



Why should we develop compassionate communities?



As a society we need to talk more about dying, death and bereavement which is why the Dying Matters Coalition, led by the National Council for Palliative Care, was set up. Around 70 per cent of people would prefer to die at home, but around 60 per cent of us die in hospital. Many of us have specific wishes about how we would like to die, or what we would like to happen after our death, but unless we discuss these with family, friends and health professionals our wishes will not be met.

It is in communities that the taboo of talking about dying and death needs to be tackled. To be effective we need to work together with everyone who has an interest in raising awareness on end of life issues. This pack provides information and tips from some of these groups on how best to engage their sector on raising awareness in your community.



Potential Partners to engage:

- General Practitioner (GP) Consortia and Primary Care
- Local Authorities and Public Health
- Health & Wellbeing Boards
- Bereavement Groups
- Mental Health and Dementia Groups
- Hospices and Specialist Palliative Care Teams
- Funeral Directors
- Legal and financial organisations
- Hospitals
- Spiritual groups
- Community services and emergency care providers
- Social and community care
- Children and young people's services
- Nursing and care homes

Don't forget to include:

- Older people
- People who are well and ill
- Carers, families and friends
- Schools, colleges and universities
- Workplaces
- Trades Unions
- Meaning, faith and belief groups
- Marginal and hard-to-reach groups

Tips for engaging communities

- Identify potential partners - use contacts, networks and organisations you know, including the statutory agencies
- Investigate how you could work more closely together
- Agree a common purpose and aims - this could include developing an agreed common set of local principles in good end of life care
- Engage local influential community gatekeepers at the outset
- Promotion of the concept of 'community champions'. These are both people and organisations that are fully committed and empowered to promoting and developing awareness around Dying Matters
- Identify and agree target groups - including the aged, well and the ill, carers and their families, children and young people with their parents, marginalised groups, BME communities, physically disabled groups, pensioners forums
- Publicise the activities that you are doing and promote positive personal stories in the media – see the *Media* insert in this pack for details

www.dyingmatters.org

Our mission is to 'support changing knowledge, attitudes and behaviours towards dying, death and bereavement, and through this to make living and dying the norm.'

Ideas for activities and events

- Poster and Painting Competition linked to loss
- Arrange a quiz evening using the Dying Matters Quiz
- Promote local debate as to how you can help disadvantaged communities
- Arrange open days with funeral directors, crematoria and hospices
- Run a remembrance day about loss
- Organise a Positive Grieving Art Exhibition
- Run some public forums on dying, death and bereavement and involve local speakers
- Performance of a play followed by discussions
- Hold an event at a museum
- Host a General Practitioner (GP) evening on End of Life Care
- Leaflet large groups such as attendees at a football game
- Sculpture or art exhibition around dying and bereavement
- Hold drop-in sessions at local venues, including religious centres
- Stalls at hospitals
- Poster campaign in the community and work settings
- Put a link to the Dying Matters website on home page
- Produce a video to be shown in community settings, doctors' surgeries and on YouTube



Case Study - Dying Matters in Devon: a 'whole systems approach'

Awareness raising on dying, death and bereavement in Devon has been led by NHS Devon and Devon County Council using a joint approach to engage patients, the public, health and social care professionals and partners in improving end of life care.

Devon has a population of over 755,000 and rising. Within the next ten years, one in four people are predicted to be over 65. The county also has a high percentage of people with long term conditions and dementia living in a broadly rural community with small cities, market towns and villages. Devon currently has about 8,000 deaths each year, 49% of which occur in

hospitals, 23.5% in nursing/care homes, 5% in hospices and 20% at home.

In Devon, a range of activities have been undertaken to bring different sectors together and engage the public. These have included:

Understanding public perceptions

Listening to complaints, feedback from surveys, consultation with citizens panels, pensioners forums, carer groups, disease reference groups, feedback from care providers and voluntary sector agencies and conference evaluation.

Engaging people in developing the Devon Strategic Commissioning Plan

Led by the Devon Palliative Care Strategic Multi-Agency Strategic Commissioning Group, this group came together in 2008 to implement recommendations in the national End of Life Care Strategy. The development process included 'big conversations' with local stakeholders plus further events to ask specific questions about which services to focus on. Representatives from the council, local NHS trusts, practice-based commissioners, hospices, voluntary organisations, independent sector and health and social professionals discussed the vision for key services and the main challenges facing the local communities. The outcomes informed the development of a local end of life care strategy and a 'good death charter', which set out the principles by which people wished to be treated. This included their right to privacy, dignity and respect.

Wider public engagement informing community development

These activities are part of a well established engagement programme which supports service commissioning and development. They include:

- Awareness raising using local media
- Holding three 'Dying Matters' themed conferences
- Ongoing dying awareness events in local communities, building upon existing work in local groups
- Collaboration with voluntary sector agencies including Age UK with plans to create a Devon Retirement Pack for older people including Dying Matters materials
- Promoting the development of Community Ambassador/ Champions across Devon
- Awareness raising in schools – introducing Dying Matters principles and materials to the Health and Social Care curriculum for 14-16 year olds
- Dedicated work with Devon Young People (14-19 year olds) with palliative care needs, around life planning, crisis management and wishes planning tools
- Work with Learning Disabilities and Physically Disabled groups to ensure advance care planning tools are developed into 'read easy' options.
- Working with Church of England Clergy and spiritual centres to explore how Dying Matters discussions can become widely accessible through preaching and local awareness events in schools, parishes and communities
- Working with Macmillan and the Citizens Advice Bureau to ensure people with life limiting disease have access to appropriate advice and benefits
- Collaboration with local solicitors, financial advisers and funeral directors in awareness raising initiatives.



- Undertaking a Bereavement Services Review and developing an electronic Bereavement Services directory for linking with End of Life Registers

Working with health and social care professionals in community development and engagement

Local governance arrangements promote and encourage local health and social care professionals to play a central role in the delivery of high quality and efficiency improvement priorities. Locality GP Commissioning Consortia are actively involved in supporting and developing local approaches so that the end of life needs of the local population are best met.

Initiatives include:

- Roll out of 24/7 community nursing and personal care / domiciliary services and 24/7 access to Specialist Palliative care advice
- Universal advance care planning tools, DNACPR guidelines, just in case medicines, locality registers
- Introduction of clinical champions in end of life care - appointment of five GP Gold Standard Framework (GSF) practice trainers and four GSF Care Home facilitators to work with hospices and other academic providers to champion good end of life care training
- Introduction of the Dying Matters Coalition Care to Learn Pack to Care Homes
- Dying Matters GP Communication Skills Pilot - 25 practices are participating.
- Development of a Dementia and Carers Strategy informed by local people

Further information can be obtained from Devon County Council, email acscomms@devon.gov.uk

**Lorna Potter, Community Development Advisor,
Dying Matters Coalition**

Engaging with our community

