End of Life Care

Empowering People at End of Life

Report prepared by Graham Lewis
Healthwatch Cambridgeshire and Peterborough

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What we did

We organised a one-day event in St Ives in the centre of Cambridgeshire on 27 March 2019. We had a main speaker, four workshops and a marketplace where 14 organisations ran information stalls. More than 130 people attended the event.

We asked Dr Philip Hartropp to open the event with a keynote speech. Dr Hartropp is a retired GP who worked near Peterborough and is an expert in palliative care. From 2001-2008, he was the primary care trust lead on Cancer and Palliative Care.

Key findings

Why people don’t talk about death

- People felt that it is difficult or “taboo” to talk about death
- When raising it with family members, people said they were told it was too soon to talk about death
- Some people had spoken with older relatives, but not with their children
- People find the legal processes to set up arrangements and wishes are confusing and the language used is also complicated
- Some people mentioned that the costs associated with these processes are difficult to meet.

What people have planned

- 50% of people said that they had written a will
- Very few people had set up Lasting Powers of Attorney or Living Wills
- Nobody had set up Do Not Attempt Resuscitation or Advance Decisions
- Some people had told their families that they wish to be organ donors
- Some people had purchased funeral plans.

What would make it easier to talk about death

- Practical, easy to understand information and some ideas of what topics need to be discussed and how to go about it
- Simple explanations of the various legal processes and associated costs
- It was suggested that information could be provided as part of people's GP Health Checks between the ages of 40 and 74.

Keynote speech

Dr Hartropp, began by explaining that most people would prefer to die at home but, in reality, it is most likely to be at a hospital.

He quoted from the 2010 PRISMA survey (see appendices page 15) that showed:

- 63% of people would prefer to die at home but only 21% did
- 29% wanted to die in a hospice but 5% did
- 3% wanted their life to end in a hospital but the actual number was 53%
- 17% of people died in care homes.

Dr Hartropp explained that palliative care is the relief of symptoms – physical, psychological or spiritual – when a patient is dying. He said that the UK provides the highest standards of palliative care in the world.

He went on to explain that people approaching the end of their life can provide information to their loved ones and to their doctor about their final wishes. This can be through:

Advance Decisions

These are legally-binding documents. They are written while someone still has mental capacity and used at a time when they may no longer have it.

They can be used to refuse resuscitation, most medication, feeding tubes and ventilation. People can also request where they would like to be treated, such as their own home.

However, people cannot refuse pain relief, comfort care or personal hygiene. And an Advance Decision cannot be used to end a life, refuse food and drink by mouth, refuse basic care or nominate someone to make decisions on their behalf.

Lasting Power of Attorney

This is a legal document that lets someone appoint one or more people to help you make decisions or make decisions on your behalf.

There are two types: one covers finance and property and the other covers health and welfare (see page 7 of this report for more details).

Dr Hartropp then answered questions from the audience. These covered a variety of related issues, including his work with ‘Compassion in Dying’.

Workshops

Mental Capacity and Decision Making

Led by Loice Zhanda, Mental Capacity Act and Deprivation of Liberty Safeguards Lead for Cambridgeshire and Peterborough Clinical Commissioning Group.

Loice explained what consent is and the type of information that must be included for people to be able to give their informed consent. The Mental Capacity Act 2005 empowers people to make decisions for themselves wherever possible and protects those who lack the capacity to do so.

The act has five principles:

1. Everyone is believed to have capacity to make decisions unless it can be proved that they do not.
2. A person should be supported to make their own decisions using all practicable steps before it is decided that they are unable to do so.
3. A person should not be considered unable to make a decision just because their decision is considered unwise.
4. Any decision made on behalf of someone who lacks capacity must be made in their best interests.
5. Any best interests decision must take account of all the circumstances and take the least restrictive course of action available to maintain the person's basic rights and freedom.

Where a person has been assessed and found to have an impairment or disturbance of the functioning of their mind or brain, a decision maker is appointed. Any decision made on a person's behalf should be recorded, including information about how the decision was reached.

Loice also explained that it is possible for people to plan for the future and have Advance Care Planning discussions. These include preparing or appointing:

- Advance Statement of wishes and preferences outlining what you want to happen
- Advance Decision (such as to refuse treatment) spelling out what you do not want to happen
- Lasting Power of Attorney who will speak and act for you.

Lasting Power of Attorney (LPA)

Jane Ollett and Minna Rae of Leeds Day Solicitors provided information about LPA and explained that there are two types:

i) A Property and Affairs LPA to
  - Pay regular bills, manage income and expenditure
  - Buy or sell property and manage investments

This type of LPA can be used while the person still has capacity or when they have lost capacity.

ii) A Health and Welfare LPA to
  - Specify where the person lives and with whom
  - Manage healthcare and medical treatment

This type of LPA can be used only when the person no longer has capacity to make decisions for themselves. It can be used to refuse life-sustaining treatment only if the person has specifically authorised this.

An LPA must be written by a person while they have capacity and then registered with the Office of the Public Guardian. It can outline a person’s preferences and instructions as their end of life approaches.

A preference is where a person tells their attorney how they would prefer them to make decisions.

An instruction is a specific action and attorneys must follow the instruction exactly.

Guidance can also be given so that attorneys are aware of the person’s views in certain areas.

Future Planning / Safe and Secure

Paul Stacey and Petra Patty from Thera Trust, which supports people with learning disabilities, talked about the trust’s book ‘Safe and Secure’.

The book helps carers and their relatives with a learning disability plan for the future and map out their social and financial wellbeing.

The book aims to:

- Help people understand the importance of future planning
- To give people tools and to help start the planning process
- To inspire people

Many people are scared to talk about death or fear they will make mistakes for the person they are caring for. So the book explains legal issues such as wills, trusts and guardianships, as well as looking at housing and ‘circles of support’.

A circle of support is a group of people who come together to look after the safety, health and wellbeing of a relative - the person at the centre of the circle. Members of the circle of support are in regular touch with each other, coordinate their involvement and are brought together by friendship, love and trust.

The circle monitors the services the person at the centre receives, advocates on their behalf, serves as an executor and a trustee, helps to make decisions, responds to any crisis and helps solve problems.

The book ‘Safe and Secure’ is a free resource that can help people write the plan.

Bounce Back Boy

Karen Andrews from Skills for Care presented the film 'Bounce Back Boy' and led a discussion on the end of life care issues that it raised.

The film tells the story of Josh Cawley who was 22 when he finally died from the catastrophic injuries his birth parents inflicted on him. These resulted in his inability to speak or to move from his wheelchair. He went on to be adopted by Lynn Cawley who cared for him until his death.

Karen talked about the resources and training available from Skills for Care which trains staff to support people at the end of their life.

What people told us

After lunch, group discussions led by Healthwatch Cambridgeshire and Peterborough staff explored some of the issues that were raised in the keynote speech and workshops.

Many people talked about how difficult it is to have end of life conversations with family members. They also told us that there is not enough information to help people start talking about death. And that information is often written in legal language and is hard to understand.

‘Have you discussed your end of life wishes with your family?’

This question brought a very mixed response. One person said ‘*The British/western society have a taboo about death*’. Other people said they had held brief discussions but that nothing was written down. Some had told their families about wanting to be an organ donor and others had written wills and made funeral plans.

Many people said that they had written a will but very few people had set up Lasting Power of Attorney or Living Wills. Nobody had made Advance Decisions or filled out a Do Not Attempt Resuscitation form.

‘Have you discussed other family members’ wishes with them?

This question also had a very mixed response.

One person said they had discussed the subject with their mother-in-law at great length, with a Power of Attorney being set up.

Others said they had talked to older relatives but not to their children.

‘What made these discussions difficult?’

People found it difficult to get their parents to talk about end of life. Some said it was hard to find the right time to raise the topic, others just did not want to talk about ‘the end’ and not being here anymore.

When people did raise it with family, they said the response was ‘it was too soon’ and so it was not discussed.

‘If you have not had these discussions, what support would you need to do this?’

People felt that GPs should make people aware of the things they need to be talking about, possibly providing some information as part of people’s health checks between the ages of 40 and 74.

People wanted more information on the main end of life issues to think about.

What should happen now?

Healthwatch Cambridgeshire and Peterborough is:

- Giving the key findings from the Empowering People at End of Life Care event in this report to the Cambridgeshire and Peterborough Clinical Commissioning Group’s End of Life working group.

- Making a list of local resources that empower people at the end of life for the Healthwatch Information Service.

- Taking information from this report, turning it into Easy Read format and taking it to the Learning Disability Partnership Boards.

- Writing a public summary report about the event. To include what people said, what Healthwatch will be doing and what we would like others to do.

Feedback from evaluation forms

Over 120 people attended the day, although only a quarter of attendees completed evaluation forms.

What did you think to this event?

- 100% felt it was good or very good.

What did you think to the agenda?

- 86% felt it was good or very good.

What did you think to the opening speech?

- 90% felt it was good or very good.

What did you think to the lunch time discussion?

- 83% felt it was good or very good.

What did you think of the workshops?

- 87% felt they were good or very good.

We also received a variety of written feedback, both positive and things which we will learn from when planning future events.

The feedback we could learn from included:

- Sessions could have been more interactive
- The sound from the microphones was not always good
- More information about what, and where, the workshops were at the sign in desk or a programme for everyone, or on each table, explaining the workshops
- Not to have a session in the lobby of the venue
- One workshop was hard to concentrate on because we could hear another workshop
- Some speakers lacked volume; some spoke too fast
- Some overhead colours were not good
- Maybe done over a shorter day
- When lots of people left early, room felt too big
- Venue cold
- More info on adults with learning disabilities around support workers and care agencies
- Opening speech not easy read
- As a stall holder most people visit stalls in the morning and at lunchtime – we could have let in the afternoon

There were technical issues with the sound that we had not expected and not everyone who spoke was used to using microphones.

Agendas were on each table and information was at the reception, however, not everyone may have seen these.

We had provided guidance to speakers and workshop presenters about making sessions interactive and accessible to all.

The positive feedback included:

- It filled the need for many present
- Stall holders gave advice and information
- It was well attended
- Very useful
- Friendly and helpful staff
- Excellent organisation
- It was great
- I did not have enough time to go to all workshops as the stands were very interesting and spent a lot of time talking to them
- Really important issues
- Lunchtime [led discussions] – it helped make issues more relatable to my own experience
- I am planning to write an Advance Decision as a result of today
- As a stall holder it was useful that we could hear the presentations

Thank you

We would like to thank:

Our keynote speaker Dr Philip Hartropp

Our workshop presenters:

Karen Andrew
Locality Manager - (Eastern)
Skills for Care

Loice Zhanda
Mental Capacity Act/ Deprivation of Liberty Safeguards (MCA/DOLS) Lead
NHS Cambridgeshire and Peterborough Clinical Commissioning Group

Jane Ollett and Minna Rae
Leeds Day Solicitors

Paul Stacey and Petra Patty
Thera Trust

Our stall holders:

- Alzheimer's Society
- Arthur Rank Hospice Charity
- Cambridgeshire County Council
  - Benefits, Scams and Technology Enabled Care
- Cambridgeshire & Peterborough Safeguarding Boards
- Caring Together (formerly Carers Trust Cambridgeshire, Peterborough and Norfolk)
- Cruse Huntingdonshire
- Healthwatch Cambridgeshire and Peterborough
- Leeds Day Solicitors
- Macmillan Cancer Support
- Sacred Stones
- Skills for Care
- Sue Ryder Hospice
- Thera Trust
- Total Voice Advocacy at Voiceability

We would also like to thank:

Turtle Dove Cambridge for their assistance with reception and supporting members of the public on the day.

The management and staff of Burgess Hall, St Ives, for all their help in making this event a success.

About us

Healthwatch Cambridgeshire and Peterborough is funded by Cambridgeshire County Council to facilitate the Adult Social Care Partnership Boards.

Cambridgeshire County Council believes that everybody who lives in Cambridgeshire has the right to be involved in the Council decisions that affect their daily lives.

As part of their commitment to support the voice of local people, they have asked us to organise and develop their four Adult Social Care Partnership Boards. These are:

- Carers' Partnership Board
- Physical Disability and Sensory Impairment Partnership Board
- Learning Disability Partnership Board
- Older People's Partnership Board (65+)

We also organise a Wheelchair Users' Forum four times a year in Cambridgeshire.

The Boards and the Wheelchair Users' Forum aim to support and improve health and social care by including the people who use the services (service users) in their design, delivery and evaluation.

As part of this work, we ask the service users about issues that they believe impact on everyone. We use this information to develop and deliver a large event on a theme. On 10 July 2018 we asked our service users for their thoughts. Out of this came the theme of Empowering People at End of Life.

Appendices

Presentations and links:

Dr Philip Hartropp, keynote speaker

- PRISMA 2010 survey promoting best practice measurement of end-of-life care
- Compassion in Dying
- Free information line: 0800 999 2434
- Website: https://compassionindying.org.uk

Cambridgeshire and Peterborough Clinical Commissioning Group

- Mental Capacity Act and Decision Making
- Website and resources https://www.cambridgeshireandpeterboroughccg.nhs.uk/health-professionals/patient-pathways/safeguarding/mental-capacity/

Leeds Day Solicitors

- Godwin House, George Street, Huntingdon, Cambridgeshire PEW29 3BD
- Tel: 01480 454301
- Powers of Attorney information on website at http://www.leedsday.co.uk/services-for-individuals/wills-and-estate-planning/lasting-powers-of-attorney/

Thera Trust

- Future Planning / Safe and Secure book
- Tel: 0300 303 1280
- Email: info@thera.co.uk
- Details of the book and how to request a free copy online at https://www.thera.co.uk/projects/safe-and-secure/about/

Skills for Care

- T: 0113 245 1716
- E: info@skillsforcare.org.uk
- Website: https://www.skillsforcare.org.uk
- Bounce Back Boy video https://www.hospiceuk.org/what-we-offer/courses-conferences-and-learning-events/educational-plays/bounce-back-boy/bounce-back-boy---watch-the-play

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Share your views

Services need to know what end of life care is like for people to help improve them in the future. Do you have an experience of end of life care you would like to share?

Talk to us and help make end of life care support better.

- You can use the contact details above to get in touch.
- You can also text us on 0752 0635 176
- Feedback via our websites

http://www.healthwatchcambridgeshire.co.uk/content/have-your-say

https://www.healthwatchpeterborough.co.uk/feedback-on-care/

Get in touch if you would like this report in a different format.

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