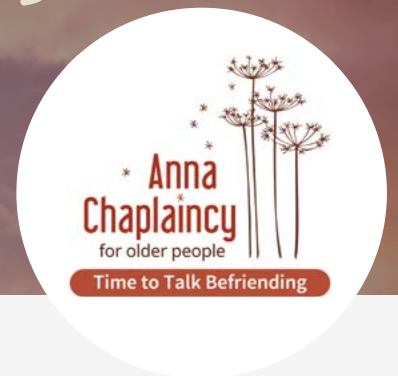


Time to Talk Befriending

in the heart of the community

DYING MATTERS WEEK
10-16 MAY 2021

What Makes a Good Place to Die?



On Wednesday 12th May 2021, Time to Talk Befriending hosted an event which focussed on this years Dying Matters Week theme of 'what makes a good place to die and why'? A facilitated conversation was led by Peter Wells who is Brighton based psychotherapist, and formerly lead chaplain at the Royal Sussex County Hospital. In attendance were health and social care professionals, chaplains, academics and charity professionals.

Who are Time to Talk Befriending?

Time to Talk Befriending specialise in supporting older people experiencing loneliness through a range of befriending and chaplaincy services. Through Anna Chaplaincy at Time to Talk Befriending we offer spiritual care to our members in their later years which includes the privilege of journeying alongside people at the end of their life, as well as providing support to help them prepare to say goodbye.

WHY IS THIS TOPIC IMPORTANT?

Due to the age of the people, we support at the Charity bereavement isn't something new, but, compared to the average of 20 deaths a year, 71 of our members have died since last April which is significant. Most died of Covid-19 and like most people this past year, we weren't able to say our final goodbyes. Many of our members died in hospital or in a care home setting rather than at home so, when the topic of what makes a good place to die was announced as the Dying Matters theme, it really got us thinking...

We remember one of our scheme members who took a folder full of scriptures, prayers, and a holding cross with her every time she frequently went into hospital. This folder had special meaning to her because when she felt unwell, she didn't

know what to pray or how to connect with her faith, so these items comforted her in her time of need. The folder went where she went!

Another scheme member insisted she took a special photo, the bear she cuddled at night, and her mobile phone with her when she was admitted to hospital, because these items also were what she held most dear. It was these items that were with her when she sadly died recently at Sussex County hospital.

It is these real-life experiences that inspired us to put on an event during Dying Matters Week. The notes from our facilitated conversation are included within this document along with a range of resources which participants have found useful.

QUESTION 1: What has been your experience of people you know talking about where they would like to die and why?

Not many conversations have been had about where a good place to die is, but most participants have had conversations with people about what they don't want. i.e. fear of going into hospital and not returning.

When a person has planned and that plan has gone well, this helps their family and friends to move on quicker.

Where there is no plan in place or an untimely death the moving on process is more difficult for those left behind. It takes a longer time to process.

When people have no relatives or loved ones there is no one to advocate for them and they can feel very alone.

Many people just do not like to talk about death.

Sudden death is not ideal, as many want to die at home - but traumatic on one level and an ideal death on another.

COVID-19 has caused protracted grief - sense of anger, denial, guilt as people have not been able to 'say goodbye'.

There was a consensus that hospital would not be a choice. Some had very negative experiences from working in hospitals and there was a view that ward are often noisy and busy with competing priorities for nursing staff.

- Home was the place most have as a preference but this can cause conflict with carers wishes or feeling able to cope/manage

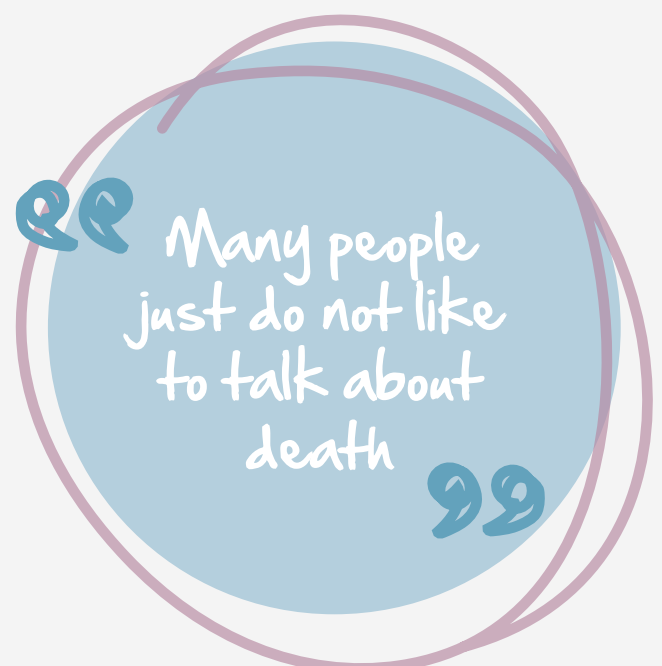
Personal experiences shape attitudes about what makes a good place to die. For example; experience of someone who died in a hospice. This was a very positive experience for the person at the end of life and their family and friends.

Past preconceptions and attitudes change once you have experienced someone coming to the end of their lives in a hospice setting.

If someone chooses to die at home but they don't have the right support in place this can be very difficult for the person caring for them if they don't have the right support. Especially in relation to pain management. Examples were given about how people at the end of life had to go into hospital because these things (additional care and medication) were not possible at home.

Guilt about not carrying out a loved ones wishes to remain at home really impacts on family when they have to go into hospital because their health has declined so much.

People who have a faith and draw on their faith i.e. through prayer show real strength and hope as they prepare for their lives to come to an end.



QUESTION 2: What resources do you know of which would help people talk about and decide where to die?

A lot of discussion needs to be at the pace of the person regardless of what resources are available. Some are reluctant to talk about their future and death.

There is a major difference in talking with / supporting someone as a professional to in a personal capacity which can be much harder.

It was thought that we often know what the end plans are i.e. funeral arrangements but we don't know much about where someone actually wants to die.

There is a sadness and disappointment that can come when you have been sat with a loved one during their final hours but when you leave the room or someone else takes over, you miss their actual passing. We talked about this being something that can happen quite often. At the Martlets they prepare family members for this in case it happens to them.

Asking people what is important and meaningful to them about the place in which they want to die is essential to helping people fulfil their wishes. So people themselves are a great resource.

Covid-19 has definitely provided an open door to talk about death and dying more openly.

Celebration - glass of wine, loved pet, being in nature etc...

For someone to know they 'are not alone'.

- TTTB have resources for guiding conversations about how to prepare to say goodbye.
- Independent Age have free accessible resources available on their website. You can receive up to 50 copies of a resource without any cost which is extremely useful! The terminology they use is very good as well as being full of helpful information.
- The better conversations are often in situations eg when driving or walking so they feel less intense.

- Salvation Army have a booklet for church leaders which is a guide on talking to groups, this includes a planning sheet which individuals can then take away.
 - There are much more resources available now online compared to 10 years ago.
-

'We all know how this ends' by Anna Lyons and Louise Winter.

The Good Grief Festival which can be watched on demand as well as attended live:
www.goodgrieffest.com

The book 'In the Midst of Life' by Jennifer Worth was recommended. Jennifer also wrote Call the Midwife. Through her nursing career she supported a lot with people at the end of their lives and reflects about the frequency of people dying when no one else is around.

Advanced care planning is essential especially for those who have been diagnosed with a terminal illness.

ReSpect.

Funeral Directors have good information.

Catherine Maddox book - What's important to you now - bucket list. - book for carers.

Suggestion - a directory like the Brighton and Hove Ageing Well resource which is updated regularly and holds information about services, answers questions that people might have about death and dying and provides helpful signposting information accessible for all i.e. professionals, individuals, carers etc.

Please see pages 6 and 7 for a full list of resources identified during our conversation.

QUESTION 3

PART 1: After previous discussions what are your thoughts about where you would like to die?

Not given this much thought before!
Even though the funeral has been planned with every detail, the lead up before we die has not been considered before.

Most had thought more about where they don't want to die, rather than where would be preferable.

Recognise the importance of having someone to advocate for your wishes and put in place what you want.

Most agreed not in sleep or suddenly as that did not give time to talk to loved ones or say goodbye.

All would prefer somewhere peaceful with privacy and with significant people.

Some would want a spiritual person with them eg Priest or Pastor.

Have the conversations whilst you can.

Be assertive in these conversations
– people often do not like to talk about this.

“It's a surprise to be surprised that I hadn't considered the actual dying part”!

Professionally talking about death and dying is quite common place but personally this is something that I haven't thought about yet. “I'm not in that space yet but I wonder if I'll get to choose?”.

Anywhere where I can get the best care needed at the time so I am comfortable and safe. The most important thing is not being in pain, having comfort and making sure that my loved ones know that I am happy with this and don't carry any guilt about i.e. not dying at home. I would definitely consider a hospice because I have had a great experience of being present in these peaceful and tranquil environments.



Have the conversations while you can...



Recognise the importance of having someone to advocate for your wishes and put in place what you want.





QUESTION 3

PART 2: And what would you like to take from this conversation?

Courage to think about this in the longer term.

Feeling more resourced to have a conversation with family and friends.

Enabled to suggest I and others need to talk about our own death.

Need not be a wholly morbid subject but can give comfort.

There is strength in planning because “it’s not going to stop it happening”.

Planning for everything so that children and close family and friends don’t have to second guess what I want and need.

How we can start to have these conversations with others and how we can utilise the great resources available to us.

Reminder of a Woody Allen quote “I don’t mind dying, I just don’t want to be there when it happens!”.

RESOURCES:

Age UK have resources about death and dying. www.ageuk.org.uk/services/information-advice/guides-and-factsheets/guides-about-death-and-dying/

Conversations for Life: www.conversationsforlife.co.uk

End of life planning via Independent Age: www.independentage.org/get-advice/advice-guides-factsheets-leaflets/planning-for-end-of-life and practical ideas for difficult conversations about death and dying more generally: www.independentage.org/information/personal-life/difficult-conversations/practical-tips

End of life planning via My Future Care: www.myfuturecare.org

Journeying Home by The Salvation Army: www.faithinlaterlife.org/wp-content/uploads/2019/01/Journeying-Home.pdf

Preparing to Say Goodbye guided conversations toolkit and/or training and workshops available upon request via www.tttb.org.uk / info@tttb.org.uk

Research opportunities. Henglien Lisa Chen, is a Lecturer in Social Work and Social Care at the University of Sussex. Lisa is interested in research relating to ageing and ageing care. Please contact her if anyone is interested in exploring research further: h.l.chen@sussex.ac.uk

ReSpect (Recommended Summary Plan for Emergency Care and Treatment) www.resus.org.uk/respect

Resources, fact sheets, guides and leaflets for older people through Independent Age: www.independentage.org/get-advice/advice-guides-factsheets-leaflets

Support for carers information via Dying Matters: www.dyingmatters.org/page/information-carers

Support for all kinds of grief: www.griefrecoverymethod.com

Support for those who would like to die at home but are alone: www.eol-doula.uk

The Good Grief Project podcasts, information, webinars, festival on demand: www.goodgrieffest.com



BOOK SUGGESTIONS:

'We all know how this ends'

by Anna Lyons and Louise Winter.

'A matter of death and life'

by Irvin and Marilyn Yalom.

'In the Midst of Life' by Jennifer Worth.

'Languages of Loss' by Sasha Bates.

**'Thinking of You: a resource for the
Spiritual Care of People with Dementia'**

by Joanna Collicutt.

'Being Mortal' by Atul Gawande.

☪☪

*Courage is strength
in the face of knowledge
of what is to be feared
or hoped. Wisdom is
prudent strength.*

Atul Gawande

☪☪

We hope that the information provided within this document is helpful. We would like to thank everyone who contributed towards the discussion about 'what makes a good place to die and why'?

We would also like to give special thanks to Peter Wells who expertly facilitated our conversation during Dying Matters Week 2021.



Peter Wells Brighton based psychotherapist, and former lead chaplain at the Royal Sussex County Hospital.

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