that public health initiatives in palliative care had been tried at national scale in England. Learning about what didn't work, or what paths led to difficult or insurmountable terrain, was as important as discovering what worked well. Early insights included that having a launch event and being part of a national initiative helped attract buy-in and support from local leadership. In addition, whilst there is considerable interest and support in principle for this work amongst health and care staff, practical knowledge about how to work with communities to build resilience and capacity is required.

Simon Chapman 2016

Chapter 5

Clinical commissioning groups and local authorities

Introduction

Public Health approaches form an important arm of the overall progress being made in end of life care. The first years of the National End of Life Care Strategy in 2008 focused on changes to the care pathway, with early recognition of terminal illness, advance care planning, better coordination of care and care in the last days of life. Despite the advances that have been made, less than a quarter of people in the United Kingdom die at home (National End of Life Care Intelligence Network). Professional care services in the community are stretched and availability of staff is problematic. If we are to build on what we have achieved, enhancing community capacity to allow people to remain in their place of choice concerning their care is a fundamental component. The way in which this is done is condensed into the Compassionate City Charter (Kellehear 2015). Through a process of community engagement, development, public education and health promotion, communities can become more able to look after patients and their caring networks.

Participatory development and communities (coproduction)

Communities are not just those that live in neighbourhoods. Death, dying and loss are part of all of our lives and is therefore everyone's responsibility. Communities occur wherever there are people, which is everywhere. This means that interventions, engagement and development need to take place everywhere. This is true in the workplace, in educational institutions, in clubs, in churches, temples and mosques as well as in neighbourhoods. The type of development that is needed cannot be found using a formula. Rather, the people who give and receive help need to be the people who decide what kind of help is needed. This uses the methodology of participatory development, aiming to enable communities to be self-reliant. Traditional commissioning tends to think of service delivery models, where a professional service will deliver care. Using participatory methods, professional support works as a form of catalyst. Groups, whether in the workplace or community setting, are built to be self supporting in the longer term without the reliance of professional support. Community development workers are experienced in using this methodology. The aim is to have a short term intervention with long term sustainability.

Most councils and CCGs have familiarity with community development but not usually in end of life care. A central issue for them both is how to draw together what already exists, how to link initiatives and how to set a strategy for public health approaches to end of life care that will be sustainable in the long term.

Social isolation and loss

More recently, many local authorities and CCGs have recognised the importance of the impact of social isolation and loss. They have initiated community development projects that seek to address this problem by providing community support and connecting people who are isolated with those around them. As part of their authorisation CCGs have to provide evidence that they are working with the voluntary sector. A number of CCGs have started social prescribing schemes, in which the needs of the frail and vulnerable are recognised as being beyond disease management. If such schemes are in place, they can be linked with end of life care initiatives. Some of these projects have been supported by the charitable sector and by government funding such as the Cabinet Office Centre for Social Action. This latter initiative has funded 215 projects in a variety of settings, with grant funding of £36 million. Linking with existing community development projects is likely to increase the chance of success, as the infrastructure and mapping of community resource will have already taken place. Adding in end of life care, community development is a relatively small addition to what may be extensive work.

Reduction in cost

A dominating influence on commissioning and delivery of service is ensuring value for money. Service delivery models, in which need is met by professional services, are generally higher in cost with limited output. By and large, need outstrips financial resources by significant amounts, particularly with the chronically ill and frail elderly.

A significant challenge for professional health and social care services is how to work with community resource, seeing it as the bedrock of care rather than seeing it as a threat. Research evidence described in the later chapter Research Evidence and Quality Improvement demonstrates the positive impact of doing this well, as opposed to unintended harm when communities are viewed with suspicion. Evidence of the cost effectiveness of community development approaches is emerging across a range of sectors, notwithstanding the complexities involved in its measurement. A recent joint report by Nesta and the Health Foundation on the value of community based approaches (Nesta and The Health Foundation 2015) concluded that these approaches are important in contributing to the sustainability of the NHS. Further studies found that when communities are involved in care for those with long term conditions, their informal care substitutes for formal health care, leading to substantial cost savings (Reeves, Blickem et al. 2014). Evidence from other healthcare areas has demonstrated that when a community engagement approach is used, hospitalisation rates are decreased and care can be managed in a community setting. Although community development approaches require investment of time, money and expertise, evidence suggests that this is more than recouped when outcomes are measured (Fisher 2011).

Mortality and morbidity from bereavement is significant (Stephen, Macduff et al. 2015) with associated cost implications. When making the case for investing in community development, it is important to remember not just prevention of hospital admission for those with chronic illness, but also those who suffer serious effects of bereavement.

Somerset Clinical Commissioning Group Compassionate Community Project

Compassionate communities publicly encourage, facilitate, support and celebrate care for one another during life's most testing moments and experiences, especially those pertaining to life-threatening and life-limiting illness; chronic disability; frailty; ageing and dementia; grief and bereavement, and the trials and burdens of long term care.

Though local government strives to maintain and strengthen quality services for the most fragile and vulnerable, those persons are not the limits of our experience of fragility and vulnerability. Serious personal crises of illness, dying, death and loss may visit any us, at any time during the normal course our lives. A compassionate community is a community that recognises and addresses this.

Somerset Clinical Commissioning Group, (SCCG), hosts the Somerset end of life and palliative care programme group, with wide ranging representation including from the CCG, 3 hospices, 3 acute trusts, the community trust, the out of hours service and ambulance service. The programme group made a commitment in July 2015 to work towards Somerset becoming a Compassionate Community.

The steps taken towards this goal since then have been:

- The Director of Patient Services at Weston Hospice presented the work done in Weston in this area, and shared the Weston Compassionate Community Charter.
- Somerset CCG has committed to become a Compassionate Organisation, and a supportive network has been developed in 1 of the 3 directorates, and is now being rolled out to the rest of the organisation, with full senior support at Board level. The CCG's experience will be shared with other member organisations of the programme group, with the aim that they too will adopt compassionate policies and networks.
- 2 areas of Somerset have been identified as being suitable to start compassionate community work – in Frome and then Axbridge & Wedmore.
- Work has started in Frome using a community development approach for end of life care. There is an existing Health Connections network in Frome, developed by Frome Medical Practice, which has a list size of over 25,000 patients. A critically decisive issue for implementation is the use of quality improvement methodology, and a key issue is the ability to source accurate data. This is being supported by the National End of Life Intelligence Network.
- The work in Frome will include identification of people likely to die in the next year; offering community led advance care planning and network development

skills; provision of training in manual handling and the intention is to develop a policy supporting administering sub-cutaneous injections by lay carers. The main emphasis is the development of supportive networks around the person who needs help.

- The success of the Frome project is dependent on approaching a 50% home death rate by 2018.
- There will then be a gradual roll out, of 2 localities at a time, dependent on the outcome of the initial phase, with the aim of all 9 localities in Somerset being involved by 2026.

Dr Chris Absolon, Lead for end of life care, Somerset CCG

Recommendations

Set ambitions

- Link with existing community development projects within the locality and look to add in an end of life care stream.
- Set up a Compassionate City and Community Charter steering group, with the ambition to become a compassionate city, county or region. This group should be as broad a coalition as possible, including community leaders, faith groups, voluntary and community sector organisations, local businesses, educational institutions as well as the mayor's office, local council and health services.
- Through use of intelligence data, through sources such as the National End of Life Care Intelligence Network, set an ambition such as diminishing the inequity of home death rates for people with cancer diagnoses compared to those with other conditions. For example, England average for home death rates for people with cancer is 30% and respiratory disease is 64% (National End of Life Care Intelligence Network). Aim for equity of care over a 10 year period. Working out actual numbers is possible.
- Set a programme of public health approaches which uses Institute of Healthcare Improvement methodology for change management, tracking changes against ambitions over time. Link with Academic Health Science Networks that have expertise in quality improvement methodology. Using community development workers, look to mentor teams regularly so that they develop the knowledge and practical skills of improvement methodology.
- A part of improvement projects, use process and outcome measures to track changes as they occur.
- Consider widespread implementation built on the success of existing projects, with evidence from one site used to build enthusiasm in new sites.

Link to broader initiatives across the geographic region

- Encourage Health and Wellbeing Boards to participate in transforming the region into a compassionate community, adopting the principles of the Compassionate City Charter.
- Link to existing community development programmes expertise, such as maternal breast feeding programmes, healthy eating initiatives, mental health community development and frail elderly volunteer community support.

Build specific initiatives contained in the Compassionate City Charter

- Develop a roll out programme of increasing sectors such as schools, universities, businesses and community groups.
- Use expertise of specialist palliative care workforce as an educational resource.
- Consider using GP federations and GP practices as geographical bases for development.
- Foster relationships and links between professional services and community resource.

Evaluation

Set specific goals with a timeframe, for example 50% home death rate within 10 years. Choose this as the main outcome measure.

Outcome measures

- Percentage desired home death rate within 10 years.
- Qualitative measures of improved experience.
- Modified Voices surveys of bereaved people used sequentially can provide this information.

Secondary Drivers-Process measure(s)

- Number of groups who support end of life care.
- Number of different sectors covered.
- Place of death of people supported.
- Health care usage – primary and secondary care, including costs.
- Sustainability of models without the necessity of long term funding.
- Use of personal health budgets.

Chapter 6
Health and wellbeing boards

Strategic role of health and wellbeing boards

Health and Wellbeing boards (HWBs) were established in 2013 to enable local authorities, CCGs and other key leaders in the local health and social care systems. The aim was for these organisations to work together to improve the health and wellbeing of their local population, to promote the integration of services, and to reduce health inequalities. They have strategic influence over commissioning decisions across health, public health and social care. Formally, HWBs are a statutory committee of each of the 152 upper-tier local authorities in England; membership is determined locally.

HWBs are required to complete a Joint Strategic Needs Assessment (JSNA) – a comprehensive assessment of current and future needs of the local population relevant to health, social care and public health across the full life course from maternity to end of life, covering children, young people and adults. JSNAs provide a foundation for the production of a joint health and wellbeing strategy (JHWS) – a strategy to shape and support the decisions of local service leaders and commissioners to inform service planning across health, social care and public health.

HWBs use JSNAs and JHWSs to set and measure outcomes for the local community; but they will also be able to align these local priorities with the National Outcomes Frameworks for the NHS, public health and adult social care. They have the freedom to cover a wide range of subjects in their strategy or to focus on a small number of key local priorities, which may or may not include end of life care.

Membership of HWBs, meeting details and other relevant information should be available through local authority websites. The King's Fund has produced a map with details and contact information for HWBs (Kings Fund 2016).

HWBs do not exist in isolation but are part of wider local authority and healthcare structures. These include the local groups overseeing the use of the Better Care Fund, Sustainability Transformation Plans, and other NHS initiatives such as Vanguards, Right Care Models and service specific planning groups and patient/public participation networks. Many plans will come from these groups to be incorporated into the wider strategy by HWBs.

Actions for health and wellbeing boards and stakeholders

Recommendations

Whether a member of a HWB or a stakeholder seeking to influence local action, consider some or all of the following:

- Understand how the local system and the roles and membership of the various groups feeding into the HWB, as well as the HWB.
- Get involved in relevant groups so that the needs of people at end of life care are being picked up in key service groups as well as in any end of life care planning group. Ensure that all ages (children and adults) are included in this exercise.
- Remember to ensure that bereavement is seen as part of the spectrum of end of life care.
- Play a leadership role: in identifying local data about needs and services, in flagging up and promoting key national initiatives, including the Ambitions Framework (National Palliative and End of Life Care Partnership, 2015) which will build the case for the charter.
- Identify which other HWB members and lead officers might be interested in supporting end of life care priorities and the charter, and seek their advice on how best to promote the charter principles locally.
- Build alliances: in many areas the voluntary sector will have structures to bring together local advocacy and service delivery groups to input into strategy engagement. They may be interested in supporting community engagement to address issues common issues such as social isolation. Similarly engage with the patient voice – through Healthwatch, patient participation groups and local voluntary and community groups.
- Work with local government to prioritise end of life care and set up a programme for the implementation of the Compassionate Community Charter. HWBs have a central role to play in drawing relevant parties together and supporting regional initiatives.

Cheshire Living Well, Dying Well

Cheshire Living Well, Dying Well (CLWDW) is the public facing brand for The End of Life Partnership, a charitable collaborative in Cheshire aiming to transform End of Life Experience and Care. Stakeholders include four Cheshire CCGs, two local authorities (Cheshire East and Cheshire West), three hospices, three hospital trusts, the University of Chester, Carers Trust For All and Macmillan Cancer Support.

The dedicated Cheshire Living Well, Dying Well Partnership also enables community voices to be heard with membership from a variety of health and social care organisations, housing organisations, local businesses, Cheshire Police, Cheshire Fire and Rescue Service, church and faith groups and various community and voluntary organisations and groups. Further information can be found at **www.cheshirelivingwelldyingwell.org.uk**

The Public Health and Wellbeing Team within the organisation, alongside CLWDW Partnership representatives and community champions are leading and involved in a range of projects to enable people to live, age, grieve and die well. This includes the following:

- Delivery of wide-ranging Public and Community Public Health & Wellbeing Projects and Skills Workshops to increase community capacity, resilience and future life planning.
- Delivery of training to enable people who work with the public to engage and empower service users and the wider community to think about, talk about and take action in relation to life, age, death and loss.
- Targeted support training for health and social care staff.
- Bespoke resource development.
- Community-led and developed workshops/awareness-raising initiatives.
- Consultation and focus groups.
- Knowledge Exchange.
- Development of 'CLWDW Compassionate Community Volunteer Models'.
- Adding to the understanding as to what influences knowledge, attitude and behaviour change and impact upon wellbeing re: ageing and end of life issues.

Example One: Working with University of Chester and Chester Students Union Staff and Students

A recent example of a project includes working with the staff and students at the University of Chester and Chester Students Union to increase confidence and practical skills. This has incorporated personal development (i.e. enabling attendees to explore their levels of comfort with discussing life, age, death and loss and to engage in future life planning activity); Brief Intervention (i.e. enabling attendees to feel confident and competent to support clients/ service users/ peers and signpost to additional support); Bereavement and grief training (i.e. enabling attendees to feel confident and competent to listen and signpost). Further training and opportunities to enable peer support networks are currently being explored and planned.

Example Two: Working with Library Service Users and Staff

A second example is a project working in library settings. The team are working with members of the public to support and increase knowledge, understanding and practical skills of supporting others, carer resilience and the use of arts and crafts to support and engage with others. They are also working with Library Services Staff to enable them to feel more confident and competent when engaging with service users in terms of living, ageing, grieving and dying well.

Example Three: CLWDW Ambassador/ Champion Programme

CLWDW Ambassadors are individuals, who are trained and supported to engage, inspire and empower people in their communities to think about, talk about and take action in relation to life, age, death and loss.

CLWDW Ambassadors and Champions have a commitment to the purpose of the Cheshire Living Well, Dying Well Partnership and have the motivation to do something practical to support the health and wellbeing of their family, friends, community or workplace. No pledge action is too small. No qualifications are necessary.

Rachel Zammit
Head of Public Health and Wellbeing
The End of Life Partnership
May 2016

Chapter 7

Evidence, research and quality improvement

There is increasing evidence on the positive impact of community develop across a range of settings. This is the case in general as well as in end of life, even in the context of the difficulties of gathering evidence.

A series of large randomised controlled trials, meta-analyses and systematic reviews examining social networks or community development approaches in general have concluded that there is strong evidence that these approaches improve a range of outcomes. These include mental and physical wellbeing, substantially reduced use of formal health services (Reeves, Blickem et al. 2014) self-efficacy, health behaviour and perceived social support (O'Mara-Eves, Brunton et al. 2013) reduced mortality in line with smoking cessation or other known significant risk factors (Smith, Holt-Lunstad et al. 2010) and a contribution to NHS sustainability. There are wider impacts on social outcomes such as school attendance, employment and volunteering rates (Nesta and The Health Foundation 2015). Substantial evidence also exists to support the benefits of volunteering and pro social behaviours on volunteers and communities (Borgonovi 2008, Woolf, Zimmerman et al. 2016).

Although the field of community development and end of life care is relatively new, there are still a number of papers demonstrating the impact of this work and a number of large trials currently underway. A systematic review of the evidence relating to community action in end of life care found a range of papers demonstrating improved outcomes for carers such as decreased social isolation and fatigue, improved social support, size of caring networks and confidence in asking for assistance (Sallnow, Richardson et al. 2015). Larger social networks including friends were associated with increased likelihood of a home death and were predictive of an increased likelihood of palliative care involvement. Papers also described the 'ripple effect' whereby those engaged in community work at the end of life took knowledge and skills they learnt into end of life care. This included undertaking advance care planning or lobbying for social change, facilitating wider spread of these messages into the community. In addition, there is extensive evidence of the impact of peer support networks in a variety of settings on improved outcomes in bereavement, from childhood death to suicide (Metel and Barnes 2011, Dopp and Cain 2012).

Undertaking research or evaluation

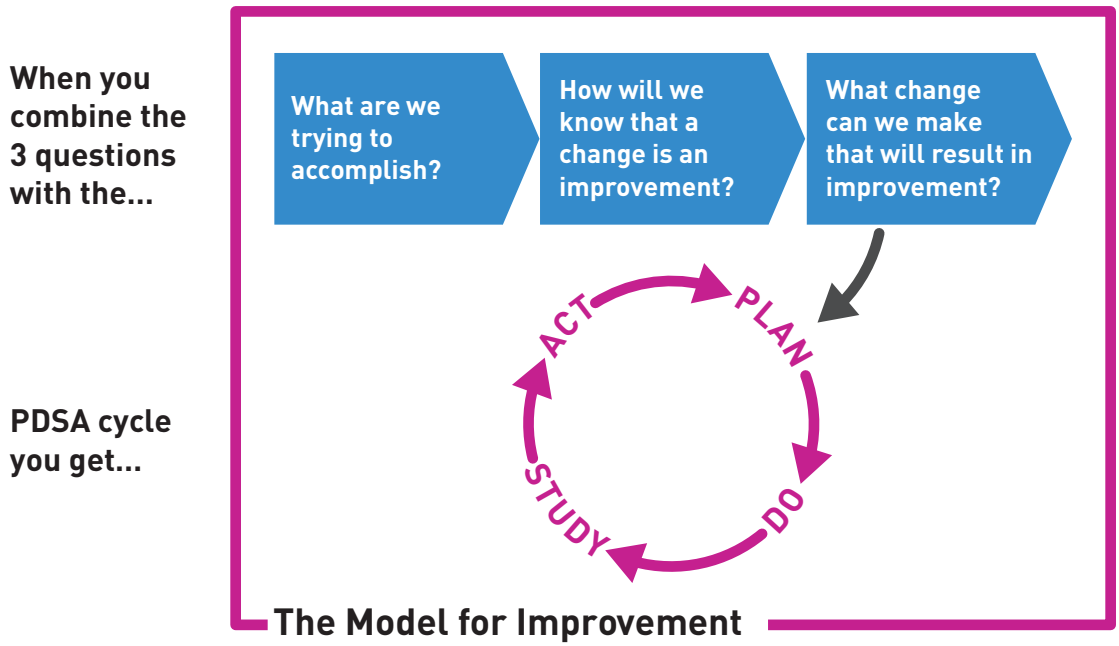
Although evidence is emerging of the value of these approaches, the evidence is still limited and it is essential that new projects attempt to capture the impact they are having. This does not necessarily have to be as part of a large research study but could be an audit or a service evaluation. Key variables or outcomes such as health service use can be captured by using GP records or asking people to keep a diary. The time

before a project starts can be compared to the time after (See Cronin 2015 for an example of this). Many survey tools exist to capture and measure social support, loneliness, quality of life, social capital and death literacy A tool could be included in the routine assessment and repeated again after a certain time interval to explore the impact it was having. Similarly, using exploratory methods rather than quantitative ones can lead to important insights. Conducting interviews or holding focus groups to explore what these approaches mean to the people involved and hearing the impact in their own words can be very powerful, revealing impacts not anticipated when planning the project. Similarly, starting such a project requires buy-in and on-going work and reflection by those in the organisation, which in turn can lead to an action research project. This looks at the process of change as the research focus and builds a 'community of practice' within the organisation which embeds the change.

Although service evaluations and audits do not usually require ethical approval and are therefore often faster to get started, applying for ethical approval means being able to publish and share work more widely. This can contribute to the growing evidence base and help to support the field. Advice on how to start a research project can be gained from local Research and Development leads. Alternatively the most valuable way can often be to approach a local university and collaborate with junior researchers undertaking masters, PhD students and senior researchers there.

Figure 1 Quality improvement methodology – demonstrating a difference

A model for learning and change



From Institute of Healthcare Improvement

Demonstrating change and assessing impact is important not only because we need to show that a change is an improvement, but because the evidence is vital in showing that the new model of care is an improvement on the old. Scientific evaluation is seen as the gold standard way of doing this. However, using this as the primary methodology demonstrating the value of change can be problematic. When providing evidence from clinical trials, a scientific study has to be designed, funding sought, and a change has to take place. This then needs writing up and publication once the study has been completed. This whole process may take a number of years, sometimes more than 10, in order to demonstrate value. In the longer term, scientific validation is essential. In the meantime, the methodology of change management that has come out of the Institute of Healthcare Improvement (IHI) is being widely adopted across the NHS as the preferred model for change.

It is necessary to be clear about how change can be an improvement. There are many examples of change in the NHS which have not been evidence based and where the change has resulted in less safe care of lower quality. For any change, there are 3 questions must be answered. These are

1. What are we trying to accomplish?
2. How will we know that a change is an improvement?
3. What change can we make that will result in improvement?

Put very simply, it is essential to demonstrate that a change is an improvement if it is to be adopted. IHI methodology is a straight forward and systematic way of managing change. It goes from starting to identify problems, developing clarity about how these problems might be addressed, using systematic thinking to identify the individual components of complex problems and then using testing cycles to demonstrate how change is continuous improvement. Measurement for improvement is a key principle. Methods for doing this are different from both audit and research. Having established a baseline, just enough relevant data is collected. Theories of change are developed and tested in a series of rapid cycles. After each cycle, review of the change is evaluated and a process of adopting successful change, adapting partially successful change and retesting and abandoning what did not work takes place. At the same time, predictions are made as to what may go wrong and data is collected to see whether this has happened. This single method alone would help to transform the NHS. The most common outcome of adopting new practice is that any new paperwork developed is burdensome and cuts down on direct patient contact. Completing paperwork can take 70% of ward nurses time. If administrative burden worsen, it is unlikely that change will be successful and adopted.

Demonstration of continuous improvement is a foundation principle of change. Use of run charts is a clear way of demonstrating this change. The charts can be annotated to show where interventions took place and the impact of these interventions can then be seen. Cycles of plan, do, study, and act are used. Once there are clear ideas about what changes need to take place and what measurement tools are going to be used, a

change is tested. The plan for this change is made, the change takes place, the impact of the change is assessed and then the cycle is repeated.

An important component of change management is to build highly reliable systems. This methodology was born out of industry where safety requirements are highly prioritised. Examples are the aviation and oil industries. In the context of healthcare, it is equally important to have highly reliable systems that produce the desired outcome 99 times out of a hundred. This is often poorly understood or neglected. For example, treating sepsis with intravenous antibiotics within an hour of diagnosis saves lives. Each hour of delay results in increased mortality. Resolving issues of complexity are therefore essential. This means swift diagnosis using the sepsis care bundle, good prescribing, availability of intravenous antibiotics in the emergency department and built in safety checks to make sure that the antibiotics are actually administered after they have been prescribed. The people who administer the care therefore need to be the people who design the change on the ground, take ownership of the change and develop the theories applicable to local circumstances.

These same principles should be followed when considering community development in end of life care in healthcare institutions. For example, use of expected date of discharge in acute hospitals needs to be made reliable by a continuous pattern of improvement. When this is done, length of stay is reduced. Commonly, implementation of expected date of discharge is done as part of a larger bundle of changes. It is poorly used and becomes ineffective as a way of improving patient care.

These principles can be applied broadly for the changes recommended in this document. NHS institutions are setting up infrastructure to support the widespread use of quality improvement methodology. Most hospitals already have projects up and running. Academic Health Science Networks are being used as a source of expertise to assist the NHS in developing and running projects. This is true for both primary and secondary care.

Recommendations

- Change management should be done through using IHI quality improvement methodology.
- Links with bodies such as The Health Foundation that have the necessary expertise to support this is advised.
- Link with Academic Health Science Networks, which are part of the NHS infrastructure providing expertise.
- Resources for improvement are widely available, such as at the IHI website, NHS Improvement, Academic Health Science Networks, Royal Colleges.

Resources

- An Overview of Compassionate Communities in England **www.compassionatecommunities.org.uk/files/PDF/CC_Report_Final_July_2013-2.pdf**
- Childhood Bereavement Network **www.childhoodbereavementnetwork.org.uk**
- Compassionate Employers **compassionateemployers.org.uk**
- Dying Matters. Available from **www.dyingmatters.org**
- Find Me Help **findmehelp.org.uk**
- Final Fling **www.finalfling.com**
- Good Life, Good Death, Good Grief **www.goodlifedeathgrief.org.uk**
- Institute for Healthcare Improvement (2015). IHI website 2015 Available from: **www.ihi.org/Pages/default.aspx**.
- Macmillan Cancer Support **www.macmillan.org.uk**
- National Council for Palliative Care Dying Well Community Charter **www.ncpc.org.uk/communitycharter**
- Public Health Palliative Care International **www.phpci.info**
- Social Action for Health **www.safh.org.uk**
- Toolkit for public health approaches to end of life care **www.ncpc.org.uk/sites/default/files/Public_Health_Approaches_To_End_of_Life_Care_Toolkit_WEB.pdf**

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Acknowledgements

This guidance has been written with the support, advice and review of many people. Our thanks go to Claire Henry and Simon Chapman at the National Council for Palliative Care, whose comments and support have been invaluable. Thanks also to Hospice UK, who have supported the formation of the guidance from the outset. Colleagues who form the board of Public Health Palliative Care UK have lent their support, with many providing helpful comments. Professor Scott Murray kindly agreed to write the chapter on primary care and Michael Kerin on Health and Well Being Boards. We thank them for doing so.

Professor Bee Wee kindly circulated the draft guidance to the National Palliative and End of Life Care Alliance. We received many comments from a variety of sources. All of these together turned our original draft into a much improved document. Our thanks go to the organisations who agreed to endorse the guidance. Macmillan in particular gave very helpful editorial support.

Professor Allan Kellehear kindly gave us the permission to use the Compassionate City Charter, under the auspices of Public Health Palliative Care International.

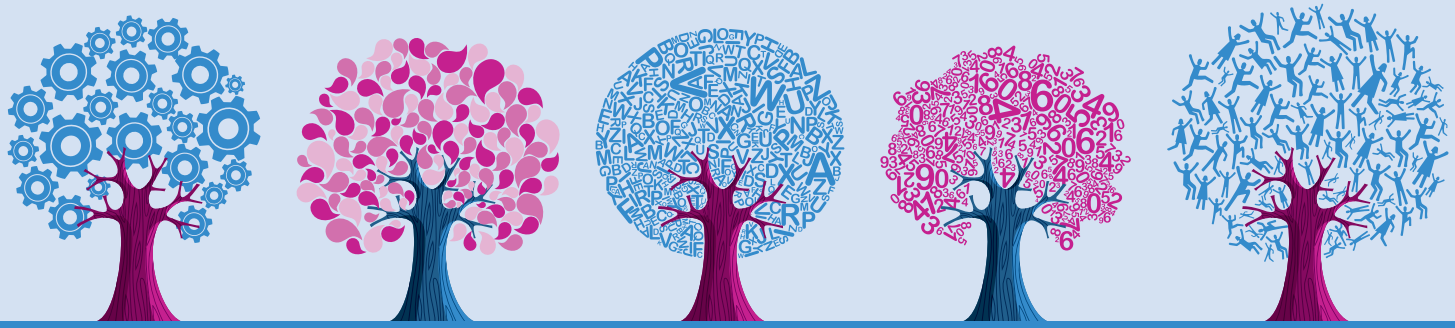
Finally, thanks are given to Professor Bee Wee, Professor Julia Verne and Claire Henry for agreeing to write the foreword to the guidance.

Julian Abel and Libby Sallnow 2016

Notes

This guidance is also supported by the following organisations:

Association for Palliative Medicine
Of Great Britain and Ireland



This document is published by
The National Council for Palliative Care

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ISBN 978-1-910286-10-4