In the News

Taking control over your care

A new Government consultation is exploring people’s choice and control over their care. It includes a proposal for a national choice offer for those people who choose to die at home (including a care home) to receive the support that they need.

Read more at www.dh.gov.uk

The Government’s Spending Review was published on 20 October. Among the commitments for health and social care are:

- Real terms increase of 0.1% in overall NHS funding in each year to meet the Government’s commitment on health spending
- An additional £1 billion a year for social care through the NHS, as part of an overall £2 billion a year of additional funding to support social care by 2014-15.

Across the board, however, Local Authorities will have a 7% cut per year, which is very likely to impact on decisions on social care funding.

A recent report by Demos, Dying for Change, highlighted the importance of talking about dying, noting the work of the Dying Matters Coalition. “Putting in place appropriate supports will be impossible unless we encourage people to have conversations”.

Find out more at www.dyingmatters.org/news/66

When you learn how to die, you learn how to live

Morrie Schwarz, author

News in brief

Dying Matters’ recent survey has revealed that:

- 75% of people in England do not set aside time with friends and family to remember dead loved ones.
- 62% of people think the English are more reserved about talking about dying, death and bereavement than people in countries with traditions of commemorating their dead. This “reserve” is directly impacting on our experience of end of life and on the services available.

Dying Matters wants to start a national debate, asking the country - Should we do more to remember our dead?

Answer this question in December’s quick online poll at www.dyingmatters.org
How we celebrated the day of the dead

On 1st November, the Dying Matters Coalition marked the Mexican Day of the Dead with a conference in London.

The event brought together representatives from organisations across the UK who have been working to open up conversations around dying and help people plan for a good death in their community.

A number of year nine students from Haberdashers’ Aske’s Hatcham College displayed pieces from their art project inspired by the Day of the Dead. Students made a skeleton or skull to commemorate their dead loved ones which were displayed on Mexican style altars. The project aimed to encourage the students to think about and celebrate life and death.

One pupil said: “I’d like people at my funeral to wear bright colours so they can remember the happy moments of our lives.”

Another said “I made a skeleton of my Granddad out of straw and paper. I made the skeleton sit on a sofa like my Granddad used to do. He wasn’t much of an active person but I loved him anyway”. We were delighted by the success of the day, which was filmed by NHS Local.

GP Pilot Project boosts doctors’ confidence in end of life conversations

This summer, Dying Matters undertook a pilot project with 59 volunteer GPs from 24 practices around England to examine how best to support GPs when discussing dying and death. A GP from each practice attended a training workshop on end of life care communication skills and shared the learning with their practice colleagues. GPs were asked to maintain a record of their conversations with patients and practices were also invited to conduct after-death audits.

The results clearly show that GPs’ confidence in initiating and continuing conversations around dying, death and bereavement with their patients increased significantly. These conversations then resulted in actions which support a good death. The participating GPs and patients also found the supporting Dying Matters leaflets very helpful.

“What I found as the most inspiring message is that, despite the initial fears that many GPs had about starting such conversations, nine out of ten patients willingly continue the conversation once raised” said Professor Mayur Lakhani GP, Chairman of NCPC and Dying Matters (pictured left).

“With the right support GPs can make a huge difference.”

The pilot has shown that a small amount of training and support has led to improved quality of patient care, which supports the NHS QIPP (quality, innovation, productivity and prevention) agenda, and will help reduce inappropriate hospital admissions. Following the success of this pilot, Dying Matters is now planning to extend the project. Contact info@dyingmatters.org for futher details.

Events

Dying Out of Hours
24/7 Care at the End of Life
Macmillan Cancer Support and NCPC
3rd March 2011 (London)

Dying Matters Awareness Week 2011
Why Dying Matters to Me
16th - 22nd May 2011
Start planning your events now!
Why not contact other organisations in your area and see if they would like to hold an awareness-raising event with you?
We will be developing a number of tools and resources for Dying Matters members to download and use for their own awareness-raising events.
www.dyingmatters.org/event

Dying Matters Activities

You can read presentations and find the film online at:
www.dyingmatters.org/page/dayofthedead-event
Jane Hillier joins the Dying Matters team as Administration and Coordination Officer. Jane worked in Botswana for five years before spending time caring for family. As a mature student she gained a BSc in Economic History with Population Studies and an MSc in Population and Development from the LSE. Jane previously worked for the National AIDS Trust. She has two grown up children and a granddaughter.

West Essex campaign launch

We were approached by a group of clergy who have requested that someone speak to their wider group about this campaign and highlight the information available. We also have a contact for the Epping community support officers who would be interested to know more about the campaign and the information available. We were delighted that four members of the hospital social care team (including the two champions) and a representative from the reablement team also came along to find out more about the campaign and the information available. The social care champions are all to be provided with further information about the campaign and are encouraged to join and offer support at events. Whilst November is the start of this campaign, we hope that it will run throughout next year and be visible at events and local meetings.

The West Essex Dying Matters campaign was launched on November 1st with a stall at Epping Market.

Members of the public were encouraged to talk about end of life care in general and how they as individuals would like to be cared for at the end of life, how services can be improved and information about how to talk to relatives and loved ones about this taboo subject. There was a selection of information leaflets that people were able to take away with them.

Visitors’ comments included:
“This has made my day. My husband has cancer and we can make sure he gets his wishes”
“We really should talk about this more, it’s so important”
“Everybody should talk about it- well done for broaching the subject and thank you for being here”

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Educating as well as caring

The education team at St Peter’s Hospice in Bristol is an established centre for provision of end of life care and is recognised both locally and regionally in teaching professionals and carers the skills they need in communication, symptom control and planning ahead to ensure that individuals have real choice, quality of life and a dignified death.

During 2010 it has been possible for them to provide a wide range of training free of charge (thanks to winning several tenders) to doctors, nurses and social care workers locally. The training is aimed at improving end of life care for all patients whether they are in the community, care homes or hospitals in the greater Bristol area.

Hillary Holman, Head of Education at St Peter’s Hospice, said: “Through education and the expertise of St Peter’s Hospice we aim to enhance the knowledge and skills of many professionals to enable them to provide the best possible end of life care for patients.”

For more information contact Becky Pierce-Jones on 0117 915 9322 or email: becky.pierce-jones@stpetershospice.org
Why me? Spiritual support at the end of life

Spiritual needs are an important part of a person’s journey at the end of life and that of those close to them. Professionals in all settings should be comfortable supporting these needs and signposting to additional help where needed.

Provision in this area is very patchy, and the End of Life Care Strategy (2008) acknowledged this, noting that further work was required to develop practice. NCPC has taken on this challenge, with two conferences this year and the recent launch of ‘The Missing Piece: Meeting People’s Spiritual Needs in End of Life Care’.

Yvonne’s story

Three years ago, at the age of 64, my father was diagnosed with lung cancer. My sister, mother and I were inconsolable and lived in disbelief. My father would not talk about anything. We tried everything as a family to find out what his wishes were, but he would not open up to anyone. My father died 6 months later and until he died, he still refused to talk.

Besides the upset of my father dying we have never got over that feeling of emptiness and wondering whether we had done the right thing by him. It also caused tension between my sister and I as we had different opinions on whether he should have been buried or cremated, and what songs to play at his funeral.

If dad had talked, this could all have been avoided, allowing us to deal with things better and giving us closure on an awful situation. Why he wouldn’t talk we’ll never know, but if it has taught us as a family, it is that you must talk about these dying matters!

The publication discusses the concepts and language best used to describe people’s spiritual needs and proposes a working definition of spiritual support. Provision in various settings is explored, along with the interplay between spiritual care ‘providers’ and other professionals, and the role each has to play. It suggests that training and development are priorities and explores models for delivery and draft quality markers that may help drive this.

Building capacity in the community is also key in meeting people’s preferred place of death, which for most is home. Dying Matters and NCPC have jointly established a new Meaning, Faith & Belief Group and we’ll develop a dedicated section on the Dying Matters website and identify new ways of mobilising communities to meet people’s spiritual needs, both at the end of life and in bereavement.

We are keen to hear your thoughts and examples of good practice - please contact us at info@dyingmatters.org

Student Project Develops

A-level students from Mossbourne Academy, Hackney, have been working with Dying Matters to create a lesson plan for teachers. Buket, Shedeh and Michael are all keen to study medicine after leaving school and recognise the importance of encouraging open and honest conversations about death and dying throughout society. After spending time with hospice day patients, the students asked to work with Dying Matters to produce the pack so other schools could benefit from their learning.

The initial project saw six students from the academy spend every Wednesday afternoon with patients at St Joseph’s. Each student was matched with a patient and spent eight weeks discussing everything from their views of each other’s generation and their taste in music to their feelings about their illness and how they felt about dying. Sam Turner from NCPC said ‘I am convinced this project has made a lasting impression on the students and what they’ve learnt from the patients will ultimately make them into better doctors’. You can read the students’ blog at www.dyingmatters.org/site/resources/publications

It is hoped the lesson plan will help teachers break down the barriers faced by young people having conversations around death and dying. It includes guidelines for teachers on starting and facilitating conversations as well as interactive exercises. This unique insight given by students for students will help to communicate important messages in the relevant language and tone. The lesson plan will be launched at a joint event with London hospices in the New Year.

Contact Us

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The Dying Matters Coalition is raising public awareness of dying, death and bereavement in England. It is led by the National Council for Palliative Care the umbrella charity promoting palliative care for all those who need it.
The National Council for Palliative Care Registered Charity no. 1005671

www.dyingmatters.org