

Newsletter

Issue 21 August 2014

Dying Matters

'Let's talk about it'



It's the bumper summer edition of the Dying Matters newsletter, reporting on Awareness Week 2014. Around the country, events took place to mark our fifth Awareness Week in May, with the theme "You only die once". Our members displayed

enormous creativity to help the nation talk more openly about end of life matters. Inside this issue we'll be telling you about as many of these great events as we can possibly fit in, along with the rest of the Awareness Week news, plus what to look out for later in the year.

Pictured above is our Chief Executive Claire Henry with staff at Thorpe Hall Hospice, sharing her wishes on their "Before I Die" chalk wall. (From left to right: Allison Mann, Susan Shackleton, Claire Henry, Katy Harrison)

Getting the nation talking: Dying Matters in the media

While Dying Matters works all year round to raise awareness of dying, death and bereavement issues, Awareness Week is our biggest chance to make a mark on the public consciousness. Each year, media coverage for the week has grown, and 2014 was certainly no exception.

Right from the start of the week on Monday 12th May, Dying Matters hit the airwaves with appearances across the BBC including BBC One's Breakfast programme, and dozens of local radio stations around the country. ITV's This Morning also ran a phone-in feature on the Wednesday about Dying Matters, advising callers on the best way to plan ahead for the end of life.

As part of the week's activity we launched new survey findings, showing that millions of people in the UK are failing to make adequate plans for their death and don't know

the wishes of their loved ones. The research received coverage in the Times, which included an editorial in support of talking openly about dying, and our Chair Professor Mayur Lakhani wrote an article for the Guardian which was one of the top articles on their HealthCare Network section. There were also double-page features in the Sunday Express and Metro about Dying Matters, plus coverage in the Daily Mail, the Independent, Time Out magazine, and online in the Huffington Post.

Dying Matters coalition members around the country did a fantastic job engaging with their local media, and events from all parts of the country were covered in the regional press. A big thank you to everyone who worked so hard to get vital issues around the end of life in the public eye where they need to be. ●

Awareness Week 2014: facts and figures

- 530 events nationwide
- 300,000 leaflets and other resources distributed
- 570,000 people reached
- 650 mentions across national and local media
- 17,000 website visitors
- 8,700 #yodo tweets
- 8,200 Youtube views

Next year's Awareness Week: save the dates!

18th-24th May 2015

Dying Matters annual lecture: Kate's Story



Kicking off this year's Awareness Week was the second Dying Matters annual lecture. Held at the Royal College of Physicians (RCP) in London, the event celebrated the work of Dr Kate Granger. Kate, a Specialist Registrar in Geriatric Medicine, has incurable cancer. Since her diagnosis, she has written two books, and also blogs and tweets extensively about her experiences as a patient. In 2013 she launched "hello my name is", a campaign for more compassionate care that encourages staff to introduce themselves to patients and make a human connection.

The lecture was chaired by Alison Holt, BBC Social Affairs Correspondent, and speakers included our Chief Executive Claire Henry and RCP Treasurer Linda Luxon. Poet and comedian Kate Fox read a warm and witty poem inspired

by reading about Kate, and there was a panel discussion with esteemed medical consultants Fiona Hicks, Dr Philip Pearson and Dr Frank Phelan.

Kate and her husband Chris took to the stage to introduce a short film, produced by Flix Films, in which they share their experiences of the last three years. Kate told the audience she and Chris had spent "two days laying ourselves totally open emotionally to make this". Since its launch, the film has seen an incredible response online, with over 10,000 views on Youtube at the time of writing.

Our sincere thanks to everyone who helped make the event such a success, including the RCP for their funding and support, Flix Films, and especially Kate and Chris. ●



Making a Difference in Birmingham

A key event during the week was "Making a Difference: Delivering compassionate end of life, dementia & bereavement care", a conference which continued Dying Matters' key partnership work with the Heart of England NHS Foundation Trust in Birmingham.

The day was introduced by the Trust's Chair, Lord Philip Hunt of King's Heath, and featured a variety of speakers including Debbie Kerslake, Chief Executive of CRUSE Bereavement Care. Subjects covered and discussed on the day included death certification reforms, dementia, and child bereavement.

Dying Matters materials were of course available on the day, with Beth Lloyd-Williams and Kate McNaboe (below) on hand to provide information and literature to attendees. ●



Bucket Project full of activities

In Liverpool, community groups, charities, businesses and individuals worked together under the banner of The Bucket Project to co-ordinate a jam-packed programme of events throughout the whole of Awareness Week.

Two launch events on the Monday, at the Central Library and Walker Art Gallery, featured an interactive Remembrance Tree and four foot high letters spelling "life" and "death" which visitors, including school groups, wrote on with their own thoughts about the subject.

Other creative activities during the week included a "Dead Write" poetry workshop, and on the Friday a vintage tea party at the local Marie Curie Hospice.

The tea party (pictured below) was a huge success with staff, patients, volunteers and visitors, with people who don't often come in to contact on a daily basis having a chance to get to know each other and the roles each of them play in the hospice.

Read more and see some great pictures at thebucketprojectliverpool.blogspot.co.uk ●



Future Matters poetry evening

Future Matters, a programme to train and support volunteers in end of life planning, held several events during the week. As well as an information stall at the Whittington Hospital, there was also a fascinating poetry evening at Waterstones Islington Green.

At the "Last Words: Death and Dying in Poetry" event, wordsmiths and brave audience members read poems covering topics including "How Close Death is to us in Life" and "Life After Death."

"One of the best things about this event was that it was almost entirely volunteer led," said Debbie Young, the programme Manager. Pictured below is Future Matters volunteer Paul Greaney during his reading.

The Future Matters project is led by Age UK Islington and Gentle Dusk, and funded by Islington CCG. ●



Events in brief

Trust Inheritance offered their services during Awareness Week by giving free presentations and talks on end of life planning at Dying Matters member events.

South East Coast Ambulance Service NHS Foundation Trust ran their first ever end of life conference for staff. Workshops covered subjects including "myth busting", and Dying Matters champion Mandy Paine gave a patient's perspective. "We hope it will become an annual fixture on the calendar," said organiser Nigel Brown.

A crew from South Korean Educational Broadcasting System flew to the UK to cover the Awareness Week as part of a documentary on "dying well". The team visited Dying Matters HQ and events around the country.

Death in Bath

The University of Bath's Centre for Death and Society (CDAS), a longtime supporter of Dying Matters, saw students and faculty working together to spread the word. At an interactive stand, visitors wrote down their wishes and chose their favourite funeral song - and there was a cardboard coffin to leave a message on (and even take a selfie with, as pictured below).

Independent funeral celebrant Su Chard led a workshop, two panel discussions on end of life issues took place, and the Bread, Print and Roses collective led a guided tour around Bath to places related to death and dying.

The university's student radio station also got involved, co-producing a documentary programme with CDAS entitled "Grave Expectations" - listen online at www.tiny.cc/grave-exp ●



DeadSocial's second pop-up week: working together



As a curtain-raiser for Awareness Week, the innovative online legacy tool DeadSocial once again held a week of events in a "pop-up" space in Camden.

Among the activities taking place was the world's first "live infographic", where facts and figures around dying, death and bereavement were colourfully displayed and updated live as people gave their thoughts via a survey.

The week of events was organised in partnership with a large number of local organisations, including Leverton & Sons funeral directors, who held a Q&A session, local NHS groups, Camden Carers Centre, the Good Funeral Guide and more. Dying-themed artwork from the UK, the USA and Finland was exhibited around the pop-up space, and the week concluded with a party, where attendees enjoyed live music and refreshments provided by local suppliers.

James Norris, CEO and founder of DeadSocial, has shared his top tips for organising your own event on our blog (www.dyingmatters.org/blog) and will be working with Dying Matters to produce practical advice on how to plan ahead for your digital legacy - keep an eye on this newsletter for details. ●

Royal visitor at Peace Hospice

In Watford, HRH Princess Michael of Kent visited the Peace Hospice during Awareness Week, contributing to their interactive Bucket List display with her wish that she will have another grandchild before she dies.

"Her visit gave such a boost to everyone on the day", said Peace Hospice CEO Sue Plummer. ●



Out and about in Hull



Hull City Council teamed up with Dove House Hospice to celebrate Dying Matters week. The team, pictured above in fabulous matching t-shirts, travelled to Leeds to attend the Death Café hosted by the Leeds Bereavement Forum. They also had practical information to offer members of the public on a stand at the famous Hull Truck theatre. ●

Busy day in Brigg

In North Lincolnshire, Respect Woodland Green Burial Parks hosted their annual "funeral cake" competition (pictured, right). Funeral Cakes are a Yorkshire Dales tradition, with links back to the Arval bread of the Vikings.

Local charities and organisations held stalls in the busy hall, with the centerpiece a wide range of creative cakes on display. funeralcake.blogspot.co.uk ●

Skipton show support

Skipton Building Society had Dying Matters posters on display and leaflets available for customers to take away in branches nationwide. The company also shared content on their social media channels and sent out an email about the Awareness Week to over 70,000 customers. ●



A Dead Good Day Out

St Andrews Church in Southampton was host to a vibrant "Dead Good Day Out" event (above) on the Saturday before Awareness Week.

Organised by Deb Wilkes of Oakhaven Hospice and Chris Townsend who works at Minstead Study Centre, the event featured many creative activities including Mexican sugar skull making, decorating a coffin with the Natural Death Centre, music from Southampton Ukulele Jam, and the exhibition of Antonia Rolls' series of paintings A Graceful Death.

Local businesses including Earth to Heaven coffins and Harmony Funeral Service supported the day with market stalls, and speakers gave short talks throughout the day. Attendee Mike Grenville captured a great video of the event: www.tiny.cc/deadgoodday ●



Butterflies at Stocks Hall

Stocks Hall Nursing & Care Group promoted the Awareness Week at their Skelmersdale Care Home and across West Lancashire. At an event on the Tuesday, home-grown butterflies were released (pictured below) as a unique way to honour and remember loved ones. ●



Trinity host funeral debate

An evening of debate at Trinity Hospice, Clapham, aimed to discover the truth behind death and funerals with honest and open conversation.

Hospice staff were joined on the panel by Poppy Mardall of Poppy's Funeral Directors, debating with members of the public and exploring some of the more prevalent myths about dying. ●



What you said

"A most positive and life affirming event with a hint of denial but also much laughter."

*Elaine Bayliss,
NHS Improving Quality*

Events in brief

In Buckinghamshire, B Legal Solicitors held their first Dying Matters event, providing the local community with free advice about Wills and probates, financial planning, long term care planning and planning a funeral.

Gloucestershire Care Services spread their efforts wide, with information stands in seven community hospitals, and held drop in information sessions for all staff. Employee Pat Anderson also ran a Dying Matters stand at the local festival in Nailsworth, and gave a talk for a group of older people on death, dying and the importance of talking to loved ones.

The Will Writing Company offered their customers £50 towards a Will or other legal services throughout the week, and encouraged building societies who they work with to take part. They also attended events and spread the word via social media and the local press.

Widowed & Young (WAY), a charity that offers support to men and women under 50 whose partners have died, held their annual Big Picnic event on Sunday 18th May, at sites around the country. The Big Picnic helps WAY members spread the word about support available for younger bereaved people.

Art Macabre's Death Drawing salons are a creative way of looking at death rites, beliefs and rituals in folk culture, in Britain and elsewhere. Two were held in London during Awareness Week, and there was also a screening of the film Restless to provoke conversation and thoughts.

Professor Mayur Lakhani was among the speakers at Ireland's first ever Primary Palliative Care seminar on 15th May in Dublin.

#YODO: connecting people worldwide

Since Dying Matters launched in 2009, we've seen more and more people engaging with our work online and using the power of social media to talk, plan and share learning with others.

Our website at www.dyingmatters.org is growing fast, with more information, resources and features being added all the time. There's Find Me Help, our directory of services for people in the last years of life, which now lists around 1,500 voluntary and statutory organisations offering over 3,000 different services, and recently we've had some fascinating and varied posts on our blog, ranging from the practical to the personal.

During Awareness Week, the site had over 50,000 page hits from 17,000 unique visitors, the highest we've ever seen. Some pages proved particularly popular: as well as our Awareness Week hub and the new film *Kate's Story*, many visitors read pages on being with someone when they die, and what signs indicate that death is near. A wealth of advice on these difficult situations and other sensitive issues is available on the site.

We are frequently surprised and delighted by the level of informed and engaging conversation on our Facebook and Twitter feeds. Twitter especially has proven a great way to connect with people and we are proud to say that [@DyingMatters](https://twitter.com/DyingMatters) now has over 18,000 followers.

For this year's Awareness Week we gave our theme of "You only die once" a twist with the hashtag #YODO. This theme really took off, with over 8,700 mentions during the week. People used the hashtag to talk about their own wishes for the end of life, share the latest news and resources covering dying, death and bereavement, and encourage people to start important conversations with their loved ones.

On the Tuesday evening, Sheffield Cancer Mafia held a live #MyFuneral tweet chat, asking people to say what they'd want for their final send-off. Answers were illustrated live by artist Sarah Smizz and there were plenty of unusual requests (pictured right is a colourful example!).

We've recently launched Dying Matters on the networks Pinterest and LinkedIn too,



so there are more ways than ever to get in touch with us.

www.facebook.com/dyingmatters
www.twitter.com/dyingmatters
www.pinterest.com/dyingmatters
www.linkedin.com/company/dying-matters-coalition

Top tweets

[@HuffingtonPost](https://twitter.com/HuffingtonPost)
 Move over #YOLO, now there is #YODO - You Only Die Once

[@StevenAE_21](https://twitter.com/StevenAE_21)
 Went through tonnes of red tape one night to arrange for dying man to have glass of wine with his wife- little things matter

[@kesleeman](https://twitter.com/kesleeman)
 Fiona Hicks: treat what's treatable. Reverse what's reversible. But don't be afraid to recognise dying.

[@mariecurieuk](https://twitter.com/mariecurieuk)
 Social media has a role in giving terminally ill people a voice & helping doctors learn to talk to patients about dying

Mae Marwolaeth o Bwys: Dying Matters launches in Wales

The work of the Dying Matters Coalition has been extended to Wales as part of a three-year plan for improving end of life care in the country, and Awareness Week saw us officially launch this new programme of work at an event in Cardiff on Tuesday 13th May.

On the day, Dying Matters launched Welsh language versions of our "You Only Die Once" leaflets and posters. Welsh Minister for Health and Social Services Mark Drakeford (below) said: "It's so significant to have an organisation here dedicated to changing public attitudes, behaviours and understanding." Research commissioned for Awareness Week

indicates that people in Wales are the least likely in Britain to have written down preferences for their future care should there come a time when they are unable to make decisions for themselves, showing a vital need for more work in Wales dedicated to talking and planning for the end of life.

We are very excited to bring Dying Matters to Wales, and while the project is still in its early stages, look out for more events and information in future issues. If you'd like to get involved, please let us know by email on info@dyingmatters.org or call Freephone 0800 021 44 66. ●



What you said

"All the stories have been fab and I've shared lots of them with work colleagues and friends."

Dawn Orr, Tameside Hospital Foundation Trust

Day of the Dead: a festival of remembrance

As ever, we'll be hosting our annual Day of the Dead celebration this autumn on Monday 3 November, at the Institute of Latin American Studies, University of London.

It's a festival of remembrance inspired by the Mexican Dia de Muertos, and this year we'll be taking a close look at how traditions of mourning, remembrance and celebration of those who have died differ between cultures around the world.

The full line-up of speakers is still to be confirmed, but one project we're drawing inspiration from comes via our partner

organisation in Scotland, Good Life, Good Death, Good Grief. Their people's festival of storytelling and remembrance, called To Absent Friends, takes place for the first time this year. See www.toabsentfriends.org.uk for more information.

Our popular Day of the Dead altar played a big part during Awareness Week, as Dying Matters champions Tony and Dorothy Bonser toured the stall around a number of events in the North West (right), as a way to grab people's interest and start those vital conversations.

Our Day of the Dead celebration is open to all Dying Matters members, and booking will be open very soon, so check the website or call 0800 021 44 66 if you'd like to be notified when places are available.

We look forward to seeing you there! ●



While There's Still Time

Our second creative writing competition, *While There's Still Time: Writing about putting things right*, has now closed. We've received some fantastic entries and we're very excited about picking the winners. Full results will be announced in the autumn. ●

Social & health care conference

**Making it work for everyone:
Coordinating Social & Health Care at the End of Life**

11th September 2014, London

Social care and health care need to be co-ordinated to give people at the end of life the best possible death; yet we know that too often this isn't the case.

This conference will enable you to hear from services who are working together well locally to provide good care and support to people at the end of life, and consider the challenges of how things ought to work.

Visit www.ncpc.org.uk/events-training to find out more and book your place. ●

New films now available

Two new additions to our popular range of short films are now available on DVD from the Dying Matters shop.

In "Playing Dead", produced by Picturewise Productions, three actors who have famously "died" in their roles use their experiences to raise awareness of the need to talk about death and dying. Graham Seed (below), who played Nigel Pargetter in the Archers, spoke to Radio 5 Live during Awareness Week and joined us for our second annual lecture. Brian Blessed and Coronation Street's Julie Hesmondhalgh also star.

Our film about Kate Granger, shown at the annual lecture celebrating her work, is also available on DVD now.

<http://shop.dyingmatters.org> ●



Subscribe to NCPC today

The National Council for Palliative Care (NCPC), which leads Dying Matters, can help you deliver better care.

An annual subscription to NCPC can benefit all those supporting improved palliative and end of life care, including hospices, charities, NHS trusts and care teams, GPs, care homes local authorities, and many more. Subscribing offers a host of benefits, including an exclusive monthly policy round-up, our quarterly magazine *Inside Palliative Care*, copies of all NCPC's new publications and guidance, and access to our online archive.

Subscribers also receive a 50% discount on delegate places at NCPC's national conferences, and on further copies of publications, so a subscription can offer significant savings while providing practical resources and professional development for your staff.

Find out more at www.ncpc.org.uk/subscribe ●

Join the Dying Matters Coalition at www.dyingmatters.org

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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.

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