An Overview of Compassionate Communities in England

Murray Hall Community Trust

National Council for Palliative Care
Dying Matters Coalition

July 2013

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Report compiled by Veronica Barry and Manjula Patel

Murray Hall Community Trust
Neptune Health Park
Sedgley Road West
Tipton
West Midlands DY4 8LU

National Council for Palliative Care Dying Matters
The Fitzpatrick Building
188-194 York Way
London N7 9AS

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The National Council for Palliative Care

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. NCPC leads the Dying Matters coalition.

Web: www.ncpc.org.uk
Email: enquiries@ncpc.org.uk
Tel: 020 7697 1520
Fax: 020 7697 1530

Registered Charity no.1005671

The Dying Matters Coalition

Dying Matters is a broad based and inclusive national coalition of almost 30,000 members which aims to change public knowledge, attitudes and behaviours towards dying, death and bereavement. This will involve a fundamental change in society in which dying, death and bereavement will be seen and accepted as the natural part of everybody's life cycle. Changes in the way society views dying and death have impacted on the experience of people who are dying and bereaved. Our lack of openness has affected the quality and range of support and care services available to patients and families. It has also affected our ability to die where or how we would wish.

Dying Matters is working to address this by encouraging people to talk about their wishes towards the end of their lives, including where they want to die and their funeral plans with friends, family and loved ones. Talking about dying makes it more likely that you, or your loved one, will die as you might have wished and it will make it easier for your loved ones if they know you have had a 'good death'. Dying Matters provides information and resources to help people hold those vitally important conversations, and plan for living and dying well.
Web: www.dyingmatters.org
Email: info@dyingmatters.org
Tel: 08000 21 44 66

Murray Hall Community Trust

Murray Hall Community Trust, based in Sandwell, West Midlands, is an independent, community led charity which acts as a community anchor. We develop and provide holistic solutions to local problems and challenges and bring out the best of local people and partnership agencies.

Murray Hall Community Trust delivers a range of services and opportunities, for the needs of children and families through to people needing end of life care. Its Bridges Support Service, known nationally for its pioneering work, supports people not only at the end of their life but through the palliative care journey. The service has tremendous

support from people in the local community. The Bridges service is featured in the End of Life Strategy (DOH 2008).

Murray Hall Community Trust was set up in 1992 and is a driving force in community renewal, and Public Health development. The organisation has a unique position of being connected both at a grass root level with people at end of life and a strategic level. It understands the implication of proposed Government changes within the NHS and the emphasis on 'Big Society' and community development. Murray Hall Community Trust has established strategic alliances with different services and organisations across all the different programmes. These partnerships ensure the organisation has greater engagement and reach, and help formulate new strategic innovations. The organisation takes a community development – asset based approach and works very closely with community groups. We have worked with community members on many different projects.

Murray Hall Community Trust was one of the first of four organisations in the West Midlands to begin to deliver a Compassionate Communities Projects. The other three organisations included Hospices from Birmingham, Telford and Kidderminster. Together we became a learning set for this pioneering work.

Murray Hall Community Trust
Neptune Health Park
Sedgley Road West
Tipton
West Midlands
DY4 8LU

Telephone: 0121 612 1900
Email: info@murrayhall.co.uk
Web: www.murrayhall.co.uk

Registered Charity no: 1040170

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Foreword

I am delighted and honored to introduce this first national report on the adoption and spread of Compassionate Communities.

For decades now, most people have embraced the 1980s call for communities to take more responsibility for their own health. Since that time, most people have become aware and committed to responsible and balanced lifestyles incorporating better nutrition, eating habits and exercise, the control, reduction and even elimination of drug and alcohol use, the importance of balancing work and recreation, and an awareness and avoidance of harmful environments and substances. However, the application of prevention, harm-reduction and early intervention ideas in matters to do with death, dying, loss and care is new. Compassionate Community programs help us make just these kinds of connections and shifts in thinking by enhancing a community's capacity to reach out to each other and learn more about these mortal verities. Families, neighbours, friends, workplaces, schools, businesses, and places of worship then become sites for genuine support, care, information, networking, and greater learning about end of life care. This is the fundamental meaning of a Compassionate Community.
This report reveals that Compassionate Communities come in a wide variety of shapes and sources. They are united by their desire to increase their community's resilience, support, and openness toward those affected by death, dying, and loss. This report describes not only how Compassionate Communities as an idea and as a community practice are rapidly spreading in England, but also how the enthusiasm for these communities are a logical development of the worldwide health promotion movement. This is a movement that has reminded us that good health services are only one small part in the development and maintenance of individual, family and community health and wellbeing. Individuals, families and communities *can* (and now do) play major roles in their own health care. We now look toward a time when our communities will play similar roles in the physical, psychological, social and spiritual challenges at the end of life itself.

I commend this report and its recommendations to all readers.

Professor Allan Kellehear, PhD., AcSS
Department of Community Health & Epidemiology
Dalhousie University, Nova Scotia, Canada.

Executive Summary

This is the first time a scoping exercise of this kind has been undertaken in England. It is anticipated it will help give an overview of the development of Compassionate Communities in England, in addition to generating an interest in the formation of a Network to move the work forwards.

In order to gather information about Compassionate Communities work in England, a short call out survey was designed, using 'Native Eye' software. This was launched via the Dying Matters website in August 2012, and remained live until the end of October 2012.

In all, by the end of February 2013, a total of 32 people responded to the survey callout, and follow up interviews were carried out. From these responses 28 case studies were written up.

The case studies given illustrate the breadth of approaches and interpretations of the vision being currently applied across England. In keeping with Kellehear's concept, there was a broad range of groups, organisations and individuals involved. Some of their work had been inspired by Compassionate Cities as well as by the models found in Australia, Ireland and Kerala, in India. Others were developing their own interpretations of the approach.

There are diverse examples of the ways communities are engaged in supporting those facing end of life, loss, and bereavement, and of professionals working closely with communities to support this aim. Communities do have the skills, knowledge, expertise and a role to play a strong partnership in end of life care; this needs to be recognised and embraced wholeheartedly. Barriers and opportunities to developing Compassionate Communities were voiced. Most of those currently working with Compassionate Communities do not have full awareness of a wider network, some work in isolation. Some groups found the mechanisms and tools for setting up Compassionate Communities unclear and were keen to learn more. There is a balance to be struck between a loose interpretation of Compassionate Communities and the need for authenticity of approach, guiding principles and clarity of context

Recommendation includes:

- Establish a network and share information about Compassionate Communities.
- Arrive at a clear understanding of the Compassionate Communities approach in order to disseminate the message.
- Support the establishment of an environment in which Compassionate Communities could develop and thrive.
- Influence strategic policy development for End of Life Care.

Introduction

Towards the end of the end of 2011 discussions took place between Murray Hall Community Trust and the National Council for Palliative Care about the potential for a Compassionate Communities Network.

The National Council for Palliative Care were interested in supporting Dying Matters members into taking forward a more practical element to raising awareness about end of life care in the community.

Murray Hall had been part of a group of four organisations that started to develop Compassionate Communities across the West Midlands from 2009. This work benefited from joint meetings between the Strategic Health Authority End of Life Lead and other groups, in order to share ideas and discussions. The group found it beneficial to be part of this learning set when developing Compassionate Communities, so as this arrangement came to an end they suggested the establishment of a network.

The Compassionate Communities approach started in England over five years ago. Although we were aware of others across the country developing Compassionate Communities, we had no idea of whom or how many people were involved.

The first priority was to establish how many people were involved in Compassionate Communities, where they were being developed, and to gauge their thoughts about a Network and its role.

Funding was secured by the National Council for Palliative Care to work in partnership with Murray Hall Community Trust. In July 2012 a part time Compassionate Communities Network Facilitator was recruited, and hosted by Murray Hall for the period of the work.

The aims of the scoping study were to:

- Discover and make contact with as many people who are or had been involved in developing Compassionate Communities in England.

- To engage with them and understand what, how and where Compassionate Communities work was happening.

- To gauge if there was an interest in being involved in a Network and what would be expected of this role.

This is the first time a scoping exercise of this kind has been undertaken in England. It is anticipated it will help give an overview of the development of Compassionate Communities in England, in addition to generating an interest in the formation of a Network to move the work forwards.

1. Overview of Compassionate Communities

Compassionate Communities is a Public Health approach to end of life care. It encourages communities to support people and their families who are dying or living with loss. It aims to enable all of us to live well within our communities to the very end of our lives.

The term 'Compassionate Communities', came from the concept of 'Compassionate Cities', developed by Professor Allan Kellehear, an Australian Public Health academic. He reminded us that health is everyone's responsibility, and that this includes death, dying and end of life care. His vision of 'Compassionate Cities' appeared in the book of the same name in 2005 (*Compassionate Cities: Public health and end of life care 2005).*

1.1. Background to Compassionate Communities

Professor Kellehear was influenced by the work of the World Health Organisation (WHO) and its approach to health developed during the 1980's.
This includes:

- WHO's Ottawa Charter for Health Promotion. This demonstrated a way for people to increase control over their health, through development of personal skills, creation of supportive environments, strong communities and healthy public policies (WHO 1986).

- WHO's 'Healthy Cities' model which sees health as the responsibility of society as a whole. It promotes a Public Health approach to support communities to take responsibility for their own health and to encourage each other to live as well as possible (WHO 1986).

- WHO recognises that community development can help to engage communities to identify needs and assets, and galvanise collective efforts to improve health (WHO, 1998). A community development approach helps to build 'social capital' through enhancing community networks and build resilience. It emphasises working *with* communities rather than *for* them, to find solutions, build on existing skills and knowledge, and create meaningful partnerships.

With the development of 'Compassionate Cities,' Allan Kellehear brought end of life care firmly into the concept of 'Healthy Cities.' He filled in a missing element by pointing out that end of life should be seen equally as part of health, recognised for its relevance within the whole life course. Healthy Cities (Compassionate Cities) are whole communities - sometimes actual cities and sometimes simply a linked group of villages and towns - that decide to promote the health and well-being of their communities in a systematic and holistic way.

1.2. Defining features of Compassionate Communities

The theoretical characteristics of Compassionate Cities as described by Kellehear draw on the principles of Healthy Cities and are outlined below.
A Compassionate City:

- Has local health policies that recognise compassion as an ethical imperative.
- Meets the special needs of its aged, those living with life threatening illnesses, and those living with loss.
- Has a strong commitment to social and cultural differences.
- Involves grief and palliative care services in local government policy and planning.
- Offers its inhabitants access to wider variety of supportive experiences, interactions and communication..
- Promotes and celebrates reconciliation with indigenous peoples and memory of other important community losses.
- Provides easy access to grief and palliative care services.

(Kellehear 2005 pp. 46)

In the Compassionate Cities vision, Professor Kellehear suggests that care for those dying or experiencing loss should involve the whole community through a 'health promoting' approach, (sometimes called Health Promoting Palliative Care). He argues end of life care isn't simply about hospice and palliative care services, or even confined to care of older people and the bereaved, but includes whole communities as part of the picture. Public Health should embrace end of life care, and death and dying should be seen not just as a medical, but a social issue. In fact, end of life care should be everyone's business. Through the Compassionate Cities (Communities) approach:

- Death, dying and bereavement would cease to be taboo subjects and would become more normalised within society.
- People's expectations of death and dying would change, as would how death is managed.
- Palliative care would re-orientate, supporting health and social care staff to work with the community in providing care to those at the end of life, and their loved ones.

The Compassionate Cities approach was summarised by Janet Shucksmith at Teesside University 5th Palliative Care Conference (2011), who identified the following four mechanisms for developing Compassionate Communities:

- Healthy Cities model - policy change through lobbying.

- Community Development model - development of community capacity; grass roots campaign.

- Community focused professional or volunteer adding community development function to their role.

- Community activism from someone who has concern with a health issue or personal experience.

(Kellehear 2005: 117-136)

Internationally, there are strong examples of the Compassionate Communities approach, both in Australia, and in Kerala, India and in Ireland. April 2013 saw the Third International Public Health and Palliative Care Conference in Limerick, Ireland, convene to showcase much of this work.

1.3. Wider context

There is growing recognition that the way we approach end of life care in England is unsustainable. Demographic changes, brought about by an ageing population, and coupled with diminishing resources, means we will have to explore new ways in which death can be managed. The 2008 End of Life Care Strategy and subsequent annual reports recognised some of these challenges, and have made an attempt to support a more joined up approach to end of life care (DOH 2008).
However, it is clear that many of us will not die how or where we imagined, and that fear within society towards death hinders us in achieving the type of death we would like.

- The annual number of deaths is predicted to rise from 503,000 in 2006 to 586,000 in 2030.

- In England every year, the majority of deaths occur in adults over 65 years old, often following a period of chronic illness and frailty (*National Council for Palliative End of Life Care Manifesto 2010, 2009).*

- A recent survey found that whilst 68% of people said they were comfortable talking about death, less than a third (29%) of people have discussed their wishes around dying. Only 4% have written advance care plans.

- Around 70% of people would prefer to die at home, yet of the 500,000 people who die each year in England, around 60% die in hospitals.

(*Dying Matters NatCen Survey, 2009)*

Compassionate Communities calls for a new approach to end of life care. It suggests a reconfiguration of services where the wider community would become involved once again in supporting those at the end of life, working in partnership with health professionals.

'Those of us in palliative care…. need to learn and be supported by those in Public Health who understand and have practice experience with community development, health promotion, policy reform and social and political change. Without their support, active encouragement and partnership in end of life care will remain in its institutionalized origin' (A. Kellehear & L. Sallnow, 2012).

1.4. Compassion in wider society

In addition to awareness of the need to change the way death is managed, there is no doubt that there is now a growing interest in the concepts of community engagement and compassion that reaches beyond end of life care, and into health and society as a whole. Compassionate Communities can support this development.
Recent developments include:

- In November 2012, Dying Matters with the Chief Nurse of Heart of England NHS Foundation Trust launched a three-year long compassionate care training programme. 6,000 nurses at the Trust's three hospitals - as well as those in affiliated community services will undergo the training, which is aimed at better equipping them to care for and support people at the end of their lives (www.dyingmatters.org).

- Launch of 'Compassion in Practice' strategy in December 2012 by England's Chief Nursing Officer Jane Cummings. She stated, 'We need to change the culture of the NHS to put care and compassion at the heart of what we do' (http://www.bbc.co.uk/news/health-20583115).

- Calls for a more compassionate approach within health care, following recent publication of the Francis Report (February 2013).

- Help The Hospices have been developing thinking around the role of community in end of life care, and this was brought to the forefront during the conference in November 2012 titled 'Community Engagement, Back to our Future.' Chief Executive of Help the Hospices, David Praill commented in the key note speech, 'As we face an ageing population and biggest shake-up of our health and social care systems for a generation, it is more important than ever that hospices find new ways of reaching out to their local communities so they can continue to help seriously ill people and their families to live well.' (www.helpthehospices.org.uk).

- Dr Libby Sallnow, and Sally Paul in a recently published article (February 2013) explored the attitudes and involvement of over 220 palliative care providers across the UK, to Public Health approaches to death and dying. They found a broad understanding and interpretation of the terms 'community engagement', 'health promoting palliative care', and 'Compassionate Communities' (*BMJ Support Palliative Care* doi:10.1136/bmjspcare-2012-000334).

- At 3rd International Palliative Care and Public Health Conference in Milford Care Centre, Ireland (April 2013) it was agreed to form a new network. The 'International Association of Public Health and Palliative Care- Developing

Compassionate Communities', will develop a network to share good practice with proposed national leads for each country involved.

- Charter for Compassion launched internationally in 2009 embeds compassionate action at the centre of religious, moral and political life (www.charterforcompassion.org).

2. Compassionate Communities: A Scoping Study

2.1. Scoping

A Compassionate Communities Network Facilitator was recruited in July 2012. Initial meetings were then held with Dying Matters and Murray Hall Community Trust to establish the scope of the work. It was agreed that the survey would work to try to determine which groups and individuals were working across England under the banner of Compassionate Communities. This would result in a scoping report which might help to ascertain the feasibility of establishing a network of Compassionate Communities.

It was recognised that there is much work going on in end of life care by a huge range of groups, falling under the banner of 'community engagement' or 'community led'. It was felt that to look at all these initiatives would be too ambitious, and the report needed to limit itself to acknowledged Compassionate Communities or public health approaches to end of life care.
Short questions were developed in order to gather summary information, with longer more in depth questions for follow up, designed to explore key themes that were seen as important. These were edited and agreed upon before the project was launched.

During this time background information was gathered about Compassionate Communities from a variety of sources including books, journals, web research, national and international examples. In addition, the project worker was able to attend a number of conferences to facilitate networking, such as the 'Day of the Dead' in October 2012, and 'Compassion and Empathy in Healthcare' event in November 2012.

2.2. Callout

In order to gather information about Compassionate Communities work in England, a short call out survey was designed, using 'Native Eye' software. This was launched via the Dying Matters website in August 2012, and remained live until the end of October 2012 as follows:

'The Dying Matters Coalition is working in partnership with Murray Hall Community Trust (a charity and health development agency based in the West Midlands). They are hoping to find out more about English organisations, individuals and groups involved in Compassionate Communities in England. We know that there is some great work going on, but we would like to find out more about this - who's doing it, where it's based and how best to share examples of good practice. We'd also like to hear about Compassionate Communities projects that ended recently. If you are working on themes that reflect Compassionate Communities approaches, or know of others doing this work, please help us by filling in the quick survey below,' (see appendix).
http://dyingmatters.nativeye.com/compassionate-communities

During this time, the callout was circulated as broadly as possible, via existing Dying Matters and NCPC and Murray Hall membership, through newsletters, regular twitter feeds http://goo.gl/655ZN , and Facebook. It was also circulated through journals such as 'Inside Palliative Care', and PCT newsletters.

2.3. Follow up

Once a response had been made to the survey, the project worker followed this up by arranging to carry out semi- structured interviews. These were made via phone calls or though face to face meetings, and lasted between thirty minutes to an hour. Each respondent varied in approach and background. The interviews were informal, and focused on conversation, with a questionnaire as a guide. Phone interviews were written in note form, and face to face interviews were recorded on a tape recorder and notes were written down soon after.

Carrying out face to face interviews was beneficial as it enabled the project worker to see the diversity of approaches at first hand. Some conversations gave an opportunity to share literature, and examples of Compassionate Communities projects to those who had not come across Allan Kellehear.

2.4. Responses

In all, by the end of February 2013, a total of 32 people responded to the survey callout, and follow up interviews were carried out. From these responses 28 case studies were written up.

Respondents came via the following sources;

- Native Eye survey via Dying Matters website.
- Journals, newsletters.
- Links to known Compassionate Communities.

Of the respondents, 24 had heard of Allan Kellehear, and had some understanding about the Compassionate Communities approach. 8 had not, but had responded to the title Compassionate Communities on seeing the callout, feeling that their work incorporated these terms in its approach.

Of the 24, most had awareness of a few others working with Compassionate Communities in England, but none had the full overview of the work being carried out. Some however, had been unaware of any other groups or individuals using this approach, and had been working in isolation.

Respondents represented a broad range of backgrounds including:

Academia/ PHD student	5 respondents
Voluntary organisation/ CIC	5
Hospice:	9
Funeral celebrant/advisor	2
SHA/NHS	3
Public Health	2
Individual	3
Faith	1

(N.B. 2 had dual functions overlapping between categories and are thus shown twice)

2.5. Report

Once all the information was gathered, short case studies were compiled to illustrate the breadth of work being carried out across England. All case studies were checked by the respondents for accuracy and edited as a result.

Based on the findings, the scoping report was written up, grouping responses into thematic areas, and using quotes from interviews to illustrate the findings. The draft report was checked by both Murray Hall Community Trust and Dying Matters.

The report is an attempt to give an overview of the work being undertaken under the Compassionate Communities banner in England. It is a reflection of those who came forward in response to the callout, and other links that were followed up. It is probable that there will be other groups working to the aims of Compassionate Communities who have not been included in the report, and it is hoped that this work will bring them forward to share ideas and good practice with others.

3. **The Compassionate Communities Case Studies**

The following are the case studies (in alphabetical order) which speak for themselves as to the range of work being carried out under Compassionate Communities. (They include one example from Scotland and one from Guernsey which responded to the call out).

3.1. Bath University, The Centre for Death and Society (CDAS)

Overview
This is the UK's only centre devoted to the study and research of social aspects of death, dying and bereavement. Established in September 2005, CDAS facilitates research, education, training, policy development, media, and community awareness.

Compassionate Communities
Professor Allan Kellehear was director of CDAS from 2008-11 and developed his thinking around Compassionate Communities and health promoting palliative care during this time.

Professor Tony Walter took over as Director in 2011 and has continued to support the development of compassionate communities. As an academic sociologist, he has researched and co-written a number of articles on Compassionate Community networks.

Tony spoke at the Cumberland Lodge conference November 2012 'Changing Expectations of Death' www.cumberlandlodge.ac.uk

In 2013 he will be speaking about compassionate communities at a range of venues including John Taylor Hospice, Birmingham; Sue Ryder Care Centre, University of Nottingham; NHS South of England conference on 'Community Development: The next step forward for end of life care'.

Resources
(2011) Abel, J., Bowra, J., Walter, T. and Howarth, G. Compassionate Community networks: supporting home dying. BMJ Supportive & Palliative Care, 1 (2), pp. 129-133.

Further articles on compassionate communities are to be published in BMJ Supportive & Palliative Care and in the British Journal of Social Work in 2013.
NHS South of England conference on Community Development: The next step forward for end of life care, April 22nd 2013.
http://www.ehospice.com/uk/Events/tabid/1060/smid/3675/EventType/0/Audience/0/Country/0/Region/0/language/en-GB/Default.aspx?NewArticleId=1218

Website
www.bath.ac.uk/cdas

3.2. Birmingham St Mary's Hospice

Overview

Birmingham St Mary's Hospice (BSMH) has been providing palliative care services for the Birmingham area since its start in 1979. In addition to a 25-bed inpatient unit where people can stay for respite care, Birmingham St Mary's has a 20-place Day Hospice, and provides support to about 300 patients in the community. Day hospice runs a range of activities including complementary therapies, art, creative projects and opportunities for relaxing and chatting to other patients and staff. The hospice also has a Family and Carer Support team who provide social work and spiritual care support to patients including bereavement support and counselling.

Compassionate Communities

Concerned with the apparent low uptake of hospice services from the Black and Minority Ethnic (BME) communities, the hospice was keen to reach out and increase access to services for patients from there. Diana Murungu, was employed in 2006 as Macmillan Specialist Palliative Care and Diversity Social Worker, to take this work forward. Initially she spent time in face to face visits to over 56 groups across Birmingham, representing a wide range of backgrounds, communities and faiths. She found that there was general lack of awareness of the hospice and its work among the BME communities. Diana also found that a few health care professionals were not referring people from BME communities, based on beliefs about people from these communities looking after each other. Communities also raised fears to do with culture and spirituality, cross gender personal support, language and fears around being misunderstood or misunderstanding service providers. This work culminated in 'The Reaching People Conference' in May 2009. This brought together service providers, potential service users and community leaders in dialogue about the impact of culture and spirituality on access to end of life care services and to find how this could be mitigated.

During the initial study (2007-2008) Diana found that many spiritual and cultural communities did look out for each other. When Macmillan Funding came to an end in 2009 and the West Midlands Strategic Health Authority took over funding, it was agreed to explore whether there was scope for developing partnerships with these 'Compassionate' Communities. One of the aims of this work was to establish whether this might support more people to achieve their 'wish' to die at home rather than in hospitals. This partnership working would also support the provision of culturally and spiritually informed services to patients and their families.

The second 'The Sharing Care Conference' in October 2010 explored the feasibility of working together. Participants and presenters were drawn from both end of life care service providers and members of the diverse communities in Birmingham.
'During my study in 2007-2008 I met communities on their own ground, and they demonstrated that they were in fact *already* Compassionate Communities. They were caring for their own in their own way. People do live with families and are within their communities before they get referred to end of life care service providers', Diana said. 'In many cases, it is these families, communities and neighbours who provide the initial support and care as described by Allan Kellehear in his book Compassionate

Cities: 2005. It is important to acknowledge this expertise and work with it to provide excellent end of life care services.'
The 'Sharing Care' conference concluded that if the Hospice worked in partnership with communities- patients and families would get an excellent service. One participant said, 'you cannot clap with one hand! You need both hands to make a sound; in the same way the Hospice and communities need to work together to provide excellent services to patients and their loved ones.' The Hospice is already becoming more aware of the way in which this work can support more people to die at home, through embracing and encouraging existing support within the community.

An Equalities Reference Group made up of community members, has since been established. They meet four times a year, act as ambassadors for the Hospice within their communities, and provide cultural and spiritual brokerage as and when needed and as appropriate for service providers and patients. Members of the Reference Group support the Hospice by participating in the provision of training to staff about the needs of patients from their communities at end of life. The BSMH Compassionate Communities work was evaluated positively by Worcester University in 2010. That report reiterated that communities were willing to support their members alongside clinicians at end of life.

The Reaching People Programme continues through the Compassionate Communities Project at the Hospice. Work which started off to increase access to people from BME communities in 2006 has widened to include communities within the nine 'protected characteristics' of the Equality Act 2010.

"… We have found through this project that the community are willing to help if we can also support them" Healthcare professional

"My role really has been to raise awareness among both communities and service providers. I'm also a cultural broker. I offer training to end of life care professionals, and get the community involved to administer this training" Diversity Social Worker.

Funding

- Initial funding for the first phase of the Reaching People Programme work was by Macmillan 2006-2009.

- Funding for the second phase of the Reaching People Programme i.e. the

- Compassionate Communities phase came from the West Midlands Strategic Health Authority. 2009-2010.

- The current work has been funded solely by the Hospice from 2010.

Staffing

- Macmillan Specialist Palliative Care and Diversity Social Worker- Study and outreach work Oct 2006- Sept 2009

- Specialist Palliative Care and Equalities Social Worker Oct 2009- present

Resources
BMJ Support Palliative Care 2011;1:209*BMJ Support Palliative Care*2011;**1**:209 doi:10.1136/bmjspcare-2011-000105.11 Poster presentations: Compassionate communities: from reaching people to working in partnership with communities at EoL Diana Murungu, Daphne Welch, Tina Swani.

Contact details
Birmingham St Mary's Hospice, 176 Raddlebarn Road, Selly Park, Birmingham, B29 7DA
E-mail: info@bsmh.org.uk

Website
www.bsmh.org.uk

3.3. Cheshire Living Well, Dying Well (CLWDW) Public Health Programme

CLWDW Programme Team (End of Life Public Health Team), St Luke's Hospice.

Timeline

- St Luke's (Cheshire) Hospice identified the need for a normalisation of death approach.
- During 2009, in-house discussions regarding the development of a Public Health Approach to End Of Life were undertaken.
- Representative local groups were approached by the Matron/ Director of Clinical Services to initiate consultation.
- In 2010, St. Luke's (Cheshire) Hospice commissioned a Community Engagement Event (facilitated by Conversations For Life) and participation in this event confirmed a widely held support for a Public Health Approach to Death, Dying and Loss.
- In 2011, a successful funding bid to Macmillan Cancer Support enabled the recruitment of a dedicated Programme Lead Post to develop and establish a programme of work.

The Cheshire Living Well, Dying Well (CLWDW) Public Health Programme
The Cheshire Living Well, Dying Well (CLWDW) Public Health Programme aims to improve health and wellbeing. It hopes to normalise death and dying in society, break down taboos and support a change in public knowledge, attitudes and behaviour to enable people to consider, discuss and plan for end of life throughout their lives.

Cheshire Living Well, Dying Well Partnership was established to enable effective multi-agency response and support for the CLWDW Public Health Programme and the needs of local communities in Cheshire East and Cheshire West and Chester.
Lead partners are St. Luke's (Cheshire) Hospice, Macmillan Cancer Support and local Public Health Teams).

Highlights of the CLWDW Public Health Programme include:

- Presentation to the All Party Parliamentary Group on Dying Well at the House of Lords. Provided opportunity to highlight the funding commitment for a dedicated Public Health Lead post for the Programme, which is understood to be unique to Cheshire.

- CLWDW Partnership Development Events

- Identification of CLWDW Champion at Health and Wellbeing Board Level in Cheshire East.

- Launch of CLWDW Partnership –including a keynote address from Fiona Bruce MP.

- Co-ordinated activity for National Dying Matters Week.

- Development of a range of awareness and training sessions for the community and wider public health workforce.

Compassionate Communities as part of Cheshire Living Well, Dying Well Public Health Programme

Compassionate Communities is embedded as one of the six strategic strands of the CLWDW Public Health Programme.

The definition of Compassionate Communities used by the Programme is to "Build community capacity for End of Life Care through informal help from family and friends or via formalised volunteering".

Six strategic strands for the CLWDW Programme were identified through consultation with the stakeholders in the community. They are as follows:

- Cheshire LWDW Public Health Partnership and Strategy Development (To embed a public health partnership approach to death, dying and loss at a local, regional and national level).

- EOL Financial Housekeeping and Future Planning (Motivate and assist people to make plans, record wishes and have more open discussions about death, dying and loss).

- Resource Development (Create and develop a toolkit of resources to enable effective and appropriate Living Well, Dying Well Public Health Interventions)

- Public Education, Learning and Development (Raise awareness and increase knowledge and understanding as to why Living Well, Dying Well is a public health issue).

- Compassionate Communities (Build community capacity for End of Life Care via informal help from relatives and friends or via formalised volunteering).

- Healthy Workplace/ Business (Phase 2) (Encourage workplaces / businesses to review organisational approaches and recognise Living Well, Dying Well as a public health issue).

Compassionate Community pilots established as part of the CLWDW Public Health Programme to date include:

- 'Good Neighbour Scheme' in Middlewich, using a time bank model.

- Support to older people's group, 'Vintage Blacon' to establish a bereavement group.

- St. Luke's Community Support –A satellite group in Alsager have set up palliative day care support with hospice support. This includes home visits and support for people with life limiting illness, families, carers, and early dementia.

Funding

Cheshire Living Well, Dying Well Public Health Programme is funded by:

- Macmillan Cancer Support (May 2011-14)
- St. Luke's (Cheshire) Hospice
- Local Public Health Funds to support development

Evaluation

Teesside University have been commissioned by St Luke's (Cheshire) Hospice and Macmillan Cancer Support to carry out an evaluation study, ending 2014
PhD studentship funded by University of Liverpool and St Luke's (Cheshire) Hospice will focus on aspects of the programme.

Staffing; Cheshire Living Well, Dying Well Public Health Programme Team

- Macmillan EOL Public Health Team Lead/ CLWDW Programme Lead
- Macmillan EOL Public Health Worker
- EOL Public Health Practitioner (Fixed term)
- Public Health Improvement Practitioner, CWaC (Protected Time)
- Community Representative (Volunteer)
- Community Representative (Volunteer)
- Additional Living Well, Dying Well Volunteer Support

Strategic links

As part of the CLWDW Strategy and Partnership Development Strategic Focus, work is being undertaken to firm up reporting mechanisms for The Cheshire Living Well, Dying Well Public Health Programme to local Health and Wellbeing Boards, Clinical Commissioning Groups as well as communication mechanisms to other local and regional partnerships and networks.

Resources

www.stlukes-hospice.co.uk/livingwell-dyingwell

Bill's Story – Cheshire Living Well, Dying Well Partnership**:** *Bill's Story is a short animation about his life and community which portrays the central concepts of the CLWDW Programme*

Dying For A Laugh**:** *This edited version of 'Dying for a Laugh', originally produced for Dying Matters by Picturewise Productions Ltd, has been created especially for the CLWDW Partnership.*

"Will Writing…Misconceptions" practical leaflet available to download

www.helpthehospices.co.uk Presentation at Nov 2012 Conference Community Engagement; back to the future 'Macmillan Cheshire Living Well Dying Well Public Health Programme' Siobhan Horton, Matron/ Director of Clinical Services, St. Luke's (Cheshire) Hospice.

www.helpthehospices.co.uk presentation at Nov 2012 Conference Community Engagement; back to the future 'Macmillan Cheshire Living Well Dying Well Public Health' Siobhan Horton.

http://www.dprconference.com/conference/dpr-13/abstracts/503-horton-siobhan-a-public-health-approach-to-end-of-life-issues-macmillan-cheshire-living-well-dying-well-programme

Contact details
St. Luke's (Cheshire) Hospice
Queensway
Winsford
CW7 1BH
Tel: 01606 551 246 Ext 2215
Email: PublicHealth@stlukes-hospice.co.uk

Website
www.stlukes-hospice.co.uk/livingwell-dyingwell

3.4. Compassionate Communities Champions- supported by Murray Hall Community Trust.

Jean Jones
Jean's husband had cancer for five years, and once he became really ill, Jean gave up her job to become a full time carer. She had some support from local cancer support scheme.

Neighbours in Jean's street rallied round her and offered support, popping in, offering to do the shopping, ironing…everyday tasks to make life easier, and to support them both.

'Compassion was found in the street, and they came to me and supported me when I needed it most.'

‘One neighbour came round, and said ‘Do you need any help?’ and I said, ‘No’, but she said ‘I’m coming in anyway’ and came in and took the ironing away to do. The street rallied round when I was at my lowest ebb.’
Jean now hopes to give back what she received...she makes effort to connect and support others, and counter the feeling of isolation. ‘We are all responsible, it’s everyone’s business…it’s in everyone’s grasp to get to know their neighbours, and there is nothing like saying “Good Morning.’” Jean organised a street party to bring everyone together, and help people to get to know one another.
She has since made two films, one with Compassionate Communities Sandwell, telling her story, and another which she uses to start dialogue with nursing staff in the local hospital.

Through the film she helps, as a lay person, to raise awareness in training sessions with nurses, telling the story of how she experienced care for her husband at the time in hospital. She hopes to raise awareness of the need for more compassionate care.
‘Every time I watch it, I think it has such an impact because it’s about the knock on effects of what they did.’
‘A touch of the hand, a smile, is worth a million to that person, we’ve lost the art of communication-fancy having to train people to be compassionate! I cared for my husband 24 hours a day, and each day I asked myself ‘How would I like to be treated myself in this situation?’ and this helped me through it.’

Jean sees that she has a legacy to leave, ‘When you’ve lost someone you love, you begin to think ‘Why am I here?’ and what better way than to change something that needs changing? That’s got to be my legacy- compassion. We can all make a change, but we need to do it together.’

Garth Murphy
Like Jean, Garth was motivated to ‘give something back’ following the experience of two very different deaths of his mother and father. He saw at first-hand how people could be treated, and how staff attitudes can make the world of difference to how a death is experienced. Garth’s mother had suffered from dementia for years, and Garth never had a conversation about what kind of funeral or end of life plans she wanted. ‘The funeral I gave mum and dad was the funeral I wanted for them, but we never talked about it.’

As an ex business man, Garth now brings his skills as a lay advisor to the local Clinical Commissioning Group (CCG), supporting the development of the end of life strategy. He also gives talks to local community groups about end of life issues, working as a Compassionate Communities Champion in Sandwell. ‘It’s a slow chipping away of attitudes, if one or two people show an interest it makes it all worthwhile.’

‘There is compassion happening out there…I live in a close cul-de-sac, and if anyone’s in trouble we just knock on the door to see if they are ok. One couple, Karen and Keith, look after an elderly neighbour, who is 86; cooks him a meal and cuts his grass...why shouldn’t we do it? It just happens, we don’t need to say why we do it.’

Resources
(A short film, 'Karen and Keith; Caring Neighbours,' can be seen on
www.compassionatecommunities.or.uk

3.5. Conversations for Life ™

Overview
Conversations for Life is a nationally recognised programme which takes both an 'asset-based' and public health approach to engaging communities and professionals around end of life conversations and care. Its diverse workshops and materials provide a catalyst to engaging communities (public, staff, health, social care and voluntary sector organisations) to take tangible actions: inspiring earlier conversations around planning for future care for the general public, and improving outcomes for healthcare staff and organisations committed to compassionate care in the communities where people live.

Its programmes are based on the lived stories and experience of professionals and family members alike, who have held, or regretted not holding, end of life conversations and lived with the outcomes. A combination of resources, training and community facilitation focus on developing the awareness, motivation, and confidence in the roles we all have in choosing and requesting our own future care.

Experiential training is also delivered to enable healthcare professionals to work in partnership with patients, families, and other community organisations to ensure the wishes of those at the end of life are acknowledged and supported wherever possible.

The approach taken by Conversations for Life reflects the vision of Compassionate Communities. The website provides a comprehensive overview of the wide range of work being undertaken at all levels, within strategy, with professionals, communities, voluntary organisations and individuals. These include:

- **Facilitation of community-wide engagement** in advance care conversations and planning- taking an asset-based and community development approach. Through this approach, Conversations for Life facilitators work with lead organizations (health, hospice, social care, voluntary sector), to bring together key leaders across a region or locality to build strategy from an informed perspective, engaging community-wide strengths and support from the start. Support and facilitation offer 'community champions' within organisations such as hospices, faith and community groups, a direct way to catalyse change at a local level.

Examples of work to date include:

- **Partnership working** across 6 localities with the Cheshire and Merseyside Clinical Networks, Palliative and End of Life Care Network, local hospice, voluntary leads and community organizations. Conversations for Life worked to support a community engagement process across the locality, leading to the development of community champions and community-led plans.

- **A Public Health Initiative** around Advance Care Conversations and End of Life Care. The first community-wide public health approach to engage communities to overcome this taboo was launched in 2009 by NHS Cumbria, local partners and the Conversations for Life Programme. This received National Endorsement by the Department of Health, End of Life Care programme in 2010.

- **Multi-Disciplinary Team Working:** Over 200 staff from multiple services (GP's, community nursing, care home, social care, acute trust) across 11 Trusts within the Greater Manchester Cheshire Cancer Network attended a one day training course to align personal/professional awareness with strategic multi-disciplinary initiatives. The "Simple Tools to Start the Conversation" session focused on supporting staff to overcome the fear of talking about death and dying with tools to support their patient/client conversations. Commissioned by GMCCN, NHS Manchester, NHS Salford, NHS Trafford, Pennine Care Foundation Trust, NHS Sussex, NHS Cumbria, MacMillan and others. Bespoke sessions have also focused on GP's, staff working with chronic conditions including dementia, renal, cardiac and stroke and mental health.

- **Development of tailor made resources,** including films that engage the stories of local people, workshops, facilitator training, and publicity materials which can be adapted to suit the needs of the groups or organisations undertaking organisational and community initiatives and awareness raising around advance care/end of life conversations.

Funding
Established as an independent Community Interest Company, the group charge fees for the products, training, consulting and workshop delivery in addition to seeking funding, sponsorships and grants, individual donations and corporate partners.

Resources
http://us2.campaign-archive2.com/?u=e597f169560e08608961a5548&id=b9527eae4b
http://gallery.mailchimp.com/e597f169560e08608961a5548/files/EAPC_C4L_poster.pdf
http://www.lancs.ac.uk/shm/research/ioelc/programmes/older-people.php work with Lancaster University to develop end of life peer educators programme
www.facebook.com/conversationsforlife
http://storiestochange.org/case-study/

Contact details
Director: Mary Matthiesen, Co-Director: Pauline Rudge

Website
www.conversationsforlife.co.uk
http://storiestochange.org/

3.6. Diocese of Lichfield

Overview

Stretching from the Welsh border to the Peak District, North Staffordshire to the Black Country; the Diocese of Lichfield is one of the largest in the Church of England, serving just under two-million-people in 1,744 square miles. The Diocese has 583 churches and 427 parishes in Staffordshire, North Shropshire, Wolverhampton, Walsall, half of Sandwell and three parishes which straddle the Welsh border.
The diocese is served by 294 full time stipendiary (paid) clergy and a larger number of non-stipendiary (volunteer) clergy and lay ministers.

David Primrose is the Head of the Transforming Communities Department, continuing the work of the Department of Social Responsibility, with a particular emphasis on helping churches serve their local communities at all levels.

Compassionate Communities

David Primrose came across the idea of Compassionate Communities through links with Murray Hall Community Trust, St Giles and Severn Hospice and immediately saw the potential within the setting of the Diocese.
Aware of challenges and opportunities presented by an ageing population, the Lichfield Diocese ran multidisciplinary workshops to look at the themes of older people as volunteers, care in the community, dementia and end of life. Professionals, voluntary sector, church and others contributed to an Age on Agenda symposium leading to the development of an action plan for older people, endorsed by the Diocesan Synod in late 2012. The aim is to provide encouragement and guidance, and share good practice to enable individual parishes to take the work forward and interpret it in their own way.

The plan is built around three themes, throughout which Compassionate Communities can be embedded.

Strand 1 - Develop training courses for working with people in the ‘third’ and ’fourth’ age, including end of life planning, active ageing, bereavement. These are now available, with staff from Compassionate Communities contributing to the concluding session of both modules.

Strand 2 - Build partnership and work in collaboration with voluntary, health and community groups across the area to increase capacity, effectiveness and expertise e.g. through Dementia strategy, and Compassionate Communities initiatives. This comes from awareness that the church can gain skills and learning from partnership working. The Diocese has joined the Dementia Action Awareness campaign, and is exploring what is means to be a Dementia Friendly Church.

Strand 3 - Use resources to build awareness of end of life and death and dying. e.g. through Dying Matters awareness week, and national dementia campaigns.

The potential for Compassionate Communities to move forward within the diocese will depend on the energy and commitment of individual churches. Building on the older people’s plan, a parish could take Compassionate Communities forward and develop it in partnership with groups in its area.

It is envisaged that through this the church could contribute to changing attitudes, supporting both those with church roles and the wider public to gain a confidence and greater openness to speak about death and loss. The church could bring recognition of spiritual needs at the end of life, demonstrating that those with dementia or at the end of life are still part of the community and should not be isolated.

Resources
www.lichfield.anglican.org **'**Age on the Agenda'
www.churchofengland.org 2012-16 research project 'Listen to England' to find out what people want from the church when someone dies.

Website
www.lichfield.anglican.org/

3.7. Dorset Cancer Network

Overview
Dorset Cancer Network (DCN) is committed to involving cancer patients and carers in developing and planning cancer services across Dorset. Working through a Patient Partnership Panel, it aims to provide a forum where patients and carers can contribute to the development of local cancer services. Membership is broad and includes both NHS, and voluntary organisations.

As a proactive group working with healthcare professionals across Dorset, they have developed guidance and strategies to support patient and public involvement and drive forward the user involvement agenda.
Key achievements include the development of a Patients' End of Life Charter, an End of Life Care communication skills programme and active engagement with the review of specialist palliative care services across NHS Bournemouth and Poole.

Compassionate Communities Dorset
Lead cancer nurse, for the Dorset Cancer Network, Verena Cooper became interested in Compassionate Communities after hearing a talk by Allan Kellehear in Winchester in 2008. She was inspired to try and set up something in Dorset. Through The National Council for Palliative Care, Verena arranged for a speaker to talk to the end of life care workforce group, about Compassionate Communities.

- June 2011 launch of Compassionate Communities Dorset with an event attended by 90 people from health, social care, voluntary sector, funeral, police, fire, ambulance, and lay people. This brought people together in workshops to look at a wide range of end of life care issues, and gain an understanding of what Compassionate Communities could mean for Dorset.

- A Compassionate Communities working group was established which meets bi monthly, made up of up to 22 people from all walks of life. The group, working from diverse lay and professional viewpoints has grappled with a range of issues, and is working towards a way that Compassionate Communities could be embodied.

- Plans include work with schools on bereavement, a conference on Diversity, focus on carers and dementia, work with Weldmar Hospice, a website, and establishment of Compassionate Communities as a movement independent from health.

- Compassionate Communities has been established as an umbrella under which groups can develop. To date the group have run Dying Matters Awareness Weeks, held events in shopping centres, hospitals etc, presented to Lewis Manning Hospice, Poole.

- Would like to see Compassionate Communities grow organically across Dorset as an umbrella under which a range of approaches and activities could take place.

- Envisage developing a 'kite mark' for Dorset Compassionate Communities that groups could sign up to. e.g. a logo in the window of a shop or hairdresser saying 'Compassionate Community member' so people know they are prepared to discuss these issues.

'The aim of the compassionate community within Dorset is to develop greater understanding of the role community plays where end of life is concerned. It will allow the concept of death, dying and bereavement to be seen and heard within the community across Dorset, rather than being hidden and seen as a taboo. A compassionate community gives ordinary people the skills to be able to address the issues raised by the end of life and other losses.'

Funding
The development of Compassionate Communities in Dorset is not funded, but works through existing networks, strategies and relationships.
Verena Cooper who has acted to facilitate the growth of Compassionate Communities vision is lead nurse for Dorset Cancer Network, hosted by NHS Dorset and Bournemouth and funded by the CCG.

Website
www.dorset.nhs.uk/dorsetcancernetwork/partnership-panel.htm
www.dorset.nhs.uk/localservices/compassionate-community.htm

3.8. The Funeral Consultancy

Overview
The Funeral Consultancy is a Leicester based, Millennium Award winning not-for-profit educational social enterprise. Its projects provide people with independent information about different funeral options, including simple ceremony ideas, ways to work within a budget, and a national telephone information service. Other support includes;

- Training courses in bereavement and end of life planning for health and social care professionals

- Training of independent funeral advisors who can provide impartial information and practical support to people arranging a funeral

The Funeral Consultancy has recently established the Association of Community Funeral Advisors (ACFA) http://www.communityfuneraladvisers.btck.co.uk, who are working to train and develop a network of independent community funeral advisors across the country.

Compassionate Communities
The founder, Colin Moore, following 25 years' experience in probate law, saw at first-hand how bereaved people could be treated following a death. He was also concerned by the lack of choice or independent information for those planning a funeral, coupled with rising costs, and increasing debt burdens faced by many. He feels the public deserve unbiased, unpressured information, to enable them to make informed choices at a time when they are often most vulnerable.
He comments that funeral debt is an increasing problem, with nearly 20% of the public found to be struggling to pay the costs of funerals, and 69,000 applications to the funeral social fund received in 2011.

The Funeral Consultancy aims to provide support and choice to those planning funerals, with a focus on helping those on low incomes plan simple and meaningful ceremonies without incurring debt. He hopes to raise awareness and change attitudes among the public to the issues of bereavement and funeral planning. The aim is that this will create a grass roots demand for more choice and information, leading to funeral directors becoming more responsive to people's needs. 'Currently between a death and a funeral taking place the public are reliant only on information provided from funeral directors- There needs to be an independent source of information for people'.

The consultancy hopes to:

- Train voluntary independent funeral advisors to help with all aspects of funeral planning, in a range of settings including within care and residential homes.

- Develop a local 'Funeral Planning on a Budget' Handbook with a directory of funeral directors who offer a compassionate and budget conscious funeral service for families on low incomes.

Funding
The Funeral Consultancy is a member of Dying Matters and was given an Un-Ltd Millennium Grant Funding Award in January 2013.

Website
http://www.thefuneralconsultancy.co.uk

3.9. Woking and Sam Beare Hospices - Sarah Ivey, Community Palliative Care Specialist, Undertaking an MSC in Palliative Care

Overview

Woking and Sam Beare Hospices, Weybridge are independent registered charities that provide Hospice care across Surrey.
As well as providing in-patient care and day care units at both Hospices the community team provide services over a much wider area including the boroughs of Woking, Spelthorne, Runnymede and Elmbridge.

Compassionate Communities

Sarah Ivey, Community Palliative Care Specialist based at Woking Hospice, works closely with people with progressive life limiting disease, both within the hospice and within people's homes.
Currently studying for MSC in Palliative Care, King's College, London, Compassionate Communities is a strong part of her research theme.

- Area of research: 'How can we best support people who are living with and dying from life-limiting illnesses? – the perceptions of representatives from South Asian communities.'

- Working in partnership with NHS Public Health, North West Surrey to look at barriers and to develop a health promoting palliative care approach with BME groups at the end of life.

- Arose from an awareness of high death rates of BME groups within local hospitals despite people saying that they wanted to die at home.

- Qualitative research to focus on determining which informal and formal support networks exist within these communities, when caring for people living with and dying from life-limiting illnesses.

- Through engaging with the local BME communities, the research hopes to appreciate what resources are drawn upon, and what gaps exist in the service. It aims to understand perceptions regarding provision of appropriate palliative and end of life care support for the BME patients, their families and the compassionate communities.

The research findings will be disseminated to the BME representatives involved in the research and then to the Hospice Board of Trustees, the local Clinical Commissioning Groups and add to the research about Compassionate Communities through the Dying Matters Coalition.

Website

www.westonhospicecaregroup.org.uk

3.10. King Edward VII Hospital Guernsey

Overview
The King Edward VII Hospital, Guernsey provides continuing care and day services for patients with physical needs, primarily in the 40 plus age group. Within a friendly and homely environment, a multi-disciplinary team are responsible for staffing wards and a day unit, and providing continuing care for the elderly and incapacitated. People come to stay in the hospital towards the end of life, for a period of 2 weeks to 18 months. Guernsey lies outside the NHS jurisdiction, although uses much of its good practice guidelines.

Compassionate Communities - Shona Pearson, Matron and Head of Support Services felt that the work at the hospital fitted under the Compassionate Communities banner, when she saw the Dying Matters callout in August 2012.

- Remodelling of the local hospice led to King Edward VI hospital building experience in palliative care as they took more people in at the end of life.

- Guernsey is a small community, and the hospital recognises this through involving the whole family with the person they are looking after. 'We have an open door for visiting, so families and friends can be as involved as they want…our ethos is to look after the whole family'. The hospital is often the person's last home, and it is important to make it as 'homely' as possible.

- 'Heaven and earth is moved to enable people to die at home if they want to,' with support from the community palliative care team.

- Many staff are trained bereavement counsellors, so can offer support to relatives pre and post bereavement. Relatives often come back for years after a death and this is encouraged, special events are held e.g. annual Christmas events for relatives.

- Shortly adopting the Liverpool Care Pathway. They are starting to have more formal conversations with people about what they want at the end of life.

- Developing 'Supported living and ageing well' strategy, with EOL care as a theme. They are holding a series of stakeholder meetings and consultations to develop the strategy until Spring 2013, with voluntary sectors, private sector and individuals.
- 'Guernsey is a small country community, and death and dying is still a taboo, people do not readily talk about it. The biggest thing is getting out there and getting people to talk about it...having the conversation when someone is ill… they often don't have these conversations...but actually everyone wants it for themselves...it's about the awareness trickling through.'

Website
www.health.gov.gg

3.11. Living Well, Dying Well, Lewes

Overview

Living Well Dying Well is a registered charity based in Lewes, East Sussex. It was set up in 2009 to encourage an approach to dying that is humane, respectful, and honours an individual's identity and sense of self. This is accomplished through

- Holding creative events where death and dying can be discussed (promoting death literacy).
- Providing training and workshops about death and dying for both professionals and members of the public.
- Enhancing the ability of communities to care well for their dying, and to be more prepared.
- Working in partnership to ensure that a quality of integrity, for the person who is dying and those closest to them, remains consistently in place.
- Pioneering the role and training of Doulas, as companions and mentors, in support of the whole family, before, during and after this important life event.

Director Hermione Elliott, has a background in nursing, midwifery, counselling, palliative care and training. She is passionate about care of the whole person -physical, emotional and spiritual and about upholding dignity and self-determination at every stage of life.

Assistant Director, Jon Bowra, has a background in nursing and social work, where he has practiced for 35 years. He has extensive experience in community and project development work in a range of settings. He has a Masters from The Centre for Death and Society at the University of Bath and is strongly interested in how to enhance wellbeing throughout life.

'Our overriding wish is to encourage an approach to dying that is humane, respectful, and honours an individual's identity and sense of self. We encourage an environment of loving support, kindness, respect and dignity, whether at home, in a nursing home or hospital, to increase the confidence and capacity of family carers to look after their dying. We recognise and nourish the abilities that already exist within people and communities to act compassionately towards each other.'

Compassionate Communities

Both Hermione and Jon through their work, and lives have a strong understanding of how Compassionate Communities can help to ensure that a person at the end of life remains embedded in the community and network to which they belong.
Jon comments that Compassionate Communities is in fact a simple concept. 'How can we promote the ordinariness, the normal everyday relationships, the valuing of the ordinariness of everyday life? If you know someone who is terminally ill, just ask 'how can we help? Can we mobilise friends, relatives and neighbours?'

Hermione comments ‘a lot of discussion is ‘out there’ but I always think, let’s come back to me...this is me, this is my life, how is it going to be for me at the end of life, how do I want this to be different for me? Once at that point then you can start to make a difference for others.’

Resources
Compassionate community networks: supporting home dying Julian Abel, Jon Bowra, Tony Walter, Glennys Howarth *BMJ Support Palliat Care* 2011;1:2 129-133

Hermione Elliott Let’s Talk about it Journal of Holistic Healthcare Issue 8.1 - May 2011

Jon Bowra Health Promoting Palliative Care Journal of Holistic Healthcare Issue 8.1 - May 2011
http://www.positivehealth.com/article/nursing/the-finest-of-arts The Finest of Arts, Hermione Elliott 1998

Website
www.livingwelldyingwell.net

3.12. Murray Hall Community Trust

Overview
Murray Hall Community Trust is a West Midlands based charity serving the Black Country and Birmingham areas. The charity was set up in 1994 by local people in Sandwell to promote health and wellbeing and continue to work in this area as well as in the wider West Midlands. They take a community development and public health approach, working to promote positive social change, empowering communities while reflecting and being sensitive to their needs and diversity. The organisation has developed a broad range of initiatives working with local people’s skills, including children’s services, community based counselling, youth initiatives, support to families and young men. The Bridges service offers person centred support to those with cancer and life limiting illness, towards the end of life, including befriending, practical home support and hospital transport.

Compassionate Communities
Murray Hall Community Trust has been involved in exploring and developing the practice of Compassionate Communities since 2008. Listening to Allan Kellehear speak at a conference at Teesside University, resonated with the experience Murray Hall had in supporting communities and those at the end of life, and has led to them undertaking a number of initiatives.

- In 2009 Murray Hall was chosen as one of four pilot sites for a study funded by the West Midlands Strategic Health Authority. This explored both the development of Compassionate Communities and the potential of care workforce development amongst the elderly population. Other pilots included Birmingham St.Mary’s Hospice, Kemp Hospice, Kidderminister and Severn Hospice, Shropshire.

- In 2009 with funds from Sandwell PCT and Public Health, a conference on Compassionate Communities, ‘Back to the Future’ was held with Allan Kellehear

as guest speaker. Over 100 people attended from health, community, religious groups. The conference combined art, locally commissioned film, storytelling and premiered Rosetta Life film to raise awareness of end of life issues and the vision for compassionate communities.

- At the conference 50 champions were recruited to help with promoting the concept of Compassionate Communities.

- A Compassionate Communities Development Worker job description was developed, combining the skill of community development with knowledge of end of life care. The job description has been shared with others across the country to support their plans to start Compassionate Communities.

- A Compassionate Communities Development Worker was employed in Sandwell to engage with a wide range of community and faith groups and explore the workforce scope.

- Initial aim to build awareness, provide training in end of life issues and enhance the capacity of people to develop their own practical acts of compassion within their setting. Included e.g. bereavement training to Sandwell's 'Strides' walk leaders, development of a 'healing garden' with local charity Ideal for All

- A short film was commissioned and funded by the media trust to show what Compassionate Communities look like. This film was shown on the community channel. Additional funding led to development of a website, including stories collected from people to illustrate '101 acts of compassion'.

- Different strands of development include; to generate dialogue, to increase community capacity to support people at the end of life, to recruit 'Champions' to take up the cause in their own lives and work, to support volunteers, to encourage individuals to 'general acts of compassion' and to integrate into strategic policy development and other opportunities i.e. Dignity campaign.

- To date there have been dialogues to develop a language and interpretation of Compassionate Communities and this continues with a wide range of community, faith and other groups, and within policy.

- Found many communities already acting compassionately, and that the ideas grow organically from one person to another. Murray Hall can support capacity building through a community development approach.

- Murray Hall continues to act as mentor for a second Compassionate Communities Development Worker across the West Midlands, funded by Strategic Health Authority (see case study).

- In 2012 non-recurring funds were secured from Public Health to continue the development of Compassionate Communities in Sandwell. This current work has involved an intergenerational photography project with students from a local

Academy school. An exhibition has been planned at 'The Public' during Dying Matters Awareness week.

- Since July 2012 jointly with the National Council for Palliative Care – Dying Matters, Murray Hall carried out a scoping study of Compassionate Communities in England due for completion April 2013.

- Strategically, Sandwell and West Birmingham Clinical Commissioning Group has integrated Compassionate Communities into End of Life Care Strategy, including reference to 'narrative based assessment' pioneered by Bridges in supporting those at the end of life.

Funding
The development of the Compassionate Communities work has been funded from a variety of sources including West Midlands Strategic Health Authority, Sandwell Public Health, and more recently support from a local CCG.

Staffing
- 2009 – 2011 Compassionate Communities Development Worker Sandwell p.t. (funded by West Midlands SHA).

- 2012 Compassionate Communities Development Worker Sandwell p.t. (funded by Sandwell Public Health, and anticipated 2013 Sandwell and West Birmingham CCG)
- Compassionate Communities Development Worker West Midlands and Birmingham wide (funded by NHS West Midlands SHA).

- Jul 2012- March 2013 Network Facilitator Compassionate Communities (funded by NCPC).

- Manjula Patel, Service Manager for Health Services, undertaking doctoral research at Warwick University on Compassionate Communities.

Resources
Innovation Exchange Compassionate Communities Champions
http://www.slideshare.net/johncraig/compassionate-communities-champion
Compassionate Communities film Media Trust
http://www.communitychannel.org/video/fnD8T2zz-ZY/

www.compassionatecommunities.org.uk website dedicated to Compassionate Communities, including 2009 conference report

Manjula Patel presentation at 5th Palliative Care Conference: Building the Compassionate Community. September 2011, Teesside
http://www.publichealthpalliativecare.org presentation April 25-27 2013 at the Third International Public Health and Palliative Care Conference, Limerick, Ireland

International Perspectives on Public Health and Palliative Care. Libby Sallnow, Suresh Kumar, Allan Kellehear. Routledge 2012

Compassionate Communities Conference 2009 report

www.redcatcomms.co.uk/documents/FINALVERSION.pdf

www.rosettalife.org

Contact details
Murray Hall Community Trust, Health Services, SGS House, Johns Lane, Tividale, Oldbury, West Midlands, B69 3HX.

Website
www.murrayhall.co.uk
www.compassionatecommunities.or.uk

3.13. The Natural Death Centre

Overview
Established 21 years ago, The Natural Death Centre (NDC) is a social, entrepreneurial, and educational charity that gives free, impartial advice on all aspects of dying, bereavement, funerals and consumer rights.
Its founder Nicholas Albery's was moved by his father's home death to develop a natural death movement to parallel the natural childbirth movement, and to spread the tenets of good hospice care to home care for those dying of all causes.

The Natural Death Centre was established with three aims in mind:

- To help break the taboo around dying and death, and make it a natural topic to discuss.

- To bring the dying person back to the centre of proceedings and enable them to die at home if they so wished.

- To empower people and make them aware of their legal rights and choices, taking the power away from institutions.

Since this date, the organisation has been a dynamic force behind raising awareness of death and dying, bringing the debate to a wide range of audiences, including the public, health, faith, and funeral professionals, and at a national and regional policy level. It is an active member of the Dying Matters Coalition and represented on a range of national advisory and professional bodies.

Activities have included for example,

- Publication of The Natural Death Handbook (now on its 5th edition), which leads and inspires the UK and worldwide natural death movement.

- Phone help and advice line and email service for public and professionals (Mon-Fri).

- Information leaflets (60,000 printed in 12 months), ‘More to Death e-magazine’ (read by nearly 10,000 people in one month) and provision of a range of resources.

- Regular media interviews, press coverage and appearances on T.V and Radio.

- Educational workshops, exhibitions, presentations, throughout the country at a range of events in order to stimulate discussion and debate. In 2012 the NDC ran or participated in over thirty events around the UK.

- Use of arts, poetry, film, Death Cafes, and a wide range of creative media to raise awareness and interest.

- Social networking Facebook Group, Facebook Fan Page, Twitter @ndccharity, over 1200 members in last twelve months, with web hits averaging over 8000 visitors per month and increasing.

- 2012, launched The Natural Death Society, in order to spread the word about choice both in the process of dying, funerals, and to tackle taboo. This includes developing volunteer roles to facilitate discussion and debate in their local area.

- 2012 The NDC launched in collaboration with Jon Underwood www.funeraladvisor.org.uk to harness the use of the internet and give independent advice and overview and discussion of funeral services available.

- Other areas of work include policy lobbying, and membership of national strategic and advisory groups.

Compassionate Communities
The NDC has been working in keeping with the concept of Compassionate Communities for many years, and the approach they have practised over the past two decades mirrors many of the Public Health approaches to dying and death. They aim to support people to be informed of their choices and rights and to be empowered to bring about change in the way death and funerals are approached.

In 2005, Director Susan Morris took part in Help the Hospices, Living with Dying Group to explore a Public Health approach with Allan Kellehear. In 2012 Susan won the national Welch Allyn Pioneers of Care Award for educating the public about dying and funerals over twenty years.

Though small, the NDC is a significant organisation whose guidance is regularly sought by professional practitioners, government departments and the media. It has a history of giving catalytic leadership, and promoting and empowering social change.
The NDC encourages health care professions to identify a patient’s social capital and network in order to promote holistic practise, and for the patient to be seen as part of a wider community.

Funding
This small organisation achieves a huge amount on limited funds. The work is funded by sales of the NDC’s The Natural Death Handbook, income from royalties of poetry

and walks books, donations, subscription to Association of Natural Burial Grounds and Google ad grants.

Resources
Natural Death Handbook (5th Edition, 2012) www.naturaldeath.org.uk
Rate a Funeral Director www.funeraladvisor.org.uk
Natural Death Society www.naturaldeath.org.uk
Association of Natural Burial Grounds www.naturaldeath.org.uk

Contact details
In The Hill House, Watley Lane, Twyford, Winchester. SO21 1QX

Website
www.naturaldeath.org.uk

3.14. Independent Funeral Officiant and Civil Celebrant - Dorchester, Dorset

Overview
Nita Tripp works as a celebrant, supporting people with planning and running a funeral both for themselves or their loved one. Her aim is to give people independent information and advice to enable them to plan and create a ceremony that reflects their wishes, through informed choice.

Compassionate Communities
Nita Tripp responded to the Dying Matters survey about Compassionate Communities as she felt her work reflected this approach.

- Has developed links with NHS through a meeting at a public event, and asked to support with 'Gold Standard' development.

- Invited to speak to a range of groups about choice in funerals including in care homes, mental health groups, to Doctors and Nurses, and those caring for people at the end of their lives.

- Develops close contact with family and friends of the dying person, helping to break down taboos around death, and support open communication. This has an impact on the grieving process 'a good funeral is a fitting thing that helps a family come to terms with death and understanding loss.'

- Works to involve all members of the family including children in the funeral celebration.

- Hopes to empower people and de-professionalise death, through developing awareness of choice

Resources
www.good**funeral**guide.co.uk

www.**independent**celebrants.com

www.highergroundmeadow.co.uk

www.funeralcelebrants.org.uk

A member of www.naturaldeath.org.uk

Website
www.funeralcelebrantdorset.co.uk

3.15. Nottinghamshire County NHS- Public Health

Overview
Sharing the same boundary as Nottinghamshire County Council area, the Public Health Directorate covers NHS Nottinghamshire County PCT, NHS Bassetlaw and Nottinghamshire County Council. Recognising the diversity of Nottinghamshire as a county with a mix of deprived former coal mining communities, significant rural areas and the suburbs of Nottingham, the Directorate works in conjunction with many partner organisations, patients and the public to assess and respond to health need by commissioning health and health care services.

Key areas of activity include health promotion and tackling causes of ill health as well as building on national strategies.

Compassionate Communities
Helen Scott, Senior Public Health Manager and end of life care lead heard Murray Hall's Manjula Patel speak about Compassionate Communities at the Palliative Care conference in 2011. She was keen to try and integrate Compassionate Communities into Public Health work with end of life care in the PCT, and to date the picture is slowly evolving across the county.

- Public Health trainees carried out a feasibility study for Compassionate Communities, which led to development of two pilots in small Nottinghamshire communities

- Partnerships developed with voluntary and community groups to support the idea. This includes Nottinghamshire Community Trust, Newark and Beaumond House Hospices, and local Patient Participation groups based at rural GP practices. Helen Scott is keen to encourage grassroots collaboration, in a community development approach, avoiding a professionally driven project.

- 2011 held Question Time style debate held at a hotel, for the public to break taboos and debate the issues around death and dying.

- 2011 Mansfield artist Tim Smith, led creative workshops around death and dying across the county which included young school children and hospice patients.

- Developing working links with 'In Kind' Nottinghamshire, a group working to encourage the council to sign the 'Compassionate Cities' charter.

- Developing arts based projects with City Arts, and with Paa Joe coffin maker from Ghana, to link to a Dying Matters week event during 2013.

- 2013 plans to develop community based training around bereavement, to build capacity of existing community groups to have confidence when supporting those facing end of life.

- Developing ideas on 'measures of compassion' and impact on health, drawing on international research.

Links to strategy

- Compassionate Communities noted in Joint Strategic Needs Assessment -Adults and Vulnerable Adults Section, pp48-49 .http://www.nottinghamshire. gov.uk/jsna/
- Incorporated into key actions in the Older People section Health & Wellbeing Strategy supporting dignity and choice for care at the end of life.

- Overall aim to develop a public health, health promoting and community development approach to end of life in order to build a movement where communities are empowered to support those at the end of life.

Staffing

Helen Scott Senior Public Health Manager and end of life lead, with a work remit covering over 6 public health programmes. From April 2013 the responsibility for Public Health will move to the Council.
Plans to fund and recruit a Compassionate Communities Project Manager
Support from Council workforce development initiative, who have held Dying Matters events for professionals.

Resources

www.inkindnotts.org local group working to implement the 'Charter for Compassion'

www.charterforcompassion.org Charter for Compassion

www.crazycoffins.co.uk exhibition of Nottingham and Ghanaian based coffin makers at South Bank Centre 2012

www.ccare.stanford.edu Stanford University Centre for Compassion and Empathy

Website

www.nottspct.nhs.uk
www.nottinghamshire.gov.uk

3.16. Strathcarron Hospice Stirling, Scotland - Sally Paul Parent and Family Support Team

Strathcarron Hospice is a charity providing a wide range of specialist palliative services to people in NHS Forth Valley, and to Cumbernauld and Kilsyth in NHS Lanarkshire.

Compassionate Communities

As part of her role as palliative care social worker, based at Strathcarron Hospice, Sally Paul has been developing children's bereavement services. She found that anecdotally there was a lack of confidence amongst professionals in supporting bereaved children and talking about death and dying more broadly. This occasionally lead to referrals for specialised bereavement support when the children's needs could have often been met in their own community. Sally is now engaged in PHD research based at Edinburgh University under the topic, 'Health promotion and palliative care. Working with schools and hospices to create a healthy discourse around living, dying and bereavement.'

Through action research she has been exploring how hospices can engage with primary school communities to support education on death, dying and palliative care with children. Working with two local primary schools, involving teachers, children and parents a number of actions have been identified and taken forward. This includes developing and piloting appropriate bereavement education tools, exploring the role the hospice can play in raising awareness of end-of-life care issues through fundraising initiatives, and developing the curriculum to include education on death, dying and palliative care.

In 2012, Sally worked jointly with Libby Sallnow to research to what extent hospices in the UK were involved in community engagement. They found varied approaches, levels and understandings of community engagement on the part of hospices. This has led them to develop proposals for a model to reflect a 'spectrum' of approaches to community engagement, within which sits compassionate communities. This was published online in February 2013 in the BMJ Supportive and Palliative Care.

Resources

www.socialwork.ed.ac.uk/phd_student_profiles/paul_sally

Paul S. and Sallnow, L. (2013) Public health approaches to end-of-life care in the UK: an online survey of palliative care services, BMJ Supportive & Palliative Care, Published Online First: 22nd February 2013, doi:10.1136/bmjspcare-2012-000334

Paul, S and Sallnow, L (October 2012) 'A Public Health Approach to End of Life Care in UK Hospices', 19th International Congress on Palliative Care, Montreal (Poster Presentation)

Paul S and Freeland K (September 2010) 'Reaching out to the community: Health promotion and support for children/young people who are bereaved and their carers', Living Beyond Loss Conference, NHS Tayside: Dundee (Presentation)

Paul S (2013) 'Public Health Approaches to Palliative Care: The Role of the Hospice Social Worker Working with Children experiencing Bereavement, British Journal of

Social Work, advanced Access published 13th February 2013, British Journal of Social Work (2013) 1–15 doi:10.1093/bjsw/bct017

Hospices and Community Engagement: theory, practice and emerging models Libby Sallnow and Sally Paul http://www.helpthehospices.org.uk/our-services/education-training/past-events/conference-2012/hospices-and-community-engagement/

www.palliativecarescotland.org.uk *Scottish Partnership of Palliative Care* As well as developing and promoting good policy and practice in palliative care the Partnership is now leading work to encourage more openness about death, dying and bereavement in Scottish society. Mark Hazelwood, Director, speaks at 3rd International Conference in Public Health and Palliative Care, Limerick, 2013.

Website
www.strathcarronhospice.org

3.17 Antonia Rolls. Painter and Soul Midwife.

Antonia Rolls is a Painter and a Soul Midwife. Her work includes Portraiture, Book Illustration, the A Graceful Death exhibition, and interpretations of Religious Themes. The Religious Paintings are painted firmly with a sense of fun and enquiry, and all of her paintings use as much colour as possible. Her Portraits are, very personal and often include items from the sitter's life to help explain who they are.

The A Graceful Death Exhibition
The A Graceful Death exhibition, of paintings and poems from the end of life, is a loving and powerful exhibition which tours the country with talks, presentations and workshops promoting discussions and conversations on what it means to die.
The exhibition began in 2007, when Antonia painted her partner's last few weeks, days and the day of his death, with no other aim but to survive and understand this terrible loss.

Antonia had no idea how paintings of someone dying and dead would be received and feared that they would be too much for the public to see. The response was wonderful Everyone who came had a story to tell, and recognised the images of the end of life with relief and understanding. The paintings deeply resonated with those who had experienced loss, and she began to receive requests to paint others at the end of life.

Now Antonia paints other people approaching death, or those with a life threatening condition, and to date A Graceful Death has 45 paintings and portraits. She includes paintings of survivors in the exhibition; survivors of the bereavement process, and those who have survived a life threatening illness.

As a Soul Midwife, she provides emotional and spiritual companion to those who are dying. Soul Midwives support and befriend those who are facing the end of their life, and will stay until the end if required, accompanying the dying with love and grace until death.

Compassionate Communities
Compassionate Communities struck a chord with Antonia, when she recognised that her exhibition was all about enabling people to speak openly about death and dying. 'The compassionate community idea resonated with me, because it gave me some words to cover this thing that I was doing and seeing. From the A Graceful Death exhibition, people are inspired to know more about the end of life. Some want to volunteer to support others. Most go away feeling affirmed, and these are the people who will face the dying of a friend or relative with a bit more strength. These are the people who go away and feel that they are not helpless and that in their own way, within their community whether in the home, the family, the street, or the town, they can make a difference.

The most memorable thing about the interactions I have had with the public met during the A Graceful Death exhibitions, is that they have all experienced something to do with death and dying. And they all want to talk about it…many of them thought that they shouldn't, and couldn't, and held all of their experiences inside. A relationship is formed not only with the images and their stories, but with other people in the exhibition. These relationships give strength to the experiences the public have had in their own lives, with death and dying.'

Resources
www.youtube.com/watch?v=KtL-QZ8eJG8 video on The Graceful Death
agracefuldeath.blogspot.com/ (regular blog comments)
www.blurb.com/b/3143670-a-graceful-death book on The Graceful Death paintings

Website
www.antoniarolls.co.uk

3.18. St Joseph's Hospice, Hackney

Overview
St Joseph's Hospice is a charitable hospice, providing care for anyone with serious and life threatening conditions, both in the hospice and in patients' homes, drawing on the skills of a multi professional specialist team including doctors, nurses, social workers and volunteers

It provides services to people living in the City of London & Hackney, Newham and Tower Hamlets. Inpatient hospice care is also offered to residents of Camden, Enfield, Haringey, Islington, Redbridge and Waltham Forest. All services are provided free.

Support by the hospice is provided in a variety of settings - day hospice, care at home, outpatient clinics, drop in facilities and inpatient wards. This support includes holistic assessment and treatment, drawing on specialist palliative care skills and embracing complementary therapies, rehabilitation, respite care, information and bereavement support, The hospice aims to provide care which is culturally and religiously sensitive, and offers 24/7 bilingual advocacy and translation services.

Recognising that the hospice was not accessed by many parts of the community, St Joseph's has focused on a strategic approach to community engagement for over six

years. This process has involved working closely with local community, BME and voluntary groups, and has led to the development of a new way of working in which the community is actively engaged in a dialogue and opportunities to develop hospice services.

Compassionate Communities
Supported by the strategic management team at St Joseph's, Compassionate Communities work is developing in response to the recognition that communities need to be at the heart of development of services around end of life care.
Dr Libby Sallnow, is engaged as PHD research fellow at the hospice, and using St Joseph's work as a case study, is looking at evaluating diverse approaches to community engagement in end of life care. In 2012, with Sally Paul from Strathcarron Hospice, she carried out a scoping of hospices in the UK, to gage their interest and approaches to community engagement. 60% of hospices indicated that social approaches to death and dying were currently relevant to them, and 30% would like to work in this way in the future. They found diverse understanding of the application of community engagement, and have developed a model for understanding the spectrum of approaches, to support understanding. This has been published in BMJ Supportive and Palliative Care in February 2013.

St Joseph's has been working closely with local community health agency Social Action for Health to bring the community development expertise needed to work collaboratively with the diverse local communities. Developing a joint intervention, they have supported community champions, or 'health guides' to engage local people in in depth dialogue about end of life care. They aim to support people to establish Compassionate Communities 'hubs' for their own communities – addressing issues around serious illness, death and bereavement, with training and support from the hospice as required.

Simon Robey, Complementary Therapies Co-Ordinator based at the Hospice will be leading on the development of elements of Compassionate Communities work in the borough of Newham. A cross disciplinary task group has been established, meeting fortnightly, to start a process of community engagement. Through focus groups and other methods, and working with local communities, service users, traders, schools, faith groups, they will begin to map people's ideas and needs around end of life. The development of services will be shaped from the bottom up, using a creative approach. The initial focus will be will be on complementary therapies and establishment of wellbeing groups including meditation, art, crafts, music, gardening. The hospice is also beginning a project in Hackney working with local communities living in that borough to identify and train individuals who will support people living with long term and serious illness.

It is hoped that these new projects will act as pilots, and that other areas will be considered for similar developments in the future.

Initial funding
Funding for the work comes from Hospice funds plus some charitable funds from grant making trusts

Staffing

- Heather Richardson, Strategy Advisor
- Community development director post, linked to fundraising
- Simon Robey Complementary Therapies Co-Ordinator, leading on Compassionate Communities
- Dr Libby Sallnow Research Fellow, St Joseph's and University of Edinburgh

Resources

- Dr Libby Sallnow, a palliative medicine registrar, is working towards a PhD in community engagement in palliative care is the research fellow at St Joseph's Hospice, and a student at the University of Edinburgh. Libby has worked closely with the WHO Collaborating Centre for Community Participation in Palliative Care and Long Term Care in Kerala, India.
- Paul S. and Sallnow L. (2013) Public health approaches to end-of-life care in the UK: an online survey of palliative care services, BMJ Supportive & Palliative Care, Published Online First: 22nd Febraury 2013, doi:10.1136/bmjspcare-2012-000334
- www.helpthehospices.org.uk Dr Libby Sallnow and Sally Paul's presentation 'Hospices and Community Engagement; theory, practice and emerging models' for Help the Hospices conference 'Community engagement: back to our future' 29-30 November 2012
- www.helpthehospices.org.uk Dr heather Richardson and Elizabeth Bayliss's presentation for Help the Hospices conference 'Community engagement: back to our future' 29-30 November 2012
- 'Conceptualisation of volunteering in palliative care' presentation by Libby Sallnow www.helpthehospices.org.uk April 2012
- H Richardson and J Koffman; Embracing diversity at the end of life; in Death, Dying and Social Differences. Second edition 2011 Oxford University Press pp70-85 Eds: Oliviere, D,Monroe,B, Payne, S.
- http://www.ehospice.com/india/ArticlesList/Palliativecareiseverybodysbusiness/tabid/3482/ArticleId/1901/language/en-GB/View.aspx article on the Kerala model
- International Perspectives on Public Health and Palliative Care. Libby Sallnow, Suresh Kumar, Allan Kellehear. Routledge 2012
- Home-based palliative care in Kerala, India: the Neighbourhood Network in Palliative Care. Libby Sallnow, Suresh Kumar, Mathews Numpeli, Progress in Palliative Care, 01/2010; 18(1):14-17
- http://safh.org.uk/ Social Action For Health is a community development charity, based in Hackney, which works alongside marginalised local people and their communities towards justice, equality, better health and wellbeing. Elizabeth

Bayliss Chief Executive (see Help the Hospices November 2012 conference presentation with Elizabeth Bayliss and Heather Richardson)
- Jul 10, 2009 Working with people from black and minority ethnic communities at St Joseph's Hospice. www.communitycare.co.uk

Contact details
St Joseph's Hospice, Mare Street, Hackney, London E8 4SA

Website
http://www.stjh.org.uk/

3.19. St Michael's Hospice, Hastings

Overview
St Michael's Hospice is a local charity providing high quality palliative care to people with life limiting illnesses across the Hastings and Rother area.
Key services include:

- In-Patient Service – short term and longer term specialist palliative care
- Hospice at Home
- Day Therapy
- Night Sitting
- Bereavement support
- Education and training – for Hospice and NHS professionals
- Chaplaincy

Compassionate Communities
In 2013, building on the model of St Nicholas Hospice, Bury St Edmunds, St Michael's launched its own Hospice Neighbours service.

Volunteer Hospice Neighbours are matched to those living with a life limiting illness, and can offer practical help and support as well as companionship.

The scheme is being launched across Rye, Northam and Ore, working with local networks, and will be followed by the remainder of the Hastings and Rother area later in 2013.

Currently there are 1.2 FTE staff working to get the programme off the ground, and some funding has been received from a Local Partnership Fund.

Contact details
St Michael's Hospice, 25 Upper Maze Hill, St Leonards on Sea, Hastings TN38 0LB.

Website
www.stmichaelshospice.org

3.20. St Nicholas Hospice Care, Bury St Edmunds

Overview

St Nicholas Hospice is a charity, providing support to patients with life limiting conditions, their families and carers in the West Suffolk and Thetford region of East Anglia. They offer a wide range of services including Community Hospice Team, Day Hospice, nursing and specialist ward, bereavement support, Nicky's Way- grief support for children and young people, outreach hospice service, education and an award winning 'Stephen Project' working with homeless individuals with a terminal diagnosis.

Compassionate Communities

Inspired by Allan Kellehear's Compassionate Cities and Dr Suresh Patel's work in Kerala, Chief Executive Barbara Gale developed the 'Hospice Neighbours' scheme, launched in 2011. It is a community based and volunteer led service providing practical support and companionship to people and their families living with life shortening conditions.

The aim of the scheme was to take a health promotion perspective to raise awareness of death and dying, as a way of building up community capacity at end of life. The hospice recognised the need to extend support into the wider community, reaching people at the end of life who would not normally come into contact with hospice care. Working in this way gives greater capacity for communities to support their own, and for people to remain at home at the end of life, and hopes to create more 'neighbourliness' for those facing isolation during ill health. It was seen as 'a fantastic way of helping to connect communities, reverting back to neighbours helping neighbours, which not only helps people when they need it most but makes the world a nicer place to live in.'

Initially piloted in Haverhill, the scheme has now been rolled out across key areas of West Suffolk and Thetford areas including Mildenhall, Stanton, Bury St Edmunds, Sudbury, Brandon and Newmarket, covering both rural and urban areas. The scheme was promoted and launched building on existing community networks and links and to facilitate networks of support for families and communities.

Hospice Neighbours aims to help those suffering life-shortening illness and their families by linking volunteers, or 'neighbours' who live nearby, to help with practical jobs such as gardening, taking the dog out, offering companionship, or getting out of the house. People in the community interested in having support of a Neighbour can refer themselves, or be referred by a health professional. The aim is to increase self-referral, moving out into the wider community and shift the balance away from hospice based referrals.

What's been achieved to date?

- To date volunteers from the Hospice Neighbours scheme have supported over 200 patients, over 1,500 hours in their own homes and are currently supporting approx. 90 patients at one time.

- Hospice Neighbours now works with 25% people with non-malignant illnesses such as MND, extending the reach wider into the community.

- Receive up to 15 ‘nominations’ to the scheme each month, 40% of nominations were community based in the last quarter, with an average of 25%.

- 67% of the support has been about companionship, and reducing isolation.

- Initial pilot extended to wider rural and urban areas, and the issues of living and dying are being raised in the community.

Staffing
The scheme has a FT Hospice Neighbours co-ordinator, working with a network of local voluntary volunteer co-ordinators who link volunteers to patients in their local community. Hospice Neighbour volunteers receive thorough induction, screening, training and regular support sessions with clear lines of supervision. Volunteers will support a patient from anything from a few months to a few years, often building up strong relationships with the wider family as well.

Funding
Initial funding for the scheme was received from PCT sources, and subsequent funding has been secured from a local charitable trust and Big Lottery ‘Reaching Communities’ for two years.

Resources
St Nicholas Hospice is keen to support other hospices in setting up Hospice Neighbour schemes. It has made all its resources available for use and adaptation, protected under creative commons licence. They are happy to be contacted for more information on how they set up the service and how it works in practice at enquiries@stnh.org.uk. volunteer.dept@stnh.org.uk

Presentation about the Hospice Neighbours scheme to Help the Hospices http://www.helpthehospices.org.uk/our-services/education-training/past-events/hospice-neighbours-study-day/ and presentation by Barbara Gale at Help the Hospices Conference Nov 2012.

BMJ Support Palliative Care2011;1:249-250 Emma Page ‘Hospice Neighbours’

Contact Details
St Nicholas Hospice Care, Bury St Edmunds Hardwick Lane, Bury St Edmunds Suffolk IP33 2QY

Website
www.stnicholashospice.org.uk

3.21. St Richard's Hospice, Worcester

Overview

St Richard's Hospice, a charity, founded in 1984, cares for patients and families in Worcestershire who are living with cancer and other life-threatening illnesses. Each year the hospice gives free care and support to around 2,300 patients and their families mostly within the community – helping them towards the best quality of life possible. St Richard's serves Worcestershire including Worcester, Malvern, Droitwich, Pershore, Upton upon Severn, Broadway, Evesham and the surrounding areas.

The new build St Richard's Hospice opened in 2006 and provides a wide range of services, including Day Care, Hospice at Home, in patients unit, and support services – counselling, bereavement and family support, financial advice, patient groups, and a busy education department. It has a vibrant volunteering community, bringing people in from the surrounding areas to provide support and care in multiple ways, thus reflecting the hospice's roots.

Compassionate Communities

Chief Executive Mark Jackson, was inspired by the ideas behind Compassionate Communities, after hearing Allan Kellehear speak in 2008 at the Help the Hospices conference. Later influences included the work of Barbara Gale at St Nicholas Hospice, and examples given by Milford Care Centre in Limerick, Eire.

- A five year strategic visioning event held at St Richards in 2011 led to plans to recapture the hospice's roots, implement a Compassionate Communities approach and get involved with the community more fully.

- Learning from St Nicholas Hospice, and adopting the model and operating procedures of their 'Hospice Neighbours' scheme, St Richard's set up a pilot in 2012. This ran successfully in the Pershore area of Worcestershire, facilitated by an experienced volunteer.

- 2013 recruitment of a full time Hospice Neighbours Coordinator following successful application for funding to a charitable trust.

- 2013-15 aim to roll out the Hospice Neighbours scheme covering up to ten new areas in Worcestershire including Worcester, Redditch, Malvern, and Broadway, reflecting both urban and rural communities.

- The hospice will work in partnership with local communities, parishes and existing organisations across the county in order to build their capacity to support those at the end of life within their own homes. The scheme will adapt to suit each local neighbourhood and enhance existing community support.

- Each area will have a team of local volunteers (Hospice Neighbours) recruited and managed by an area volunteer, and is expected to develop its own identity and approach suited to each local area it serves.

- The scheme will work closely with clinical nurse specialists, who work throughout the community, across the county GP practices. They will help to identify people who are interested in taking up on the support of a Hospice Neighbour. The

Hospice at Home capacity is to be expanded, and Hospice Neighbours will add non-clinical community based support.

- Once the need is identified, The Hospice Neighbours, will be matched with people in their local community who are coming towards the end of their life. They will offer practical support, directed by the person at home, covering tasks like walking the dog, popping in for a cup of tea, or gardening. The main aim is to build relationships and reduce social isolation, ensuring the person remains in contact with their wider networks and community.

- Hospice Neighbours receive training, support and supervision from the Hospice Neighbours coordinator.

Strategic links
The hospice has developed excellent strategic links through the 3 CCGs covering the Worcestershire areas, and there is growing interest in the Hospice Neighbours approach.

Funding
Coordinator post funded via a Charitable Trust for two years

Staffing
Hospice Neighbour Coordinator FT recruited 2013

Resources
www.strichards.org.uk/News/hospice-neighbours-offer-helping-hands
Inspiration for compassionate communities initiative at St Richards came from

www.facebook.com/BillUnited provided inspiration

www.compassionatecommunities.ie Irish compassionate communities based within Milford Care Centre, http://www.milfordcarecentre.ie/

www.helpthehospices.org.uk Barbara Gale 2011/12 conferences, Allan Kellehear 2008

Website
www.strichards.org.uk

3.22. Severn Hospice

Overview
Severn Hospice covers a wide geographical area reaching across Shropshire, (Shrewsbury and Telford) and Powys. It offers services from three sites at Bicton Heath, Shrewsbury, Apley Castle, Telford, and Newtown Hospital, Powys, as well as wide reaching support to people in their own communities.
Services include Day Hospice, inpatient care, Hospice at Home, spiritual care, bereavement and family support, and education and an active volunteering programme.

Compassionate Communities

- Severn Hospice first explored the concept when chosen as one of four pilot sites for West Midlands Strategic Health Authority's study into workforce development and compassionate communities in 2008 (including St. Mary's Hospice, Birmingham, Kemp Hospice, Kidderminster and Murray Hall, Sandwell). This linked to hospice findings of wide interest in volunteering support roles following an emergency pandemic planning exercise.

- Initial findings within the community highlighted social isolation and lack of support as a trigger for crisis and emergency interventions when people faced long term or life threatening illness.

- Chief Executive Paul Cronin, has become a passionate advocate of the Compassionate Communities approach, and Severn Hospice now supports 'Co-Co' in a number of areas.

- Severn Hospice sees a Compassionate Community as one in which citizens support frail people and those living with long term illness to remain active members of the community, with the aim of reducing social isolation.

- Severn Hospice will only provide support to develop Co-Co initiatives on invitation from the community, in whatever form this takes. The community must identify the need and actively request support. The hospice then acts as an 'honest broker' and provides support to interested groups, ensuring that initiatives are fully community led and owned.

- The hospice will provide support with initial community engagement, volunteer support, training and advice, and provide working procedures and practices for groups to adopt and adapt to their needs.

Example - Co-Co, Church Stretton

GP Sal Riding, formerly based in Church Stretton, Shropshire was keen to explore a model of care within the community, for frail elderly and those at the end of life.
Initial community meetings showed interest in this approach, and a partnership with the local charity, Mayfair Centre developed. The centre has an established network of local volunteers, keen to offer practical support to people within their own homes.
The GPs gain informed consent from a person needing support, and refer them to the co-ordinator who will then link them to a volunteer. Following agreement with the person the volunteer will provide practical, non-clinical support e.g. going for a walk, chatting, support with paperwork etc. 80 volunteers have been trained to date, and currently over 40 people are being supported. Volunteers act as a 'citizens' extension' of the primary care multidisciplinary team, and any issues of concern can be raised with the team.

Severn Hospice acted to support the initial community engagement, and provide two days training for volunteers, on all aspects of end of life, communication skills, and boundaries. Support to volunteers continues with advice, and provision of monthly group reflective practice sessions.

- Other Co-Co initiatives developed with support from the hospice, Clun 'Good Friends' group, a volunteer led scheme stemming from an existing Good Neighbours group.
- Cleobury Patients' Voice, a patients' group based at Cleobury Mortimer Medical Centre have set up Co-Co to support frail elderly and those with life limiting conditions
- Many communities and GPs surgeries are now approaching the hospice for support to set up their own Compassionate Communities initiatives, and to date, 7 communities have established themselves.

Staffing and resources

- Some funding has been secured for aspects of the work, within community settings. However, the emphasis is on establishing a sustainable model using local resources, and building on existing networks and strengths.
- Each area taking on the Co-Co has developed its own model of delivery to suit local needs ranging from purely volunteer run programme, to embedding the work within an existing volunteer co-ordinator role, or employing staff.

Example - Cleobury Mortimer set up a Co-Co intuitive from a GP practice working with patient's group. Successful funding bid enabled the employment of a development worker, with the aim of establishing a charity within its own right to carry out the work.

Example - GP practice in a rural area co-ordinates and supports volunteers and referrals to patients, working through a trusted member of the community to broker the initial introduction.

Evaluation

- Evaluation by the PCT of 38 participants gaining support through Church Stretton showed substantial reductions in contacts and use of unscheduled health care services through GP phonecalls and appointments, emergency and unplanned admissions following six months support from a volunteer (as illustrated in table below). Similar results have been found in Cleobury Mortimer.

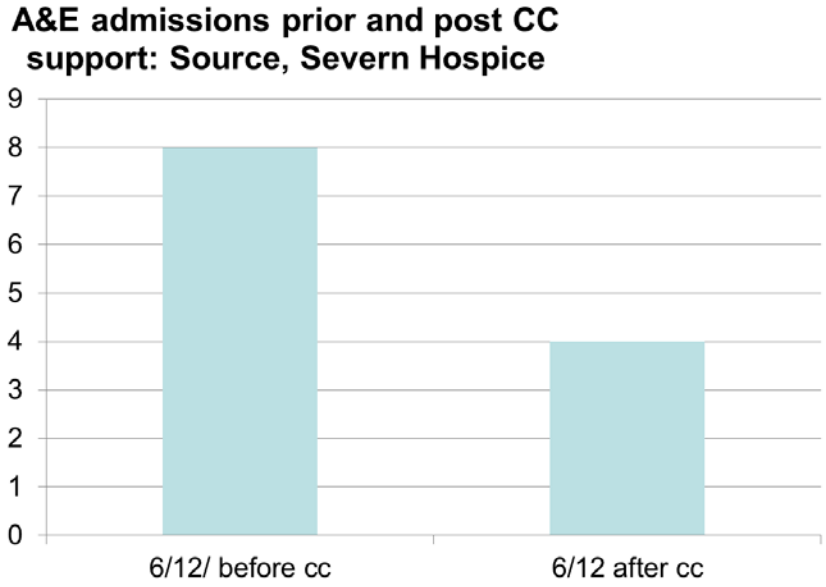


Table 1 Source: Paul Cronin Help the Hospices Conference November 2012

- Qualitative information has shown that there is a reduction in loneliness, a positive impact on carers, and increased ability for patients to self-manage their condition with this type of support
- See Paul Cronin's presentation at Help the Hospices 2012 conference for more slides of this evidence.

Strategic links
Compassionate Communities embedded in NHS Shropshire CCG QIPP Plan 2012/13 www.2shrop.net
2012 CCG funded 24 Care and Community Co-ordinators to arrange care packages for patients. Co-Co support cited as one possible intervention choice.

Resources
Paul Cronin speaker at International Public Health and Palliative Care Conference, Limerick April 2013.

www.youtube.com/watch?v=Y7Hngly_N2U Church Stretton scheme- 'volunteer scheme helping people in rural Shropshire'

Website
www.severnhospice.org.uk

3.23. The Shakespeare Hospice - Stratford-upon-Avon

Overview
Shakespeare Hospice is an independent local charity which provides specialist care for people affected by life limiting illness. It operates as a Day Hospice, has an established Hospice at Home service, and a Family Support Service and active volunteering schemes. Services are available to patients, carers and their family members across both rural and urban areas of South Warwickshire and the North Cotswolds (pop 120,000). Services offered include nursing care, personal care, counseling, complementary therapies, occupational therapy, physiotherapy, chaplaincy and creative

therapies. In 2013, the hospice aspires to taking on the role of supporting children over the age of 16 with life limiting conditions in a variety of ways (subject to funding). The hospice will be developing Young Carers, Work Experience, Transitional Care and Pre and Post Bereavement services.
The hospice is developing strong links within the local community and local schools.

Compassionate Communities
Inspired by seeing Allan Kellehear speak, Chief Executive, Angie Arnold was keen that the Hospice explored a Compassionate Communities approach. This is seen as a way of engaging community and starting to address some of the issues faced by hard to reach areas. Social isolation can be a particular problem in rural villages for those at the end of life, where poor transport, lack of amenities for example can have an isolating effect. The hospice saw that some communities look after their own, and that this could be supported further through reaching out and working more closely with existing networks.

The hospice aims to develop a network of volunteers, matching them to a person with life limiting illness living near them, or in the same village. The volunteer would receive support and training to provide both emotional and practical support, such as shopping, getting out and about and befriending. The Hospice aims to work closely in partnership with local volunteering organisations such as the W.I., to build on existing local knowledge and skills.

Through working closely with schools, and through work experience placements at the hospice for secondary students, they also aim to bring young people into providing volunteer support through a 'buddying' system to young people. This will help to meet some of the potential needs of young people using the hospice. Local Youth Parliaments and user groups were consulted in focus groups to look at the social and other support needs of this group.

The Compassionate Communities approach will also be used to link to the existing work carried out by the hospice, including work within schools, building on existing volunteers knowledge, and with professionals as a way of raising awareness of the role to be played both by community and the hospice in support and awareness of end of life issues.

Initial funding
A needs assessment and business case for the Hospice was initially funded by Stratford Town Trust, leading on to funding of a project proposal. Four areas for development were identified following consultations, including the extension of work within schools, linking more to young people, and launching the Compassionate Communities work.

Staffing
The hospice has a volunteer co-ordinator working with the existing volunteers.It recognises that Compassionate Communities is a new venture which requires dedicated capacity, and aim to employ a co-ordinator with HR experience to recruit and train volunteers and further develop the Compassionate Communities work.

Contact details
The Shakespeare Hospice, Church Lane, Shottery, Stratford-upon-Avon, Warwickshire, CV37 9UL

Website
www.theshakespearehospice.org.uk

3.24. Soul Midwives

Overview
Soul Midwives are non-medical holistic companions who guide and support the dying in order to facilitate a gentle and tranquil death. Using a range of therapeutic techniques, and drawing on ancient traditions, their most important role is to provide comfort, continuous support and reassurance in helping the patient to experience the death he or she wants. They can support someone at home, hospital or hospice.

Felicity Warner, Director of Soul Midwives has pioneered this role in England, and provides training, consultancy and support throughout the country. She is also supporting hospices and care homes with training on 'Gentle Dying' to enhance skills to be with people at the end, with compassion and dignity. To date over 200 Soul Midwives have been trained and are offering their skills at all levels to support those at the end of life.

'A good death is an extraordinary, moving and sacred experience. It can also have a healing quality, not only for the person who is involved, but for their families, friends and wider community.'

(Felicity Warner- Gentle Dying)

'The living see less of death than we used to, and we have lost our instinctive way of coping with it. Most modern deaths are, at best, efficient but also soulless,' says Felicity. 'I learned that it was possible for death to be gentle and humane, and we can all help by being there and being calm, loving and kind.' (Daily Mail 13.8.08)

Resources
Warner, F. 2008 Gentle Dying. Hay House

Warner, F. 2011. A Safe Journey Home. A simple guide to achieving a peaceful death. Hay House.

Warner, F. 2013. The Soul Midwives Handbook. May 2013.

www.gentledying.com

http://www.dailymail.co.uk/home/you/article-1053809/Felicity-Warner--8216-I-soul-midwife-8217.html#ixzz2MQ4Dr4N7

3.25. Teesside University, Institute of Health and Social Care

Overview

- In 2008 NHS North East produced a 25 year public health strategy 'Better Health, Fairer Health' incorporating 'A Good Death' (advocating a public health approach to end of life) as one of its ten key themes.

- A 'Good Death Charter' was produced by a multi-agency advisory group following extensive and creative public consultation to gather over 2,500 people's views. The pioneering charter set out proposals for the kind of care and support which people who are dying, their families and carers can expect.

- The development of the charter was supported by consultant in end of life care for North East, Professor Edwin Pugh, (Teesside University) and the Dying Matters Coalition.

- The Compassionate Communities project was developed to take forward the recommendations of the NHS Public Health Strategy.

Compassionate Communities

- Teesside University has led the way in supporting and researching public health approaches to transform end of life services and develop Compassionate Communities.

- Establishment of a dedicated Compassionate Communities unit at Teesside, enabled public health approaches to end of life to be tried. This has established the North East as an innovative test bed for implementing the ideas behind the Good Death Charter.

- The aim is 'normalise' death and to address not just personal aspects of the topic, but also the structural and societal factors which impede people's ability to respond compassionately to those nearing end of life.

The Compassionate Communities approach developed included the following:

- mapping existing end of life public health activity in the Tees Valley to identify and share good practice.

- promotional activities to highlight the Charter's approach through creative and other media.

- focus on Human Resources policies amongst major Teesside employers to bring about change of leave entitlement in support of both carers and bereaved

- Developing and delivering training in end of life issues for professionals and in community settings.

- raising awareness in schools of public health at end of life.

- developing patient and carer networks within the Tees Valley.

- Community development workers were employed to take the Charter to community groups and explore needs and views whilst raising awareness of end of life issues.

In addition the School of Health and Social Care has led the development of academic research and learning about Compassionate Communities including

- Series of Master classes on public health approaches to palliative care including international speakers.

- Workshops on death and dying working with NE Strategic Health Authority.

- Sept 2011 5th Palliative Care Conference; building the Compassionate Community?

- Working closely with Dying Matters coalition to advise on policy and strategic developments.

- Numerous publications on health promoting palliative care.

Funding
The pilot study on Human Resources Policies was funded through the University Research Fund of Teesside University

Staff working on Compassionate Communities
Professor Janet Shucksmith- Professor in Public Health and Director of the Health and Social Care Institute

Professor Edwin Pugh, Consultant in end of life care (retired)

Deborah Hall, Project Manager, Compassionate Communities Project

Resources
http://www.northeast.nhs.uk/

http://www.agooddeath.co.uk

http://www.phine.org.uk/a-good-death/charter

http://www.dyingmatters.org/news/nhs-north-east-publishes-good-death-time-think

http://www.tees.ac.uk/sections/Research/health_socialcare/compassionate_presentations.cfm Seminar presentations on compassionate communities

5th Palliative Care Conference Building the Compassionate Community? Practical Public Health at the End of Life Friday 9 September 2011

Governing Death and Loss: Empowerment, involvement and participation. Steve Conway (Ed), Oxford University Press 2011

Website
www.tees.ac.uk

3.26. West Midlands NHS Strategic Health Authority with Murray Hall Community Trust

Compassionate Communities
From 2008 onwards, West Midlands Strategic Health Authority has supported an innovative approach to exploring the development of Compassionate Communities. Led by Pauline Smith, the then clinical end of life care and dementia care lead, a range of initiatives began. Much of this focused on developing public awareness of the issues, and encouraging open discussion and debate. Despite strategic reorganisation taking place across the NHS, some continue today, in part supported by Murray Hall Community Trust in Sandwell.

- 2008 commissioned work around the development of Compassionate Communities across the West Midlands, with a funding focus on generating a future workforce in end of life care. This took four pilot sites; Kemp Hospice, Kidderminster, Murray Hall Community Trust, Severn Hospice, and St Mary's Hospice, Birmingham. All pilots developed their own approach to the issue of training and supporting people in caring for those at the end of life within their community.

In 2009 Birmingham and East PCT launched a programme of creative media work to develop a high profile end of life care campaign working with the charity, Rosetta Life.

The charity, dedicated to working with people who have life-threatening illnesses, worked with Murray Hall, hospitals and hospices in the West Midlands to encourage sharing of stories and experiences through the arts. 'Let's Talk About Living' held a series of events and shows across Birmingham culminating in a festival on World Palliative Care Day, including a Children's concert held with the CBSO, a photographic exhibition, workshops and theatre productions involving users from nursing homes and hospitals. A film 'Night and Day' was premiered at the Electric Cinema, following six Birmingham people approaching the end of their lives

- Dance and theatre productions including '*The Magic Glow of the Co-op'* at the Repertory involving people from local hospices

- A photography project was commissioned for professional photographer and community youth development worker, Ade Marsh, to work with groups across Birmingham. The aim was to depict aspects of living, dying and death and open a dialogue about the subject. The themed photos led to a three day exhibition 'Saying the Unsayable.'

- The next stage of the project led to the development of a resource pack as a tool in which the photos and information could be used in a range of settings to encourage people to talk about end of life issues. A number of sessions were funded for Ade to aid the original Compassionate Communities to facilitate workshops on Saying the Unsayable

- The photography exhibition was part of a three day exhibition at Centenary square in Birmingham. The exhibition included a display of recorded interviews, other interactive installations and live performance from a theatre company with participation from members of the public.

- The third stage was to fund Murray Hall Community Trust to support and mentor Ade Marsh to deliver further Saying the Unsayable sessions as an aid to developing Compassionate Communities across other areas of the West Midlands. His work has included developing links and building capacity with housing associations, Birmingham St Mary's Hospice, Walsall Time bank, and a range of community groups. He has been filming and collecting stories on compassion to share on the Murray Hall Community Trust – Compassionate Communities website and in a film.

- Murray Hall Community Trust continue mentor and support Ade's work, which links well to their own Compassionate Communities programme. This has included working with Murray Hall Compassionate Communities Development Worker to develop a photographic project with a secondary school in Sandwell and an exhibition at The Public for Dying Matters Awareness Week 2013.

Resources
www.ademarshphotography.co.uk Compassionate Communities development worker and photographer

http://www.wellbeingindying.org.uk/ website to raise discussion around death and dying

'Evaluation of the development of Compassionate Communities and generating a future workforce resource; Final Report: University of Worcester, Institute of Health and Society Professor Dominic Upton et al. NHS West Midlands 2010.

2nd Nordic Symposium of Death and Dying, Helsinki, April 2012 – "Death, Dying and Bereavement – Nordic Perspectives' www.nnthelsinki2012.wordpress.com/
Presentation by Ade Marsh on the Saying the Unsayable project
www.compassionatecommunities.org.uk

3.27. Weston Hospicecare

Overview
Weston Hospicecare is a hospice serving the people of Weston-Super-Mare and the surrounding areas – from Burnham-on-Sea in the south, to Cheddar in the west and Clevedon in the north.

The hospice looks after people with life-limiting illnesses such as cancer, motor neurone disease and multiple sclerosis, and their families. Hospices look after the whole person and pay particular attention to their families and loved ones that will be left behind afterwards. The hospice offers a range of services, including in patient and day care, Hospice at home, a 24 hour phone line, chaplaincy, and bereavement support. The hospice has developed short courses for carers and patients called 'Sharing and Travelling the journey' and runs other educational events regularly. Volunteers play a central part in the life of the hospice, fulfilling a broad range of roles including 'Companion Sitters'.

Compassionate Communities

Weston Hospicecare has been committed to exploring the development of Compassionate Communities for some time. Staff made a visit to Australia to learn more about Allan Kellehear's vision and see working examples of the approach. Palliative Care Consultant Dr. Julian Abel and Specialist Palliative Care Nursing Manager John Bailey, have developed a model for this work which rejects an expert driven, service delivery approach in favour of a community development model.

The model takes two forms:

Carer Companions

- Volunteers with significant life experience, often having done caring in an end of life context, support others doing caring. At a basic level, it involves emotional support and signposting to useful resources right through caring and into bereavement. But as well as doing their own needs assessments, those doing the caring are enabled to map their own support networks, identifying others who can care, gaps, and opportunities to strengthen and broaden the network.

- The first port of call for managing practical tasks (including the organising function itself) is always a person's existing networks. Volunteers and professionals are only considered when the gaps in what these networks can provide are identified.

- Tasks identified and the support given can mean that the person and their carer are not isolated at this critical time, but continue to be surrounded by a network of support within the community. Not only can this mean that a person is more likely to be able to have a home death, but unplanned hospital admissions are reduced, and the key carer is not so subject to burn out, as well as actually stimulating community development by building social capital.

- Task and network identification is now a standard part of advanced care planning.

Community mobilisation

Ways are being explored to stimulate existing and new community groups and networks to take an active role in supporting those at home with palliative care needs, and to support others doing a significant amount of informal caring.
We anticipate that these groups and networks will be boosted by the addition of people who have developed skills 'on the job' through supporting someone caring for a dying family member or potentially even these carers themselves. They will be enabled to offer care to someone in their neighbourhood who is 'network poor'.

Roles provided by Carer Companions vary and can include signposting, daily household tasks, companionship, and continuing into bereavement support, formal training and ongoing support is provided.

Whatever the mechanism by which these community-based groups and networks operate, the ultimate objective is not to build a dependency on the Hospice, but rather to enable community-owned solutions and community development. Both approaches help to build a real sense of capacity within a neighbourhood to support both those at the end of life and their carers, reducing isolation and ensuring that they remain embedded within the community. The Weston model could be seen as a series of concentric rings with the dying person at the centre, surrounded by family, neighbour, and working outwards to include the wider community including groups such as church, with professional support on the outer edge.

Julian Abel commented, 'We're very passionate about this project. We meet local people every week who are caring for someone who is nearing the end of their life; it can be demanding, socially isolating, exhausting and emotionally intense. Without the right support such caring can have a devastating impact on both the individual who is ill and the carer.'

Funding
Weston Hospicecare was awarded nearly £143,000 in August 2012 by the Big Lottery Fund's 'Reaching Communities Programme.' Launched in January 2013, this funding is supporting the development of the Weston Hospicecare's Compassionate Communities project.

1 FTE Compassionate Communities Network Coordinator was appointed in January 2013 to recruit, train and support Carer Companions.

Resources
(2011) Abel, J., Bowra, J., Walter, T. and Howarth, G. Compassionate community networks: supporting home dying. *BMJ Supportive & Palliative Care*, 1 (2), pp. 129-133.

www.healthcarechaplains.org Community Development Conference April 22nd 2013 'The next step forward for end of life care'

http://blogs.bmj.com/spcare/2013/02/12/proposal-for-the-development-of-community-end-of-life-care-a-guest-post-by-julian-abel//

http://www.westonhospicecaregroup.org.uk/2012/08/lottery-cash-injection-for-hospice-gives-rise-to-compassionate-communities-network/

Website
www.westonhospicecaregroup.org.uk

3.28. York Carer's Forum

Overview
York Carer's Forum, a voluntary organisation of over 200 members offers support to all unpaid carers and former carers aged over 18 who live, work or care for someone in the City of York area. There are no paid staff.
York Carer's Forum raises awareness and empowers unpaid carers and former carers by:

- Providing a focus across all carer groups.
- Identifying and promoting unpaid carer's needs.
- Gathering and sharing information for carers - monthly newsletter 'York Carer's Voice'.
- Working with related statutory and voluntary organisations (both locally and nationally) to help develop appropriate services.
- Raising the profile of unpaid carers through a united voice.
- Meeting together monthly for socials or to host guest speakers.
- Twice monthly meetings to support bereaved carers, helping them pick up social links and reduce isolation following a death.

Compassionate Communities
York Carer's Forum responded to the callout and felt that their work reflected the Compassionate Communities approach.

Chair of the organisation, Katie Smith along with Irene Mace (both ex nurses) have begun to develop a focus on 'a good death' developed through an initial talk given to over 200 people at the cancer care network.

Through storytelling, the two women recount the events of their own mother's illnesses and deaths. Role playing a discussion between their mothers, 'Marjorie and Phillis,' they ask each other 'Was your death as good as mine? How was it for you?'

This leads to them describing two very different deaths. Katie as her mother's sole carer, was isolated and struggled, and felt her mother was not able to have a good death, whereas Irene's mother was able to die peacefully with support.
Through describing their experiences in this way, the women are able to share their stories and use them as a platform from which to open a wider discussion about death and dying with the audiences. This includes helping people to start planning for their own death, including will writing, power of attorney etc.

Katie points out that we all need to prepare for the unexpected, asking, 'when does the end of life care pathway start? It is not always easy to define. My mum had her first major stroke in her 70's but went on for 20 years, so that was her pathway…Yes, it was that long.'

The talk has generated a lot of interest, and has snowballed. It enables people to open up and tell their own stories as well…'people ask what do I really think…but it starts with getting people to think about their own end of life and their own plans…'
The work is also impacting on the work with the carer's forum, as many carers face the death and loss of a loved one, and helping people prepare can be transforming. They are campaigning to have 24 hour support for those at the end of life.
'Once a loved one dies, people say they are 'not a carer anymore' but of course they are, still in that role, people appreciate it is a loss, a grieving when someone goes.'

Contact details
York Carer's Forum, c/o 15, Priory Street, York, YO1 6ET.
Tel: 01904 422437
Email: yorkcarersforum@tiscali.co.uk

Webite
http://www.yorkcarersforum.org

4. How Compassionate Communities was defined

4.1. It's not 'rocket science'

Before we look at what respondents said about their view of Compassionate Communities, it is important to remember that in many ways this is nothing new. Compassion already exists and many are already providing support and care to those nearing the end of life. The personal experiences of individuals in the population can influence how they approach death and dying, and living well.

'*This is just about having normal everyday relationships…the ordinariness of this is just what confuses people, this is so ordinary, it's not rocket science, it's about people linked to other people because that is what life is about. It's about sitting with people and saying, let's ask a neighbour to come and have a chat...it's so ordinary… this is the confusion.'*

'*If we had Compassionate Communities, more people would know one another. It's important just to say 'good morning' and to check if you don't see them…take the time. The art of being compassionate is with everyone but it's been removed because of the way we live. When you're not well and you live alone you need to talk to another human being, you need a neighbour.'*

It is these ordinary social relationships that can disappear when someone is dying, and the medical system moves in…daily tasks, activities and social networks become overlooked. The challenge is to provide care whilst supporting the ordinary to continue.

4.2. Respondent's interpretation of Compassionate Communities

Allan Kellehear's vision of Compassionate Communities and health promoting palliative care has been described at the beginning of this report, along with other influences on the development of this work at present.

The case studies given illustrate the breadth of approaches and interpretations of the vision being currently applied across England. In keeping with Kellehear's concept, there was a broad range of groups, organisations and individuals involved. Some of their work had been inspired by Compassionate Cities as well as by the models found in Australia, Ireland and Kerala, in India. Others were developing their own interpretations of the approach.

The case studies give an overview of the creativity and diversity of the work being done under this banner.
As indicated earlier, initiatives were being driven by

- Hospices
- funeral celebrants
- grassroots community and voluntary organisations
- informally within communities
- academia
- faith groups

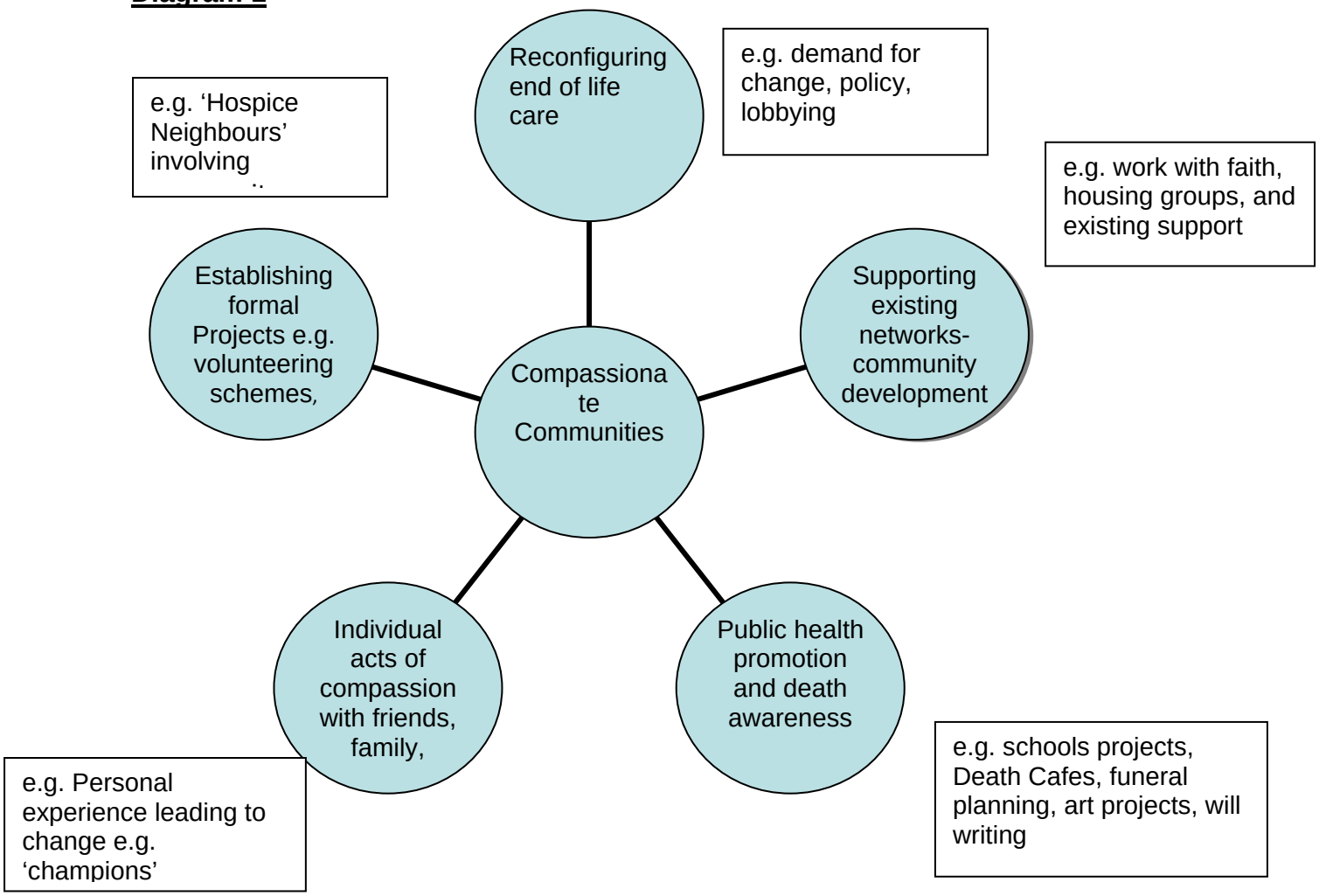
- public health
- individual acts of compassion

They encompassed a number of strands or approaches,

- **individuals** building Compassionate Communities within their own sphere.
- awareness raising of death and bereavement through creative **health promotion** approaches, using art, media, festivals and events.
- **community development** approaches working with schools, community groups, and enhancing existing networks.
- **formal volunteering** schemes giving practical support and help to those at the end of life.
- engagement of communities in dialogue and **shaping of end of life care** services.

Diagram 1 below is an attempt to summarise the strands pictorially before we look at each strand in turn.

Diagram 1



Many groups took one or more of these approaches, working across a number of themes at once and at different levels.

4.3. Individual acts of compassion

Personal experience of death and bereavement can lead individuals to both offer others compassionate support, and to demand change in the way death is handled. They can often be motivated to become involved in raising awareness of death, highlighting how it could be different if we were more prepared.

There are many examples of this approach as told through the power of stories, such as in Dying Matters and the Compassionate Communities, Sandwell websites (*www.**compassionatecommunities**.org.uk)* The 2012 Day of the Dead, for example, a moving film 'Beyond Goodbye' about the funeral following the death of a young man, Josh, was shown by his parents Jimmy Edmonds and Jane Harris. This has stimulated debate on how funerals can support healing for all involved if planned with care (www.beyondgoodbye.co.uk). Similarly, with the York Carer's Forum, two volunteers now share publicly the story of the 'good' and 'bad' deaths of their mothers, as a way of engaging others to think about the issues.

These Compassionate Communities 'champions' act as individuals who take their personal experiences to influence change in their own sphere, be it family, friends or work places. One champion, following the death of both parents, now sits as a layperson on an end of life care group within a newly formed Clinical Commissioning Group (CCG). Another, motivated by the difficult and unsupported death of her sister, uses her position as a consultant within a CCG to raise end of life care issues in strategy wherever she can.

For others, it might mean that they feel more empowered to stand up for change,

'*One champion, learning what Compassionate Communities meant, was able to stand up and stop her mother being taken into hospital to die…got her to stay in her care home...it was only because she knew that things could be different that she was able to do this.'*

'*Compassion needs to be reinvented and reinvigorated…we have to re-remember it's about social relationships giving meaning. It's the sense of worth, the social connexion we have with one another, particularly at this point when people are vulnerable.'*

4.4. Health promotion approaches and death awareness

Health 'promotion' may seem a misnomer in dealing with issues of death, but this approach is central to the view of Compassionate Communities, enabling people to become more informed and empowered and to 'live well' even into death.

Raising awareness of death in some of the case studies was seen as a way of stimulating discussion and developing momentum for change from the bottom up. This involved creative ways to break through the taboos surrounding death and dying, bringing people together to share and talk.

'*Change is impossible or very difficult where the communities involved do not identify a need for change. Therefore a Public Health model of grass roots up from a multifaceted and non-traditional approach is likely to be most successful.'*

This 'multi-faceted' approach involves a broad range of groups, from community groups, schools, artists, Death Cafes, and funeral celebrants, all with different approaches and audiences. Dying Matters website, again, has many examples of the different ways in which conversations, festivals and events on death are springing up across the country.

One group said, '*we run death literacy events, creative arts projects, and all sorts of other things, trying to do it under the radar, so it's not some big dramatic event, doesn't promise any fantastic fixes but makes people think.'*

'It is very liberating to have an open space where people can share and learn from others.'

'We hope to nudge people into talking, it's good for health and well-being…reducing fear and regrets…helping more positive bereavement.'

'We run will making workshops, bite-size 'how to' sessions with all sorts of groups so people can look at end of life issues easily.'

Supporting the community to identify issues, can begin to increase the potential to be caring and compassionate, improve skills to face end of life issues and, some hope, stimulate a movement for change around the culture of death and dying.

4.5. Supporting existing networks- community development approaches

Community development approaches are central to the vision of Compassionate Communities. For some of the respondents, this represented a new way of working, sometimes challenging to understand, involving a move away from service delivery and 'letting go' of control. Professionals were being asked to learn new skills, and work in partnership with community, to support and enhance existing networks. For those coming from an already established community development ethos the approach was more comfortable, and in keeping with existing work.

Where successful, it acted to give professionals a more informed approach to developing services and work with those at the end of life.

'*The (community-led) process not only gave individuals and community members a starting point but Public Health also then had a strong community led action plan at the end that they would work with*.'

A community development approach can build on the assets a community has to offer in finding solutions to problems. Some saw Compassionate Communities as a way of working with existing community strengths to identify needs, stimulate ideas and solutions to support those facing death and loss.

‘*Communities have the capacity, it’s so overlooked why don’t we do something to promote it, their capacity to care for their own dying? Let’s promote the ordinary networks people already have, in partnership with experts and professionals.’*

‘I have been working with housing and faith groups, and a range of community groups to raise awareness of compassionate communities. They have all shown an interest in exploring it further and developing their own approach.’

‘It’s really very simple, can be replicated anywhere, uses little resource...it’s about communities supporting their own, and from the initial feedback it’s highly popular.’

For some it was essential that communities were the first to identify a need and invite in support, not the other way around...the approach needed to be owned and developed by the community, with professionals acting in partnership.

‘*It needs to remain local and what the community identifies and want… not one model fits all, it varies from community to community.’*

‘It’s not a service provided by outsiders in a given setting...but from people with their own communities. This is about the life experience as well as the death experience.’

Others echo this as being an authentic community development approach,

‘*True community development principles say there are existing community networks that may not be working well for all sorts of reasons, but if we offer assistance, mentoring or partnership to those existing networks they can begin to grow their own shape and strengthen without us prescribing how those should be.’*

The approach to strengthen and mentor existing networks, relationships, and skills, can build alliances between health care professionals and communities. Some felt that this had a knock on effect, building ‘social capital’ and bringing more profound change than just immediate ‘solution fixing’.

‘Don’t go out to fix the community, say “This person may already have a social network”. If we can galvanise this, it’s likely that it will be a more realistic community primed for the next occurrence of something requiring a compassionate response. If you work with that dying person’s compassionate network, it’s a bit like yeast- it grows above and beyond that starting point.’

Community development as an approach however, to some can seem nebulous and difficult to understand and pin down.

‘*People know this is not easy, it’s very intangible work, the value of this work is much less tangible than the medical approach where you can show job done proven worth, and targets met, but community development is about the intangibleness of relationships*.’

4.6. Establishing formal projects

A more directed approach, still under the banner of community development, is for a formal project to be established which involves the community. Rather than waiting for ideas to bubble up, a scheme will be initiated by an agency or group based on perceived need. It will then actively work with the community to become involved and contribute to shaping its development.

Examples of this approach could be seen in the development of 'Hospice Neighbours' schemes, where a hospice establishes a scheme and actively engages members of the community as volunteers to offer support to those facing end of life within their local neighbourhood. This approach was particularly valuable to those who might not have strong existing support networks, and might face isolation. Working with health professionals to identify the need, volunteers could be matched up with local people to provide practical every day support and companionship.

'*For us it is easy because we have the clinical nurse specialists who have this relationship with GPs and they talk to the patient and asks permission to bring in a volunteer, then the coordinator matches someone with the patient.'*

'The person identifies the kind of help they might like…dog walking, mowing the lawn, cutting the hedge is part of it, but 70% of it is about companionship.'
'It's growing fast, and came from recognising that there is a gap to fill, in promoting self-help in neighbourhoods.'

Although this approach involved establishing a scheme, it was still seen as essential that it worked sensitively with existing networks, without imposing a set solution,

'*There are a few groups where neighbours have looked after people, and they were there before service providers turned up. Now that we are working in partnership with communities, we don't foist people on them; we ask the patient if they would like other members of the community to come in.'*

'If a hospice is already in a community and sets up a local volunteer based project, it must be careful that it doesn't step on toes. There will already by parish teams and other organisations; we are there to work in partnership and not be the big 'I' coming in.'

4.7. Reconfiguring End Of Life Care?

Through health promotion, community development, partnership working and increasing awareness some hoped that a Compassionate Communities approach might contribute to a case for a 'reconfiguration' of end of life (EOL) care.

'It's not about replacing services but enhancing, supporting and widening them.'
'The communities said they want to partner with EOL care providers. You are asking them for something, saying you are experts in who you are and in who this person is, and we are experts in the medical area and care. If the two experts work together then it will be much better for the person.'

This was coupled with recognition that the existing system of care was increasingly unsustainable.

'*There are gaps that the medical model just isn't sufficient to meet, if we are really looking at the holistic care of the dying. Hospices and professionals can disempower by going in and providing services, not working with what is already there within that family network and community.'*

In speaking to respondents, there was evidence that the work with compassionate communities was beginning to impact on decision makers. Some of the case studies show how it has been incorporated into strategic planning both within organisations and in wider health strategies.

'*The way forward has been shown, and this has gone into the Joint Strategic Needs Assessment (JSNA).*'

'*It's incorporated into key actions in the Older People section of the Health & Wellbeing Strategy- supporting dignity and choice for care at the end of life.'*

'*The Clinical Commissioning Group (CCG) is watching its development carefully and with interest.'*

'Supported by the strategic management team, Compassionate Communities work is developing in response to the recognition that communities need to be at the heart of development of services around end of life care.'

There was an indication that the ideas might slowly be taken more seriously, albeit driven by concerns about future resourcing and capacity.

'Public health realise that with baby boomers reaching end of life that they just can't provide enough professionals for this, communities will have to provide some support.'

'We are going to have hospitals full of dying people if we don't get Compassionate Communities brought into the mix to add to what's already there…without it we are just tinkering on the edges.'

'Compassionate Communities ideas arose from hearing all the time that the care is not going to be there in the future and that there is a ground swell towards it.'

'The local Clinical Commissioning Group chose end of life care to demonstrate a new approach to commissioning called 'experienced led commissioning'. We were involved in this process to develop the new end of life care strategy. Compassionate Communities is included as a key element.'

4.8. A spectrum of approaches to Compassionate Communities

It was apparent speaking to respondents that there is a wide range of interpretations along with some confusion, about both what community development approaches are and what Compassionate Communities is.

Some questioned the authenticity of approaches used by others and expressed concerns that without clarity, Compassionate Communities might lose its essential links to public health. Others felt that people used the term Compassionate Communities to describe projects without any understanding of context or concept. In addition, there were tensions between the enthusiasm to start Compassionate Communities and the lack of clarity about what that might mean and how to go about it.

'*There is a danger of losing authenticity…we need to be clear about what it is and what it isn't. Communities need to be supported to develop what they believe is the most important, and create in their own ways.'*

'There are lots of community initiatives in the wider sense…there is a sense that when the Compassionate Communities name is used literally, it's often just a loose link, and they have no understanding of the wider context or meaning.'

Others raised fears that due to lack of clear definition and approach, it would become absorbed into institutions as, 'just another service delivery approach.'

'*Some prefer the institutional model because that is a task delivery model. They are saying "they are the community, we are the experts, we will go out, and fix a problem." It's all about problem fixing, we identify that community as lacking capacity, as not responsive, and we will bring a series of tasks to fix it. It all comes down to understanding of community development and its authenticity*.'

Some found the title Compassionate Communities held various meanings. Some were using it for functions which might not be seen as true Compassionate Communities approach, limited in scope or without the wider understanding.

'*A reservation with the title Compassionate Communities is that people interpret it differently…it needs to have an overarching understanding for it. If people call themselves that, they need to know what it is and have a sense of being related to Public Health.'*

'The title has usually been used to describe just a 'project' in the community.'

This included ideas that Compassionate Communities could be a vehicle for raising funds for organisations, or involved adoption of good practice guidelines.

'*They are funding it on the basis that we believe the in the longer term it will lead to further fundraising and donations.'*

'We are implementing the Liverpool Care Pathway.'

Research published in the BMJ Supportive and Palliative Care in February 2013, by Dr Libby Sallnow and Sally Paul echo these issues. They undertook a scoping study of 220 palliative care providers across the U.K. which showed 60% of respondents felt that Public Health approaches to death, dying and loss were a priority for their organisation. They found, however, a broad understanding and interpretation of the terms community engagement, health promoting palliative care, and Compassionate Communities. To help clarify this, they have begun to develop the idea of a 'spectrum' of approaches, to define more clearly a shared language and understanding of community development and engagement, recognising that it is important for groups to know where they are coming from before they start. (BMJ Supportive and Palliative Care online 22nd Feb. 2013 doi:10.1136/bmjspcare-2012-000334)

Some respondents have come to their own pragmatic understanding of what Compassionate Communities means in their own setting.

'*Locally the title is confusing…and we have come down to a Public Health approach model for the overall work, and defining Compassionate Communities as a strand in that, as the practical based response within the community.'*

'We are now using the definition 'health promoting end of life or palliative care' more generally… and we have settled on a definition to mean practical care communities can give to one another- practical compassion.'

What is apparent is that if Compassionate Communities is to gather momentum as a viable movement, there is work to be done in getting the message across, and in defining clearly what an authentic approach would include, as well as clarifying approaches to community engagement and health promoting palliative care.

5. Why do we Need Compassionate Communities?

As we have seen, the need for Compassionate Communities was seen as driven in part by demographic and resource changes, and a recognition that the existing system of caring for those at the end of life was not sustainable. It also carried a sense that communities needed to be able to reclaim death, and regain knowledge about the dying process into its appropriate setting. All felt hopeful that Compassionate Communities could contribute to achieving a reconfiguration of the way we approach death and dying today, so that communities could work with health care professionals to give support, and become more literate and less afraid. Some saw it as having the potential of a 'social movement', capturing people's imaginations from the bottom up, whilst working with professionals to bring about change.

5.1. Proving the value

A key question is how do we know all these initiatives actually have an effect in making life better for those at the end of life, and for their families and communities? Is it possible to evaluate? Anecdotally, many respondents have evidence that the process of developing Compassionate Communities brought about positive change. Some of this was not easy to identify or capture, because intangible by nature, it encompasses changes in attitudes, relationships, and outlook to death and dying. For example, in the work to develop 'Compassionate Communities Champions,' individuals pledged to make small changes where they could within their personal lives or at work, to be more open and informed about end of life issues.

This is often the challenge for Public Health interventions…how to prove something is worthwhile? Does a health promotion approach or a community development approach make a difference? As with any so called 'upstream' intervention, benefits might be seen longer down the line. Some spoke of the vagueness of aims, as being 'tricky… this is the nature of community development as you don't know where it will end up.'

This was seen as not always sitting comfortably with the need for proof based on outcomes, to demonstrate value for money or win funds from health and other commissioners, particularly in the current austere and risk adverse climate.

'*Spend money on a project and we can see where the money goes. The mentoring of networks is far more intangible, and if you are drawing up descriptions for funding bids, how are you going to say well, part of this work is sitting on someone's bed having a pizza and watching football? Doesn't go down well…but strengthening someone's networks is about encompassing the full range of human relationships. It requires a certain perspective that doesn't really fit.'*

'They (commissioners) are watching the work closely...in terms of how it develops in Public Health. The Compassionate Communities side, they're not sure yet…see it as 'off the wall.'

'When was the last time you heard love on a policy agenda? Love with an output?'
As these discussions continue, some of the Compassionate Communities initiatives have begun to build in evaluations which demonstrate compelling evidence. The case

study of Severn Hospice illustrates this extremely well. Results following support via Compassionate Communities volunteers showed consistent drops in need for out of hours and emergency support from the health system, with only planned admissions showing an increase. It was evident that support from a volunteer reduced isolation and anxiety, and supported a person to self-manage their condition.

Teesside University is currently carrying out an evaluation of the joint work being done by St Luke's Hospice Cheshire and Macmillan, Living Well, Dying Well. The evidence from this will be available in 2014. Others nationally are currently involved in academic research.

There is an increasing body of research internationally which can be drawn on to show the benefits of compassion both within health care and wider society. Some respondents involved in public health were exploring this, as a way of building up evidence for Compassionate Communities, and develop 'measures of compassion.' They drew on international evidence from Stanford University's Centre for Compassion and Empathy and the benefits of 'pro-sociality' as well as studies looking at social capital (http://ccare.stanford.edu).

Gradually, the evidence will be brought forward, although there is a need for a more consistent approach.

5.2. Compassionate Communities: the future vision

Respondents were asked 'what would your vision be for ten years-time if Compassionate Communities take off as you hope?' This enabled respondents to think beyond the daily practicalities and difficulties and link back to initial inspiration.

Answers given were a mix of hopes for a reconfiguration of palliative care services, and vision for a more caring and compassionate society. This was not a return to a romantic view of 'how things used to be' but an indication of how things could be moved forward in end of life care to encompass community again, renewing skills across society to be able to face and manage death better.

More people might be able to die in a place of their choosing, reducing inappropriate hospital admissions, and the family or immediate community would be included as part of the support given…

'*We will have to have the ability to enable far more people to die at home...we have medicalised death and have taken it away from its most natural environment …50 years ago far more people died at home… this would have been common, but how many people walking down the street now have seen a dead person?'*

'Compassionate Communities will enable 'natural' death to return to where it belongs, at 'home'...it will help people to die at home with their families but also move into the care and nursing homes.'

'Most people would be dying in their place of choice. Professional health care can't achieve this…we need to turn the clock back to where death sits at the heart of community.'

Death 'literacy' would be supported, building skills and enabling people to discuss the issues more openly and to make plans for the end of life. Death and dying would become 'everybody's business' once again, not just held in the hands of professionals. Death would become more of a social issue.

'Now the skills and knowledge sit with professional groups, the general population has lost the skills to manage if they want to...with Compassionate Communities they can gain the skills and support to facilitate where to have death.'

'There would be the skills of human compassion and caring and neighbours and community groups would reclaim end of life care back like at the beginning.'

'People would be more prepared and more open and it's much easier to have a discussion with them and their families before and to prepare for death.'

'End of life issues would be normalised and routinized back into the community to reflect modern ways of dying. A self-conscious community is a help conscious community.'

'Compassionate Communities promotes a shift towards 'community' in that the construct of a good death will become a social and collective issue.'

Hopes also included that those in the healthcare system, including commissioners, would recognise the place of a Compassionate Community in supporting end of life care. Public Health would particularly embrace the idea of health promoting palliative care as its own, and health professionals would recognise the value of community support.

'*Commissioners need to fund this support in community as a reality and we would have a wider Public Health end of life care movement taking off.'*
'Reconfiguration is around wider acceptance of the volunteer as providing a bonafide role.'

'Issues of social isolation and community development would be clearly supported and acknowledged at a national level.'

Recognising the wider benefits on social capital offered by Compassionate Communities, some saw that it had a contribution to make in rebuilding a sense of wider belonging within community.

'*I am idealistic about it, but Compassionate Communities has the ability to help re-establish community identity as one part of the jigsaw*.'

At it's best, it is a compelling vision, which most of us would want to see embodied, '*Compassionate Communities is giving each frail and vulnerable person a son or daughter in the village.'*

'I would want to live in a place like this…I am seeing the impact. This is happening anyway, but not acknowledged and supported.'

6. Challenges to Developing Compassionate Communities

During interviews, the respondents were asked about the challenges they had experienced in trying to develop Compassionate Communities. A range of issues were raised which have been grouped in the following themes;

6.1. Challenges faced within community

For many, talking about the theme of death and dying within a community setting could sometimes be tricky. How easy it was to talk about it, seemed to depend on how, when and where people were approached and how comfortable they felt. Underlying this was the need for skills in genuinely engaging communities on their own ground. Fear of death, and an inability to talk about it was seen to impact on the level of support communities were able to give one another, and whether they felt they could 'offer' or receive help.

'*Who is in the group reflects on how the message is taken…some older people can remember how death used to be normal, people laid out in the house, and the street involved…to younger people who have no experience, it's much harder.'*

'People who are unprepared are hugely fearful and isolated. It keeps them in that state of fear, and if the neighbours don't know what to say and don't come round, then it keeps them isolated.'

'People react in different ways, it was challenging to some personally , but it always starts a group discussion… even if it's difficult and you don't know how to talk about it, if you don't you will never be able to convey what you want at the end of your life...this message is part of Compassionate Communities.'

However, when approached in the right way, building on personal experiences, or using creative approaches such as art and photography, people were often more than keen to share stories and look at the issues.

'*Don't really see the taboo. Particularly people seem keen to talk about this.'*

'When we finish telling our story, people ask what do I really think?…it starts people thinking about their own end of life and their own plans…and they say "please come and see us" so it goes on.'

Finding a genuine and appropriate way to engage communities was particularly important within the BME community. Some respondents had learnt a lot from efforts to listen and genuinely find out why many people from the BME community did not engage. Misunderstanding, poorly informed assumptions and fear featured on both the part of communities and health care professionals.

'*Many people from the BME community do look after their own and thought (hospice) was a nursing home. So why would they want to come here to a nursing home? That myth also lies with a lot of GPs they think that "they look after their own, so why would they need the referral or support?"'*

'*They know this is not a safe place to go to, it's a place to come and die, so I have been trying to change assumptions.*'

Other barriers that arose were linked with concerns, for example, around gender separation, for some BME communities, especially when meeting with health care professionals, and views that religious and cultural practices would not be accepted. Terminology around 'end of life' also proved difficult for some groups, especially to those faiths that view death not as an end but as a transition to an afterlife. Understanding other faiths was a challenge in some predominantly Christian settings.

'*Working with other faiths, this was new terrain for many people, including within the spiritual care team. They have to find a way of negotiating around these issues*.' Other groups such as LGBT also faced barriers to engagement, due to perceived prevailing assumptions and attitudes of a dominant view point.

Physical and resource barriers were also mentioned by groups, often reflecting different contexts of rural and urban work. In rural areas, lack of transport and communication was seen as a problem, in addition to increasing ageing population in villages, and loss of support networks and community life as people commuted long distances to work.

6.2. Professional attitudes

Some professionals found the ideas and concepts behind compassionate communities, and a health promotion approach to palliative care challenging on a number of fronts. Building relationships and genuine dialogue was seen as important in breaking down barriers, and enabling professionals to start to work beyond a clinical service delivery approach. Establishment of trust between health professionals and the community was essential, including with GPs, District Nurses and commissioners, to enable more formalised Compassionate Communities projects to take off.

'*Some clinicians find it hard to see beyond the current patient and family, those in the system with immediate diagnosis...they find it hard to see upstream*.'

Genuinely held fears for the safety of the cared for person were felt by many, when working with the community to provide support. Fears about vulnerable adult protection, risk management, confidentiality were all raised. How could they trust that the person would be safe when the community got involved in their care and support?

'*Initially, it's the professional barriers, we have got health care so wrapped up in risk aversion and NHS bureaucracy nurses were saying 'I am not sure about this and that', but for goodness sake, people have gone to have a cup of tea in peoples' houses for centuries.'*

'I got the message that communities are ready and willing, but with professionals, it is a different view. We fear around confidentiality, that was the main fear for professionals, and I think a genuine fear, but at the same time, you are working with someone who is supported by 20 people working with them in the community and those people know

everything about them anyway …and the person wants these people there, so it's about working with them.'

Others found the challenge to professional boundaries difficult,

'*There is definitely some professional resistance to the concept of this. What are the clear dividing lines between clinical and non-clinical care? People are nervous about what it means …will they be done out of a job?*'

Volunteering schemes established to meet the needs of people in a community often focused on those who did not have existing networks and were socially isolated. Within such schemes, safety issues were addressed through providing robust support, training, risk management, and guidelines on confidentiality, thus enabling members of the community and professionals to confidently work together in supporting someone.

'*Within our own staff, people are still not always sure as to how the volunteers will complement what they do in the community. However, many volunteers are from highly skilled backgrounds, and this helps to make staff feel that they can be effective. People are generally cautious, and this creates resistance to new things*.'

Building a Compassionate Community involves professionals 'letting go' to recognise and enhance already existing networks of support within a community. These networks have always been there; many communities and families are already looking after their own. Many faith groups, neighbours, local friends groups are already compassionate communities giving support to people towards the end of life. The challenge is for health professionals to recognise this and build on it to provide a more holistic care, so a person can remain linked to their community.

'*Actually people live with families and are within their communities before they turn up to the hospice. They are cared for and washed at home …then we turn up as service providers and we disable this facility around the person telling them that we are the experts, telling them that we will do all of these things for them, and alienating them from their community*.'

Once people began to get used to the approach, and see the benefits, professional staff and others became more confident about working with it. 'Managing relationships' was seen as a core part of establishing this work.

'*No barriers on the care side, health care professionals see its value and wholeheartedly want more.'*

'It's about selling it really, all the staff now know about the project and embrace it.'
'We have had positive support from Councillors, which has helped to move it on.'

6.3. Neighbours or service providers?

Responses given highlighted tensions between what might be seen as service delivery approach to Compassionate Communities, and one in which communities were able to

develop organically. Questions were raised about whether a more controlled approach actually could hinder natural acts of compassion already existing within communities. It was seen as important to enhance existing networks and not take over. When professionals meet and link with people within a community, different agendas and perceptions need to be balanced to enable a genuine partnership. The strengths of each need to be valued and recognised in order to build holistic support.

'*Meeting communities on their own ground, showed me that they were Compassionate Communities. In each community I went to there was some communal support. We are doing a very good job, and they are doing a very good job; if we actually wanted to work with them we would be able to give an excellent service, acknowledging what is around the patient*.'

As aforementioned, many people already provide compassionate support within communities, giving this freely as part of everyday life. The question 'who owns Compassionate Communities?' was alluded to. Motivations for giving compassionate support within a neighbourhood can be different to those driving more formal volunteering. When providing neighbourly support, people might not see themselves as formal 'volunteers', and might indeed be put off by being so defined. There is a balance to be struck, in recognising and regulating the varied roles played, and avoiding hindering acts of compassion, or absorbing them into an organisation's service delivery.

'*We talk about volunteers as service providers, in the same way as professionals are service providers, but in communities they don't talk about volunteering…they wouldn't call it this.'*

'One of the concerns for the volunteers was how regulated they would become. "We don't want to be regulated too much and come into all sorts of meetings, we just want to get on with being neighbours.'"

Balancing the demands of health care and strategic agendas with the views of local communities and a community development approach needed to be handled carefully, so as not to alienate people from giving support. This was particularly the case once commissioners became involved, and compassionate communities integrated into strategic planning.

'*GPs are now interested because too many people are being admitted to A&E. But people on the ground are not interested in the NHS agenda, but in making a difference on a community level…so it's a tension.'*

'The biggest threat by far is the clash of priorities and interest…writ larger now because of the CCG supporting this at their level.'

'The CCGs want to champion this, because it gives results…but they are also the people who have the most difficulty with the compassionate communities and community development model…it's not a service.'

'The danger is it becomes subsumed under other handy slogans e.g. Big Society and ultimately discredited.'

6.4. Finding the right skills

For organisations wanting to develop Compassionate Communities approach, a new and particular skills set may be needed. Developing the human capacity was not always easy, as was learning to work across sectors, to engage community and develop partnerships, particularly for those coming from a medical model.

One organisation developed its own job description for a Compassionate Communities development worker, only to find that the combination of community development skills and end of life were almost impossible to find. In the end, they chose the community development skills and offered training in the end of life issues.

For groups, such as hospices, not always coming from a community development background, building confidence to genuinely engage the community was important. The issues found varied in understandings and approaches to community development and have been discussed in a previous section.

'*Many want to know how to start the dialogue with communities, and start the process of engagement.'*

'It's a new role, we need a coordinator, as it's a lot of work to get off the ground…and it needs intensive work, the role is different...'

'There are tensions as people would love to be doing it, but are not sure about how to start it and don't really know what the terms mean.'

Supporting groups to engage across sectors and communities was seen as essential, and again identified as an area where skills and experience might be lacking. A culture of working limited to 'silos' was seen as a barrier. Some groups brought in the skills of 'community convenors' to facilitate initial engagement and dialogue.

'*These organisations have great skills sets but don't have skills to catalyse cross sector working. That is the gap*.'

'*It's about community development work and service pedagogy for service providers…we need people who will look at others as equals and see their knowledge and work with it because it is right for them… we need training and education and a wanting to know attitude*.'

6.5. Working in the current climate

Respondents spoke of the challenges in developing Compassionate Communities within the current fast changing strategic and political climate. Working within a complex environment, faced with austerity and budget cuts, coupled with ambitious NHS reforms were seen as definite barriers to progress. Not only that, but though the loss of significant posts, as PCTs dismantle, working relationships that had been built up over years were being lost. Some felt the progress made since the 2008 National End of Life Care Strategy was being eroded as a result.

'*I am passionate about building compassionate communities into my work, but not sure I will still have a job next year with all the NHS changes going on!'*
'I'm trying to keep track of people's posts, into the new structures (Public health)...lots of organisational changes, losing relationships.'

'People are all stressed at moment with political and NHS changes, job losses.'

'Volunteers will walk away if they think the work they are doing is about money saving and cuts…they feel they are doing a valuable role.'

Finding funding to support and sustain compassionate communities initiatives was also seen as an important issue. Some small voluntary organisations doing the work, spoke of struggling to survive, and having to compete with others for diminishing resources, despite fulfilling an important role. Although many saw Compassionate Communities as a potentially 'sustainable model' working through existing structures, there was still a recognition that financial, human and support resources were needed to coordinate and develop schemes over time.

'*Often organisations most committed don't have the money to initiate it.'*

'Everyone is saying where is the money coming from? If there is no low level money it makes it hard to deliver anything.'

'It's people's capacity and time…so much is voluntary and keeping voluntary groups and individuals engaged is tricky.'

'There is enough passion and ideas out there, but limited money to galvanise the human resources to enact it.'

The danger is that Compassionate Communities led by enthusiastic individuals but not embedded, and resourced become subject to 'burn out' or loss of impetus once the individual moves on. Commitment over time was needed, and community development could take years to build a sustainable model. It was important to recognise that investment 'upstream' would have long term benefits. NHS changes are also affecting how commissioners view new ideas, making conservative decisions and being wary about anything new.

'*We need someone committed to spend the time developing this, the person who will get it off the ground…it's a new area*.'

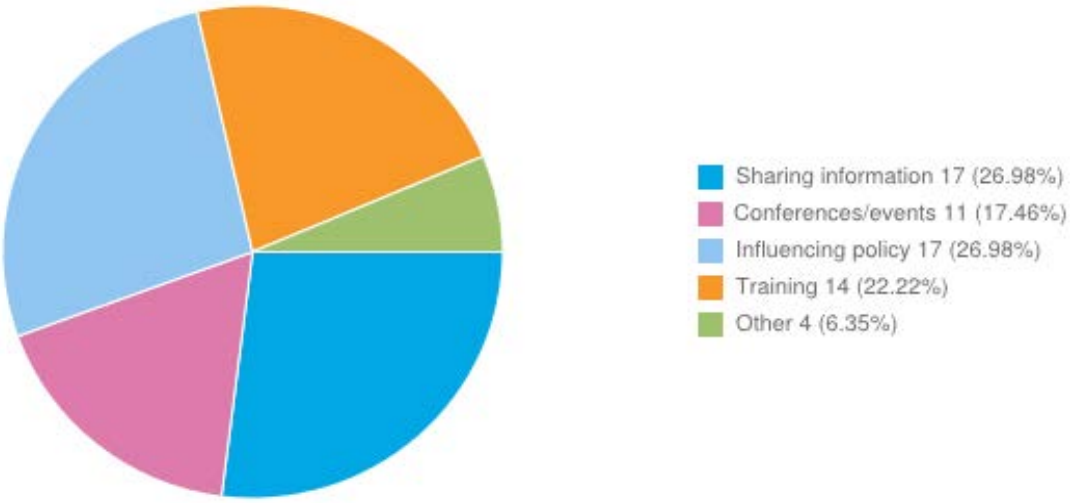
‘Commissioners are watching it but see it as an unknown.’

Groups involved were actively grappling with these challenges as they tried to define and support the development of Compassionate Communities on the ground. There is much to be learned and lessons could be shared to positive benefit within a wider network.

7. The Role of a Compassionate Communities Network

One remit of this scoping study was to establish interest in some kind of Compassionate Communities network. All of the groups interviewed felt that a network would be valuable, and that Dying Matters could play an important part in facilitating this. Respondents had varied views as to the form a network would take, and the role it could fulfil.

Q: What role would you like to see a network develop?



Source: Native Eye survey.

7.1. Raising awareness of Compassionate Communities and its approach

A network was seen to have the potential to play a valuable role in building awareness of the concept and work of Compassionate Communities in order to share information and inspire others. Currently there is no consistent way that groups can hear of Compassionate Communities or learn of its approach.

Eight of the respondents were not previously aware of compassionate communities, or of anyone else working in this way, and of those who did know of other work, none had a full overview. One respondent described how isolated she felt in developing the work with no support or awareness of others facing the same challenges.

It was interesting to see that inspiration played a strong role in initially encouraging people to develop Compassionate Communities. Some had heard Allan Kellehear speak, or had chance meetings with others involved in the work. This often created a passionate response, often from an individual, leading to action. Many felt, 'I could do that too' and began to explore how they could make changes both in their own lives or work settings. The role of 'stories' about compassion was important in developing the vision.

'I hard Allan Kellehear speak…it was really close to my heart and inspired me to do something.'

'I saw Allan Kellehear talk about what he had done in Australia, fascinating. It called to us, and the final catalyst was the Help the Hospices conference at a Public Health session... it struck a chord with me.'

Disseminating this vision through a network and beyond could play a valuable role in helping others get going and capturing imaginations.

'I suspect what we are doing will take off as soon as we start raising awareness, and share ideas.'

'Would like to come together with others working in Compassionate Communities and to learn what's out there.'

'Be inspired by other groups.'

7.2. Sharing good practice and ideas

A network was seen as having a valuable role to support learning and develop expertise in the practical issues of developing Compassionate Communities. It was recognised that there was not a 'blue print' to work from, and that compassionate communities must be free to develop in its own way in response to the community itself. Reservations were expressed about the danger of 'packaging up' compassionate communities into a 'one size fits all'. It was seen as essential to respect the integrity and creativity of the core approach. This is a difficult balance to strike, involving letting go of control, allowing ideas to develop and bubble up, but seen as essential if compassionate communities are to remain authentic.

> *'Learning to know about what is going on would stimulate ideas, but do it without pinning it down so it becomes another 'service delivery model.'*
> *'Yes, bringing ideas together is a really good idea and how people respond to that is beyond our control.'*

'Compassionate Communities can become an umbrella, with guidance people can work as they need to.'

'It needs to grow organically...and evolve.'

A network was seen as being able to provide support whilst respecting autonomy of those involved.

'Not someone telling me what I should be doing but telling me about what's going on and the methods being used.'

However, this being said, a network would help groups to learn from each other, sharing approaches tried out in different contexts, finding out what has been successful, or challenging. This could help individuals feel less isolated, knowing that someone else had also been down similar routes.

Facilitating a discussion on the difficult issues of developing a compassionate community was seen as useful, such as those around risk, boundaries, safeguarding, models of community engagement, and supporting professionals and community to work together and develop understanding. It was suggested that groups with a particular focus, such as academics, or faith groups working on a particular theme could create their own working groups. Sharing understanding and frameworks for evaluation was also mentioned.

'Sharing methodologies, sharing good practice, and work on the issue of how to put forward a compelling case to draw in resources.'

'How to make CC actually function on the ground, and not be just an academic view… it's very challenging.'

'It's been hard work having to address all sorts of ethical and professional boundaries.'

'Would be good to get together as a network and share experiences, and ideas, it can be a lonely business, we need to get together.'

Physical meetings and conferences, although valued as an occasional, were seen as time consuming and costly, if not carefully planned, whereas the use of web, social media and other links was seen as a good way of communicating. If information about compassionate communities was held centrally, groups and individuals could access and make use of it as suited, and develop their own links.

'A network available to share ideas, network, possible regional meeting, (time and transport an issue) reading materials and a newsletter.'

7.3. Helping others to start off

Not only could a network help to raise the profile of existing Compassionate Communities, and help to develop an authentic approach, but could act to help new initiatives be inspired to start something themselves. Again the creative and varied approach needs to be highlighted, through sharing examples and stories.

'Support those who are interested in starting a compassionate community project but unsure of how to start.'

'Develop a Compassionate Community Toolkit: how to create the right conditions for groups to grow and flourish, provide transformational leadership, stimulate co-creativity, support good governance.'

Helping people through the complexities of the approach was also seen as beneficial, as aforementioned.

'CC is not as straightforward as one might imagine, it brings up a lot of difficult issues that have to be worked through.'

‘Needs to stay a creative process...there is no exact model…recreating spaces where people can come together.’

Before this can happen, however, it would be essential to reach an agreement on an authentic definition of compassionate communities approach. This, along with approaches to community development has been discussed in a previous section.

‘Practical examples of the community development approach and how it starts…maybe it needs to be a sliding scale of participation and approaches from service model to pure Compassionate Communities and community development.’

7.4. Role of national strategic support

The need for some kind of bigger, national picture to move compassionate communities on was recognised as important. Dying Matters Coalition was seen as being able to offer valuable support in this role, perhaps working with other organisations such as MacMillan Cancer Support, faith groups, Help the Hospices to name a few that were mentioned. Working in this way would enable compassionate communities to gain a profile, to be built into existing national capacity, strategy and networks, in a way which local groups on their own could not achieve.

Again, groups held reservations about Compassionate Communities losing its authenticity, and being absorbed into being another ‘service development approach’ or into a bigger organisation.

‘*The danger is the state will grab it, and take credit for it, saying ‘we will commission it, and by the way here are some regulations’, but we really have to resist that because what we are really doing is going back to being a good society and we shouldn’t need rules for that.’*

‘CC needs to be linked...encouraged by national strategies but ownership needs to happen at a local level.’

The role that could be played nationally was voiced as follows:
‘Need a national strategic voice, supporting the adoption of compassionate communities within strategy’

‘We could use thread of Olympics to encourage people to volunteer more nationally…promoting the advantages of volunteering.’
‘In the longer term, strategically, could do with national media coverage, on T.V. adverts etc to change public attitudes…this has a role.’

‘Supporting funding for the work and highlighting evaluations.’

‘Sharing the stories and ideas at a national level.’

‘For the local CCG we need to codify what Compassionate Communities is in this model locally…and what the key aspects are…we might not always be the one supporting it...so could do with a ‘how to ‘ guide’.’

'Public Health nationally need to champion Public Health approach to palliative care to give local legitimacy to the development of emerging Compassionate Communities.'

7.5. Role of Dying Matters

Dying Matters with its existing strength in showcasing national initiatives, and linking across sectors was seen as a valuable ally.

'Dying Matters could become a 'hub' for the information and sharing ideas, holding it for the network virtually, showing examples and spreading the idea through other means.'

'They could support good public health media messages, learning through T.V.'
For Dying Matters to work with partners was seen as a way of building capacity, for example,
'NCPC need perhaps to work with other organisations who are now developing wider strands of work, including end of life care and cancer care…Is there capacity of organisations to make the most of their influence and work together on this and bring Compassionate Communities into it?'

Again, groups wanted to retain their local autonomy, whilst recognising the value of a national strategic support

'Dying Matters can have an influence, yes and a role. Some colleagues are a little sceptical about having one promotion by just them, but they do have resources available that couldn't be produced locally…and they can champion media campaigns. They have done well, have had an impact.'

'Compassionate Communities resonates really well with dementia friendly communities part of the PM's Dementia Challenge, the two could be dovetailed. The Dementia Challenge has already launched a high profile campaign to recruit dementia champions. Strategically Dying Matters could make the links with their existing relationships with i.e. Alzheimer's Society.'

8. Outcomes of the Study

8.1. What has been achieved through the scoping?

- An overview of Compassionate Communities work in England has been achieved through this scoping study.

- Gauged unanimous interest in supporting a network of Compassionate Communities to share good practice, ideas and support.

- A database of contacts and case studies has been compiled which could support the establishment of a network.

- A foundation and resource bank of information for dissemination about Compassionate Communities in a range of formats.

8.2. What has been found?

- There is a broad range of approaches and work taking place under the banner of Compassionate Communities across England.

- To date, 32 respondents said they were working to develop Compassionate Communities. This work is driven from a variety of sources including individuals, academics, faith and voluntary organisations, funeral consultants, hospices and mainstream health agencies.

- There are diverse examples of the ways communities are engaged in supporting those facing end of life, loss, and bereavement, and of professionals working closely with communities to support this aim.

- Communities do have the skills, knowledge, expertise and a role to play a strong partnership in end of life care; this needs to be recognised and embraced wholeheartedly.

- Barriers and opportunities to developing Compassionate Communities were voiced:
    - Barriers included taboo around death, professional attitudes, concerns of trust and risk, lack of resources, changing strategic environment and uncertainty about definition and approaches to develop Compassionate Communities.

    - Opportunities included skills and strength of communities, recognition of the need for sustainable approaches to end of life care, and increased popular interest in death and dying.

- By its nature, the work is diverse, creative, and difficult to define.

- Most of those currently working with Compassionate Communities do not have full awareness of a wider network, some work in isolation.

- Some groups found the mechanisms and tools for setting up Compassionate Communities unclear and were keen to learn more.

- There is a balance to be struck between a loose interpretation of Compassionate Communities and the need for authenticity of approach, guiding principles and clarity of context.

- There were some examples of Compassionate Communities being integrated into strategic approaches. There were limited examples of the approach being adopted under a Public Health remit.

- There is a fast emerging interest in community engagement in end of life care, on behalf of hospices, and other groups, for whom Compassionate Communities could be a useful approach.

9. Recommendations

9.1. Establish a network and share information about Compassionate Communities

- To establish a network of Compassionate Communities in a form appropriate and relevant to those involved.
- Explore relevance of special interest sub groupings.
- To highlight the diverse approaches to Compassionate Communities so as to raise awareness and build interest in the approach and its potential to contribute to end of life care.
- To share the case studies and findings in forms accessible to defined target audiences and need.
- For Dying Matters to explore ways to act as a ‘hub’ for information and resources on Compassionate Communities.

9.2 To arrive at a clear understanding of the Compassionate Communities approach in order to disseminate the message

- Work with those in a network, and wider international stakeholders to arrive at a broad understanding, definition and vision of an authentic Compassionate Communities approach (linking to newly emerging International Association.)
- To work to clarify the language, understanding and principles of community development and health promoting palliative care as used in Compassionate Communities,
- Develop tool kits for groups interested in setting up Compassionate Communities with guiding principles whilst maintaining creativity of approach and interpretation.
- Explore ways to hold existing resources and tool kits from the broad range of Compassionate Communities groups so that others can learn and share.
- Develop frameworks for evaluation to build evidence based approach for Compassionate Communities.
- Build a research base on the benefits of Compassionate Communities approaches and the role of mobilisation of social networks around the end of life.

9.3. To encourage the establishment of an environment in which Compassionate Communities could develop and thrive

- To encourage Local Authorities to promote palliative care and Compassionate Communities as part of their Public Health remit.

- To develop ways of supporting Compassionate Communities to gain momentum as a social movement e.g. through public communication campaigns and working with Dying Matters and others.

- To support the development of structures, attitudes and skills which enable members of the community to be involved and supported in looking after their own.

- To highlight need for funding and resources to support the development of this approach.

- To enable development of a locally guided approach, to ensure developments are embedded recognising local needs and assets.

9.4. Influencing strategic policy development for End of Life Care

- To recognise the benefits of Compassionate Communities in palliative and end of life care at a local level, and develop coherent national and local policies to include this.

- To explore ways to embed Compassionate Communities approaches into emerging NHS structures, within local authorities, and with voluntary groups, through engagement of a broad range of partners at all levels.

- To support the development of an appropriate skills set, and understanding required for developing public health around palliative and end of life care.

- To encourage a population wide commissioning framework taking into account public health promoting end of life care.

Conclusion

This is a fast moving arena. Interest in re-engaging community living well through and to the end of life is rapidly emerging both from community itself, but also from a growing body of health professionals and others. Compassionate Communities in all its complexity can offer a way forward, to inspire a change in the way we approach end of life care.

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This report reveals that Compassionate Communities come in a wide variety of shapes and sources. They are united by their desire to increase their community's resilience, support, and openness toward those affected by death, dying, and loss. This report describes not only how Compassionate Communities as an idea and as a community practice are rapidly spreading in England, but also how the enthusiasm for these communities are a logical development of the worldwide health promotion movement. This is a movement that has reminded us that good health services are only one small part in the development and maintenance of individual, family and community health and wellbeing. Individuals, families and communities *can* (and now do) play major roles in their own health care.

Professor Allan Kellehear, PhD., AcSS
Department of Community Health & Epidemiology
Dalhousie University, Nova Scotia, Canada.

Compassionate Communities is a Public Health approach to end of life care. It encourages communities to support people and their families who are dying or living with loss. It aims to enable all of us to live well within our communities to the very end of our lives.

The Compassionate Communities approach started in England over five years ago. Although we were aware of others across the country developing Compassionate Communities, we had no idea of whom or how many people were involved. This is the first time a scoping exercise of this kind has been undertaken in England and gives an overview. There are diverse examples of the ways communities are engaged in supporting those facing end of life, loss, and bereavement, and of professionals working closely with communities to support the aims of developing Compassionate Communities.

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.

Dying Matters is a broad based and inclusive national coalition of almost 30,000 members which aims to change public knowledge, attitudes and behaviours towards dying, death and bereavement.

Murray Hall Community Trust, based in Sandwell, is an independent community led charity and was one of the first in the West Midlands to begin to develop Compassionate Communities.

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