



# Information to help you at end of life

## Summary of Empowering People at End of Life report

Published September 2019



**In March 2019, we organised a one day event in St Ives in the centre of Cambridgeshire to highlight End of Life care.**

The aim was to explain the choices people have as they reach the end of their life and the information they need to help make decisions about final wishes.

The idea came from the four Adult Social Care Partnership Boards that we run on behalf of Cambridgeshire County Council, and the Wheelchair Users' Forum.

Board and forum members felt that end of life care was an issue impacting everyone and needed talking about and explaining. So we set up the event at Burgess Hall in St Ives and more than 130 people came along.

Our guest speaker was Dr Philip Hartropp, pictured right, a retired GP and palliative care specialist who worked near Peterborough. From 2001-2008, he was the primary care trust lead on cancer and palliative care.

We also ran four workshops, held group discussions on topics raised during the day as well as a marketplace where 14 organisations ran information stalls.





## Key findings from the event

### Why don't people talk about death?

- It's a difficult or 'taboo' subject
- Timing can be key - some people feel it's too soon to discuss
- The legal processes surrounding end of life arrangements and wishes can be complicated and confusing to understand
- Costs can be difficult to meet

### What people have planned

- Half of those attending had written a will
- Very few had set up Lasting Powers of Attorney or Advanced Decisions
- Some have told their families they wanted to be organ donors
- Some have bought funeral plans

### What would make talking easier?

- Practical, easy to understand information
- Knowing what to discuss
- Simple explanations of legal processes and costs.

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

### Dr Philip Hartropp's talk

Most people would prefer to die at home but in reality, it is most likely to be at a hospital.

A 2010 medical survey 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

## Final wishes

Passing on information to loved ones, family members and doctors is important and can be done through:

### Advance Decisions

Legally-binding documents written while someone has mental capacity and used at a time when they may lack capacity. 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. 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

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 for finance and property and the other for health and welfare.





## Our Workshops

### Mental Capacity and Decision Making

Loice Zhanda from Cambridgeshire and Peterborough Clinical Commissioning Group talked about the Mental Capacity Act (MCA) and decision-making.

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 MCA empowers people to make decisions for themselves wherever possible and protects those who lack the capacity to do so.



### Future Planning

Paul Stacey and Petra Patty from Thera Trust spoke about planning the social and financial wellbeing of someone with a learning disability.

The Trust's book, Safe and Secure, helps carers understand the importance of future planning and gives them tools, inspiration and ideas on how to start.



### 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 died from catastrophic injuries inflicted by his birth parents.

As a result, he was unable to speak or move from his wheelchair. He went on to be adopted by Lynn Cawley who cared for him until his death.

### Lasting Power of Attorney

Jane Ollett and Minna Rae from Leeds Day Solicitors explained the two types of Lasting Power of Attorney. There is one for **property and affairs** for paying bills, managing investments or buying and selling property.

And one for **health and welfare** to specify where the person lives and with whom and to manage healthcare and medical treatment although this can be used only when the person no longer has capacity to make decisions for themselves.





## What people said about the event...



“I found it really thought-provoking,” said sandwich carer Sue Honour, left, who cares for her daughter, husband, elderly parents and mother-in-law.

“It was such a good event as it clarified a lot of things I’d heard a bit about.

“It also made me have conversations with my mum and mother in-law and discuss what they would want rather than having to guess what their wishes might be when it is too late.

“It’s important for my daughter to be taken care of when I’m not around, so my husband and I really need to make a will and get everything in place to ensure that happens.”

### What we did with all the information from the day

We have:

- Passed on the key findings from the event to Cambridgeshire and Peterborough Clinical Commissioning Group’s End of Life working group.
- Made a list of local resources that empower people at the end of life or the Healthwatch Information Service - see details on the right.
- Taken information from our full End of Life Care report, made it into Easy Read format and passed it to the the Learning Disability Partnership Boards.



### Need information or want to share your views?

Services need to know what end of life care is like for people to help them improve in the future.

Healthwatch can help you find:

- Health or care services near to you.
- Organisations that can give you help or advice.

Call: 0330 355 1285

Text: 07520 635 176

[enquiries@healthwatchcambspboro.co.uk](mailto:enquiries@healthwatchcambspboro.co.uk)

[www.healthwatchcambridgeshire.co.uk](http://www.healthwatchcambridgeshire.co.uk)

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