In the News

Dying Matters discussed in Parliament and the media

The New Year has seen the work of the Dying Matters Coalition feature prominently in debates about the future of end of life care. On 17th January, a debate in the House of Commons on Care of the Dying saw David Burrowes MP highlight the importance of the work done by Dying Matters and its members. Mr Burrowes said: “The aptly named Dying Matters coalition, across the public, voluntary and private sector, should be commended and supported when it has its annual awareness week in May.”

In a letter published in The Guardian in the same week, Eve Richardson, Chief Executive of Dying Matters, urged the government to make a good death a priority. Eve wrote that the gap between what people want when they are dying and what they get “remains huge”. She continued: “Every minute in the UK someone dies. That’s over half a million people a year, but many of us are still not receiving good end-of-life care or having our dying wishes met. This can cause unnecessary pain and suffering.”

The Dying Matters Coalition is committed to building on the progress that has been made in helping people die well in this country, and we look forward to supporting our members in their great work moving forward.

Welcome to the spring issue of the Dying Matters Coalition newsletter

In this issue we’re excited to unveil our new Awareness Week postcards and posters on this year’s theme - “Small Actions: Big Difference”.

We’ve got details of the recent Awareness Week launch event, which saw Dying Matters members from up and down the country come together to share ideas. There’s also news of two great new videos that Dying Matters has produced, as well as the latest developments in our writing competition, along with details of upcoming members’ events.

It’s quieter down here now. God help them up there!

Statement from the family of comedian Frank Carson announcing his death

News in brief

Millions of British people in their late 40s and 50s are facing a miserable retirement living in poor health for longer and in unsuitable housing according to new report by the National Council for Palliative Care and the National Care Forum. The report warns urgent action is needed to deal with demographic and social changes, including over five million more people aged 60 and over by 2030 and more people living longer with chronic life-limiting conditions.

New research suggests that more than one in five people now die in their own homes, the highest number in ten years. A total of 102,416 deaths took place at home in 2010, or just over 20 per cent, compared with 93,907 in 2004.

Full details on these stories can be found at www.dyingmatters.org
Dying Matters Activities

Small Actions: Big Difference
New postcard resource for your campaigns

Dying Matters has created a new series of five postcards to support Awareness Week. Four of the five postcards flag up five small actions people can take that will make a big difference to end of life care. This could be as an individual; for someone you know; as an employer; or in your community. The final postcard is left blank for people to write down what they did for Awareness Week and send it back to Dying Matters so that we can collect information on all the activities taking place around the country.

The postcards come in a small booklet, which will make an excellent campaign tool and is easy to distribute. For your own small action why not give a set of the postcards to five people you know?

We’ve printed thousands of postcards and posters for our members to use, so get your order in early and in good time for Awareness Week!

Dying Matters members can order a free pack of posters and leaflets on request (but there is a charge for larger orders).

Please email info@dyingmatters.org or call 08000 214466.

Awareness Week Launch Event

In February Dying Matters held a launch event to help members gear up for our Awareness Week, which runs from 14th-20th May. Focusing on the week’s theme of “Small Actions: Big Difference”, the event was attended by delegates from a wide variety of sectors, including charities, the NHS, funeral directors, hospices, local authorities and more.

Sanjay Chadha, Dying Matters champion and founder of the Asian MS Support Group, chaired the event and introduced a range of speakers who gave engaging presentations about their plans for Dying Matters Awareness Week, and shared success stories from their own awareness-raising work.

Chris Dainty presented Marie Curie Cancer Care’s range of initiatives including a social media campaign asking the public to write their own epitaphs – or “tweet their maker” – and spoke highly of the progress that has seen the Dying Matters Coalition grow to over 16,000 members.

Kathleen LaCamera and Carmel Wiseman talked about NHS Bolton’s film “Dying for a Laugh”, which was produced for last year’s Awareness Week and uses humour to tackle the subject of dying. The video, available on the Dying Matters website, was a great success, winning two How-do Public Services Communications Awards. Plans for a follow-up are already underway.

Simon Cox of Sun Life Direct shared some fascinating research on the cost of dying and the importance of taking action on end of life, and Manjula Patel of Murray Hall Community Trust talked about how building compassionate communities can make a big difference.

Presentations were interspersed with round-table action planning sessions, and delegates also contributed to collaborative displays which highlighted the small actions that we can all take to make a big difference.

The response to the event has been overwhelmingly positive, and many members have said that the event helped inspire new plans for Awareness Week. Many thanks to all our members who came along for helping to make the day such a success.
Pilgrims Hospice cycle challenge

Staff at Pilgrims Hospice are cycling to 30 hospices in the UK covering a distance of over 600 miles this May. The aim of the challenge is to raise awareness of hospice care during Awareness Week 2012 and to celebrate Pilgrims Hospices’ 30th anniversary. At each hospice visited, a swap of patient artwork will take place and all the pieces will be brought back to Pilgrims Hospices to form an exhibition that will further promote hospice care.

Guest riders from each area are invited to join the team for a leg of the journey. All hospices are encouraged to use the visits to seek as much publicity in their own area as possible to help raise awareness of hospice care.

Visit www.pilgrims hospices.com for more information.

Footprints - a walk to remember

Cruse Bereavement Care are encouraging people to step into spring this May by taking part in ‘Footprints... walk and remember’. Cruse offer support, advice and information to children, young people and adults when someone dies and to enhance society’s care of bereaved people. Services are free of charge and available over the phone, online and face to face, ensuring that there is somewhere to turn when someone dies.

For more information on the event please contact info@cruse.org.uk quoting: ‘Footprints’ or call 020 8939 9552.

Research project looks at Funeral Payments Scheme

The University of Bath is conducting a short independent project into the Funeral Payments Scheme (FPS) as part of the Social Fund. As part of the research, the team would like to hear your experience of applying (either successfully or unsuccessfully) or supporting people to apply to the Scheme. They are keen to understand how/if the FPS works, if so why, and if anything could be improved.

Your contribution to the project can be made through a telephone interview that would be arranged at your convenience and take no longer than 30 minutes. All contributions would be treated anonymously.

If you would like to take part in this research, please email info@dyingmatters.org and we will put you in touch.

Events

Awareness Week 2012
14th - 20th May
Small Actions: Big Difference
www.dyingmatters.org

The Cicely Saunders Lecture 2012
3rd May
International & national policies for palliative care: can they make a difference?
www.csi.kcl.ac.uk/events.html

CDAS Conference 2012: Dying in the Digital Age
9th -10th June 2012
Bath Royal Literary and Scientific Institute (BRLSI)
www.bath.ac.uk/cdas

Tell us about your events!

Are you planning an event to help raise awareness of the issues around death, dying and bereavement? Whether it’s during Awareness Week or at any other time why not promote them through the Dying Matters website’s events calendar? Whether it’s a coffee morning, a conference or a charity fundraiser, just let us know the details and we’ll help get the word out.

Visit www.dyingmatters.org/events and click on ’Share Your Event’.

Young Adults care conference

St Catherine’s Hospice and Derian House Children’s Hospice are joining forces for the first time to host a conference that will look at the challenges involved in advanced care planning for young adults.

The conference, Promoting Choice In End Of Life Care For Young Adults, will take place at the start of Dying Matters Awareness week on Monday 14th May 2012 at the Education Centre, Chorley and South Ribble Hospital, Preston Road, Chorley, PR7 1PP. Tickets cost £90 with lunch and refreshments included in the price.

Email patricia.clarkson@derianhouse.co.uk or call 01257 233300 for more information.
How Long Have I Got, Doc?

Dying Matters has launched a new DVD aimed at boosting GPs’ confidence in end of life conversations. “How long have I got, Doc?” has been released to coincide with new research by Dying Matters which reveals that increasing GPs’ confidence in talking to patients about dying and death can transform their end of life care.

The DVD evolved from a series of GP communications pilots Dying Matters ran in 2010-2011. 113 GPs took part in workshops aimed at boosting their end of life communications confidence. Following the training, the GPs were asked whether their practise had changed. When the project commenced, just under half the GPs (45%) rated themselves as “not very confident” or “not confident” in end of life conversations. By the end of the four-month training programme, confidence levels had been transformed, with 94% of GPs rating themselves as either “confident” or “very confident”.

“How long have I got, Doc?” is published this March, price £29.99.

You can watch a trailer at www.dyingmatters.org/page/gpdvd or email info@dyingmatters.org to order your copy now.

Final Chapters

We’re delighted to have received a huge response to the Dying Matters writing competition, “Final Chapters”, with hundreds of entries arriving at our offices. Thank you to everyone who has submitted their work.

We are pleased to announce our panel of judges: Playwright Nell Dunn, academic Yasmin Gunaratnam, publisher Roger Kirkpatrick (Chair) and writer Diana Melly (the widow of the legendary Jazz musician George Melly) have kindly agreed to assess the entries. The winners will be announced at a special awards ceremony during Awareness Week.

There’s still time to enter the competition. We’re looking for new writing of up to 2,500 words of prose or 40 lines of poetry in English, in which the experience of dying, death or bereavement has been crafted into a work that excites and retains the reader’s interest.

The closing deadline is 31st March. See www.dyingmatters.org/finalchapters for more information and full terms and conditions.

Join the Dying Matters Coalition at dyingmatters.org/join

Dying to Know

The film came about as part of hospice community engagement work carried out by Dying Matters. It was commissioned by Earl Mountbatten Hospice on the Isle of Wight, where it was also filmed. Originally a play by Helen Reading, director of the Isle of Wight RedTie theatre company - who also appears in the film - the script was adapted by Dying Matters and the film’s maker, pFlix Films, to further promote the importance of end of life discussions.

You can see a trailer for the film at www.dyingmatters.org/page/dying-know and a DVD will be available in the spring.

Dying Matters’ latest film, ‘Dying to Know’ is an intergenerational drama about the difficulties and benefits of talking about end of life. It tells the story of a family trying to come to terms with the imminent death of a beloved family member.