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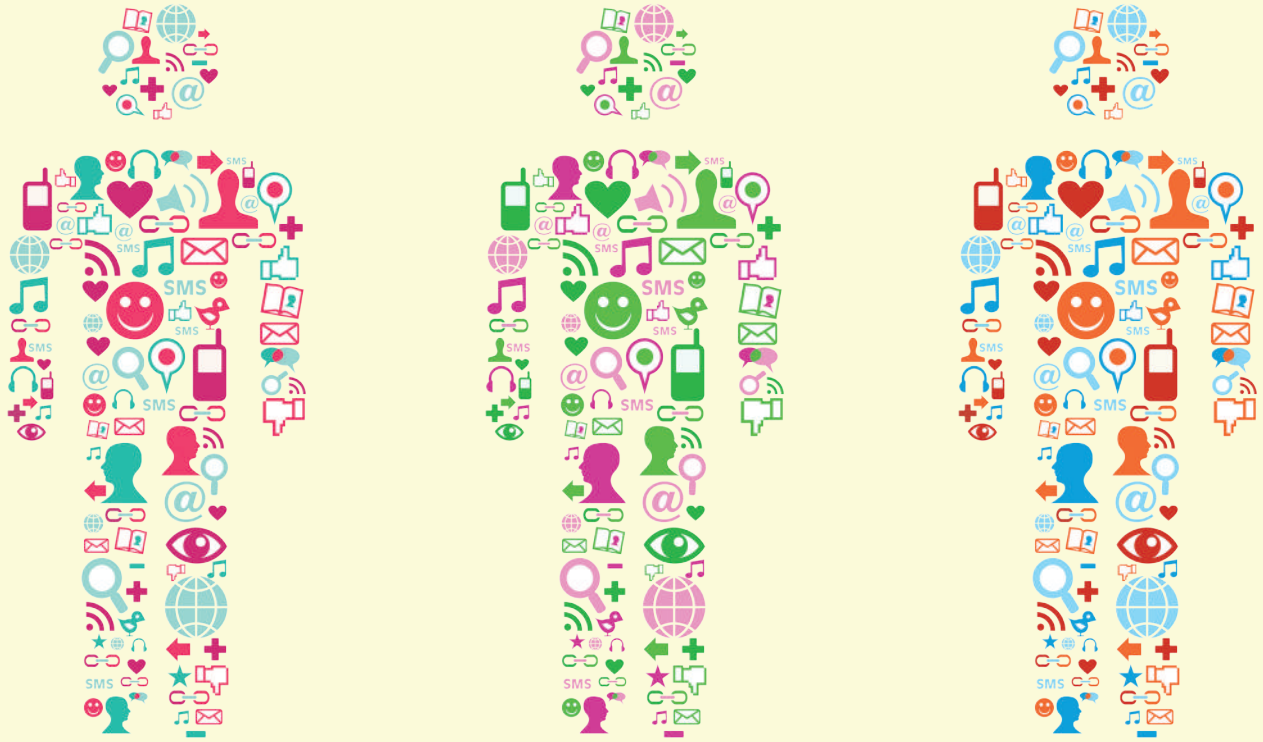

Public Health Approaches to End of Life Care

A Toolkit

Public Health England

THE NATIONAL COUNCIL FOR PALLIATIVE CARE

About The National Council for Palliative Care (NCPC)

The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. We believe that everyone approaching the end of life has the right to the highest quality care and support, wherever they live, and whatever their condition. We work with government, health and social care staff and people with personal experience to improve end of life care for all.

The NCPC is a registered charity number 1005671 and a company limited by guarantee number 2644430. Visit www.ncpc.org.uk for more information.

About Dying Matters:

Dying Matters is a national coalition led by the NCPC which aims to support changing knowledge, attitudes and behaviours towards dying, death and bereavement, and through this to make 'living and dying well' the norm.

The Dying Matters Coalition, which has over 30,000 members, is working to address this by encouraging people to talk about their wishes towards the end of their lives, including how they would like to be cared for, where they want to die and their funeral plans, with friends, family and loved ones.

Membership is free and will enable you to access a wide range of resources to help you talk about dying, death and bereavement. To find out more, or to join, visit: www.dyingmatters.org

About Public Health England

This Toolkit was commissioned and supported in its development by Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing and reduce health inequalities. It does this through advocacy, partnerships, world-class science, knowledge and intelligence, and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health.

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The public health approach to end-of-life care is concerned with social efforts led by a coalition of initiatives from governments, their state institutions, and communities, often in partnerships with health and other social care organisations, to improve health in the face of life-threatening/limiting illnesses, caregiving and bereavement.

These efforts occur through public education, improvement of social capital (trust, empathy and cooperation) and community development, enactment of laws, partnerships with health services and their professionals, and the creation of safe and sustainable social and physical environments.

Compassionate communities represent a major form of community development efforts that aims to accommodate death, dying, loss and care into our public health ideas, and to create supportive environments for those experiences.

Educational institutions, workplaces, faith organisations, trade unions and other social organisations and settings reflect upon their own end-of-life care experiences in order to develop their own local policies and responses to these experiences.

Compassionate communities can be outcomes of multiple processes, negotiations and partnerships, but mainly involve community practice efforts initiated by healthcare services, sometimes enacted by governments but implemented and decided upon by communities themselves.

Compassionate communities involve policies created by communities themselves in order to actively involve citizens in their own end-of-life care concerns. In doing so they change social environments, cultures, conduct, and attitudes towards end-of-life experiences and care.

It is imperative for public health to include end-of-life care because:

1. A public health approach to end-of-life care expands the reach and effectiveness of end-of-life care services by engaging communities.

2. It can address a greater range of needs including social, psychological and spiritual needs, and do so more comprehensively.

3. It can raise awareness about death, dying, loss and care.

4. It can enlist communities in caring for their own at the end of life.

5. In a population health sense, a public health approach is incomplete without provision of care for those experiencing serious illness, ageing and frailty, long-term care, and loss and bereavement.

6. Heart disease, cancer, HIV, and ageing - the major concerns of public health policy - also present major end-of-life care challenges that have wider public health impacts beyond our clinical attempts to address them.

7. Because end of life experiences often take place within community contexts these are also logically the best sites where they can be effectively cared for.

8. The needs and wellbeing of dying, caring, and bereaved people are best met within a wider public health/community focussed approach to end-of-life care because many of the social morbidities associated with the end of life are amenable to traditional public health methods - health promotion, public education, or community development.

9. Social supports that result from increase of social capital (trust, empathy, cooperation) benefit experiences of death, dying, loss and caregiving because they counteract serious psychological and social morbidities, such as depression, anxiety, or loneliness, many of which can be traced to experiences of social isolation, neglect, or stigma.

How to use this toolkit

This toolkit has been written for everyone who is interested in extending end-of-life care to community settings and developing public health responses to death, dying and loss. Public health end-of-life care has promising potential in today's increasingly diverse communities that need to adapt their responses and be flexible in order to meet unique and highly individualised needs.

A compassionate approach to end-of-life care guarantees sustainable responses and networks of care that adapt and are flexible, depending upon need and demand.

In compassionate communities citizens are encouraged to be knowledgeable and informed about death, dying, loss and care and adapt their practices and behaviour to meet needs that they encounter in their everyday lives. Services and local authorities play a significant role in providing and sustaining quality end-of-life care, but people from all walks of life should be involved in designing suitable end-of-life care policies that meet their needs.

This toolkit provides introductory information on the origins and development of modern end-of-life care, and explains how we can differentiate a service-oriented approach from a broader public health approach to death, dying, loss and care. It then proceeds to describe the development of this broader public health approach.

We clarify the difference between service efforts to extend their services to community settings and an organised community response to end-of-life care issues and concerns. Communities with a public health approach to end-of-life care organise in ways in which the responsibility of care for experiences of death, dying and loss is shared between community members.

Institutions and services design end-of-life care polices and practices that reinforce a compassionate attitude in times of death, dying and loss. Examples are used to contextualise descriptions and exercises invite reflection upon processes and actions that could be taken into consideration when developing a community approach to end-of-life care.

This toolkit is best studied over an extended period of time to allow comprehension of the finer theoretical and practice differences within the public health canon, and to make time for reflection on how these differences might impact upon subsequent practice in end-of-life care. Because we are recommending an alternative way of viewing and practicing end-of-life care this will often involve reconsideration of established practices.

This is a process that may require substantial reflection. The purpose of creating a toolkit for public health end-of-life care is that many of the traditional processes and practices of the public health approach are clarified in the newer process of applying and translating these across to the field of end-of-life care.

Finally, it must be noted that this toolkit is not intended to provide a step-by–step guide on how to design and implement a public health approach to end-of-life care. This is a multi-faceted process that cannot be described within a toolkit that intends to introduce the approach.

The nature of community end-of-life care itself is inherently variable and diverse as it depends upon contextual circumstances and needs. For this reason, we concentrated upon providing an outline of the origins, principles and methods of Compassionate Cities as the most comprehensive theoretical and practical framework of public health end-of-life care.

Where appropriate we describe methods of community development and employ relevant examples to indicate how theory and methods apply in practice.

In the future, communities with experience in this area may wish to share their experiences and contribute towards designing a toolkit that outlines stages and processes of designing and implementing a public health approach to end-of-life care. Such a guide, however, can only be used as a heuristic device as each community is unique.

Executive Summary

This toolkit is designed to inform the reader about the public health approach to end of life care. It begins by describing the historical rise of the conflated understanding of 'end of life care' with 'end of life care *service provision*'. This equating of 'care' with 'health services' is neither historically true nor reflected in wider health policies and practices in areas outside of end of life care.

At the core of major public health efforts in all the major health and medical fields is a blended approach of direct service provision, community participation, and individual responsibility. Both community participation and individual responsibility are at the heart of major efforts in prevention, harm reduction and early intervention.

The methods underpinning these efforts are community development and engagement, health promotion and education, changes to the social and policy environment, social marketing, and the primacy of participatory relations. These methods are largely new to end of life care.

Furthermore, end of life care has a commonly narrow health services meaning referring mainly to palliative care and not to other areas also responsible for care of the dying and the bereaved - intensive care, trauma care, care of older people, bereavement care, or disaster management.

The ability of any of these services to provide quality care and continuity of care before, during, and after dying, death, and loss is limited, and mainly limited to short periods before and after death.

The more protracted part of care at the end of life heavily depends on the far longer periods of time spent outside of professional contact – with family, friends, co-workers, contact with social media, public spaces, and other major sectors of social connection such as faith groups, clubs, schools, or workplaces.

Just as the promotion and maintenance of health and wellbeing is everyone's responsibility so too is our health and wellbeing at the end of life. In this way, everyone has a role to play, however small, in end of life care in their community.

The toolkit describes the policy and practice similarities between Healthy Cities approaches to health care and Compassionate Cities approaches to end of life care. The differences and similarities in meanings between community-based health services, community engagement, and community development are explained.

Practice examples of these three approaches are described. Raising awareness about death, dying, loss and care, developing new policies about them, and changing practices towards them are discussed in relation to the use of volunteers but also the participation of major social institutions within a community – schools, workplaces, faith groups, media, and sites such as high streets or museums and galleries.

Significant discussion is devoted to emphasizing the participatory and autonomous nature of community development as the ideal method for public health approaches to end of life care. This is because community development approaches have distinct advantages over traditional health service ways of working.

Community development requires styles of partnership working that are inclusive, accommodating, and leadership-promoting of all people including populations with protected characteristics (by law*) such as different religious or racial groups, older people, people living with disabilities or diverse sexual orientations.

The toolkit ends with suggestions for evaluation of public health programmes in end of life care, a list of text and web-based resources, and a Charter for Compassionate Cities that can be used by services to engage local government and other social sectors of the community.

The Compassionate Cities Charter, when used with the Dying Well Charter, creates a social care approach inclusive of families and communities that also complements the efforts of all health services in the end of life care field. Only through this inclusive policy and practice approach can we adequately address the social epidemiology of dying, death, loss and care.

* The Equality Act 2010

Section 1

Introducing modern end-of-life care **Page 15**
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Sets the historical and intellectual background within which modern end-of-life care emerged. Current end-of-life care is largely service oriented. In this section we argue that end-of-life care needs to revisit earlier traditions that promote community responses to death, dying, loss and caring. A public health approach is recommended to expand current service offerings and limitations. Healthy Cities provide a good working framework within which a public health end-of-life care policy can be developed. Compassionate Cities represent the proposed public health end-of-life care policy that shares Healthy Cities' principles and methods.

What is end-of-life care? **Page 15**
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Current end-of-life care is commonly direct service care with palliative care being the dominant provider. End-of-life care services prioritise certain needs to the exclusion of early care and certain life-threatening/limiting illnesses experienced in community settings (eg. dementia care). Social problems associated with experiences of death, dying, loss and caring need to be considered within the contexts in which they arise. This means that end-of-life care needs community partners, initiatives and contributions.

Public health and end-of-life care: beyond a services approach **Page 20**
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A public health approach to end-of-life care includes needs and experiences commonly left out by service provision because it reorients attitudes and behaviours towards death, dying, loss and caring, and encourages community participation through the development of their own policies and practices. Education that is developed collaboratively by governments, community organisations and services can play a significant role in shaping community responses to end-of-life care.

Why do we need a public health approach to end-of-life care? **Page 23**
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Life-threatening/limiting illnesses have social implications that make the need for community end-of-life care urgent. The prevalence of non-communicable illnesses, increased life expectancy and prolonged illness experiences mean that people are increasingly more likely to deal with the end of life and its care in community settings where social issues are likely to compound illness progression. Furthermore, loss, bereavement, sudden and slow deaths present a raft of additional epidemiological problems beyond themselves (e.g. anxiety, depression, loneliness, stigma etc.).

Public health and Healthy Cities **Page 27**
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Public health includes all civic and health service efforts to improve health and combat the major disease burdens of a society. 'Old' public health was concerned with sanitation and the containment of communicable illnesses, while 'New' public health is concerned with health promotion in societies with increased life expectancy, where non-communicable illnesses present the major disease burden. Public health works in partnership with communities to develop collaborative relationships that support health and wellbeing.

Compassionate Cities **Page 31**

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Compassionate Cities represent a similar approach to public health as Healthy Cities but with an orientation towards death, dying, loss and caring. By developing compassion – the capacity to share and support in another person's suffering – compassionate communities organise around death, dying loss and caring and create appropriate responses to those experiences in the form of institutional policies and community practices.

Section 2

The public health approach to end-of-life care **Page 40**

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Health-promoting palliative care represents the initial attempts by palliative care services to adopt a public health approach by extending end-of-life care collaborations to community partners. Health-promoting palliative care acknowledges the social character of dying and provides for the continuing healthcare needs of people with life-threatening/limiting illnesses in community settings.

The aim is to improve health and wellbeing at the end of life. However, a public health approach to end-of-life care goes further still to encourage communities to develop their own approaches to death, dying, loss and caring. This is often achieved through educational activities delivered in community development programmes that enable community members to identify their unique needs.

Palliative care services have been involved in efforts to deliver services in community settings or engage community members in their work. However, the meaning of community development is to empower communities, either through voluntary or institutional action, to be actively and independently involved and to take responsibility for the design and implementation of their own end-of-life care policies and practices.

What is health promotion in palliative care? **Page 40**

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The adoption of health-promoting principles and strategies in palliative care reflects a recognition that needs associated with the onset of serious illness, the care of the frail and the aged, and certain life-threatening illnesses are best served in community contexts. Health promotion in palliative care attempts to improve health and wellbeing at the end-of-life by making interventions through education, social reorientation, ecological changes and policy development.

Health-promoting palliative care **Page 42**

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Health promotion and palliative care were initially considered exclusive of each other, but in the late 1990s and early 2000s the recognition of end-of-life experiences as social led to the promotion of health and wellbeing at the end of life. Supportive social environments, relationships and education improve health and wellbeing as well as addressing the social epidemiology of dying, care and bereavement.

Community practice models in end-of-life care

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Community development in the form of policies and practices formulated to serve end-of-life care purposes is part and parcel of any public health approach. Some community development programmes are end-of-life care service driven, while others are community driven. Ultimately, communities will have to move beyond a services approach that involves the transfer of end-of-life care services into community settings and actively promote the development of policies and practices that serve their individual needs.

1. Community-based end-of-life care service model

Page 53

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A community-based end-of-life care service model was initiated after concern that patients were not cared for or dying at their preferred place. For some people this is their own home. The extension of end-of-life care services into community settings means that a greater range of end-of-life care needs can potentially be met.

2. Community engagement model

Page 55

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Community engagement models represent a basic form of community development initiated by end-of-life care services. A community worker or volunteer helps communities to build the capacity and networks that support their end-of-life care needs, paving the way for the development of end-of-life care policies and practices.

3. Community development model

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Community development programmes support a public health approach to health and wellbeing at the end of life. They do this by independently establishing strong care and support networks that are important in reinforcing a sense of control over life-threatening/limiting illnesses, and enhancing the community's ability to deal with death, dying, loss and care. Community development programmes are led by governments and all communities, commonly in partnership with some health and social services. Ultimately, however, it the communities themselves that independently create the policies and practices for their own end-of-life care needs.

Community development model examples **Page 64**
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Public health approaches to end-of-life care often require a central source of organisation. This organising body could be the local government or a major community organisation (e.g. a church/temple or a senior citizens' association). These community organisations then draft their own end-of-life care policies and practice guidelines. The two most common types of community development action in public health end-of-life care are voluntary and institutional.

1. **Community development in the voluntary sector** **Page 65**
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Service and community volunteers create educational opportunities and partnerships between community sectors and end-of-life care services. Communities are encouraged to develop their own approaches towards death, dying, loss and caring in their own social worlds, accessing services on their own terms.

2. **Community development in the institutional sector** **Page 69**
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Community development programmes draw their end-of-life care directions and priorities from a charter of policy goals. The Compassionate City Charter is a key example. Major sectors of the community (e.g. schools, workplaces and religious organisations) are systematically encouraged to design their own end-of-life care policies and practices. The Charter guides community groups to the main sectors that need to be involved and included in community wide end-of-life care participation.

Section 3

The final section of this toolkit cautions the reader and healthcare professional involved or interested in becoming involved in community development work about possible misunderstandings and best practice in public health end of life care. It also provides a basic introduction, links to further reading and advice on how to evaluate community development programmes in end-of-life care.

Traps for new players and how to avoid them **Page 77**
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Evaluating Compassionate City programmes **Page 80**
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Introducing modern end-of-life care

Sets the historical and intellectual background within which modern end-of-life care emerged. Current end-of-life care is largely service oriented. In this section we argue that end-of-life care needs to revisit earlier traditions that promote community responses to death, dying, loss and caring. A public health approach is recommended to expand current service offerings and limitations.

Healthy Cities provide a good working framework within which a public health end-of-life care policy can be developed. Compassionate Cities represent the proposed public health end-of-life care policy that shares Healthy Cities' principles and methods.

What is end-of-life care?

Summary
• Modern end-of-life care is largely service-driven.
• Palliative care is a major player in modern end-of-life care.
• Palliative care prioritises terminal cancer care, serious neurological disorders, AIDS, as well as, other life-limiting conditions in the last weeks and hours of life.
• Community settings commonly escape formal end-of-life care service engagement.
• Social experiences associated with dying, caring and loss such as loneliness and social isolation, as well as, break down of relationships create psychological troubles.
• Palliative care is at best psychosocial, and it is more 'psycho' than 'social.'
• Palliative care needs to revisit its early community oriented tradition.
Want to know more? **YES/Read on** **NO/Jump to next section**

1. Introducing Modern End-of-Life Care

What is end-of-life care?

End-of-life care in England today is largely based on direct healthcare service provision such as observed in:

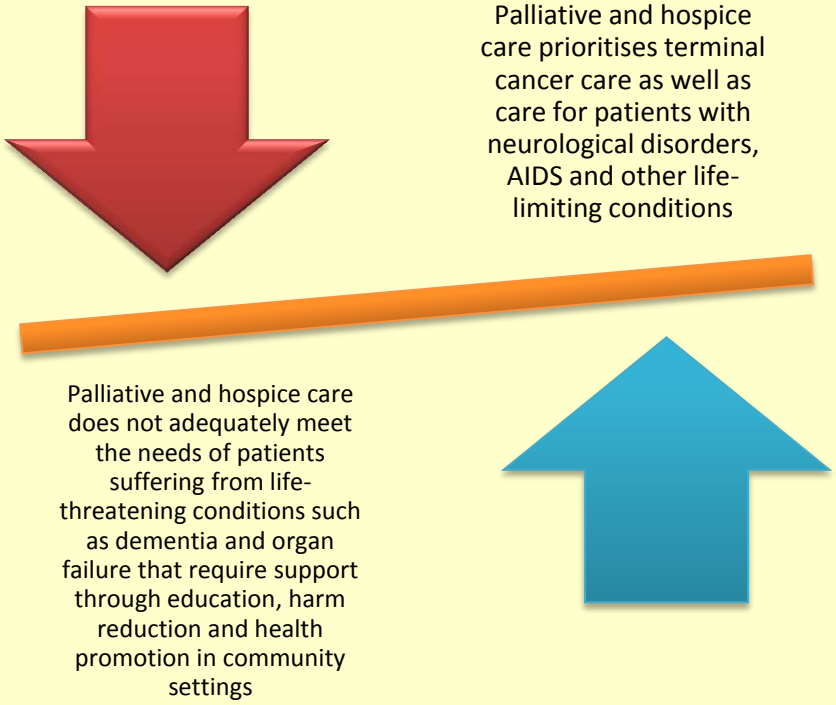
- Palliative and hospice care
- Intensive care
- Bereavement care
- Aged care

Table 1.1: Health service end-of-life care.

The mentioned services provide bedside and/or clinical care during the last months and weeks of life. Occasionally, end-of-life care is considered to be care during the final days and hours of life. Care in these services commonly involves the alleviation and control of physical and psychological symptoms that arise at the end of life. This type of end-of-life care is administered by healthcare professionals to patients or clients in nursing homes, hospitals, hospices or home care teams.

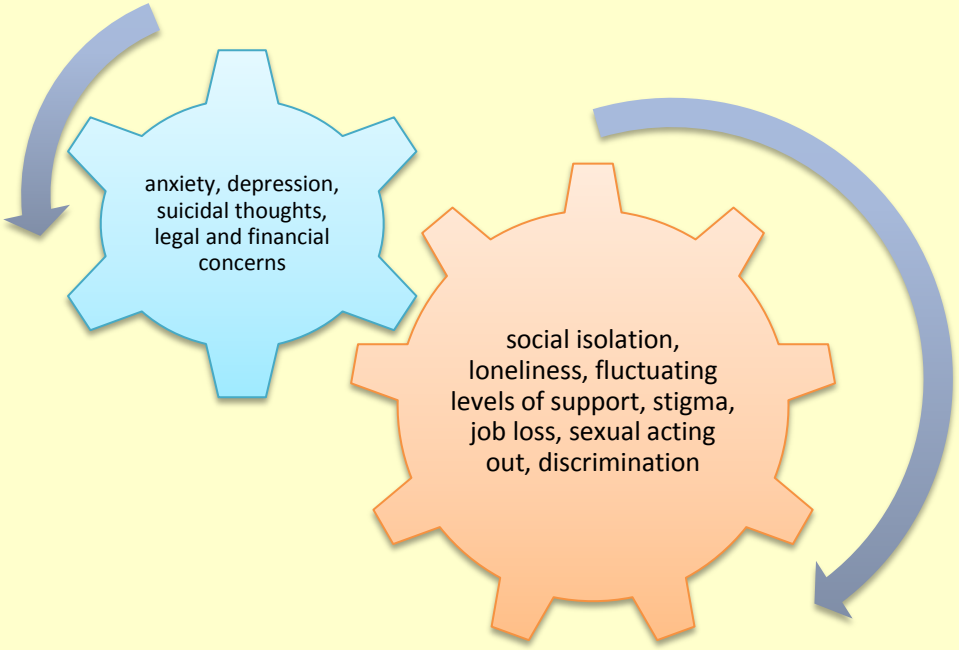
Most commonly, however, end-of-life care is linked to palliative and hospice care. This type of care predominantly serves the needs of patients with cancer, neurological disorders, AIDS and other life-limiting conditions during the last months or weeks of life. Prioritising terminal cancer care, however, commonly excludes people with other life-threatening conditions (e.g. dementia, organ failure etc.).

Table 1.2: Palliative and hospice care priorities.



The continuity of care for all life-threatening and life-limiting conditions is not served well by face-to-face professional care characteristic of direct service provision. Care earlier than the last weeks and months of life is patchy and sporadic, as is bereavement aftercare. Most of the time people spend living with life-threatening/limiting conditions outside professional contact time. The many social and psychological troubles that people encounter in the majority of the time that they are not in contact with professionals or services are inadequately addressed. Some social problems with psychological consequences associated with life-threatening/limiting illness are presented in table 1.3 below.

Table 1.3: Social and psychological problems interact and cause each other in life-threatening/limiting illness.



Palliative care offered as direct service provision in clinical sites by professionals accepts death as the outcome of terminal illness, and recognises the futility of clinical interventions aimed at cure.

It is rather committed to care for physical, psychological, social and spiritual needs during the final stage of life. According to the World Health Organization (WHO) (1990) palliative care aims to:

- Neither hasten, nor postpone death
- Relieve distress
- Integrate the psychological with the spiritual dimensions of life
- Provide appropriate support for the dying person and his/her family

Table 1.4: World Health Organisation (WHO) (1990) definition of good palliative care.

End-of-life care takes its whole person approach from the early hospice tradition. Images of medieval care for dying pilgrims and travellers at roadside hospices run by religious organisations create the impression that end-of-life care is 'bedside' patient focused care. Progress in medicine and clinical interventions also changed attitudes towards a direct service form of healthcare. The recently developed palliative care services were required to find their common ground with other direct healthcare services run by professionals trained in clinical and bedside skills.

The combination of early tradition and modern developments in medicine and healthcare prioritised medical and psychological needs of terminally ill patients or clients. The social support strategies in palliative care are the least developed. At best palliative and hospice care provide psychosocial support.

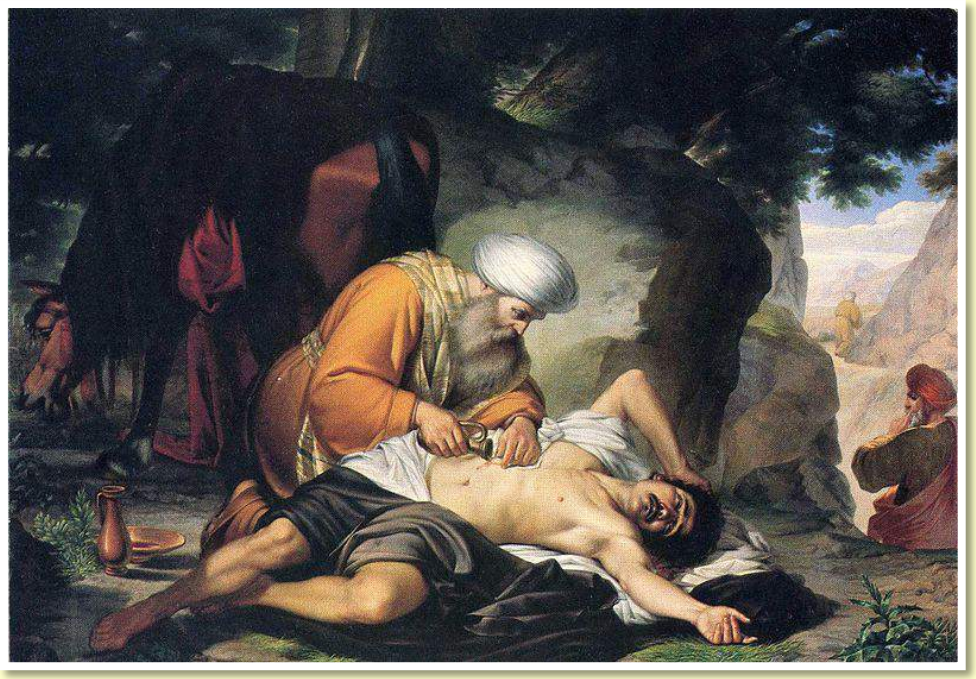
During the Middle Ages, hospices were places for peasants or wealthy pilgrims and travellers. They operated as formal care settings for the dying. These institutions were run by religious organisations. Some of these early hospices survived into the 20th Century.

In Britain, for example, Anglican and Catholic religious organisations ran several hospices. These were succeeded in the 1960s by government funded hospice and palliative care services in Britain.

In 1967, Cicely Saunders established St Christopher's Hospice. Her interest in care for the dying was directed at people dying of cancer. This early informal emphasis had wider implications for later end-of-life care policies.

In the Middle Ages, compassionate care for the dying was a community matter that involved a number of actors.

Compassionate care for the dying by religious organisations, whether in stable community settings or roadside hospitals and hospices, was part of a community tradition and ritualistic way of dying. Nonetheless, it is only the popular bedside images of dying that influence a largely service driven modern palliative care tradition.



Despite the community oriented early palliative and hospice care tradition, palliative psychosocial care often emphasises psychological symptom control in hospitals, hospices, nursing homes, respite care or home based care sites and services by professionals.

Psychosocial palliative care is often (1) more 'psycho' than 'social'- emphasising psychological issues over social issues; (2) any psychological or social issues are addressed by professional interventions alone.

Palliative care services research and policies have formed closer ties with clinical and institutional paradigms of care and in so doing have inherited the medical emphasis on the importance of direct clinical interventions particularly psychological and physical remedies (Kellehear, 2005: 9)

The role of social workers and counsellors in psychosocial palliative care is to work with clients and their families in order to provide companioning, assessment, planning and evaluation, counselling, education and support with 'the team' in clinical sites and services.

The objective is to facilitate communication and liaise between health care providers, patients and their families in order to coordinate and deliver clinical direct service care.

Government concerns with service cost-effectiveness also prescribe a determinate period of end-stage care. This limits the range of issues and concerns that services can care for.

Instead of reorienting services to meet psychological and social needs right from the first stage of diagnosis of the life-threatening/limiting illness, palliative care services commonly take action when matters become problems. They deal in a limited way with the psychological and social issues that arise when awareness of the existence of life-threatening/limiting illness changes personal and social relationships and roles.

People with a terminal illness diagnosis continue to be active social citizens, and live amongst their families and communities until their physical health no longer permits it.

Their emotional and social needs continue to evolve along with the progression of illness, but unlike the physical needs the social and emotional dimensions of care are more difficult to address.

Social and psychological troubles are embedded in families and the often changing and complex networks within the community where those families live out their lives.

People living with life-threatening or life-limiting illness or loss have complex needs whose sources – and therefore solutions – are found in their communities. Unfortunately, psychosocial approaches in palliative care and bereavement services often have a limited community definition.

They are committed to notions of service sector and professional development. Programmes of community development and participation are rudimentary, and mainly engage the patient and family as service users.

Table 1.5: Palliative and hospice care is seldom community care.

Palliative and hospice care

- is commonly direct service care in clinical settings that concentrates upon individual psychological support

it is seldom community care that recognises the dying person as social agent with roles and responsibilities, and needs for continuity of care in community settings

Public health and end-of-life care: beyond a services approach

Summary
• Public health end-of-life care provides post-diagnosis and early care, care for experiences that take place in community settings (eg. sudden deaths), and wider support for loss and bereavement.
• Public health end-of-life care relies upon relationships and partnerships between communities, governments and services.
• Health and death education provide guidance in communities where dying and loss is not viewed as normal and routine.
• Cultural organisations (museums, galleries, media, etc.), workplaces, schools, churches, local governments and a range of other community actors engage in collaborative partnerships.

Want to know more? **YES/Read on** **NO/Jump to next section**

Public health and end-of-life care: beyond a services approach

A public health approach to end-of-life care offers a successful model of community care. It builds partnerships between healthcare services and communities in recognition that death, dying, loss and care take place in everyday life within the family and community, at home or at work, in villages or other settings, activities and experiences.

End-of-life care is more than palliative care. There are many forms of dying including accidents and road traumas, suicides, homicides, disasters and morbidity and mortality associated with heart-disease, ageing, HIV/AIDS and other illnesses. Losses from refugee experiences and bereavement also have a morbidity and mortality burden with not only physical and psychiatric implications, but most importantly social, moral and economic ones. These experiences commonly escape end of life direct service provision.

Table 1.6: Public health end-of-life care.

WHAT IS IT THAT WE NEED TO DO THEN TO CARE FOR ALL END-OF-LIFE EXPERIENCES?

The design of a systematic end-of-life care approach involves the creation of normal and routine community relationships with an educational and voluntary character. The state may be involved in the design of policies that promote prevention and harm-reduction as part of community end-of-life care – as it already is in other forms of healthcare (e.g, health and safety, nutrition, accident prevention, drug and alcohol use/abuse, etc).

Partnerships go beyond mere services and involve the family as a basic unit in recognition of the principle that people are members of social systems from which they should not be divided during clinical interventions.

Community end-of-life care is organised care for the dying and other end-of-life experiences. And historically it should be remembered that community care preceded professional care. Traditional ways of practicing community end-of-life care indicate the instrumental building blocks of any public health end-of-life care. These are the following:

1. In pre-industrial times communities had significant experience of death, dying and loss. The care of the dying was **normal and routine**. Today, public health and death education can guide communities without direct experience of death and loss to create sustainable partnerships that make end-of-life care part of everyday life.

2. **Community relationships** between health professionals and community members and organisations are necessary in public health end-of-life care. Policy development, workplace changes, school and public education need contribution from a wide range of people and institutions.

3. Palliative and hospice care and literature emphasise **whole person care.** To take into account social relationships, palliative care should be **whole sector care,** meaning that it should include all the major sectors of the community (schools, churches, workplaces, businesses, social media, etc.) – in contexts where they live as citizens. For this reason, whole person care involves the networks of friends, family and co-workers, as well as, the values and belief systems of the community.

4. Palliative and hospice care and literature emphasise the family as a basic unit of care**.** But the public health approach requires us to include **communities and the state** as important partners in all end-of-life care.

5. End-of-life care, like all health care, must go **beyond mere services** in order to create sustainable for health environments and relationships. In this way, end-of-life care is everyone's business.

The history of end-of-life care tells us that the community has played an invaluable role in social support and can continue to do so today.

Historically, the care of the dying was vital and gave meaning to families and communities. For this reason, community end-of-life care was organised care guided by the performance of rituals and cultural practices.

Community care brought together a collaboration between professionals, families and the wider community. The dying person was commonly at the centre of efforts to create meaning and make peace with friends, family and community.

This normative end-of-life care practice that recognises the dying person as a citizen with a range of needs and obligations, and brings together a cast of actors in the performance of clinical, psychological, spiritual and social care is what contemporary public health end-of-life care can revisit.

Why do we need a public health approach to end-of-life care?

Summary
• Dying, death, caring and loss create an array of social and psychological troubles.
• These troubles are amenable to health promotion strategies in community settings
• Social issues such as isolation and stigma have adverse effects upon terminal illness, ageing, care and loss.
• Bereavement and loss present mortality and morbidity burdens that can most effectively be addressed by communities.

Want to know more? **YES/Read on** **NO/Jump to next section**

Why do we need a public health approach to end-of-life care?

We need to adopt a community approach to end-of-life care that integrates clinical, psychological, spiritual and social efforts because:

1. End-of-life care is more than palliative and hospice care, and more than cancer care. Age-related and other life-threatening illnesses present end-of-life care issues experienced at home among friends and relatives, and in community settings. The awareness of dying changes social roles and relationships. Social changes are also encouraged by physical, psychological and psychiatric morbidities. These social matters related to life-threatening illness experiences can only be addressed within the same networks and contexts that they arise.

2. End-of-life care also refers to sudden deaths like suicide, homicide, accidents, road traumas, or war casualties. Equally, it refers to loss such as dispossession and bereavement that have a morbidity and mortality burden with social and economic implications. Community partnerships, education and social ecological changes can create secure environments that care for these experiences. The inclusion of end-of-life care issues and concerns in the organisational structure of communities makes care normal, routine and sustainable and expands the range of needs that can be accommodated.

3. Non-communicable illnesses present the greatest morbidity and mortality burden in Western societies.

- In 2010 cardiovascular disease (CVD) was the biggest killer in the UK. The prevalence of the disease is high with over three million Britons suffering from it. Overall, 200,000 people die from CVD every year of which 50,000 die prematurely (British Heart Foundation, 2012: 10).

The Office for National Statistics (2011) reports that:

- Between the ages of 35 to 79, coronary heart disease, breast cancer and lung cancer, conditions linked to lifestyle, are leading causes of death.
- For those aged 80 years and above, coronary heart disease and stroke are leading causes of death.
- Males less than 35 years of age are more likely to die of accidents and suicides.

Contemporary mortality patterns and illness experiences introduce additional care issues that cannot be dealt with by health services alone. Treatment options, prolonged illness experiences, and sudden deaths present community care issues. Current end-of-life care experiences are amenable to health promotion, prevention and harm reduction based on knowledge and practices developed by communities in partnership with professional services.

4. Service oriented end-of-life care approaches seldom or only partially target issues routinely cared for in social and community contexts. Physical, psychological and psychiatric morbidities associated with life-threatening illnesses transform social relationships.

   Social isolation or stigma can have adverse effects upon terminal illness progression. This has implications for care practiced in family and community contexts. For example:

- People diagnosed with HIV/AIDS now live longer lives in their communities. However, social stigma towards the disease has psychological consequences that lead to depression (Simbayi and colleagues, 2007; Cook and colleagues, 2004).

  Depression, stressful events and traumatic experiences have been reported to aid HIV illness progression (Leserman, 2008). These are end-of-life care experiences that present public health challenges and require immediate attention.

- Stigma, social exclusion and depression can potentially have further sexual health implications among people affected by HIV/AIDS. Although Vanable and colleagues (2006) found no link between stigma-related depression among HIV-positive individuals and risky sexual behaviour, other sources provide evidence of related challenges.

  Palmer and Bor (2007) found that grief, guilt, care, safe sex and financial strain were issues that challenged the relationship of homosexual HIV serodiscordant couples, and Hortensia (1995) describes the social inequalities that need to be taken into consideration in HIV/AIDS prevention that targets women.

  Vicioso and colleagues (2005) report that in gay communities some men may seek out environments to engage in sexual behavior in order to escape from distressing thoughts, feelings, and emotional vulnerability.

Depression is common among motor neuron disease and other neurologically disabled patients, which is linked to a generalised sense of social isolation. Brown and Addington-Hall (2008) found that among motor neuron disease patients progressive physical disability and loss of ability to communicate challenged their will to stay active and engage in social life.

Hecht and colleagues (2002) suggest that loss (of speech), rumination, communication, social integration and community information and education – which are community care matters - were important to people coping with motor neuron disease.

Dementia and motor neuron disease and other neurologically disabling illnesses present similar community end-of-life care issues.

Prolonged experiences of physical deterioration often lead to social isolation, depression, and carer burden (Tedman et al., 1997; Ray and Street, 2006), if there is no community effort to create supportive networks that alleviate the social problems that life-limiting illnesses present.

Bereavement has been linked to increased mortality, as well as, physical, psychological and psychiatric morbidity. Stroebe and colleagues (2007) found that social isolation and dysfunction are among the symptoms of grief. However, more research is now being carried out to link bereavement to social life - the legacies that it creates together with other positive experiences of growth.

Education on loss and grief can create environments that support all bereavement experiences – environments that care for the adverse reactions and enhance the positive attributes of grief.

Public health and Healthy Cities

Summary
• Public health policies include all civic and health service efforts to control and improve the health of populations and combat the major disease burdens of a society.
• The 'old' first wave public health aimed to improve sanitation and combat communicable diseases in rapidly industrialised and urbanised settings.
• The 'new' second wave public health is concerned with issues of health-promotion and education in societies where non-communicable diseases present the major disease burdens.
• All public health involves an educational component, a community effort and a government role.
• The aim of public health policies is to promote community development and increase social capital (trust, empathy and cooperation).
• Healthy Cities is the public health approach that promotes health and wellbeing with 'cities' as the most basic political and administrative unit.
• In Healthy Cities, health is an ecological concept that depends upon the nurturing role of physical, social, political, economic and spiritual environments.
Want to know more? **YES/Read on** **NO/Jump to next section**

Public health and Healthy Cities

Public health policies include all organised efforts to control and improve the health of populations. Public health is more commonly used to refer to all the civic and health service initiatives to combat the major disease burdens of a society. There is a historical distinction between the 'old' first wave of public health, and the 'new' second wave public health.

- The 'old' first wave public health was concerned with sanitation, the procurement of fresh water supplies and the containment of infectious diseases. Industrialisation brought large numbers of people to urban settings, where new health threats appeared.

  As people left their rural communities where strong support networks existed, there was need to introduce government led initiatives to combat the major health and disease burdens that had negative impact upon productivity and the economy.

- The 'new' second wave public health is concerned with health-promotion issues of public education on lifestyle issues and diet, harmful substances in the environment such as tobacco or asbestos, and health and safety in the workplace.

  The 'new' public health represents a response to the increased burden that non-communicable diseases such as cancer and heart disease place upon healthcare services.

All public health involves an educational component, a community effort and a government role.

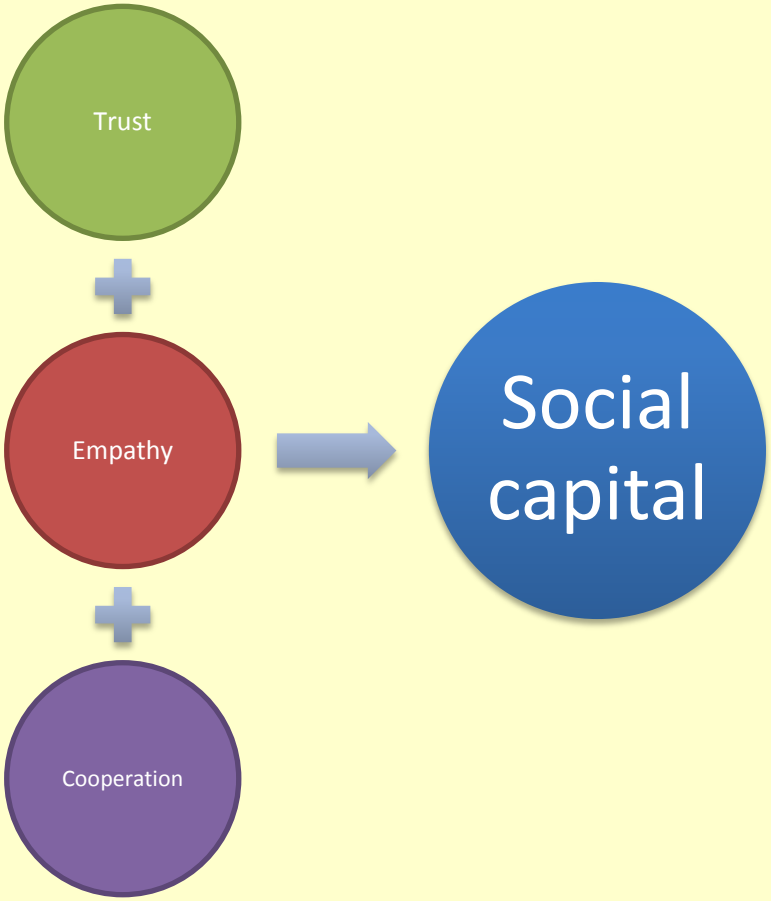
> Public health is a concern with social efforts led by governments and actioned by communities, often in partnerships with health and other social organisations, to lessen disease and/or improve health at the broadest population level.
>
> These efforts occur through education, improvement of social capital and community development, enactment of laws, partnerships with health services and professionals, and the creation of safe and sustainable social and physical environments. (Kellehear, 2005: 19)

Governments lead public health initiatives that fund education or information campaigns designed to prompt communities into action over one or several health or disease issues that affect their population.

The solution to epidemiological problems requires community support and involvement from schools, churches, workplaces and the media. The aim of public health policies is to promote community development and increase social capital.

Communities will then take an interest in their own health and welfare because the development of partnerships between institutions, communities and organisations builds trust, empathy and cooperation in matters that affect everyone.

Table 1.7: The definition of social capital.



In 1984 the idea of public health as community, holistic and systemic approach to health was redefined by Dahl at a major public health conference in Toronto, Canada.

Dahl coined the term 'healthy cities' to express the view that health is inexorably linked to ecological environments, habitats and people.

The idea of the 'city' draws from two main sources of inspiration. First, a city as a primary site for public health policy approaches seem appropriate because cities are the most basic political and administrative level for assembling political and financial resources, and engaging participation and intersectorial cooperation.

Secondly, the word 'city' itself is derived from the French term *citeyon* meaning citizen – a modern term referring to the rights and obligations of every human being in a community irrespective of caste, class, gender, 'race' or any other medieval or tribal category (Turner, 1993).

In 1986 the World Health Organization (WHO) published the Ottawa Charter for Health Promotion.

It consisted of five important principles for the environmental support of health. These are:

1. Building healthy public policies
2. Creating supportive environments
3. Developing community action
4. Developing personal skills
5. The reorientation of health services

In 1987 Healthy Cities was established as a policy programme of WHO's European Regional Office. By 1992 the WHO office worked with 35 cities and since then hundreds of Healthy Cities programmes have been established worldwide. A Healthy City:

1. Has a clean and safe physical environment
2. Meets the basic needs of all its inhabitants
3. Has a strong mutually supportive, integrated non-exploitative community
4. Involves community in local government
5. Offers inhabitants access to a wide variety of experiences, interactions and communications
6. Promotes and celebrates its historical and cultural heritage
7. Provides easily accessible health services
8. Has a diverse, innovative economy
9. Rests on a sustainable ecosystem

The three underlying concepts of the Healthy City are:

1. Health is a positive concept; it is not simply the absence of disease. It concentrates upon health-promotion
2. Health is a holistic concept that depends upon the nurturing role of physical, social, political, economic and spiritual environments (not simply the quality of direct services alone)
3. Healthy cities must always be concerned with inequalities in health because, like wealth, health is unevenly distributed in the population depending upon age, gender, ethnicity and socio-economic background.

Public health approaches tend to *exclude* end-of-life care experiences. However, the same principles can be applied to expand these public health approaches to *include* the end of life and its care.

What are Compassionate Cities?

Summary
• Compassionate Cities is the public health approach to end-of-life care that incorporates death, dying, caring and loss into current public health policy.
• The building of compassion – the ability or attitude to share and support in another's suffering – is a central element of public health end-of-life care policy and practice.
• Compassionate Cities recognise the universality of loss and include grief experiences such as migration, dispossession, bereavement and other social losses that create a morbidity and mortality burden that should be recognised in end-of-life care policy and practice.
• Compassionate Cities promote care for the aged, the seriously ill, those living with loss and long-term care in a way that is sensitive to cultural and spiritual diversity.
• Compassionate Cities involve communities, local governments and health and social services in creating health-promoting environments and supporting ethical choices for all citizens affected by end-of-life issues.
Want to know more? **YES/Read on** **NO/Jump to next section**

What are Compassionate Cities?

Current end-of-life care needs to widen its definition to include experiences that take place beyond healthcare services. End-of-life care is largely taking place within relationships and interactions in community settings.

In addition, loss and grief present fundamental end-of-life care issues because they create death and loss in others in their social, symbolic and sometimes even physical lives.

What end-of-life care needs is a public health approach, which will make health-promoting strategies focal, and will be community building and partnership oriented.

The WHO idea of the Healthy City best meets the above mentioned criteria. However, Healthy City approaches do not include end-of-life care experiences. Their focus upon health promotion seldom considers dying and loss as experiences in which these principles can be applied.

In order to incorporate end-of-life care needs in public health and community care policies we need to develop partnership strategies based upon compassion and social empathy. This toolkit therefore refers to the public approach to end-of-life care Compassionate Cities.

'Compassion' means to pity or to share or show mercy and sympathy in another person's suffering.

The term 'compassionate' is to have this quality of attitude and action. It is a commiseration – a joint journey of sharing with another. Funk and Wagnell's *New Standard Dictionary of the English Language* (Funk, 1963) observes that the term 'compassion' derives from two Latin root words: 'cum' meaning 'together' and 'patior' meaning 'suffer'.

Under the terms 'compassion, compassionate', Partridge's (1958: 13) *Dictionary of Etymology* provides the intriguing advice 'See patience'. This suggests a *sharing with* another's suffering, to bear and support suffering.

It also has another etymological life as the basis for the English term 'patient' – a person who shows patience in his or her own suffering (Kellehear, 2005: 41-42).

Compassionate end-of-life care approaches are partnership based and emphasise social interrelatedness. They presuppose the care of experiences of dying and loss within communities of people who understand and support one another. Comp assionate Cities represent holistic approaches to end-of-life care. In this sense, they include formal healthcare services, but also extend the definition of care and create partnerships with a number of people and organisations in communities that offer skills, which serve end-of-life care needs.

Compassionate Cities stress the following four concepts:

1. Compassion is an ethical imperative for health. It is the human response, the tender response aroused by the distress and suffering of others. It is the moral, social, political and physical basis of our attempts to give aid and support in a time of difficulty.

2. Health is a positive concept that can coexist in the presence of disease, disability or loss. The WHO stresses that health is not simply the absence of disease. On the contrary, for most of us disease is ever present in the form of atherosclerosis, arthritis, hypertension, diabetes and many more. Equally, disabilities in movement, sight, hearing or touch are endemic. Indeed, chronic illness and disability are so widespread that any definition of health that excludes these experiences promotes an unrealistic idea of health. Disease is not the opposite of health, death is. Under this definition that recognises disease, loss and disability as issues best served by health-promoting strategies, end-of-life care needs can equally be met by public health policies.

3. Compassion is a holistic/ecological idea. This means that it must express itself not simply in an individual attitude but in changes in the workplace, churches, services and schools. Death and loss are universal experiences that we all share, and their provision must be integrated in policies and practices at those sites.

4. Compassion necessarily implies a concern with the universality of loss. Loss can result from terminal illness (cancer, HIV/AIDS, motor neuron disease, etc.) but also from violence (victims of war crime and abuse). The forced separation of peoples from their land or their cultural traditions and identity (refugees, indigenous peoples and international adoptions) must make dispossession equal to bereavement as a compassionate concern for end-of-life care. Social and physical rejection (from racism, sexism, ageism, disability, relationship disintegration or unemployment) involves 'risk' factors of equal concern to a Compassionate City approach to public health policy and practice.

The above-mentioned basic Compassionate City concepts translate into the following nine defining characteristics, which must be read together with the nine WHO defining characteristics of Healthy Cities. A Compassionate City:

1. Has local health policies that recognise compassion as an ethical imperative
2. Meets the special needs of its aged, those living with life-threatening illness and those living with loss
3. Has a strong commitment to social and cultural difference
4. Involves the grief and palliative care services in local government policy and planning
5. Offers its inhabitants access to a wide variety of supportive experiences, interactions and communication
6. Promotes and celebrates reconciliation with indigenous peoples and the memory of other important community losses
7. Provides easy access to grief and palliative care services
8. Has recognition of and plans to accommodate those disadvantaged by the economy, including rural and remote populations, indigenous people and the homeless
9. Preserves and promotes a community's spiritual traditions and storytellers

When compassion is considered an ethical imperative, healthcare takes up the hard challenge of viewing health as a social (not only physical and psychological) experience.

Towards the end of identifying the social dimensions of end-of-life issues and concerns, healthcare has to host debates on the practical links between ethical choices and supportive health promoting environments. In this light, death, dying, loss and care are viewed as predictable and permanent experiences in relation to which we can strive for quality of life.

The inclusion of difference is central in effectively caring for the end of life, because dying and loss are universal matters that affect everyone.

In Compassionate Cities, bereavement and palliative care services are involved in local government and planning, and citizens are offered access to a wide variety of supportive experiences, interactions and communications in the course of which they can see their private experiences reflected in others in society.

The experiences of dispossessed populations and those affected by personal and community losses, those disadvantaged by the economy and the needs of rural populations are recognised and accommodated because grief has a wider definition. Policies are inclusive of experiences of death, dying, loss and care beyond physical disease. Compassionate Cities are supportive of diverse religious beliefs, as well as, public health ideas.

The idea of the Compassionate City highlights a departure from current ways of thinking about end-of-life care, and particularly palliative care. This means that palliative care will face several challenges in its effort to adopt a public health community care approach. The reorientation of service directions and practices will enable palliative care to serve public health purposes.

- When the idea of citizenship becomes central and defines care entitlements, services need to see their role as partners in education and learning rather than mainly as care providers to 'patients'.

- It follows that palliative care services need to invest upon existing social capital and support partnerships that promote trust, empathy and cooperation. More healthcare services will not necessarily support a public health approach to end-of-life care.

- The networks that Compassionate City approaches involve go beyond the idea of the 'family' and include workplaces, schools, churches and other community organisations and the media. Palliative care will need to adjust its methods and practices in order to serve partnership efforts.

- The idea of holism in palliative care focuses upon the individual. Community care holism includes all social relationships, interactions and partnerships and their role in healthcare.

- It follows that palliative care will need to reorient its focus from professional capacity building to community capacity building, in order to enable communities to utilise their own resources in end-of-life care which is normal, routine and sustainable.

- In community care the skills needed to address a greater range of end-of-life care needs are diverse. They become available only when palliative care services create partnerships and work directly with communities.

A Compassionate City approach to end-of-life care is realistic because community relationships are ever present in society and support healthcare. Relationships that sustain a sense of belonging and provide emotional aid and security are not utopian. They merely represent a social criticism and a healthcare vision that promotes social change. If community partnerships are marginal then we need to work towards mainstreaming them. Research and evaluation of community end-of-life care programmes can be undertaken to guide public health policy directions.

Section 1 summary
• Modern end-of-life care is commonly health service provision.
• Palliative care dominates understandings of end-of-life care defining its character and orientation.
• Palliative care mainly involves bedside medical, psychological and spiritual care during the final weeks and hours of life.
• Broader end-of-life experiences that take place in community settings – sudden deaths, frail ageing, bereavement - commonly escape formal end-of-life care service provision.
• A public health approach to end-of-life care promotes care for a greater range of end-of-life care needs and experiences.
• A public health approach relies upon cooperative partnerships between governments, communities and services in order to promote health and wellbeing at the end of life.
• Healthy Cities is the public health approach that relies upon communities as a basic organising unit of partnerships, resources and activities that promote health and wellbeing and combats the major disease burdens of societies.
• Compassionate Cities encourages the sharing of suffering as an ethical imperative in relationships and collaborative partnerships that promotes and reinforces health, wellbeing and care for the aged and those affected by death, dying, care and loss.
• Healthy Cities and Compassionate Cities share the same principles and methods.
• Compassionate Cities reorient Healthy Cities towards death, dying, care and loss.

Diagrammatic Summary

Table 1.8: The roles and character of health service, public health and compassionate community end-of-life care.

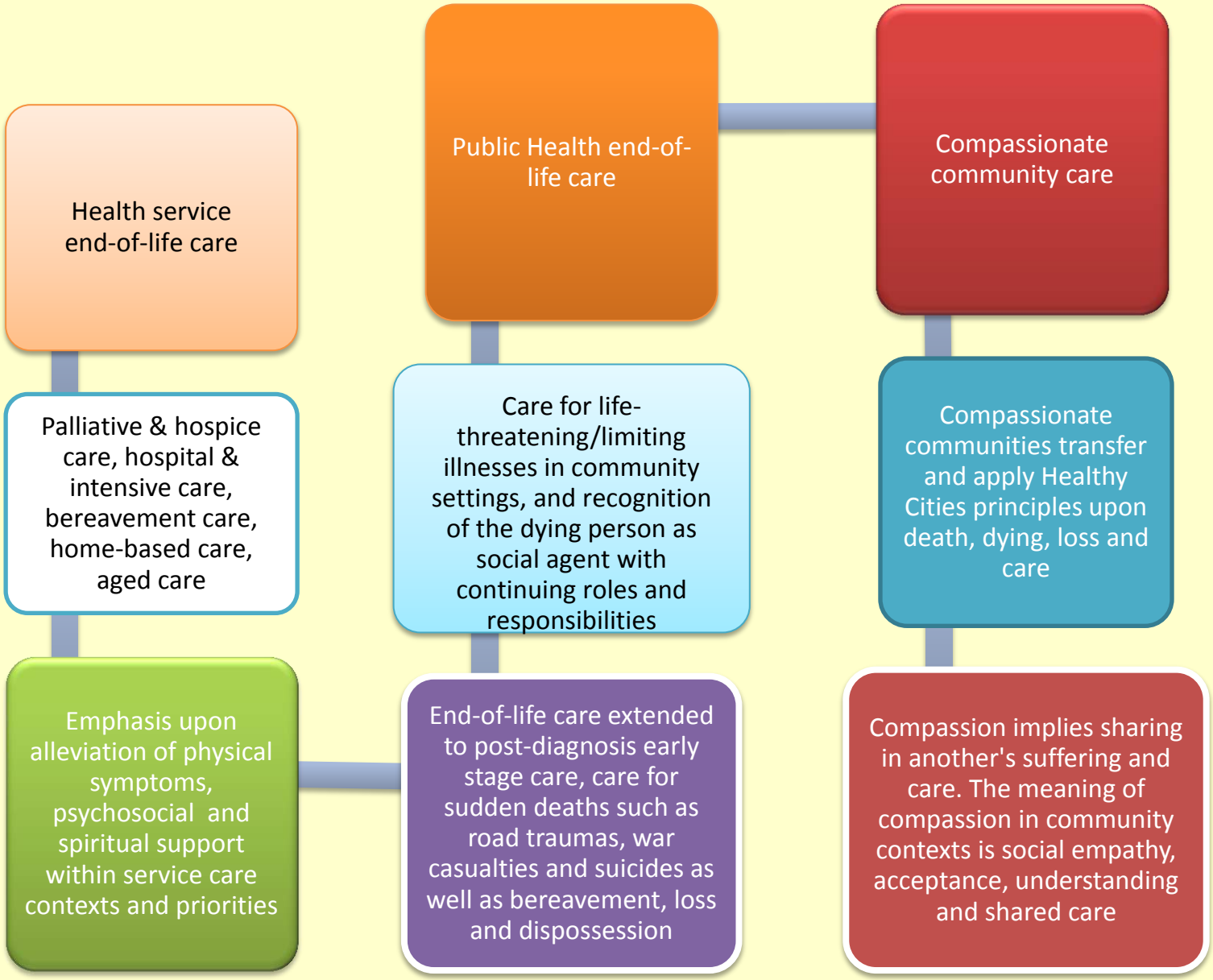


Table 1.9: Compassionate communities.

Compassion is an ethical imperative for health.

Disease is not the opposite of health. In compassionate communities experiences of illness, care and loss are subject to health promotion, harm minimisation and health and death education. A holistic idea that includes all types of death, dying, loss and care within new compassion oriented social attitudes and environments.

Compassionate communities offer healthcare services; have local government policies; offer supportive interactions and communications; promote social inclusion and diversity, culture and spiritual traditions.

Activity

Consider the following questions and provide answers (Preferably on paper). Go back to the text and look for answers in relevant sections and paragraphs. Revisit your answers and refine them. Try to write down short answers to aid comprehension.

1. What are the aims of health service end-of-life care, including palliative and hospice care? From which historical experiences, social relationships and circumstances does palliative and hospice care draw its philosophy and mission?

2. How far does health service end-of-life care meets its objectives in caring for people living with death, dying, loss and care-giving? Which end-of-life care experiences are prioritised, which are partially included, and which are difficult to reach given healthcare service limitations?

3. Which end-of-life care needs and issues are best met by community support, information, education, health promotion, prevention, harm reduction and public health policies that change attitudes towards end-of-life care?

5. What do we mean by public health end-of-life care? Which additional needs and experiences are included in community end-of-life care?

6. What are Compassionate Cities and how do they relate to Healthy Cities?

The public health approach to end-of-life care

Describes the public health approach to end-of-life care. Health-promoting palliative care represents the initial attempts by palliative care services to adopt a public health approach by extending end-of-life care collaborations to community partners. Health-promoting palliative care acknowledges the social character of dying and provides for the continuing healthcare needs of people with life-threatening/limiting illnesses in community settings.

The aim is to improve health and wellbeing at the end-of-life. However, a public health approach to end-of-life care goes further still to encourage communities to develop their own approaches to death, dying, loss and caring. This is often achieved through educational activities delivered in community development programmes that enable community members to identify their unique needs. Palliative care services have been involved in efforts to deliver services in community settings or engage community members in their work.

However, the meaning of community development is to empower communities, either through voluntary or institutional action, to be actively and independently involved and to take responsibility for the design and implementation of their own end-of-life care policies and practices.

What is health promotion in palliative care?

Summary

- Health promotion in palliative care acknowledges that social, psychological and clinical needs are best addressed by early interventions in community settings.
- Health promotion in palliative care recognises that health and illness reflect patterns of our social lifestyles.
- Health promotion in palliative care involves social efforts including education, social reorientation, ecological changes and policy development.
- Health promotion in palliative care can significantly enhance quality at the end-of-life, and even extend it.

Want to know more? **YES/Read on** **NO/Jump to next section**

2. The Public Health Approach to End-of-Life Care

What is health promotion in palliative care?

Health promotion in palliative care describes the idea that end-of-life social and psychological needs are best addressed through health and death education, community development, personal reorientation, and policy and environmental change. Health-promoting palliative care employs public health methods and concepts to change the way in which *healthcare services* approach end of life experiences. Health-promoting palliative care addresses a greater range of end-of-life experiences and serves a broad range of needs of people suffering from life-threatening and life-limiting illnesses. It also engages caregivers, the bereaved and communities in their own care by working with those communities to identify issues associated with health and wellbeing at the end-of-life.

Health promotion is the idea that combined educational, environmental, policy and community strategies that prevent illness, minimise risks and reduce harms in societies can improve peoples' health. Health-promoting strategies are social approaches that emphasise health and wellbeing rather than illness and disease. The underlying assumption is that health and illness reflect patterns of our working lives, as well as our leisure and relationship styles, benefited or disadvantaged by our age, gender, culture, social class and environmental situations (Kellehear, 1999: 10).

In health promotion philosophy, health and illness is not idiosyncratic and, therefore, subject to isolated biological and psychological factors - it is also an interpersonal experience.

For this reason, health-promoting strategies need to provide both personal and community supports. Participatory community relationships that support and sustain health through education, practical social support, and ecological and policy development serve health-promoting purposes.

Health promotion is for everyone - those who are well and those who are ill - because health is everyone's responsibility. Policies of harm minimisation that target behavioural risks such as smoking, drug and alcohol use and unsafe sexual health practices, prevent specific morbidities and mortalities in the population, and promote health and wellbeing. Illnesses such as cancer, heart disease and HIV/AIDS carry their own morbidity and mortality burden and, for this reason, are subject to prevention and health-promoting principles.

Age-related and other life-threatening illnesses that involve slow and gradual progression offer the opportunity to experience quality of life and wellbeing among family members and in communities, despite the very real possibility that life will eventually come to an end. Health-promoting strategies and education within those settings can significantly enhance the quality of life at the end of life, and may even extend it. In order to support health promotion ideals, personal and community attitudes, as well as, service and policy development need to be reoriented towards prevention, harm reduction and risk minimisation aims, practices and methods.

Health promotion:

- Is participatory
- Recognises the social character of health and illness
- Emphasises education, information and policy development
- Is designed for the well and the ill
- Is everyone's responsibility (not just the individual's)

Health-promoting palliative care

Summary
• In the late 1990s and early 2000s, emphasis in palliative care shifted towards early care and health promotion.
• Health promotion and palliative care are not exclusive of each other.
• End-of-life experiences are social and, for this reason, the promotion of health and wellbeing in community settings is relevant to end-of-life care.
• Health-promoting methods and principles such as education, participatory relations and social support increase a sense of control over life-threatening/limiting illnesses, caring and loss and therefore improve health and wellbeing.
• Access to a wide variety of experiences, interactions, communications and resources in community settings serve educational, supportive and health-promoting purposes.

Want to know more? **YES/Read on** **NO/Jump to next section**

Health-promoting palliative care

Health promotion principles were not immediately associated with palliative care aims and objectives because of the early emphasis in late-stage dying experiences, and were only gradually incorporated into service models of end-of-life care as the emphasis shifted towards earlier care.

In the late 1990s and early 2000s, health promotion ideas that had permeated all branches of public health and medicine, were gradually advocated for palliative care. Health promotion and palliative care can be mistakenly thought of as exclusive of each other, because the conventional approach to health promotion has highlighted health and illness prevention while palliative care has emphasised illness management in the face of death.

The social and participatory character of health promotion with its emphasis on health, positive lifestyle and wellbeing has made its philosophy somewhat 'death-denying'.

The social character of health, the notion of prevention and early intervention are ideals that seem to slip away and have little application for palliative care. And yet there are important reasons why these ideas are relevant.

The crucial point to remember is: Living with a life-threatening or life-limiting illness, living with bereavement, and living with long-term caregiving ARE social experiences. Therefore, the goals of health and wellbeing are just as relevant to these groups as any other.

There is no reason why clinical, psychological and medical interventions and supports cannot be combined with health-promoting practices in community settings. People in the last months or weeks of life can enjoy periods of good health and wellbeing, and share these with family, friends and community members. Professional partnerships and increased community participation and involvement can facilitate processes that support and promote health at the end of life.

Palliative care also needs to expand its services to serve a greater range of end-of-life care needs and experiences that mostly take place within community settings among family and friends.

Age-related life-threatening/limiting illnesses and other life-threatening illnesses like heart disease, cancer and HIV/AIDS can be monitored, treated and supported by palliative care services in partnership with communities. Health promotion is a shared objective in these collaborations.

For example, maintaining a healthy mind and spirit in interpersonal relationships and community settings can be crucial to warding off infections that might threaten and erode the immune system of someone living with HIV/AIDS.

Community supports along with medical and nursing treatments during the course of cancer or cardiac failure, no matter how serious the stage, can help prolong life, improve its experienced quality, and/or help a person to cope with the side-effects of treatment.

Since one of the greatest fears of those with a life-threatening/limiting illness is the prospect of loss of control over their health and their lives more generally, health promotion can be an important source of empowerment. Education can challenge personal fears and change attitudes.

Participation can renew confidence and a sense of agency. Support can encourage hope and be a valuable and steady source of comfort (Kellehear, 1999: 15).

These are important resources and activities for people with life-threatening/limiting illnesses who commonly encounter anxiety, depression, social isolation, social stigma, social rejection, family breakdown, premature job loss, financial strain, spiritual dilemmas or crises, even suicide, among a host of other troubles.

All of the above are problems best served by preventive strategies that make early interventions, reduce risk and minimise harm with the help of methodologies used in other successful public health campaigns.

End-of-life care, including dementia care and bereavement care, can partner with schools, workplaces, places of worship, the mass media or local businesses in order to shoulder together the responsibility of care and promote health and wellbeing among people with a short time left to live within their communities, or with a life-threatening/limiting illness and the awareness of impending death at some uncertain time in the future.

Health-promoting palliative care necessarily includes communities in end of life issues and concerns. It enables services to utilise community resources and networks in order to educate everyone, the well and the ill; carers, people with life-threatening/limiting illnesses and the wider public about health needs and risks.

It also creates social supports and alters environmental settings in order to meet the needs of people who seek clinical and psychological treatment in palliative care services.

Table 2.1: Health-promoting palliative care.

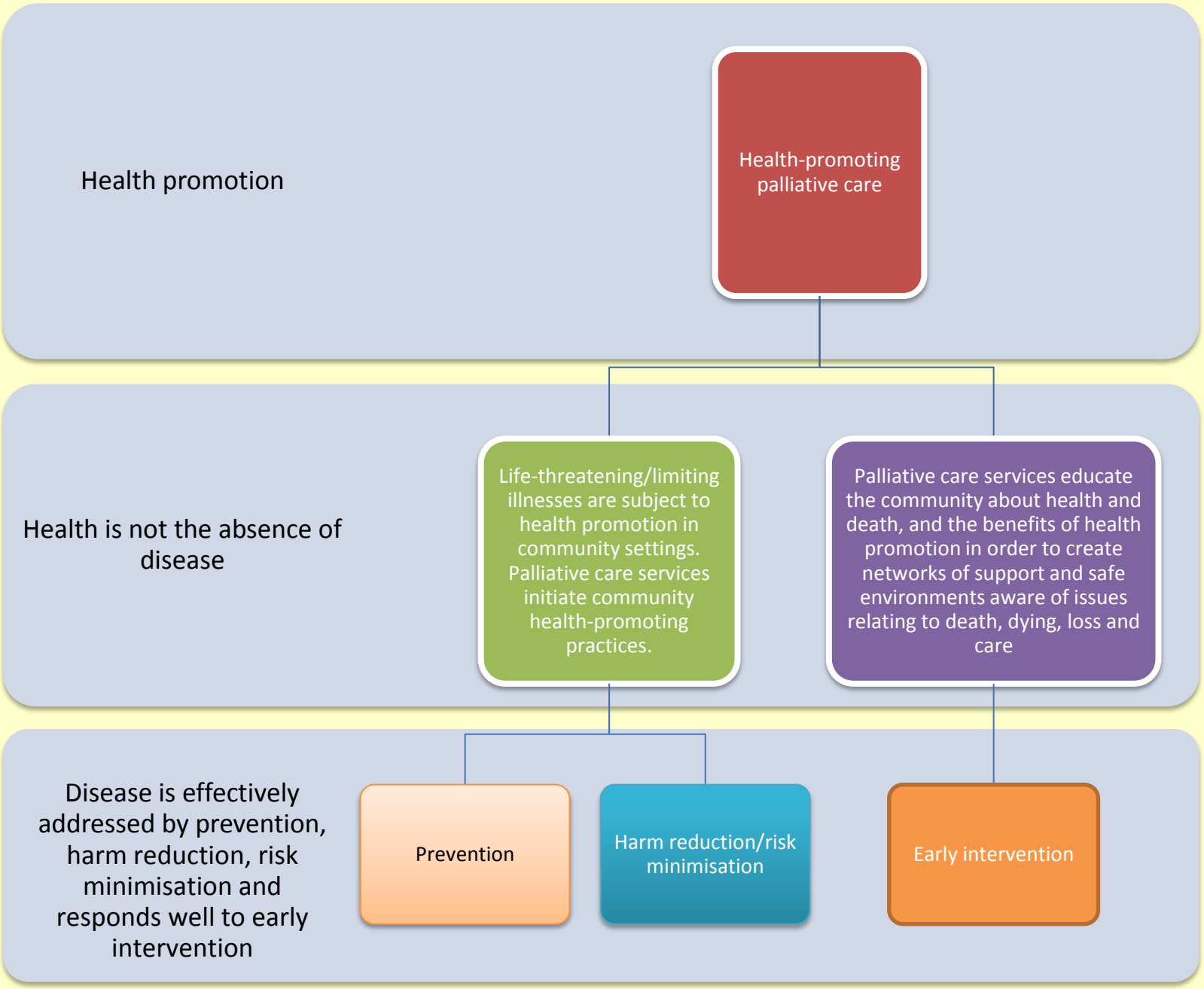


Table 2.2: Basic concepts and strategies in health-promoting palliative care. Definitions by Naidoo and Wills (2009)

Health promotion - a broad concept encompassing not just individual action but also social, political and environmental action to change the determinants of health and thereby improve health. Health promotion is the process of enabling people to increase their control over, and improve, their health (World Health Organization, 1986)

- Health education - the communication of health-related information and the development of attitudes, skills and confidence necessary to enable people to take action to improve their health

Prevention - measures taken to prevent disease or slow its progress. Prevention is achieved through harm reduction, risk minimisation and early intervention strategies

- Harm reduction/risk minimisation - action taken to reduce known risk factors to health and wellbeing
- Early intervention - action taken to make an intervention early before health issues become problems. This could involve screening or pre-symptomatic intervention. In end-of-life or palliative care early intervention involves a mixture of medical, psychological, spiritual and social approaches to care

Sustainablity - meeting the needs of the present generation in a way that does not compromise the ability of future generations to meet their needs. Sustainable health promotion actions are embedded in services and structures so that their positive effects continue beyond the life of the programme or intervention

A diversity of collaborative relationships and interactions is necessary to deliver health-promoting palliative care services. A number of professional specialties collaborate with communities in order to promote health and wellbeing for people with end-of-life care needs. Health-promoting strategies have expanded palliative care goals and vision in the following directions:

- Social science and public health perspectives
- The social side of care
- Early-stage care (not just end-stage)
- Active treatment of disease
- Care for those with life-threatening illness (not simply terminal illness)

Health-promoting palliative care can start with one-to-one consultations between professionals and individuals who need information on the benefits of maintaining a health-promoting approach to life-threatening/limiting illness. Initially, assumptions about the particular illness, its causes and symptoms, personal and social issues, and fears are explored and discussed. The purpose of a health-promoting approach is to be reflective and critical. A desirable outcome is for participants to become encouraged to seek actively to clarify their own personal needs and values and to pursue their own visions of 'health', quality of life, and/or 'control and empowerment' (Kellehear, 1999: 62).

Exposure to new social networks (e.g., support groups) can add to knowledge gained in initial interactions with professional services and enables dying people and their carers to identify their own unique needs. Participation in support and self-help groups encourage people to reflect, brainstorm and consider a number of options and approaches to health, as well as explore solutions to the social and psychological problems they may encounter from social stigma, breakdown of relationships and job loss.

Some further strategies that help people process their new learning about life-threatening illness experiences, caregiving or bereavement include:

- Audiovisual aids - books, films, documentaries, television, posters and internet sources
- Individual instruction - discursive tutoring on personal health promotion needs
- Inquiry learning - in books and book clubs/reading groups, and the internet
- Lecture/discussion forums - traditional and effective methods that palliative care services and academic institutions can employ to deliver large amounts of information to large audiences
- Peer group discussion - learning within small groups
- Expert panel - visits by palliative care services, hospices and hospitals to community organisations to stimulate ongoing conversations on end-of-life care issues

Personal strategies that complement social strategies and help people with life-threatening/limiting illnesses, caregiving and bereavement to focus upon their unique needs are:

- Journal writing – experiences are recorded and analysed, patterns are identified and brought to a group or counseling session for discussion
- Letter writing – written pieces that reflect upon a particular issue or experience of life-threatening illness that concerns or interests the individual
- Audio and video recordings – as an alternative to writing this method is suitable for reflecting upon particular questions
- Mind maps – maps, drawings and illustrations that describe end-of-life care experiences and link and order related variables
- Photograph album or life story – old photographs organised in an album tell a life story as self-reflective exercise
- Blogs, personal internet sites and social media – record information in an interactive manner and provide opportunities for monitoring and self-reflection

Specific issues of death education that help people adjust their health attitudes, behaviours and understanding of illness can be further explored in literature, film, music, art, the social media and popular culture. These sources provide insights on existential and practical concerns that may arise in the face of life-threatening/limiting illness, caregiving and bereavement – these may include the role of death and dying in the human experience, social legacies, farewells, material preparations and funeral arrangements, life beyond death, spirituality and near-death experiences, and loss and grief. Referral to those sources is a sensitive way to introduce people to issues relating to death and dying, loss and care, and relevant information should be available in organisational documents, newsletters and institutional websites, libraries and archives where they can be easily accessible.

Useful educational sources on death, dying and loss:

Some examples of popular books

Raymond Moody ([1975] 2001) *Life After Life*; Leo Tolstoy (2012) *The Death of Ivan Ilyich*; Elizabeth Kubler-Ross (2008) *On Death and Dying*; Collin Murray Parkes (1998) *Bereavement: Studies of Grief in Adult LIfe*; Allan Kellehear (2007) *The Social History of Dying*; Allan Kellehear (2009) *The Study of Dying*; Allan Kellehear (2014) *The Inner Life of the Dying Person*; Robert Dessaix (1996) *Night Letters*; William Faulkner (1996) *As I Lay Dying.*

Films

About Schmidt; Love Story; Steel Magnolias; Rabbit Hole; Up; Big Fish; Sunshine; The Descendants; Terms of Endearment; P.S. I Love You; Truly, Madly, Deeply; The Iron Lady; The Lion King; the television series Six Feet Under; The Sea Inside; Osage County; Beginners.

Music

Richard Pacholski (1986a) – a bibliography of musicology as a general introduction to the theme of death.

The popular songs *Don't Speak* by No Doubt; *Candle in the Wind* by Elton John; *Sometimes You Can't Make It On Your Own* by U2; *Tears in Heaven* by Eric Clapton; *Say Something* by A Great Big World and Christina Aguilera; *The Last Goodbye* by Red Sovine; *Will The Circle Be Unbroken* by Johnny Cash; *Gone Too Soon* by Michael Jackson; *Fly* by Celine Dion; *I'll Be Missing You* by Puff Daddy and Faith Evans.

Jazz, Blues and Reggae sing about death and loss. Indigenous and Folk songs are equally informative about loss, and raise awareness about the subjective experiences of marginal communities.

Arts

Richa rd Pacholski (1986b) – a bibliography of art as a general introduction to the theme of death.

Theatre productions and art exhibitions with references to death, dying, loss and care are frequent. Palliative care services and organisations with an interest in end-of-life care should provide information on relevant venues and opportunities of learning in their newsletters. The following websites provide such information:

Death, Commemoration and Memory: Exploration of Representation, Concept and Change (A Virtual Research Group), University of Edinburgh http://dcm.ace.ed.ac.uk/index.html

Centre for Life and Death Studies, University of Durham https://www.dur.ac.uk/cdals/

Other interactive websites with information on death, dying, loss and care are:

- Death Reference Desk http://deathreferencedesk.org/
- Dying Matters http://www.dyingmatters.org/
- Compassionate Communities
- http://www.compassionatecommunities.org.uk/
- Good Life, Good Death, Good Grief http://www.goodlifedeathgrief.org.uk/
- The National Council of Palliative Care http://www.ncpc.org.uk/
- Scottish Partnership for Palliative Care http://www.palliativecarescotland.org.uk/
- Marie Currie Cancer Care http://www.mariecurie.org.uk/
- The Association for the Study of Death and Society http://www.deathandsociety.org/
- The Natural Death Centre http://www.naturaldeath.org.uk/

Community practice models in end-of-life care

Summary
• Public health end-of-life care involves the development of policies and practices by local communities.
• Community development programmes enable communities to ultimately design and implement end of life care policies and practices.
• There is a gradation of community development programmes in end-of-life care some of which are service driven (least effective) and some of which are community driven (most effective), or both.
• Community development in end-of-life care should extend beyond healthcare service delivery in community settings, wherever possible, to the development of local policies and practices by schools, workplaces, cultural groups and religious organisations.
• Community development programmes in end-of-life care help communities to build capacity and support networks that they need to care for their own end-of-life experiences.

Want to know more? **YES/Read on** **NO/Jump to next section**

Community practice models in end-of-life care

Health-promoting palliative care employs community engagement methods in order to extend its services to community contexts where its purposes can be served.

At this point I would like to invite you to pause in order to consider what community end-of-life care is and how it is implemented. Use your experience in order to reflect upon the question.

In the following part of this toolkit we will demonstrate that the development of community end-of-life care is not a straightforward process and that it relies upon a number of partnerships and approaches, some of which are end-of-life care service driven while others are government and/or community driven.

Community end-of-life care includes community based end-of-life care service delivery and community engagement programmes such as those initiated by palliative care services in order to serve health promotion purposes. However, community end-of-life care ultimately evolves beyond these approaches and extends (or should extend) to the development of local policies and practices by schools, workplaces, social groups, religious organisations and other social settings regulated by local authorities.

This dimension of community work is often overlooked by end-of-life care services, and yet it is crucial in order to create sustainable networks of care towards experiences of death, dying and loss. *This is what we call community development in end-of-life care.* We will first revise the different levels and meanings of community practice conducted by services before we explain how community development works in end-of-life care.

Finally, we will illustrate using community development in Scotland as an example that public health models can actually rely upon all three community practice models in order to evolve, and that community practice models are actually not exclusive but feed into each other.

Most community practice models do not aim to create policy or cultural change, but to extend or transcend current service offerings and limitations.

The chief aim is to 'capacity build' – build an 'ability' or a 'resource' or 'skill set' within communities to help support those at the end of life, caregiving or grieving. They begin to do this by helping communities to identify their end-of-life care needs in order to create sustainable and supportive care networks and localised public health policies.

However, community practice models vary depending upon the agency or body that initiates their development. Some community practice models encourage communities to reflect upon their end-of-life care needs in order to design compassionate care policies and practices. Yet others are service driven and their purpose is to extend their services in community settings and engage citizens in their own care.

Community practice is an essential aspect of all service models, but the extent to which communities are allowed to 'independently' design their own policies or need the agency that regulates their activities varies.

This means that we can differentiate between the following community practice models:

1. Community based health service model
2. Community engagement model
3. Community development model

Community practice models in end-of-life care

1. Community-based end-of-life care service model

Summary
• A community-based end-of-life care service model is primarily about the provision of services into a patient's home.
• This model commonly offers the option to be cared for and die at home.
• This model cares for the usual palliative care populations but in their homes.
• Improves health and wellbeing at the end of life primarily through direct service provision and professional care.

Want to know more? **YES/Read on** **NO/Jump to next section**

Community based end-of-life care service models are initiated by institutions such as palliative and hospice care, and other health and social care organisations in order to extend the delivery and application of their services within community contexts and serve a wider range of end-of-life care needs.

In the United Kingdom, the National Council for Palliative Care (NCPC), in its *End of Life Care Manifesto* (2010) identified a number of needs, which are currently not adequately being met by end-of-life care services.

These include the improvement of dignity defined by the ability to choose a preferred place of death, support for carers, meeting the challenges and needs of people with dementia, caring for the ageing population who may experience multiple life-threatening/limiting conditions, and enabling people to remain within their communities.

The End-of-Life Care Manifesto also reports that while only 25% of the population die of cancer, 95% of palliative care service provision is occupied with the needs of people dying of cancer.

In recognition of the need to extend the scope and range of service provision, healthcare services discuss the possibility of better co-ordination of services, including health and social care services.

Other services - the effective co-ordination of which can promote the extension and transfer of service provision within community contexts are - education, transport, housing and work and pensions.

Community based end-of-life care service models are concerned with the extension of service delivery in community contexts where end-of-life care needs and experiences are diverse and socially embedded.

One of the ways in which this objective can be met is through the organisation and promotion of home based end-of-life care service provision.

In 2013, Public Health England published information indicating that 'home' is a preferred place of care and death for the majority of the population, and the extent to which home-based end-of-life care is being utilised is considered a key performance indicator for end-of-life care.

This is a measurement that focuses on place of death, namely 'usual place of residence', as a proxy marker for quality, and relevant data is based on death registration information collected by the Office for National Statistics (ONS).

In addition to being a preferable option, home based end-of-life care is cost effective. Marie Curie Cancer Care (2012) suggests that changing the setting of care for a patient at the end-of-life has the potential to reduce the daily cost of care by £280.

Although end-of-life care service based models involve community development, relevant efforts concentrate upon the education and training of professionals to perform end-of-life care within community contexts rather than the empowerment of communities themselves to look after their own.

Community based end-of-life care service models are necessary in enabling communities and providing the resources to develop appropriate responses to end-of-life care issues, but additional steps must be taken towards this end.

Community practice models in end-of-life care

2. Community engagement model

Summary
• Community engagement programmes represent a basic form of community development in end-of-life care.
• Community engagement programmes are initiated and led by healthcare services.
• A community development worker or community development volunteer helps communities to build their capacity to care about their own experiences of death, dying, care and loss.
• The extent to which communities can set their own goals is variable.
• Community engagement programmes work 'with' communities rather than solely 'on' communities.
• Community engagement programmes have the potential to enable communities to go beyond engagement to design their own end-of-life care policies and practices.
• Community engagement programmes are a crucial first step and contribute towards a greater realization of a public health vision of end-of-life care based upon partnerships and collaborative relationships.

Want to know more? **YES/Read on** **NO/Jump to next section**

Other programmes engage communities in work that promotes health and wellbeing at the end-of-life.

These programmes involve the organisation of events by end-of-life care services in recognition that counselling, medical and social services have their limitations in addressing issues such as drug and alcohol use, diabetes or heart disease, which are subject to health promotion in community contexts.

This is the key reason why many health and welfare agencies employ a task-specific worker with the official resignation of 'community development worker' or 'community worker' whose role is to educate and persuade the community about the importance of certain information regarding health and wellbeing at the end of life.

Such appointments reflect the fact that addressing human need must employ both direct service and community approaches to wellbeing.

End-of-life care services may employ a community development worker who will visit community settings to initiate discussion on specific issues of health promotion in end-of-life care.

Bereavement, palliative care or community health agencies with a commitment to community end-of-life care and the necessary funding to implement it, may employ a community development worker to lead and manage that program under the governance of the agency.

The mission of the community worker is to empower others in the community, to problem-solve their anxieties, or resistance to supporting their neighbours and promoting health and wellbeing at the end of life.

Community development work connects people with one another and employs outreach methods – visiting communities, organising public meetings, enlisting volunteers, talking to the media – to create grass-roots campaigns that promote community end-of-life care.

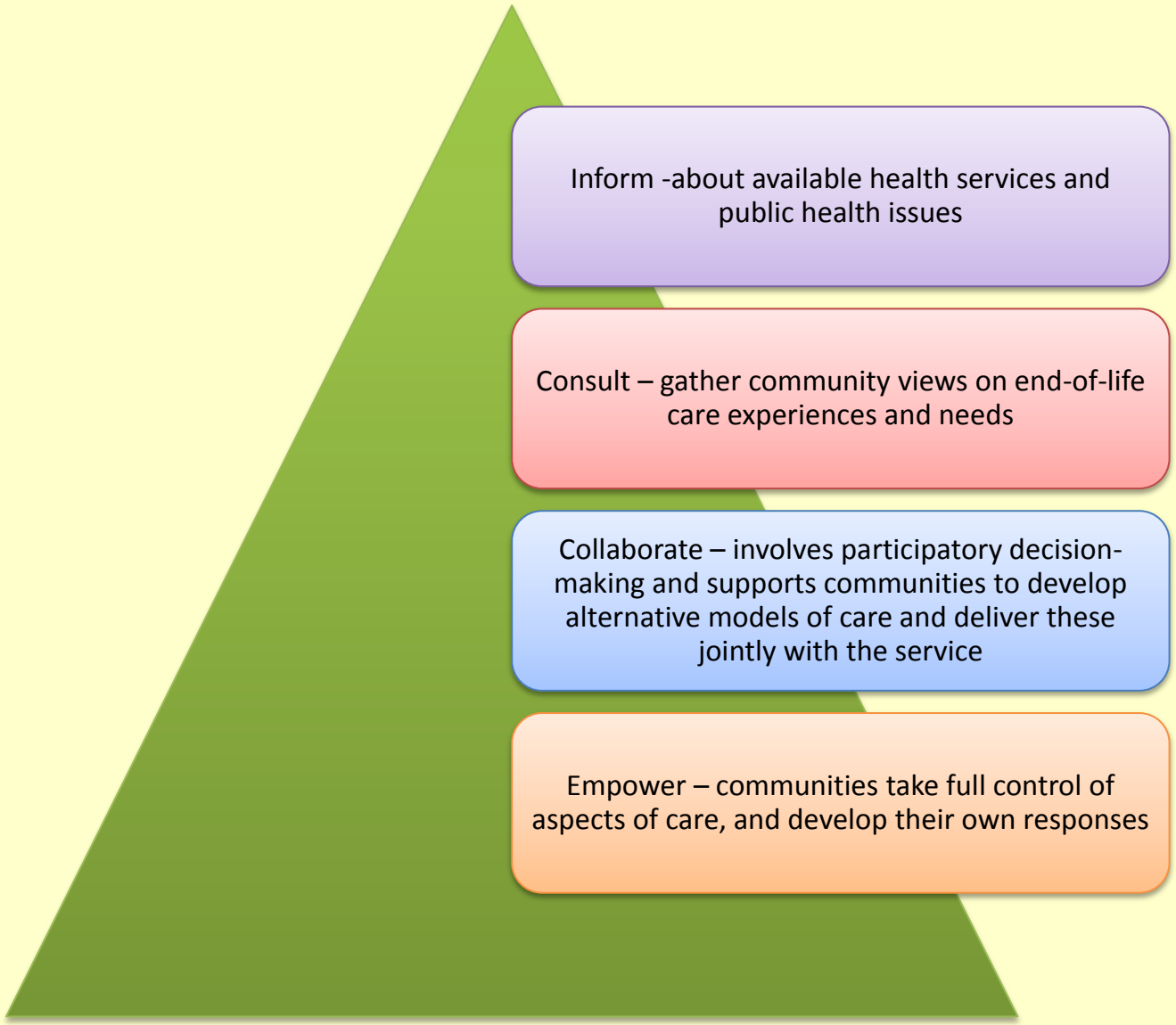
Community engagement programmes are often run by community development workers or volunteers and involve a leadership committee that works closely with local authorities and health services.

Healthcare services with public health interests and objectives empower and work *with* communities to set their own goals and shape their end of life experiences.

Sallnow and Paul (2014: 5) identify variations in the degree of community engagement that end-of-life care service activities promote.

The variation is presented in table 2.3 and ranges from the provision of basic information about healthcare and public health issues to the empowerment and enablement of communities to design their own end-of-life care policies.

Table 2.3: End-of-life care service community engagement.



The extent of community involvement in decision-making depends upon the goals set, the degree of power shared by the organization, and the capacity and experience of communities to mobilize their skills and resources to identify and serve their own healthcare needs.

A key feature of community engagement in end-of-life care that differentiates it from a direct service approach is that it involves work *with* the community, as opposed to work *on* the community irrespective of the level of community participation.

In order to reflect this perspective on end-of-life care, Sallnow and Paul (2014: 3) proposed the following definition of community engagement:

> Community engagement in end-of-life care is an umbrella term for a process which enables communities and services to work together to understand, build capacity and address issues to improve their experience of end-of-life and bereavement and their related wellbeing.
>
> It exists on a spectrum of engagement that extends from informing through to empowering, depending on a range of factors such as the degree of participation from the local community and the intention of the work.
>
> Community engagement activities by end-of-life care services go beyond working in the community to working with the community to improve its experience of end-of-life care.

Community practice models in end-of-life care

3. Community development model

Summary
• Community development programmes led by local governments or sections of the community aim to establish strong and diverse networks of support and care that improve health and wellbeing at the end-of-life.
• The example of community end-of-life care in Scotland indicates that efforts may start from the transfer of healthcare services in community settings and evolve into community-led development programmes.
• Community development programmes led by communities themselves operate within a wider public health end-of-life care framework.
• Community development programmes in end-of-life care represent collaborative efforts between governments, communities and services.
• Community development programmes enable schools, workplaces, religious organizations and other social and cultural groups to build the necessary skill-sets, support networks and policies that will allow them to deal effectively with death, dying, care and loss.
Want to know more? **YES/Read on** **NO/Jump to next section**

Partnerships between communities and healthcare services make important contributions to public health, because formal healthcare cannot undertake the task of health promotion on its own. Partnerships vary according to the formality of their arrangement, their degree of autonomy, style of interaction and mode of governance.

When they extend to include communities and involve people in the decisions and actions affecting their health and wellbeing, partnerships usually operate through networks that bring individuals and communities together on the basis of established relationships and/or shared interests.

In this way, they minimise social isolation and create opportunities for health education, change of attitudes and care within community settings.

Community development ensures that the needs and wishes of the populations that use healthcare services are represented in their design and delivery.

Community development initiatives have a specific advantage over community engagement initiatives in that they foster and encourage ALL communities to articulate and deliver their own solutions rather than rely solely upon professional expertise. This feature of community development is particularly important for populations with protective characteristics in cultural, religious and sexual diversity as well as those with disabilities. Community development is a flexible approach that places prime emphasis and importance on the role of diversity, and hence diverse needs and voices, in any community

In this way, community initiatives are more likely to be owned by local people, and represent the needs of socially excluded populations.

Community development initiatives strengthen social capital because they reinforce existing relationships and bonds based on trust, empathy and cooperation in the context of supportive networks and informal interactions.

These relationships can protect people against disease and mental illness, because they form an important resource that provides information, education, support and care as health promotion measures in times of illness and in times of health.

People with strong and diverse networks are healthier and happier, suffer less from heart disease, recover more quickly from emotional traumas such as bereavement, and seem to be more resistant to the debilitating effects of illness, perhaps because of some emotional buffer which gives them a more positive outlook on life (Orme et al., 2007: 142).

Community development initiatives have been recognised as a valuable activity.

In order to make these initiatives accessible to the wider public, health professionals have looked into ways in which they can offer tools and techniques to guide citizens through the process of assessing their health and care needs, consider solutions and implement effective health-promoting strategies.

In this context, community development is a form of professional and social leadership that helps people to help themselves by encouraging them to set up or be involved in collective activities that address shared problems.

Community development projects encourage social change and justice by helping communities to:

- Identify their needs, opportunities, rights and responsibilities
- Plan, organise and take action
- Evaluate the effectiveness and impact of the action

All in ways that challenge oppression and tackle inequalities

(Federation for Community Development Learning, 2003)

Examples of toolkits and resources that can be used by communities to organise development, identify their needs and priorities and promote change can be found in the following sites:

Homes and Communities Agency - Community Engagement Toolkit http://www.homesandcommunities.co.uk/community-engagement-toolkit?page_id=&page=1

The Manchester Community Engagement Toolkit http://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=4&ved=0CFMQFjAD&url=http%3A%2F%2Fwww.manchester.gov.uk%2Fdownload%2Fdownloads%2Fid%2F234%2Fcommunity_engagement_toolkit&ei=Gk_lUpjxIo2v7AalyYCgBg&usg=AFQjCNEBitpHZFKUGdsOmN2Wn2nMxrVYqg&bvm=bv.59930103,d.bGQ&cad=rja

Community Engagement Toolbox http://www.community-toolbox.org

Community Planning Toolkit http://www.communityplanningtoolkit.org/community-engagement

Community development in end-of-life care commonly involves community based health service and community engagement practices, but goes further in that it enables communities to design their own policies and responses to death, dying, loss and care. Scotland provides a good example of an organised community response to end-of-life care that includes and goes beyond healthcare service efforts to reach communities and serve their needs in social settings. Community development initiatives in Scotland work under the regulation of a government sponsored community end-of-life care programme. The example in table 2.4 demonstrates how community development programmes evolve and how they are practically implemented and coordinated.

Table 2.4: Community development in Scotland

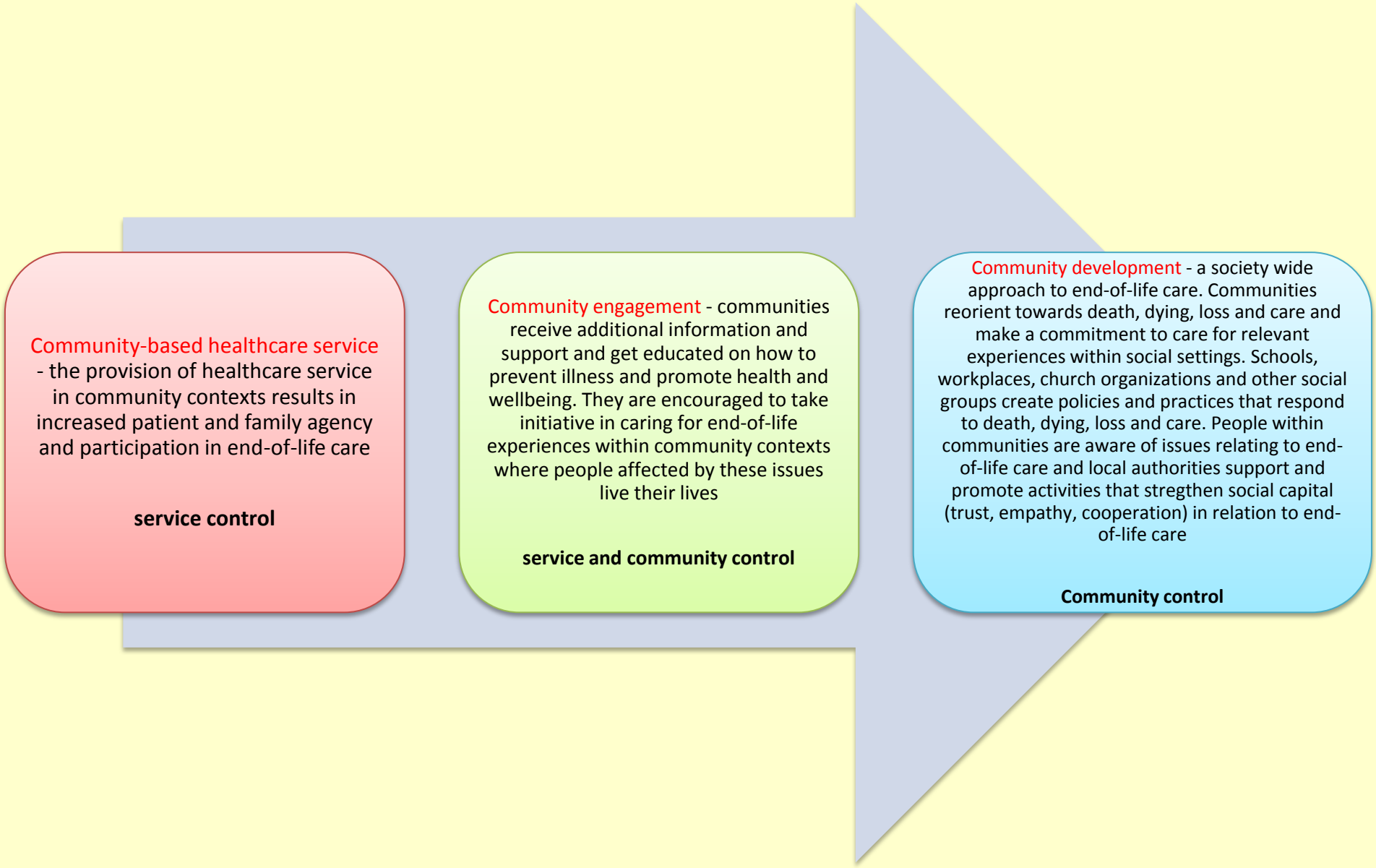
The Scottish government is involved in a number of activities that aim to better coordinate end-of-life care services, meet end-of-life care needs and engage communities in their own care. In 2008 the first plan for palliative and end-of-life care called Living and Dying Well, was conceived to ensure the provision of equitable and consistent palliative and end-of-life care throughout Scotland. Living and Dying Well has a strong emphasis on person-centred care and advance care planning. A number of bodies including NHS Boards, The Scottish Partnership for Palliative Care (SPPC), NHS Education for Scotland, and Healthcare Improvement Scotland support the implementation, governance and leadership of palliative and end-of-life care through the Living and Dying Well National Advisory Group that co-ordinates practices. This is a service partnership approach to end-of-life care that aims to deliver services in community contexts.

Scotland is now promoting community development within a public health end-of-life care framework. Initial attempts to co-ordinate services in order to more effectively serve community end-of-life care needs concentrated upon the development of services and their application in community settings. Awareness of the limitations of services in meeting community end-of-life care needs led to the initiation of community engagement programmes by health services and local authorities. These programmes aim to educate communities about health and wellbeing at the end-of-life in order to extend service care in community settings and serve a greater range of needs and end of life experiences.

However, The Scottish Partnership for Palliative Care (SPPC) in association with Marie Curie Cancer Care identified a number of areas that require attention and indicate directions for change in end-of-life care policy and practice. Specifically, they call for greater engagement of the Scottish public in end-of-life care and the identification of patients' and families' diverse needs, wishes, experiences and expectations. End-of-life care in this context needs to be defined as a society-wide issue, subject to a public health approach that involves domains other than health and social care. Education and communities are equally important, as are statutory, voluntary and independent sectors. The objective is to create communities that accommodate experiences of death, dying, loss and care, and increase openness and resilience to deal with the hard times, which can come with these experiences.

Knowledge gained through community engagement initiatives and an interest in community end-of-life care by Scottish local authorities led to the promotion of community development programmes and locally organized responses to death, dying, loss and care. Health services and local authorities support and promote community development and provide leadership in end-of-life care approaches and directions. Communities are involved in development projects that change their approach towards death, dying, loss and care. Local organizations, institutions and groups of people are encouraged to reflect upon their perceptions of death, dying, loss and care in order to design appropriate responses to those experiences. Openness and resilience are cultivated in community development programmes regulated by the Good Life, Good Death, Good Grief Alliance. The Alliance maintains a website http://www.goodlifedeathgrief.org.uk/ where members and associate organizations can record their community development activities and efforts towards developing community end-of-life care.

Table 2.5: Community practice models in end-of-life care.



Community development model examples

Summary
• Public health end-of-life care often needs direction from a central organizing group such the local government.
• Local governments set their priorities in executive committee meetings attended by various stakeholders and community representatives.
• Services and communities draft their own practices and policies within a wider public health end-of-life care framework.
• Community development efforts are either initiated by healthcare service volunteers or involve institutional programmes aiming to establish public health end-of-life care policies and practices.
Want to know more? YES/Read on NO/Jump to next section

Community development model examples

Local governments and authorities play an important role in policy design and the promotion of community development programmes. Institutions and organizations are equally important decision-makers, but they need direction from a central authority that coordinates activities across different groups and stakeholders in society.

In this way, interested parties create their own policies within a certain vision of community end-of-life care. Local governments coordinate their activities in executive committee meetings similar to those organized for Healthy City programmes, but with an orientation towards end-of-life care. Local authorities with an interest in Compassionate Community Care engage institutions in the promotion of their vision and in policy and decision-making.

Other groups and organizations rely upon voluntary action in order to promote Compassionate Community Care and allow communities to independently draft their own end-of-life care strategies. Here are some examples

Community development model examples

1. Community development in the voluntary sector

Summary
• End-of-life care services are involved in the promotion of public health end-of-life care programmes.
• End-of-life care service volunteers educate communities about end-of-life care.
• End-of-life care service volunteers help communities to identify their unique end-of-life care needs.
• End-of-life care service volunteers work with communities to help them design their own practices and policies that address those needs.
• End-of-life care services open up to communities to become a genuine partner in community end-of-life care.

Want to know more? **YES/Read on** **NO/Jump to next section**

End-of-life care services such as palliative and hospice care employ volunteers in order to extend and diversify their services within community settings. Their aim is to create sustainable networks of care within communities that reinforce and reproduce supportive relationships and serve peoples' needs and prefer ences at the end of lif e. Priority in these community development programmes, run by volunteers, is the community's wishes and needs rather than the delivery of services, and for this reason they usually have an exploratory and evolving character. They, therefore, lead to the development of community end-of-life care policies and practices.

Example 1: St Joseph's Hospice (Richardson 2012)

In East London, for example, the St Joseph's Hospice based in Hackney has made significant effort to reach socially excluded groups and ethnic minority communities.

Furthermore, the hospice, which has been providing care to people facing life-threatening illnesses for more than 100 years, has created partnerships with community institutions such as schools, the police and other community care organisations in order to identify needs and create spaces for people who are interested in becoming involved in the activities of the hospice and in community end-of-life care.

Volunteers are appointed to reach ethnic minority communities and create sustainable networks of care that respect their needs and wishes at the end of life.

Richardson (2012) describes the activities of the hospice in more detail. Following demand and feedback from minority ethnic communities, St Joseph's Hospice recruited and trained new volunteers – 'bridgebuilders' who work between the hospice and local communities.

Following demand and feedback from minority ethnic communities, St Joseph's Hospice recruited and trained new volunteers – 'bridgebuilders' who work between the hospice and local communities. 'Bridgebuilders' are recruited from within the communities and trained by the hospice and a local community development organisation, the Social Action for Health (SAfH).

During 2010 the number of volunteers working at the hospice increased by nearly 50 per cent, including 28 volunteers recruited and trained as 'bridgebuilders' who are in the main from minority ethnic communities. The representation of ethnic minority communities in the hospice also increased by 33 per cent.

In addition, St Joseph's Hospice is involved in promoting educational activities and encouraging people from within the communities to develop an interest in end-of-life care and talk about issues that they may find difficult. By watching others who die well they can reflect upon their own end-of-life care preferences.

Art projects and exhibitions stimulate such discussions and reflections. The hospice has also created a new physical space, which is less clinical and serves the needs of people who have been diagnosed with life-threatening/limiting illnesses, but at this early stage they have different needs. The aim of these activities and physical spaces is to make early interventions and draw the general public into the hospice, increase access to information and social support, and promote wellbeing and self management on the part of individuals diagnosed with a life-limiting condition, their families and carers.

The service is also available to the general public who would just like to learn more about end-of-life care, including bereavement.

St Joseph's Hospice is aware that a new strategy towards end-of-life care is required, one that acknowledges the diverse and changing nature of the local population, its capabilities and preferences.

A public health approach appears to be an appropriate response towards current concerns and issues because it addresses the requirement of self-management and wellbeing while it reinforces aspects of the history of St Joseph's and other hospices around innovation, local empowerment and community engagement.

In an economic climate where resources are scarce there is an additional reason to look at alternative public health models of end-of-life care. St Joseph's Hospice is making efforts towards this direction by creating partnerships and implementing community development programmes that offer new opportunities for end-of-life care, education and learning in and with communities.

Example 2: St Christopher's Hospice (Hartley 2012)

St Christopher's Hospice opened in London in 1967. It was the inspiration of Cicely Saunders who initiated the palliative care and hospice movement in the UK, and changed attitudes towards death, dying and end-of-life care. Saunders promoted the idea of acceptance and understanding of end-of-life care from the start of life-threatening/limiting illness, encouraged the view of death as a normal experience, and developed the concept of 'total pain' (Clark, 2002), which incorporates and addresses the physical, emotional, social and spiritual elements of dying.

End-of-life care takes place in the context of multi-professional working and aims to relieve distress that arises from physical, psychological, social and spiritual concerns and problems. Saunder's innovations relied upon extensive research and educational activities, which remain central to the mission of St Christopher's Hospice.

A purpose built education centre draws around 5,000 students on-site every year with a further 2,000 students being reached through outreach education programmes. The education centre runs approximately 70 training courses each year including an MSc in Palliative Care delivered jointly with King's College, London, and diplomas in both child and adult bereavement accredited by Middlesex University.
Educational activities that involve communities are considered necessary because demand for end-of-life care is likely to increase in the future. Increasing life expectancy, diversity and social exclusion, mobility, transnationalism and migration, as well as other social problems that involve drug and alcohol abuse, and diversity of illness experiences means that demand for end-of-life care will remain constant or increase.

St Christopher's Hospice has created numerous partnerships with schools interested in educating pupils about bereavement and end-of-life care as part of their curriculum. The purpose of these partnerships is to use the expertise and knowledge that hospices possess in order to support and address the aims of organisations that sit as part of the communities which hospices serve. In this way, communities are more likely to change their attitudes towards end-of-life care and dispel myths and misconceptions about death, dying, loss and care.

They are also likely to forge sustainable relationships and opportunities for community care among people who will grow to become knowledgeable about issues and problems in end-of-life care.

The St Christopher's School Projects are well planned and org anised and involve students visiting the hospice. Following some introductory educational material being presented to the students, they meet the patients and collectively they are invited to reflect upon death, dying and end-of-life care, and ask relevant questions. There is always apprehension and nervous energy in the encounters, especially among hospice staff who worry about the welfare of patients. However, instinctively both students and patients do the right thing, and patients demonstrate that they are resilient and willing to engage in social activities.

The St Christopher's School Projects are always very constructive for both students and patients. Impressions and knowledge gained are usually expressed in art, which is exhibited in other social contexts and lead to further educational opportunities. School projects that involve teenagers are particularly creative and lead to theatre and music productions and performances that travel nationally and internationally. School projects always end in celebrative events and reinforce the relationships formed between students and patients.

The feedback received from both students and patients reflects the positive experiences of both groups of participants and the change of attitudes that they undergo. They realise that dying is normal and natural and that hospices are not to be feared. Some students expressed interest in volunteering and continuing their relationship with the hospice while patients realised that they can talk about dying in social occasions.

Since 2004-2005 when the St Christopher's Schools Project was set up it has been repeated more than 40 times with different schools and age groups. However, St Christopher's Hospice is aiming to diversity its educational activities. Funding has been secured from Arts Council, England, to further develop the project into the care homes of south London over the next two years.

Plans include working with community groups other than schools, such as churches, pubs and further education colleges and universities. Hospices have the responsibility to reflect on gaps in their services and to do all they can to create new relationships and partnerships, which can furnish the communities that they serve with high quality, cost effective end-of-life care within what is becoming an increasingly complex and challenging world.

The St Christopher's Schools Project not only shows what is possible, but also illustrates the potential that hospices have to continue to innovate and challenge and also to change the way that death and dying is both viewed and experienced.

St Christopher's Hospice maintains a website with useful information about their roles in education, training and research.

For more information please visit
http://www.stchristophers.org.uk/

St Christopher's Hospice also published a document detailing its vision and community role.

For more information please visit
http://www.stchristophers.org.uk/sites/default/files/annual review/Annual_Review_2013.pdf

Community development model examples

2. Community development in the institutional sector

Summary
• Local authorities and institutions draw public health end-of-life care directions in executive committee meetings similar to those implemented in Healthy Cities programmes.
• In developing these end-of-life care directions and priorities these meetings may draw upon the Compassionate City Charter.
• The Compassionate City Charter identifies the key sectors of the community that should be encouraged to design their own policies and practices.
• These actions derived from the Charter have the potential to reorient community attitudes and practices towards death, dying, loss and care.
• Institutional action in public health end-of-life care includes marginal populations and respects cultural diversity.
Want to know more? **YES/Read on** **NO/Jump to next section**

Compassionate Cities programmes employ Healthy Cities style community development models, which are corporate and executive driven in order to design their vision and draw their implementation strategies. Institutions such as churches or schools are often part of these executive board meetings, and independently follow similar procedures in order to design their policies and practices in relation to end-of-life care.

Healthy Cities facilitate community development programmes supported by local government committees and influential power brokers within the community. These programmes have a political and corporate character. Their aim is to introduce changes in the community in order to enhance its health and wellbeing at the end of life.

This will often require events, information and institutional experiences that bring about attitude and behaviour change. In other words, a Healthy Cities programme is a programme of policy and culture change. And so is a Compassionate Cities programme in relation to end-of-life care.

Healthy Cities programmes are designed to change paternalistic policies and cultural attitudes (among professionals and in communities) that readily acknowledge 'expert knowledge' and authority in healthcare, but not local knowledge or experience with health and illness.

The objective in implementing community development programmes is for people to facilitate a participatory and partnership approach to health care. In Compassionate Cities, practice emphasis is upon death, dying, loss and care.

Healthy Cities community development programmes advocate involvement with a statutory authority, such as the local council. According to Dahl, initial negotiations take place in the context of 'community round tables' forums where anyone can come, literally to a large table – and discuss with others from the same community the problems and solutions in health or end-of-life care as they all see it.

At these round tables people are able to sort out 'needs' from 'wants', set priorities and plan the initial steps for political and social action. The character of these committees is usually political and corporate.

In Healthy Cities programmes, the involvement of local governance in the implementation of change may bring together multiple personalities, social positions and ideas in the context of public debate. This may enhance problem-solving ability and broaden the initial resources base of the program.

It may also enlist important members of the community who represent powerful agencies, or who are themselves powerful and influential figures in their communities. In Compassionate Cities, as in Healthy Cities, local government involvement can mean the development of important and sustainable gains through local policy development.

Healthy Cities programmes involve political style community development. Writing skills and the ability to network and enlist the support of diverse agencies, such as radio stations, art galleries or local schools, will be important.

Organisational and management skills are crucial to the success of any Compassionate Cities approach employing this political style. The idea is to create robust communities that are supported by their key leaders and social settings to enhance support, safety and health to a level that goes beyond the sufficiency of current services.

Community development in end-of-life care does more than community engagement, education and health promotion, and more than community based service care. It involves communities in the identification of their end-of-life care needs and the design of appropriate policies and support networks that respond to experiences of death, dying, loss and care.

The holistic and ecological nature of public health end-of-life care means that all end of life experiences are included, and new approaches develop that reorient attitudes at a national level towards the normalisation of death, dying, loss and care.

Starting from the identification of community needs and experiences rather than the relationship between healthcare services and communities, the approach highlights the diversity of end-of-life care needs, including the needs of marginal populations.

The variety of networks and interactions involved in community end-of-life care ensures that the needs of socially marginal and ill-affected groups in society are taken into consideration.

Compassionate Cities community development programmes with a corporate and professional character are important mediators that manage the process of designing and implementing public health policies and practices for end-of-life care. The Compassionate City Charter below provides an example of institutional guidance for community development that local governments and church organisations have been interested in promoting.

The Compassionate City Charter

Compassionate Cities are communities that recognize that all natural cycles of sickness and health, birth and death, and love and loss occur everyday within the orbits of its institutions and regular activities.

A compassionate city is a community that recognizes 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, 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 our lives. A compassionate city is a community that squarely recognizes and addresses this social fact.

Through auspices of the Mayor's office a compassionate city will - by public marketing and advertising, by use of the city network and influences, by dint of collaboration and co-operation, in partnership with social media and its own offices – develop and support the following 12 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 churches and temples 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 create an incentives scheme to celebrate and highlight the most creative compassionate organization, 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 recognize 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 organizations.

- 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 & higher education, charities, community & voluntary organizations, police & emergency services, and so on.

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Section 2 summary
• Health promotion in palliative care represents the first attempts to adopt a public health approach to end-of-life care.
• Health-promoting palliative care emphasizes that the principles of prevention, harm-reduction and early intervention can be effectively applied in end-of-life care.
• Education serves purposes of health promotion in palliative care and enhances health and wellbeing at the end of life.
• Health-promoting palliative care is most effective when it makes early interventions in community settings.
• A public health approach to end-of-life care involves community development.
• A public health approach to end-of-life care engages communities in developing an understanding of end-of-life care issues and building the capacity to respond to related needs.
• The transfer or delivery of healthcare services in community settings represents the narrowest understanding of community development in end-of-life care.
• Community engagement methods have been employed mainly by palliative care services to educate communities about death, dying, loss and care and create collaborative networks of care.
• The extent to which community engagement programmes allow communities to design their own end-of-life care policies and practices varies.
• Communities that address their own needs develop their understanding of end-of-life care issues that help them reflect upon their unique needs and design their own end-of-life care policies and practices.
• Palliative care services can use volunteers to help communities to identify their end-of-life care needs and develop appropriate responses to death, dying, loss and care.
• Public institutions such as schools, workplaces, local governments and religious organizations can foster end-of-life care policies and practices that meet their needs using the Compassionate City Charter.

Activity

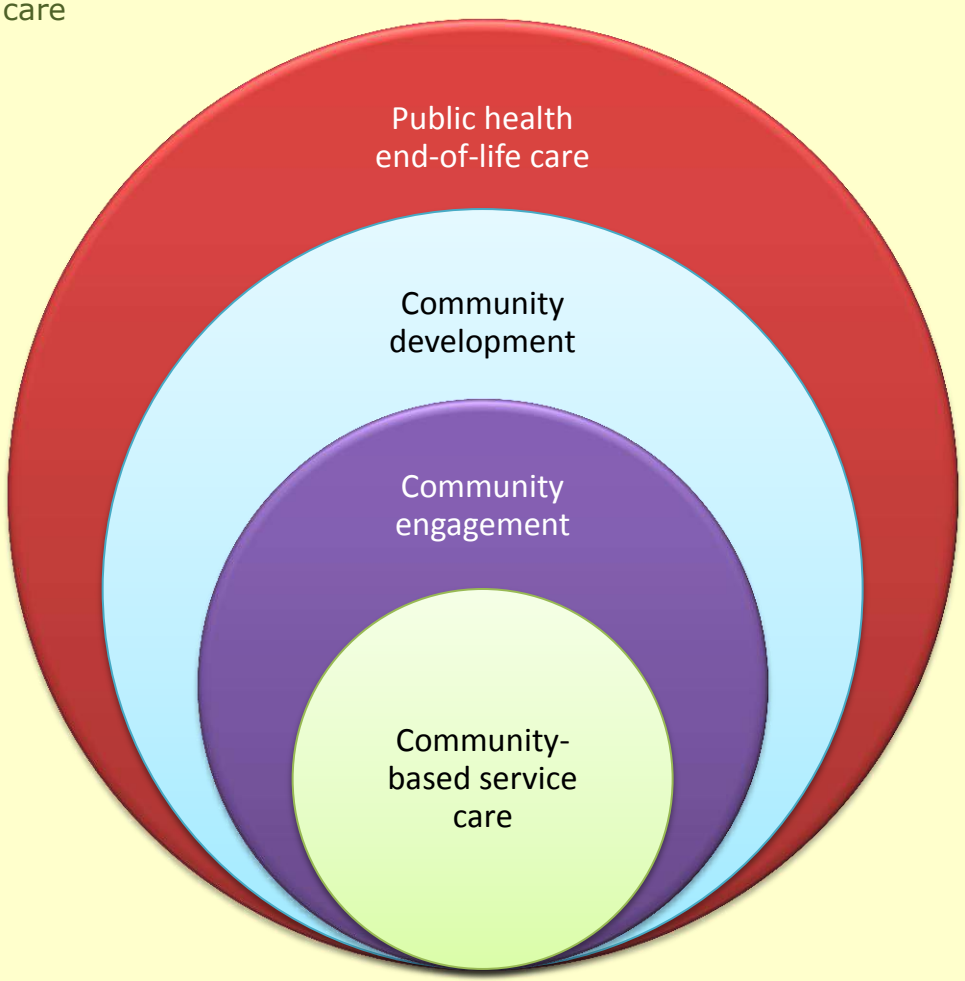
Community development for end-of-life care cannot be single-handedly implemented by services or communities alone. Local authorities can create the wider vision for compassionate community end-of-life care in the wider society and encourage social groups, institutions and communities to pursue relevant policy objectives.

Healthcare and other services can provide the resources necessary to deliver some public health end-of-life care and maintain quality of life in community settings when health is challenged.

Institutional settings and communities are then responsible to design and implement their own end-of-life care policies and materialize the vision of a public health approach to end-of-life care with compassion and companionship as their drive and objective.

Table 2.6 illustrates the progression from community-based service end-of-life care to the realization of a broader public health vision of end-of-life care.

Table 2.6: Developing a public health approach to end-of-life care



We would now like to ask you to consider the following questions. Don't exceed the time recommended for each question.

Provide examples of both as these might apply to people with protected characteristics such as populations with disability, older people, people with diverse sexual orientation or religious/ ethnic beliefs.

1. What is the difference between community development (working with) and community work (working on)? Give examples of both. (5 mins)

2. What does 'sustainability' mean in relation to community development projects? (5 mins)

3. Identify three examples of social problems in relation to death, dying, loss or caring at the end of life that are preventable or amenable to harm-reduction interventions. (5 mins)

4. Identify one or two projects that might be undertaken by a service that would qualify as attempts to prevent or harm-minimize these problems and are also sustainable. (10 mins)

5. How could a community development approach to end of life care be 'sustainable' within a service whose main mission is clinical care? (5 mins)

6. How would you go about designing and implementing a vision for compassionate community end-of-life care? What practices, approaches, and even professional priorities internal to your organization might you need to amend in order to serve this new purpose? (10 mins)

Traps for new players and how to avoid them

This toolkit has made several fundamental observations about end-of-life care and the role of a public health approach inside this field. Let's recall these now.

These are:

1. There are limits to service provision in addressing all end of life care needs but especially those related to social, psychological and spiritual experience

2. There are serious problems of access to end-of-life care services anyway, especially in rural and remote areas, some demographic groups such as ageing populations in care homes, prisoners, or the homeless, and in resource-poor countries

3. Experiences of dying, caregiving and bereavement can occur over long time periods and this means that their experiences will have a presence in a diversity of institutional life beyond the family – workplaces, schools, places of worship, the high streets and recreational venues, among many other sites.

4. Public health approaches have a powerful role to play in addressing these gaps and needs in these kinds of populations and for everyone across a wide spectrum or cross-section of communities. Health promotion and community development activities complement service goals often beginning their work where direct professional work ends.

The public health approach has a number of important methods associated with its usual work and all of these are equally relevant and valuable in end-of-life care.

These are:

1. Individual and community death education

2. Developing personal skills for end-of-life care

3. Developing community action for end-of-life care

4. Creating supportive environments for dying, death and loss experiences

5. Creating partnerships between services and community institutions

6. Encouraging health services to embrace clinical as well as community work

7. Encouraging ALL social and cultural sectors to develop end-of-life care policies, not simply the health sector

But there are several common problems with attempting to adopt a public health approach if your main education and experience as a professional is mainly in direct service provision. It is important to remember that a public health approach often requires a different way of thinking about health care.

Several common pitfalls include:

1. The tendency to work *on* rather than work *with* individuals and communities. In other words, it is common to feel that you know best or that you can take the action in the 'best interests' of the individual or community

2. The common tendency to be seduced by the prevailing view that we are a 'death-denying' society. This pop sociological view can often obscure the rival and parallel reality that many people's lived experience includes a history of loss, caregiving or serious illness and that many people do draw on this experience for their insights as well as their compassion toward others

3. The common tendency to believe that end-of-life care is solely a health care responsibility when in fact good and bad experiences at the end of life are everyone's responsibility. And provided that people are encouraged to do so, everyone can have a useful role to play in promoting health and wellbeing at the end of life irrespective of their usual social roles and occupations.

To avoid these three problems as a person working in the health professions, it is crucial to keep the following observations ever-present in all your attempts to promote a public health approach in end-of-life care.

Always, at every time, in all your work, and at all the places you might visit to offer or facilitate care – remember the following:

1. The key to all the best public health work throughout history – for clinical services and in community health work – is the development of early interventions in the service of prevention and harm reduction of a raft of threatening morbidities and mortalities. The same ethos and reasoning applies to end of life care. Clinical work and community work are essential hand-in-glove health care approaches.

2. Health promotion is not a didactic but rather a *participatory relationship between two or more parties.* Be careful not to impose.

3. Community engagement is *not* community-based care, and community development is not solely community engagement. Genuine partnerships with community display all three of these dimensions of community work because all three are essential for the health and wellbeing of communities. Be clear about the distinctive work of each approach.

4. *All societies and all ethnic groups communicate about death, dying and loss.* The challenge is to understand *who* is able to talk about these matters, *who* does not have the right, what are the best times and opportunities, and what language is best employed in these kinds of communications. And when we say 'languages' we mean 'ways of speaking' about these matters rather than dialects of speech. Death and loss are universal, cross-cultural. It is communication about these matters – and not the topic itself - where our differences are to be found.

5. Partnerships with communities that encourage communities to identify their own needs, problems and strengths in the worlds of death, dying and bereavement are a form of health care leadership that ensures that any solutions to problems come from that community and not the academic or clinical authority of professionals. Partnerships maximise cultural appropriateness at the same time as ensuring sustainability of everyone's efforts. Partnerships are absolutely essential to a public health approach.

6. Because a public health approach to end-of-life care must enlist the co-operation and commitment of social and cultural organisations such as local government, churches/ temples, schools or trade unions do not assume there is only one way to do this. If you are intimidated by the prospect of meeting the local mayor, newspaper editor, radio personality or trade union leader you can begin slowly and incrementally. Sometimes, volunteers in your organisation can provide good direct supports to dying people, families and the bereaved, but they can just as often supply introductions to new contacts and social networks. Sometimes an advertisement or public meeting can attract these new contacts and influential figures. Never assume there is only one way to do community development, or to put it another way, never assume there is one way to develop your community.

7. And remember, if any of your community projects rely on your continued involvement this must mean that these projects are not sustainable and this fact probably also means that the projects have poor community buy-in or ownership. The sustainability of your projects is the measure of their success as public health interventions.

Evaluating Compassionate City programmes

The complex and highly individualised character of community development programmes in end-of-life care mean that they need to be regularly evaluated in order to refine practices, assess their impact and outcomes and identify the unique purposes that they serve in each context.

All planned community development activities, and especially those funded or supported by local authorities and services, should be evaluated in order to enable an assessment of the value or worth of the intervention that they make (Naidoo and Wills, 2009: 287). The evaluation will ensure continuing support and will add to the credibility of community work.

Evaluations serve different purposes for the various stakeholders involved in community development programmes. For professionals or community workers they provide the necessary feedback that their programmes are working (or not).

Evaluations also tell them whether the programme is worth continuing or whether it may be successful in a different context. For local authorities or funders, evaluations indicate whether their resources have been spent well and where and in what areas they might continue to be most usefully channelled.

For community members, evaluations provide opportunities to refine their policies and end-of-life care practices to ensure that their needs and problems are being addressed effectively.

Evaluations are essential simply because it is only through feedback that we gain wisdom and insight into whether our new practices are working in the way that we had intended.

Table 3.1: Reasons for which evaluations of public health end-of-life care programmes are necessary:

1.	They assess outcomes and highlight the purposes that community development programmes serve.
2.	They are necessary if communities are to acquire continuing support from local authorities and add to the credibility of their work.
3.	They obtain feedback used to improve the skills and practices of professionals and community workers.
4.	End-of-life care programmes need refinement and assessment to decide whether they are worth continuing or whether they can be adopted by other or different communities.
5.	End-of-life care policies and practices need ongoing revision and evaluations help to identify what is needed in each context.
6.	Regular evaluations improve skills and practices and lead to greater independence and empowerment of communities.

In public health a combination of quantitative and qualitative methods are employed to carry out evaluations of community development programmes and other interventions. The experimental research design (Randomized Controlled Trials) is generally preferred by medical researchers and is considered the 'gold standard' of research designs. However, the evaluation of community development programmes in end-of-life care could potentially be very complicated because these interventions involve a number of stakeholders who often have diverse interests and want to know different things about a single programme.

In this case, a multi-method approach would be more useful. In addition, it would be unethical to conduct an experimental research design and compare groups that developed their knowledge about death, dying, loss and caring in community development programmes with groups that did not have this type of experience.

The sensitivity of the topic would require a 'softer' approach to research than the Randomized Controlled Trial (RCT) allows.

The case study where a single community development programme is the 'case' being evaluated may be a more suitable research strategy in public health end-of-life care. This means that the programme will be scrutinised in order to reveal details of what is happening and which aspects of it have been effective.

Surveys can be employed to serve the same purpose and they are often combined with interviews, observations and content analysis of documents in order to meet the multifaceted needs of evaluations in end-of-life care.

The rise and fall of specific service use, number and type of supportive interactions at home, levels of depression and anxiety in target groups, the number and quality of end-of-life care policies developed in different community sectors (e.g., schools, faith-groups, workplaces etc.) can all be recorded as part of an evaluation.

Community end-of-life care evaluations of development programmes can be employed to assess the *process* of:

1. Educating communities about death, dying, loss and caring.
2. Establishing collaborative relationships with various stakeholders.
3. Creating networks of care in communities.
4. Designing end-of-life care policies and practices that serve the unique needs of schools, workplaces, religious and other organisations.
5. Changing attitudes towards death, dying, loss and caring.

As well as:

6. Practical changes/outcomes to the social epidemiology of living with dying, caring and bereavement.

Community workers may be interested in evaluating the process of their programmes in order to improve their professional practice.

Community members may be equally interested in the results of process evaluation because in Compassionate Cities they are the main drivers of community development.

Overall, process evaluations are part of the practice of evaluating the effectiveness of community development programmes.

However, **impact** and **outcome** evaluations are generally the standard type of community development programme assessment. Naidoo and Wills (2009: 293) make a distinction between impact and outcome evaluation:

- impact – the immediate effects or outputs of a programme such as increased knowledge, or decrease in anxiety or social isolation.
- outcome – the longer-term effects such as positive changes in lifestyle for people living with life-limiting conditions, carers or the bereaved.

Community development programmes are commonly evaluated right after they finish through they may also document the changes as these occur. Participants are asked about their experiences since connecting with the programme and the differences that the intervention made to their life practices, experiences and beliefs.

However, in closely-knit communities and in on-going programmes deeper and more complex outcome evaluations may be possible and useful in highlighting the progressive and long-term changes in people's attitudes and experiences.

Questions in community development programme evaluations need to be worded carefully in order reveal the changes that the intervention made to participants' practices and the results that these had upon their health and wellbeing.

A programme evaluation in end-of-life care may ask participants to describe using examples the difference that the particular programme made to their responses to issues of death, dying, loss and care. The impact of established polices and practices may also be examined in detail.
Problems and challenges encountered in the process of developing end-of-life care policies and practices may be openly communicated to improve future community development

The following links provide guidelines for community development programme evaluations:

- Learning, Evaluation and Planning (LEAP) by the Scottish Community Development Centre (SCDC) http://www.scdc.org.uk/what/LEAP/ . SCDC has also published a 'Manual for Learning Evaluation and Planning in Community Learning and Development' http://www.scotland.gov.uk/Resource/Doc/205858/0054730.pdf

- Community Tool Box, Chapter 36: Introduction to Evaluation http://ctb.ku.edu/en/table-of-contents/evaluate/evaluation

- The Community Development Evaluation Framework by `the Local Government Association of South Australia – The Voice of Local Government http://www.lga.sa.gov.au/page.aspx?u=2443

Useful Resources

If the public health approach to end-of-life care is new to you the following resources will provide a basic introduction to the issues addressed in this toolkit.

Kellehear, A. (1999) *Health Promoting Palliative Care.* Melbourne, Oxford University Press.

Kellehear, A. (2005) *Compassionate Cities: Public Health and End-of-Life Care.* Oxfordshire, Routledge.

Naidoo, J., and Wills, J. (2009) *Foundations for Health Promotion.* Third Edition. Elsevier.

If you are already familiar with the public health approach to end-of-life care the following resources may further add to your understanding.

O'Mara-Eves, A., Brunton, G., McDaid, S., Oliver, J., Famal, F., Matosevic, T., Harden, A. and Thomas, J. (2013) Community engagement to reduce inequalities in health: A systematic review, meta-analysis and economic analysis. *Public Health Research,* Vol. 1(4).

Sallnow, L., Jumar, S. and Kellehear, A. (2012) *International Perspectives on Public Health and Palliative Care.* Oxon, Routledge.

Sallnow, L. and Paul, S. (2014) Understanding community engagement in end-of-life care: developing conceptual clarity. *Critical Public Health,* April 2014.

The Centre for Critical Public Health focuses research on the multiple experiences, values, and beliefs of people whose voices are often left at the margins.

This centre also offers a list of important publications for further reading. Please visit http://criticalpublichealth.org/readings-in-critical-public-health/

Useful Resources

For everyone the following organisations specialise in public health and/or public approaches health end-of-life care. In their websites you will find useful information, additional educational resources and opportunities, links to related websites and organisations, further examples and ideas about community development in end-of-life care, public health and health promotion.

Public Health and Palliative Care International: Developing Compassionate Communities (PHPCI) is an association that communicates the importance of public health ideas and approaches in palliative care. Its mission is to promote a health-promoting philosophy and attitudes, offer opportunities for practice learning, research and development, professional support and international communication between members promoting a common endeavour.
Please visit http://www.phpci.info/

Good Life, Good Death, Good Grief is an alliance established and hosted by the Scottish Partnership for Palliative Care. It brings together organisations and individuals interested in raising public awareness of ways of dealing with death, dying and bereavement, and promoting community involvement in end-of-life care.
Please visit http://www.goodlifedeathgrief.org.uk/

Public Health England (PHE) was established by the government on April 1st 2013, in order to bring together health professionals and researchers in collaborative partnerships that help improve the nation's health and wellbeing, and reduce health inequalities. Public Health England is responsible for consulting the government, the NHS, local governments, as well as, other people and organisations about health issues. Public Health England supports health promotion and protection, and is actively involved in research, training and development. Please visit https://www.gov.uk/government/organisations/public-health-england

Public Health England has created the **National End of Life Care Intelligence Network** to help improve the collection and analysis of information related to the quality, volume and costs of care provided by the NHS, social services and the third sector to adults approaching the end of life. Please visit http://www.endoflifecare-intelligence.org.uk/ho

Institute of Health Promotion and Education (IHPE) is a professional association that brings together people engaged in the practice of health promotion and health education. Please visit http://www.ihpe.org.uk/home/index.htm

The **European Commission** offers a wealth of information about health research and innovation, health promotion and international public health and health systems. Please visit http://ec.europa.eu/research/health/public-health/index_en.html

Glossary

Community-based healthcare service: healthcare services applying their services in community settings. In this way, healthcare services care for a greater range of needs and experiences.

In end-of-life care, service delivery in community settings often lead to the development and organization of home care teams that allow people to die at home.

Community development: development programmes aim to empower communities to design their own responses that support and promote health and wellbeing.

In end-of-life care a community development approach involves local authorities, social services, cultural institutions and faith organizations into reflecting and responding to death, dying, loss and care. Community development in end-of-life care provides holistic approaches and changed attitudes towards the end-of-life and its care.

Community engagement: healthcare service attempts to engage communities in their own care by providing education, information and support. Healthcare service delivery extends to community settings and includes a greater range of needs and experiences by promoting health education for the purposes of prevention, harm reduction and early intervention of social troubles relating to the end of life.

These are practices most effective in community settings where people diagnosed with life-threatening/limiting illnesses continue living their lives among family and friends.

Compassionate communities: communities that promote a public health approach to end-of-life care that relies upon the ethics and practice of compassion – the human capacity to withstand another's suffering and share responsibility in care. Compassionate communities make a commitment to care for people with end-of-life care needs.

Towards this end they design suitable polices and practices and establish networks of care and sustainable relationships that protect, support and respond to death, dying, loss and care. Compassionate communities share most of the characteristics of Healthy Cities but with an orientation towards death, dying, loss and care.

Early intervention: action taken to make an intervention early before health issues become problems. This could involve screening or pre-symptomatic intervention. In end-of-life or palliative care early intervention involves a mixture of medical, psychological, spiritual and social approaches to care.

End-of-life care: End-of-life care is not merely or solely terminal or palliative care. It includes all care within the community for issues and experiences that have a morbidity and mortality burden associated with death, dying, caregiving and loss. End-of-life care includes care for life-threatening and terminal illnesses shared between professional services and communities, families and friends.

Sudden deaths from road traumas, suicides and accidents also present end-of-life care issues amenable to prevention, environmental change and policy intervention. Bereavement, loss and dispossession equally have a morbidity and mortality burden associated with death, dying and loss.

Education and health promotion within the community in partnership with services can reduce the harm caused by these experiences.

Harm reduction/risk minimization: action taken to reduce known risk factors to health and wellbeing.

Healthy Cities: Healthy Cities represent new policy directions in public health that emphasize health promotion, education and community. Healthy Cities aim to reduce inequalities that impact negatively upon health and wellbeing by promoting cooperation and partnerships between communities, governments and services in order to create opportunities within supportive and healthy ecological environments. Cities are considered to be a suitable basis for analysis and development in public health policy because they often are the lowest administrative level (compared to regional or federal governments/authorities), which can manage resources and have the political authority to develop and implement inter-sectorial approaches to health.

Health education: the communication of health-related information and the development of attitudes, skills and confidence necessary to enable people to take action to improve their health.

Health promotion: emphasizes that health involves social, political and environmental action to change the determinants of health and improve it. Health promotion is the process of enabling people to increase their control over, and improve, their health (World Health Organization, 1986).

Health-promoting palliative care: the adoption of health promotion principles and practices specifically by palliative care services. This includes an emphasis on early intervention for physical, social, psychological and spiritual troubles associated with dying, caregiving and loss.
Major health promotion methods such as health and death education, community development and/or engagement, policy development, or social marketing are promoted in both patient and non-patient community populations. These initiatives are usually led and managed by palliative care services and are usually additional functions beyond the clinical services provided.

Life-limiting illness: illness that will shorten life expectancy such as dementia, motor neuron disease and advanced malignant forms of cancer.

Life-threatening illness: illness that poses a serious threat to life, but may not necessarily cause early death. People with life-threatening illnesses may live for prolonged periods in their communities, provided that they receive treatment and engage in good medical and health-promoting care. HIV and many cancers are life-threatening illnesses.

Terminal illness: refers to the final days and hours of life.

Palliative care: palliative care helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement.

It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support (National Council for Palliative Care, 2006).

Prevention: measures taken to prevent disease or slow its progress. Prevention is achieved through harm reduction, risk minimization and early intervention strategies.

Sustainability: meeting the needs of the present generation in a way that does not compromise the ability of future generations to meet their needs.

Sustainable health promotion actions are embedded in services and structures so that their positive effects continue beyond the life of the programme or intervention.

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