

End of Life - starting the conversation

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Deaths each year

- Each year, around 480,000 people die in England. This is predicted to increase to 550,000 by 2035.5
- 1,107 Reading residents died in 2016.



Place of death (2016)

Place of death	Reading	IMD 4 th less deprived LAs	England
Hospital	51.3	45.5	46.9
Home	23.9	22.7	23.5
Care home	15.2	23.5	21.8
Hospice	7.3	6.0	5.7
Other places	2.3	2.2	2.2



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Ambitions for Palliative and End of Life Care: a national framework for local action 2015 - 2020

- Each person is seen as an individual
- Each person gets fair access to care
- Maximising comfort and wellbeing
- Care is co-ordinated
- All staff are prepared to care
- Each community is prepared to help

What's important to me

What's important to me...
at the end of life or in the end of life care



- Independent review into choices available about end of life care.
- Issues which people would like a choice about included:
 - Place of death
 - Pain control
 - Involvement of family and others close to the person nearing end of life
- It all starts with finding out what's important to the person at end of life.

Our Commitment to you for end of life care (July 2016)

Government response to *What's important to me* was a commitment to support people approaching the end of their lives to:

- have honest discussions with care professionals about their needs and preferences
- make informed choices about their care
- develop and document a personalised care plan
- discuss their personalised care plans with care professionals
- involve their family, carers and those important to them in all aspects of their care as much as they want
- know who to contact for help and advice at any time.



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Dying Matters

A national coalition to help people talk about death

Information available on the site covers being with someone when they die, facts about funerals, personal stories, reviews of books covering death and bereavement

www.dyingmatters.org/

Leaflets available include

- *Five things to do before I die* - Information to help you think about the plans you might like to make before you die.
- *Remember when we...* - Tips on starting a conversation with someone you know about their end-of-life wishes
- *Being there* - Top tips for what to say and so when someone has been bereaved



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Dying Matters Week 2016

The 'Big Conversation' at St Laurence Church

- RBC End of Life Champion, Rachel Eden
- Berkshire West CCGs
- Citizen's Advice
- A local law firm to talk about wills and lasting power of attorney
- a hospice chaplain
- Around one dozen information and advice stalls run by local support organisations and charities

However, only 37 people attended



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Dying to Talk 2017

A series of smaller community-based conversations covering topics such as legal and financial issues, organ donation and funeral planning.

Events included

- a slot on Reading's community radio station
- open day at the crematorium
- drop in sessions for cake and a chat about Dying Matters
- planning sessions with the Duchess of Kent hospice
- BBQ at the Sunrise Home in Sonning
- event at the RISC café, hosted by the Utulivu Women's Group.



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Dying Matters Week 2018

- Sue Ryder hospice promotion @ The Oracle
- BLAST FM shows around Dying Matters, linking with Thames Valley TV
- Sue Ryder Forget-Me-Not walk at Englefield Estate
- Open morning at Reading Crematorium with talk
- Reading Film Theatre showing of 'That Good Night'
- Cllr Eden's cuppa and chat in Whitley ward
- Dexter-Montage fund-raising quiz for Daisy's Dream
- Talk on the psychology of death @ Reading University
- Sue Ryder talk on community support



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Our approach

- We offer a personalised service which values the individual at every stage.
- This includes End of Life, and we try to start planning with individual residents from Day One.
- Conversations are led by specialist End of Life / Palliative Care nursing staff.
- We involve the resident, their family, the GP and faith leaders where appropriate.
- Plans are reviewed – when the time is right, so as to bring reassurance and not cause distress.

The Challenges

- Thinking about End of Life may raise various big questions:
 - What will happen to my family?
 - What will happen to my pet?
 - What about funeral costs?
 - Will I get pain relief?
 - Will I die alone?
- It's a big subject, and planning needs to be broken down

Why it matters

- People matter at every stage of life – including their final months, weeks and days
- Planning can do so much to improve things – but people often need help to get started
- Trained staff can pick the right moment and the right words

Talkback ‘Matters’ sessions

Talkback has been supporting adults in Reading with learning disabilities and/or autism for over 10 years. This has included community meetings to help people explore their understanding, feelings and views.

In 2016, Talkback invited people to consider what was important to them in terms of wellbeing

- Most welcomed the opportunity to talk about death and dying
- Many had struggled to find a space to consider these issues before.

In 2018, Talkback ran a special Matters session as part of Dying Matters Week

- People again said it was good to be allowed to talk about this. They welcomed support to deal with something ‘messy’.



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Addressing the strategic challenges of the urgent and emergency care system from an end of life perspective (Feb 17)

- Organised by the End of Life Networks for Thames Valley, Wessex and the South West
- Included talks from NHS England officials outlining government expectations on palliative care, plus a range of clinicians including Pangbourne GP Dr Barbara Barrie, a Thames Valley end of life champion.
- Around 120 people attended, mostly professionals or academics.



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The Importance of End of Life Planning (Mar 17)

- Organised by Balmore Park Surgery's Patient Participation Group (PPG) organised this event to give local people information about end of life planning.
- Speakers included a GP from Balmore Park Surgery, and representatives from Duchess of Kent House (hospice), a solicitor, a funeral home, and Age UK Reading. A question and answer session was also included after the talks.
- Reached 86 members of the public, 57% who are registered at Balmore Park Surgery. In total, people from 10 different Reading GP surgeries attended.



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Health and social care

- ReSPECT stands for Recommended Summary Plan for Emergency Care and Treatment. ReSPECT is a PROCESS and a FORM. It creates a personalised recommendation for your clinical care in emergency situations where you are not able to make decisions or express your wishes.
- Work is underway to establish this process locally, commencing with roll out across the Royal Berkshire Hospital Foundation Trust

Local organisations

- Duchess of Kent Hospice - 15-bed inpatient or day hospice for adults run by Sue Ryder. Specialist nursing teams also provide advice and support to people in their own homes.
- Naomi House Children's Hospice - respite and hospice care for children and young people
- MacMillan - cancer information & support
- Alzheimers Society - dementia information & support
- Carers Hub - information, advice and support for those providing unpaid care



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Bereavement support

- The Listening Place at Tilehurst Methodist Church - bereavement support for everyone, regardless of religion or beliefs.
- Cruse Bereavement Care - face-to-face, telephone, email and website support for people who have been bereaved
- Daisy's Dream - support for bereaved children
- Rosie's Rainbow Fund - bereavement counselling to families who have lost a child, and music therapy
- AB Walker have a bereavement team and you do not need to use them for the funeral in order to access their free services for either a group bereavement course (the Link) or individual counselling.



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Useful websites

- Reading Services Guide
- NHS Choices
- Sue Ryder online community
- Alzheimers Society, especially factsheets section
- Berkshire West Clinical Commissioning Groups

The short film ‘Molly’s Story’ is intended to offer a starting point for families wanting to discuss end of life care with their health and social care teams

www.youtube.com/watch?v=nSZLucUnMcl



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