

# Dying Matters: The Reading Perspective



*Reading Crematorium in the grounds of Henley Road Cemetery, Caversham, Reading. Photo courtesy of Google Street View*



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## INTRODUCTION:

As Reading marks the 2017 Dying Matters week from 8-15 May, this short report reviews local end-of-life initiatives over the past year, including actions Healthwatch Reading has taken to ensure public, patient and carer views are heard about care in the last stages of life.

### Why focus on death and dying?

In July 2016, the Department of Health announced [six new commitments](#) the government had made to the public to end variation in end of life care across the health system by 2020. These commitments aim to support people approaching the end of their lives to:

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

The new commitments were in response to an independent review - which included input from members of the public talking about their own experiences - called, [What's important to me, A Review of Choice in End of Life Care](#).

### What's happening in Reading?

The past year has seen a series of initiatives launched in Reading. These include:

- a patient-led information and advice event on end of life planning that was very well attended
- the appointment of an end of life champion, and a public event, by Reading Borough Council
- the launch of a 24/7 nurse helpline for dying people and their families, funded by the Berkshire West federation of NHS Clinical Commissioning Groups (CCGs) (and its subsequent early closure on 5 May 2017)
- the production of a short [film](#) by the CCGs, in which a woman describes how services helped her mother achieve a good death at home.

This report reviews most of these initiatives and the lessons learned. There is also a chapter containing links to national and local information and resources.

## KEY FACTS AND VIEWS ABOUT DEATH AND DYING:

Here we present latest figures from the Office for National Statistics, the Care Quality Commission, and the National Survey of Bereaved People

**500,000** people die in England each year. Only 29% of these deaths are caused by cancer

**82%** of people would consider donating their organs when they die, but only 50% have talked about it with others

**Two-thirds** of people who die are aged 75 and over

**Nine out of 10** hospices that have been quality-checked by the Care Quality Commission have been rated as 'good' or 'outstanding'

**69%** of people answering the latest national survey of bereaved people, rated hospital care as outstanding, excellent or good, compared with 82% for care homes, 79% for hospice care, or 79% for care at home

**47%** of cancer patients received outstanding or excellent care, according to bereaved relatives, compared with 38% of cardiovascular patients and 41% of people dying from other causes

**19%** of bereaved people felt that pain relief was provided 'completely, all the time' to patients in their own home, compared with 64% in hospices

**19%** of relatives disagreed that they were kept informed of their relative's condition with staff when the patient was in a hospital

## CHAPTER 1:

### Talking about death and dying in Reading

This chapter outlines events that have been held for the public, and/or health and social care professionals between May 2016 and April 2017.

**8 JUNE 2016:**

#### **Big Conversation Event, St Laurence's Church In Friar Street.**

##### **Aims:**

Organised by Reading Borough Council (RBC), the free event for the public aimed to break the taboo of talking about death and encourage people to discuss their wishes with family about care in the last stages of life.

##### **How?**

The event included talks from:

- RBC End of Life Champion Rachel Eden;
- a representative from Berkshire West NHS Clinical Commissioning Groups (that plan and buy health services, including palliative care, for the local population)
- Citizen's Advice;
- a local law firm to talk about wills and lasting power of attorney;
- a hospice chaplain; and
- around one dozen information and advice stalls run by local support organisations and charities (including Healthwatch Reading).

##### **Who did it reach?**

Only 37 people attended the talks (and some of these were from the organisations running information and advice stalls at the event).

##### **Lessons learned:**

At a planning meeting for the event, Healthwatch Reading had suggested a clinician give a talk aimed at educating the public about what care could be provided in the home (including pain medication), should they prefer not to go into a hospital, care home or hospice. We also suggested holding the event in smaller community venues that would target the 'seldom heard' population. These suggestions were not fully taken up.

However, we note that the RBC 2017 Dying Matters week beginning 8 May, has moved away from a single big event, towards a series of smaller community-based events, including a 'Talk about it over tea and cake' event in Whitley, a community radio discussion, a hospice-based event and a care home BBQ featuring a speaker from the Dying Matters charity. Events have been well publicised, through a leaflet distributed to community venues, and also via Facebook.

**28 FEBRUARY 2017:**

**Conference for professionals: Addressing the strategic challenges of the urgent and emergency care system from an end of life perspective, Holiday Inn, Reading South**

**Aims:**

Organised by the End of Life Networks for Thames Valley, Wessex and the South West, this day-long conference aimed to educate a range of health and social care professionals about national priorities and local case studies.

**How?**

The event 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.

A woman called Roberta Lovick (pictured right) also gave a talk describing her experience of caring for her daughter Louise, who died aged 28 after developing breast cancer. Her daughter died in A&E after they waited four hours for emergency services to arrive after a 999 call. She has worked with Macmillan and other organisations to campaign for better support for people and their families.

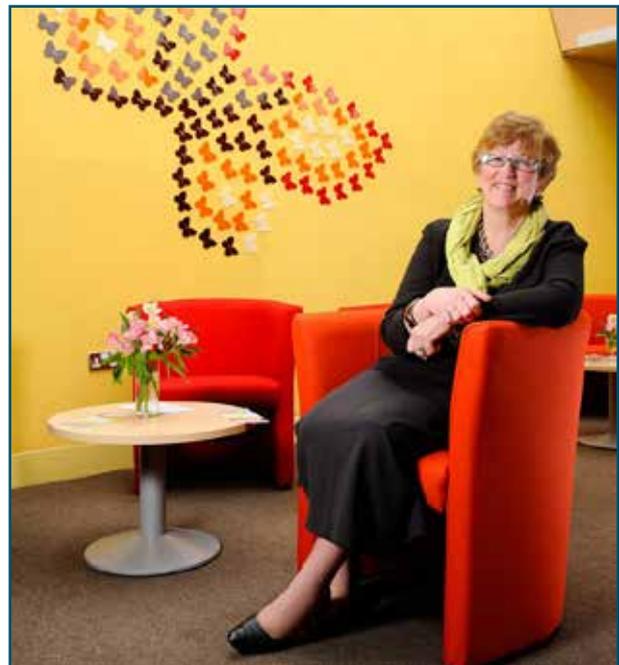
**Who did it reach?**

Around 120 people attended, mostly professionals or academics.

**Lessons learned:**

Stories from people who have lost loved ones are a powerful way of learning what goes right and wrong at the end of life, and how services can get it right for the future. Healthwatch Reading noted that the evaluation form for the event did not name Ms Lovick as a speaker that delegates could give feedback on, despite many delegates finding the talk very

powerful. Healthwatch Reading asked the organisers to ensure future forms would give attendees the opportunity to give feedback on any talks given by patients or carers about their experience, and to try and ensure their talks were recorded for future sharing and learning, especially if they did not use PowerPoint presentations or other media as other delegates had that could be shared electronically.



*Pictured above: Roberta Lovick, carer and campaigner*

Talks that Ms Lovick has given at other events can be found at: <http://bit.ly/2qriBrE> and <http://bit.ly/2pS6j9Z>.

Other stories and views from bereaved people can be read in the latest [\*National Survey of Bereaved People \(Voices\)\*](#): England, 2015, published in 2016, which focuses on the quality of care given to dying adults in the last three months of their lives.

22 MARCH 2017:

## The Importance of End of Life Planning, public event, Caversham

### Aims:

Baltimore Park Surgery's Patient Participation Group (PPG) organised this event to give local people information about end of life planning.

### How?

The morning event was held at a local church that provided the venue for free. It was publicised in local surgeries, church notices, the *Caversham Bridge newspaper*, the *Round and About* guide, via a resident's association, and also through North and West Reading Patient Voice, and Healthwatch Reading networks and website. Speakers included a GP from Baltimore 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.

### Who did it reach?

86 members of the public, 57% who are registered patients at Baltimore Park Surgery. In total, people from 10 different Reading GP surgeries attended.

### Lessons learned:

The strong publicity and PPG's effort to develop a useful programme, attracted a good attendance. An evaluation form showed 80 per cent of people found the GP's talk most useful, perhaps suggesting that people are keen to hear from a trusted professional they know. The GP's talk had focused on what was involved in 'advanced care planning', with examples of documents used by clinicians, covering topics such as whether people have made an 'advance decision to refuse treatment', whether they had a Lasting Power of Attorney (to give



Pictured left to right Gillian Wilson, John Atwill and Barbara Macrae from Baltimore Park Surgery's PPG

someone they trust the ability to speak up on their behalf if they were unable to) and whether they had a 'do not attempt cardiopulmonary resuscitation' document. The questions asked at the meeting showed that people also wanted to know what to do immediately after somebody dies. One attendee said organ donation should be included as a topic in any future event, while other feedback asked if a future meeting could be held early evening to ensure people who worked, could get the opportunity to attend.

NHS Foundation Trust			
Thinking Ahead – Advance Care Planning Discussion for Adults			
<small>There may come a time when you lack the energy or the ability to take an active part in deciding about the care that you would like to receive. We wish to be able to provide the best care possible for all patients/residents and their families, and to do this we need to know more about what is important to you and what your needs and preferences are for the future. This document serves to be a record of any advance care plan wishes. There are explanatory notes for both the healthcare professional and the patient and their family for this document. The slip at the bottom of this page is to be placed in a message in a bottle scheme.</small>			
Patient name			GP name
Address			Surgey address
D.O.B.	NHS no.	GP Tel:	
Family members involved in Advance Care Planning discussions: (is there someone who you would like to be involved in decision making on your behalf and who agrees to do so? Can they help us understand your views and wishes?)			
Name:	Contact No:		
1.	1.		
2.	2.		
Name of Health Care Professionals involved in Advance Care Planning discussions: (GP, Dr, R.N., Clinical Nurse Specialist, Care Home manager)			
Name:	Contact No:		
1.	1.		
2.	2.		
Diagnosis/current health issue:			
Do you have a Lasting Power of Attorney (LPA) if YES who:			Yes/No
Do you have an Advance Decision to Refuse Treatment (Living Will):			Contact No:
Do you have a DNACPR? (Do not attempt cardiopulmonary resuscitation) document?			Yes/No
Guidance/explanatory notes are available			

Pictured: An advance care planning document

## CHAPTER 2:

# Improving services that care for people who are dying

The launch of Pall Call for people in Reading, Wokingham and West Berkshire

### Aims:

Launched in October 2016, this scheme was designed to offer a single point of contact for patients, carers, and health and social care professionals from 15 different organisations, through a 24/7 nurse-led telephone helpline and home visiting service.

Nurses would give timely advice that could prevent unnecessary hospital admission by giving carers confidence on how to manage care needs or home, or arrange any necessary home visits. It was funded by the Berkshire West federation of NHS Clinical Commissioning Groups, for people living in Reading, Wokingham and West Berkshire. It was based on Gold Line, a successful scheme run in Bradford, Airedale, Wharfedale and Craven, which had resulted in 97% of the 7,242 calls, allowing people to remain in their homes.

### How?

A steering group met monthly to help launch the scheme, made up of the CCGs, doctors, Sue Ryder (the hospice service which would run the service), and patient representatives, including Healthwatch Reading. The group discussed issues such as nurse recruitment, the name of the service, and how people would get to know about it.



Supported by

**NHS**

*Sue Ryder*

**PallCall: 0300 365 1234**  
24 hour support and  
co-ordination of palliative  
care across Berkshire West

**Benefits for patients, their families  
and carers:**

- A first point of contact that is responsive and that allows timely access to the services they require.
- Flexible care provision in line with the patient's choices and preferences that supports them, their families and carers to achieve the best quality of life and outcomes.
- More opportunities to receive end of life care at home and to minimise the need for hospital admission in an emergency.
- Improved continuity of care for patients, their families and carers.
- Higher skills and knowledge base in staff who are delivering their care thanks to a structured training programme for staff.
- Improved overall experience of end of life care for patients, their families and carers.

*Pictured above: The front cover and some of the content of the Pall Call leaflet*

Healthwatch Reading also helped to develop a questionnaire that would be used to collect feedback from people using the service.

### Who has it reached?

A conference [presentation](#) described how Pall Call had received 564 calls, and had prevented 42 hospital admissions and 60 contacts with GPs. There had been three times as many calls to the service during February 2017 compared to November 2016, showing it was becoming better known.

However, on May 4 2017, an announcement was made that Pall Call would stop running from 5pm 5 May 2017.

A statement on the Sue Ryder website said this was ‘unfortunately, due to recruitment challenges reflective of the national shortage of palliative care specialists’.

### Lessons learned:

The anecdotal feedback from Pall Call users, plus evidence of averted emergency admissions to hospitals, showed the scheme had real potential to be a valuable addition to existing services. But recruitment proved to be a major challenge.

Initially the aim was to staff Pall Call with one lead nurse, nine nurses and one administrator, but this changed to instead focus on recruiting three health care assistants to support fewer nurses. At launch, Pall Call was staffed by four nurses and an administrator, with other staff being trained in preparation. By the time it was closed, the service was not thought to have a safe number of staff.

There had also been initial teething problems involving IT and arranging permanent desk space for Pall Call staff.

The statement on the Sue Ryder website

also said: ‘The concept of PallCall, with the coordination of all the service providers working together to ensure supportive palliative care is available 24 hours is right and we will continue to work with local commissioners and supporters to best meet the palliative care needs of people who use our services.’

The CCGs said they were unable to issue any public statement on the service’s closure during the run-up to the General Election.

All patients or relatives/carers who had used Pall Call had been contacted and would receive support to move them back to care of mainstream services. These include: palliative care consultants working out of Sue Ryder and the Royal Berkshire Hospital, district nursing teams, GPs, the Westcall out-of-hours GP service, night sitting services and social care support.

A new 111 service starting for people living in the Thames Valley (including Reading) is due to be launched in October 2017, that aims to deliver better 24/7 helpline health advice with instant access to more clinicians, including experts on end-of-life care.

The news about Pall Call’s closure came just before a separate and similar service was launched by the East Berkshire Clinical Commissioning Groups on 8 May 2017. The CCGs are funding Thames Hopsice to provide a Rapid Response Service, which includes a 24-hour end-of-life care telephone service to give advice to local people and their families, as well as healthcare professionals who need guidance and support on delivering palliative care. The specialist team is available 24/7, 365 days a year, to provide guidance on symptom control, practical advice and emotional support.

## CHAPTER 3:

# Speaking up for vulnerable people at the end of their life

Some people are unable to express their wishes about care at the end of their life, due to frailty, disability, mental health needs, or communication difficulties.

These people are legally entitled to help from an advocate, under provisions such as the Care Act (2014) and Mental Capacity Act (2005). The general public is also entitled under NHS regulations, to receive free advocacy if they want to make a complaint about any NHS-funded treatment (including palliative care).

Healthwatch Reading helps these people have their say, through the NHS Complaints Advocacy Service it runs for local people. Healthwatch Reading also coordinates the Reading Voice network of Care Act advocates (from the charities Age UK Reading, Mencap Reading and Talkback) for vulnerable people undergoing social care needs assessments or safeguarding checks.



**ReadingVoice**

### Case study:

Healthwatch Reading helped to find a Care Act advocate with experience of working with older people, to spend time with Mr Smith. A 62-year-old man, he had a life-limiting condition and very limited speech, and needed help to express his wishes about his care and daily living at a nursing home.

The advocate visited him eight times over five months before he passed away. These short, regular visits, helped Mr Smith to trust the advocate. She spent time repeating back to him what she had understood he had said, to give him the opportunity to confirm his views and wishes. Mr Smith eventually disclosed the reason for his low moods, and the cause of the falls that had resulted him being taken to hospital on one occasion.

The advocate was also able to use observation to check that his basic human rights and dignity were being upheld. She noted that sometimes he was not dressed warmly enough, leaving him feeling cold. He could also not reach a drink placed on a nearby table by himself and had no way to get attention of the staff if they were in another room. During those occasions, the advocate was able to talk to staff about meeting his immediate needs.

The advocate drafted a wellbeing plan for Mr Smith, based on her visits, and brought it in on a laptop to check he was happy with it and make any changes he wanted. This was then shared with his social worker, and nursing home staff so they could consider what changes they could make to improve his wellbeing.

The wellbeing plan was written in Mr Smith's own words. Below are some excerpts:

*"I need others to be patient with me and give me time to answer, when I talk, so I do not feel rushed".*

*"I find my room very dull and dreary. It is not very homely. In my room, I would like to see a bit of colour, pictures on the wall, to give it a warm, cosy feel. Sometimes my room can be quite chilly."*

*"I do not watch television or listen to the radio anymore as I find it difficult to use the remote."*

*"I used to read a lot but have not been able to of late because I struggle to turn the pages of books and newspapers. I would like to find a way of reading again."*

*"I need assistance with all aspects of my personal hygiene and would like this to be by male staff only."*

As a result of his wellbeing plan, the nursing home had started to take action to improve Mr Smith's daily life. This included making a referral to an occupational therapist, using a falls

alarms, and making contact with the Reading Talking Newspaper service that delivers a weekly magazine-style selection of audio news from Reading newspapers, either via the internet, or a memory stick through the post.

Reflecting on her time with Mr Smith, the advocate said as well as addressing the important issue of his physical safety, she was pleased to have helped him to highlight the importance of "small things" that contributed to his wellbeing during the last months of his life, which other people might take for granted, such as being able to independently read, have a conversation, and keep yourself warm.

## About Reading Voice advocates



### Advocates will:

- Spend time with you
- Give you information
- Encourage you to make your own choices
- Help you tell your social worker what care you want or need
- Look out for your rights
- Speak up for you if you can't

Pictured above: Page from the Reading Voice leaflet

## CHAPTER 4:

### Useful organisations and resources

#### **Dying Matters - a national coalition to get people talking about dying**

If you want to start talking about your wishes, or approach someone close to you about what their wishes might be, you can get helpful leaflets from [Dying Matters](#):

##### ***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

***Organ donation:*** *have you made your decision known?*

***Being there:*** Top tips for what to say and do when someone has been bereaved

#### **Local organisations**

[Cruse Bereavement Care](#), a national charity with a Thames Valley branch, offering face-to-face, telephone, email and website support for people who have been bereaved.

[Daisy's Dream](#), a Reading-based charity offering support to bereaved children.

[Duchess of Kent Hospice](#), the Reading-based 15-bed inpatient or day hospice for adults, run by Sue Ryder. Its clinical nurse

specialist teams also provide advice and support to people in their own homes.

[Naomi House Children's Hospice](#), providing respite and hospice care for children and young people across central and southern England (including Berkshire).

[North and West Reading Clinical Commissioning Group information about end-of-life care](#).

[Rosie's Rainbow Fund](#), a charity offering bereavement counselling to families who have lost a child, as well as music therapy, across Berkshire, Buckinghamshire and Oxfordshire.

[Reading Services Guide](#), run by Reading Borough Council, provides information on bereavement services and how to register a death.

[South Reading Clinical Commissioning Group information about end of life care](#).

#### **National policy and standards**

[Our commitment to you for end of life care](#), Department of Health, July 2016

[Care of dying adults in the last days of life](#), and [End of life care for adults](#) (covering the last 12 months), guidance from the National Institute for Health and Care Excellence.



To give us your feedback on end-of-life care, or to discuss this report, please contact us at:

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