

Changing the nation's approach to dying

THE
NATIONAL
COUNCIL FOR
PALLIATIVE
CARE



*Let's talk
about it*

DYING—
doing it better

A close-up photograph of a honeycomb with many bees working on it. The honeycomb is made of hexagonal cells, some of which are filled with a golden liquid. The bees are of various colors, including black, brown, and orange, and they are scattered across the honeycomb, some standing on the cells and others flying or moving. The background is a soft, out-of-focus yellow, suggesting a bright, warm environment.

If we are going to succeed we must continue to grow the number of people and organisations that work with us and to help build a better approach to end of life care.



ongoing commitment

Dear supporter

Twenty years on from the creation of the National Council for Palliative Care (NCPC), I am proud of our work. As an umbrella charity, the independent and authoritative voice we provide and the knowledge and expertise we draw upon is needed as much as ever.

As you can see from this short report, NCPC working alongside its subscribers and partners, continues to be actively involved in improving end of life care, and continues to make a difference.

Whether it is through working with policy makers, improving practice or leading the Dying Matters Coalition to change public attitudes towards dying, death and bereavement we remain committed to helping to

ensure that the country changes its approach to dying for the better.

As a practising GP I know how important it is to ensure end of life issues get the attention and the priority they merit. Three years on from the Government's End of Life Care Strategy, much good progress has been made but there is still a long way to go and a lot more that NCPC wants to achieve.

We would not have been able to have had the impact we have so far had without the amazing support we have received. I have been especially heartened by the number and range of organisations that have joined the Dying Matters Coalition and the progress we have together made in increasing conversations

about end of life care.

If you already work with us I would like to say thank you and to urge you to continue to support us. And if you are not already an NCPC subscriber or Dying Matters Coalition member please do join us today. By working with us and supporting us you can help us to ensure that everyone receives excellent palliative and end of life care and support.



Professor Mayur Lakhani CBE
Chair, NCPC and the Dying Matters Coalition

problem

every minute in the UK someone dies

We have a problem. There is a solution. Over half a million people die each year, yet 70% have not discussed their own end of life wishes with their partner, family, friends or health or social care professionals.

This hampers end of life care planning and often means that people do not get the care they want, where they want it. For example, although 70% of us would prefer to die at home, more than half of us die in hospital, often unnecessarily. 40% of the people that do die in hospital have no medical need to be there and 20% of all hospital beds are occupied by people who are dying, many of whom neither want nor need to be in hospital.

Although in many respects Britain has excellent palliative care and is fortunate to have a dedicated palliative care specialism, an outstanding

hospice movement and excellent examples of care within the NHS, voluntary and independent sectors, there is significant room for improvement. Too many people are still unable to access end of life care where and when they need it. We know from our research that creating the conditions and triggers for having discussions about these issues is not easy and that there are many social factors and taboos that can get in the way. However our research and the success of many of our programmes also demonstrate that it is possible to change this situation for the better.

This short review of our work makes it clear that with a sustained comprehensive programme of activity and with your help we can make dying better possible for everyone.



**We work to ensure people
live and die well**





solution



PUBLIC

PRACTICE

POLICY

THREE PRONGED APPROACH

changing the nation's approach to dying

We are committed to ensuring that everyone has the best possible end of life care and support and feels able to discuss dying, death and bereavement openly.

To achieve this we have a three-pronged approach:

1 Policy development

Helping government to develop policies that meet end of life care and support needs.

2 Practice development

Working with professional groups, organisations, community groups and people with first hand experience to capture, develop and spread good practice.

3 Public awareness

Raising awareness about the need to openly discuss dying, death and bereavement.

We're targeting three key groups, which we believe are the most important to achieve the change we need: 55-65 year olds, 65-75 year olds and GPs.

“Everyone deserves to live well and die well and this is more likely if as a society we feel more confident talking about it and thinking about the realities of dying – and planning for our end of life care”

Eve Richardson Chief Executive, NCPC and Dying Matters

FACT

According to NatGen research for Dying Matters in 2009, **71%** of people had not discussed with anyone what their wishes would be if they did not have long left to live.

Just **4%** had written down wishes about end of life care.

MAKING A DIFFERENCE

Concerned that end of life care had been omitted from the draft national dementia strategy, NCPC successfully campaigned for its inclusion. *Living well with dementia: A National Dementia Strategy* (Department of Health, 2009) includes end of life care as a key strategic objective.

NCPC worked with Marie Curie Cancer Care, Sue Ryder and Help the Hospices to ensure the National Guidance for the Cancer Drugs Fund included end of life care. This will help more people with cancer have informed conversations about palliative care options with their doctors, alongside drug treatments.

influencing and informing policy

NCPC has an excellent track record of working to ensure dying better remains a government policy priority.

We have built strong relationships with policy makers, government ministers, and across the political spectrum so that we can inform and influence on behalf of our subscribers and members.

Key to this is our independence and our

unwavering commitment to improving end of life care.

By working closely across government we are able to ensure the concerns of our subscribers, members and partners are heard and play an active part in shaping policy and practice. This dialogue means we are in an unrivalled position to inform people about the latest developments in end of life care policy and their implications.

*“Thank you very much for inviting me to the joint launch of **Difficult Conversations** by the two All Party Parliamentary Groups. Rest assured that end of life care is quite firmly on my agenda.”*

Professor Alistair Burns
National Clinical Director for Dementia

- We have been active in informing discussions about the future of palliative care, including the Palliative Care Funding Review which was published in July 2011.
- We continue to play an important role in informing and influencing politicians – providing the secretariat to the All Party Parliamentary Group on Hospice and Palliative Care.
- Keeping our members and partners up to date is a key part of our policy work. In April 2011 our Policy Round Up E-bulletin was launched with the aim of keeping subscribers, supporters and decision makers briefed about emerging policy proposals and research.
- We play a key role in collecting and analysing data on palliative care. Our minimum data set on specialist palliative care is used by the majority of commissioners to improve understanding and assist with service provision.

Our publications and events
help educate and inform





MAKING A DIFFERENCE

NCPC's 20th anniversary debate in May 2011 formed part of the Government's listening exercise on NHS reforms. Secretary of State for Health Andrew Lansley addressed and listened to our 300-strong audience, drawing publicly for the first time on personal experience of his own

father's experience of palliative care.

Our Chief Executive and Chair are both members of the National Implementation Advisory Board for End of Life Care and through this directly guide and influence national plans.





MAKING A DIFFERENCE

Our development events have received on average a **90+%** satisfaction rating amongst those who attend. In the last eighteen months we have held sessions across the country on subjects including Dementia, Dying Matters, End of Life Care and the Mental Capacity Act. Over 1,500 professionals have attended these events.

We published 'Thinking and Planning Ahead' training materials developed by the University of Nottingham for volunteers about advanced care planning.

NCPC's Meaning, Faith and Belief Group's work with the Department of Health led to the government adopting NCPC's definition of spiritual support.

Our 'Can you See Me' DVD led to more services finding out who was in their community and then asking them about their needs.



“I used the NCPC Minimum Data Set to argue with local commissioners for the need for two more palliative care nurses, it's invaluable”

PCT Lead Nurse West Midlands

FACT

More than **78%** of us think that it is a key part of a health professional's job to discuss end of life care issues.

59% of people are scared of dying in hospital.

After friends and family, GPs are the people that we want to talk to about death and dying. **31%** of the public want information about end of life care from their GP.

We put people with personal experience at the heart of all our work



influencing and informing practice

One of our key principles is to involve professionals and people with personal experience in all aspects of our practice development work.

We have recently produced resources relating to spiritual support at the end of life, personalisation for people and carers approaching the end of life and tools to support people with neurological conditions.

Building the confidence of healthcare professionals in discussing end of life issues is also a key part of our work. Through our GP pilot project, we have been able to demonstrate how doctors can become more confident in discussing end of life care with their patients. At the outset of the project, 60% of the participating doctors said that they were not confident in initiating discussions on

end of life. By the end of the four month pilot 86% reported that they did feel confident.

We have also produced guidance for working with especially vulnerable or marginalised groups – including homeless people, people with dementia and the lesbian, gay, bisexual and transgender community. We also worked with people with learning disabilities on discussing end of life wishes.

In addition, we have presented at a wide range of professional development seminars and conferences, including the Royal College of General Practitioners Annual conference, the Pensioners Parliament, the International Palliative Care Congress, the Social Workers Annual Conference, the Probate Society and the Law Society.

raising public awareness

*“Wow!
You have taken away so much fear, for so many people. So much said in so few moments.”*

From a supporter who had just viewed our recent NCPC film of Amy Logan, entitled ‘I’m having a very good death’.

Raising public awareness and getting more people feeling able to talk about dying, death and bereavement is a key part of our work – as unless people make their end of life wishes known it is virtually impossible to act upon them. That is why we set up the Dying Matters Coalition. Since it was established in 2009 Dying Matters, which aims to raise awareness about the importance of discussing dying, death and bereavement, has gone from strength to strength. The Coalition’s membership has grown to over 15,000 members and its impact and profile has significantly increased, including through our media work.

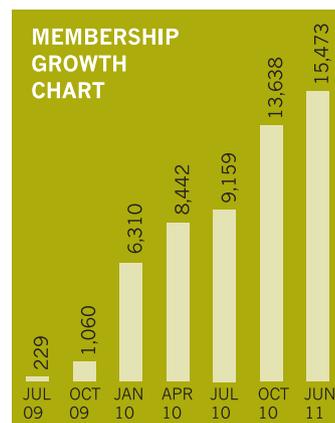
The second ever Dying Matters Awareness Week was held during 16-22 May 2011. Hundreds of events were held across the country, in cinemas, hospitals, shopping centres, markets, hospices, libraries and town halls. We also secured a wide range of national, regional and local media coverage – ensuring millions of people had the opportunity to hear about the importance of discussing dying, death and bereavement

and planning for their end of life care.

We were also delighted during the awareness week to have been able to launch our pilot ‘Let’s Talk About it’ drop-in service at Age Concern’s Lewisham and Southwark branch. The service, in partnership with the Lewisham Pensioners Forum, aims to open up discussion and engage with older people in the local community.

We have produced an extensive range of information materials for the public, all of which have had great feedback. Materials include guides on how to have end of life conversations, how to deal with practical issues around dying and dealing with bereavement.

We have also produced several short films to support conversations about end of life issues, including “Why Dying Matters to Me”, containing short clips with a wide range of people, and “Dying for a Laugh”, which features leading comedians including Ardal O’Hanlon and Ricky Tomlinson, tackling the taboo of talking about dying. This short film, produced by the Dying Matters Bolton Group



and Picturewise productions, is now being widely viewed via our website and YouTube.

Community engagement is a key focus for us, which is why we produced resources and tools for our subscribers and members including a Community Engagement Pack, a Volunteer Educator Toolkit and a short video featuring people with learning disabilities talking about their end of life wishes.

We have also taken forward activities to support inter-generational work, including a schools lesson plan to support discussions around dying, death and bereavement.



Our resources help Dying Matters members to spread the word and start the conversation

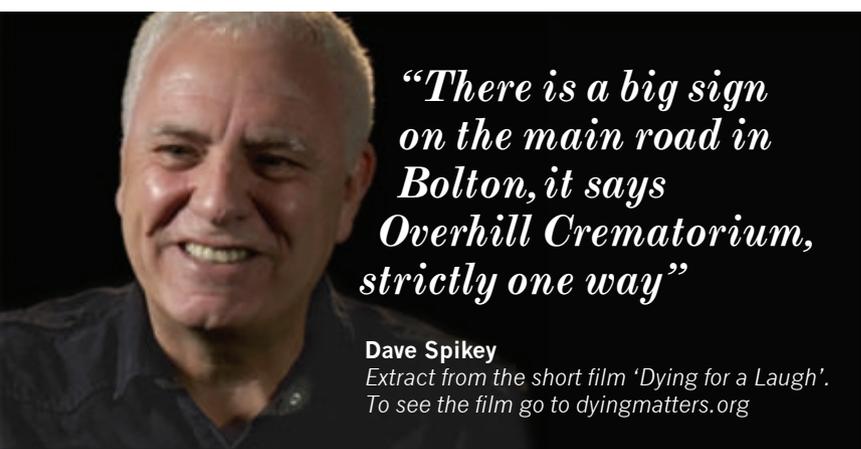
MAKING A DIFFERENCE

In 2011 there was significant media interest and coverage for Dying Matters Awareness Week, including an editorial in the Guardian. Across the week over 32 million people had a chance to hear about the issues via radio alone.

Our video 'A party for Kath' demonstrating the benefits of greater openness around death and dying was awarded a 'Highly Commended' for 'Best Video' at the 2010 International Visual Communication Association Clarion awards.

The number of visitors to the Dying Matters website has grown significantly, reaching almost 9,000 during the awareness week in May 2011. We have an ever-growing number of Facebook supporters and followers on Twitter joining in the conversation online. We have just launched the Dying Matters online community, providing a valuable space for people to discuss end of life issues.

Over the last year we have distributed hundreds of thousands of our information materials, including leaflets, posters and fact sheets. They've been highly positively evaluated by both public and professionals.



“There is a big sign on the main road in Bolton, it says Overhill Crematorium, strictly one way”

Dave Spikey

Extract from the short film 'Dying for a Laugh'.
To see the film go to dyingmatters.org



“Fantastic leaflets, they are just what the doctor ordered, common sense information produced in a readable and eye-catching way!”

Sharon Paradine

Director of Care, Fair Havens Adult Hospice

the task ahead

FACT

People are living longer, and due to population growth, deaths in England and Wales are due to rise to 585,000 by 2030.

Instances of dementia are projected to rise from 822,000 now to 1 million in 2025.

Lack of capacity in hospitals and hospices will increase demand in care homes, supported housing and home deaths.

As we build on our achievements so far and face the challenges that lie ahead, we will be putting more effort into growing the range of people and organisations we work with to improve end of life care and to achieve a more open approach to discussing dying, death and bereavement. We want to develop an even more dynamic movement to bring about the step change that is needed in society.

We will continue to work with our subscribers and members by providing relevant policy and practice support and by continuing our efforts to work with communities to bring about a significant shift in public attitudes and behaviour.

Our top three priorities going forward are:

- 1** Working with our existing subscribers and members and building new partnerships to ensure we all have the best possible end of life care.
- 2** Work with a wide range of partners to ensure that everyone has access to coordinated round the clock end of life care, where and when they need it.
- 3** Empowering all people to talk openly and with more confidence about death and dying.

By working with and through our supporters we have together made significant progress over the last few years. The challenge now is to sustain and grow the programme in what will clearly be difficult times. With your help we want to continue to make a difference to people's lives and deaths.

MAKING A DIFFERENCE

78% of members of the Dying Matters Coalition agree or strongly agree that the Coalition has helped highlight the need for more open discussions around dying and death.

96% agree or strongly agree that NCPC effectively communicates palliative and end of life priorities to national and regional decision makers.

90% think the NCPC subscription is good value for money.

moving forward together

There can be few of us who have been untouched by dying, death and bereavement, which is why the work of the NCPC and the Dying Matters Coalition is so important.

We are extremely grateful for the support we continue to receive – support which enables us to take forward our important work as an umbrella charity and to have a positive impact.

As we face the future, the support we receive will inevitably become more precious than ever. Whilst we are fortunate to have a very active and growing supporter base, we want to attract more subscribers, supporters, funders and sponsors so that we can continue to make the difference that we know is needed for people to get the end of life care they deserve.

During the coming years, we will be looking to develop our range of partnerships. We would also like to be

able to share our expertise with all those who have an interest in improving end of life care and support. Please do get in touch with us if you share our commitment to improving end of life care and would like to discuss how we can work together.



Eve Richardson
*Chief Executive, NCPC and the
Dying Matters Coalition*

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