

**END OF LIFE DOULA UK**

Doing Death Differently

end of life  
matters 

# End of Life Doulas

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U3A

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# My Background



- IBM, Franco-British Council
- The Charterhouse Almshouse
- Founder of End of Life Matters
- Volunteer & Trustee of St Christopher's Hospice
- Trustee of Cruse Bereavement
- Member of EoLDUK & Companion Voices



# How I came to this work

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## ❖ Trauma of father's death:

- ❖ Powers of Attorney
- ❖ Legacy
- ❖ Gravestone
- ❖ Shock of will

## ❖ Shock of mother's death

- ❖ Sibling arguments
- ❖ Administrative chaos
- ❖ Financial challenges

# Agenda

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What is an End of Life Doula?

History of the movement

Why End of Life Doulas?

Case Studies

Hospices & NHS

How we can help everyone



# The Elephant in the Room

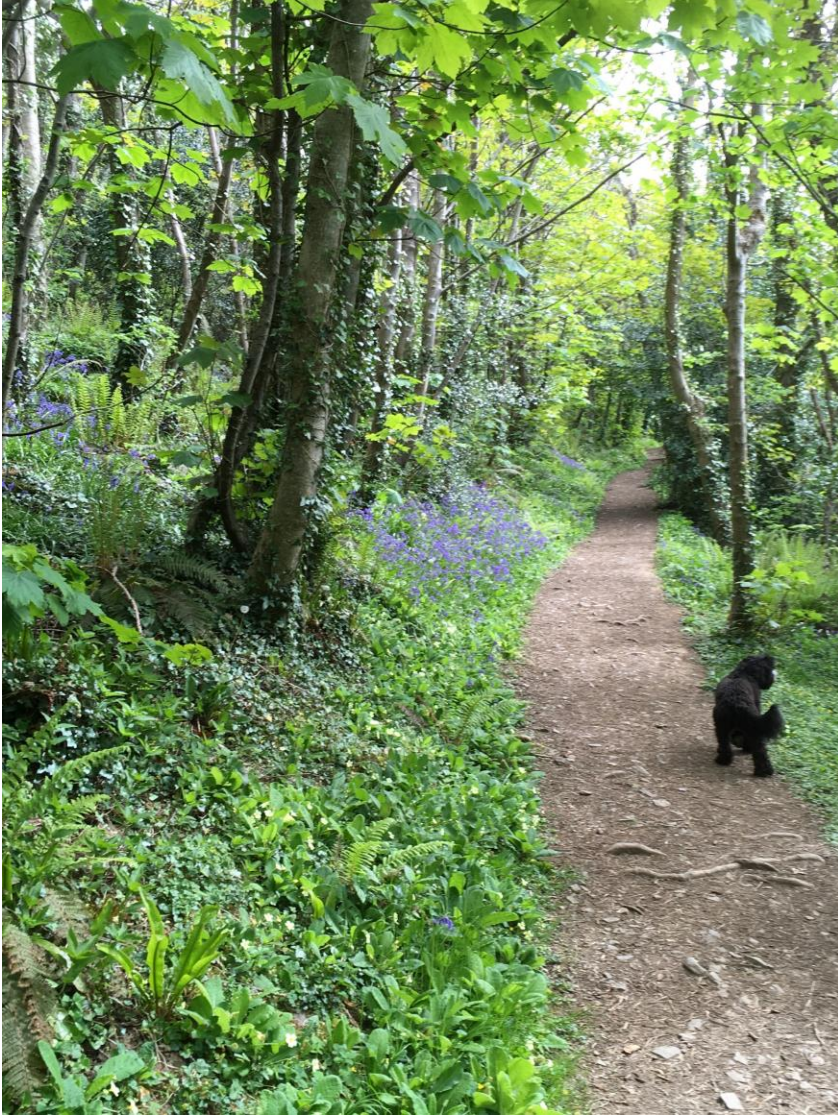


- Denial and fear of death
- Complexity and lack of knowledge
- Talking about death won't make it happen!
- Take time out if you need it
  
- **Poll time: DO YOU KNOW WHAT AN END OF LIFE DOULA DOES?**

# The History

- ❖ Meaning: Doula is 'one who serves' in ancient Greek
- ❖ Concept not new – the work we do has been done for centuries
  - Medieval Soul Midwives
  - Buddhist Death Companions
  - Victorian Book of the dead
  - Indigenous Death rituals
  - USA 19th century – Harriet Tubman
- ❖ More recently communities have become separated from everyday death and dying- handing it over
- ❖ informed companionship and resources before, during, and after death



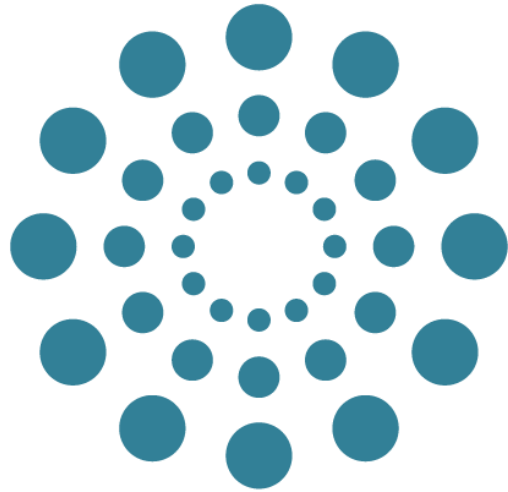


# Death in the UK today

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A few statistics:

- 1% of UK population are in their last year of life. 33% of the NHS budget is spent on this
- The demand for palliative care is set to rise by 25% by 2048 in the UK
- Even when someone is in the last year of life only 5% is medical support, 95% is community support



**END OF LIFE DOULA UK**

Doing Death Differently

- ❖ Membership organisation and community of practice founded 2001, charity in 2024
- ❖ Sets standards, provides mentoring and Continuing Professional Development
- ❖ Central point of contact for those seeking EoL Doula support in UK

# What is the role of Doulas?

- ❖ Over stretched and underfunded health and social care systems mean people are looking to their own communities to care for their own
- ❖ Even when someone is in the last year of life only 5% is medical support, 95% is community support
- ❖ Birth doulas and End of life doulas provide support – like the bookends of life
  - Emotional
  - Practical
  - Spiritual
- Our role is one of compassion, advocacy, and companionship, ensuring that people feel heard, respected, and supported as they approach the end of life

**Poll time:** Have you lost a parent or partner or loved one in the last 20 years?



# What else do we do?

- Our key skills are listening, holding the space and access to expertise and resources
- Guide people through decisions and choices that need to be made
- Act as a single point of contact
- Navigate health and social care systems
- Practical – housework, prepare meals, walk the dog
- Take time to sit with the dying person and ‘hold space’
- Have conversations with the person and those they love so death is approached without fear or loneliness
- There for all the family – before, during and after death

# Case Study One: Amy (100)

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- Connecting the family with options for financial advice
- Planning ahead – talking to a humanist celebrant and recording her wishes.
- Navigating nightmare of Hackney and Lambeth social care systems
- Advocacy with medical team and with family
- Creating a lovely environment – flowers, good food, peace
- Practical and emotional support for family after she died



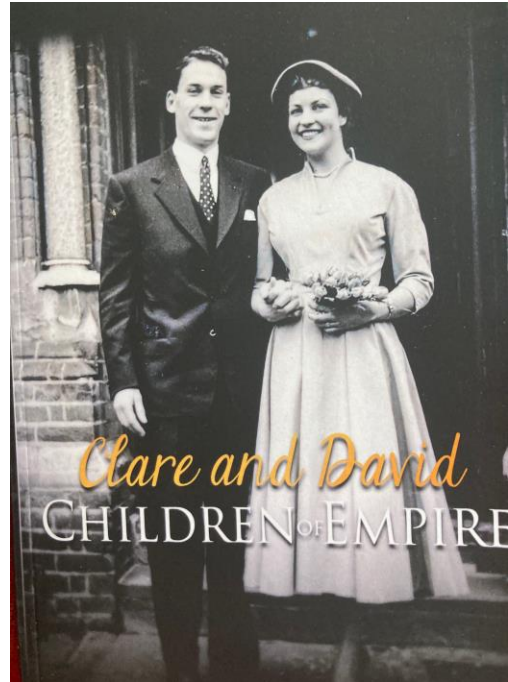


# Case Study Two online : Joan (45)

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- Two month diagnosis of brain tumour
- Coaching her to communicate news to elderly mother in South Africa
- Advice and guidance on funeral options and content
- ***calm and sure guidance***
- Practical advice on household matters – dog food bowls!
- Access to local resources – hosting her siblings without stress
- Five minute legacy love letters

# Case Study Three: Clare (91)



- Considering legacy in broadest sense
- Funeral planning
- Advocacy with husband (carer)
- Listening to secrets - unburdening
- Practical access to support
- Planning ahead – Advance Decisions and Statement to record her wishes
- How she likes her whisky!

# Case Study Four: Mary (65)

- Planning ahead – getting Will sorted and PoAs in place
- Accompanying her to the Lido for cold water swimming
- Listening to her talking about her life and childhood
- Working out what matters most – focusing on enjoying the present
- Encouraging her knitting and creativity
- Massage and Reiki
- Accompanying her to church to reconnect with her childhood and speak to the local vicar to discuss what she wants for her funeral – no hymns and no readings!



# Kingston & Richmond NHS Pilot

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## Why?

- To provide person-centred, non-clinical support to individuals with terminal or life-limiting illnesses and their families alongside regular clinical support
- To reduce unplanned hospital admissions and support people to die in their preferred place of death

## Findings

- Doulas can play a vital role in enhancing person-centred care, supporting families, and complementing existing healthcare services
- Cost effective to integrate doulas into public health frameworks

## Challenges

- Late referrals limited scope of end of life planning



## Sasha: St Christopher's Hospice Doula: tackling inequalities

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- Global majority and first-generation UK residents
- Creating a connection with people with cognitive and learning disabilities through music or memories
- Focus on homeless individuals and individuals with a history of abuse and trauma
- Making room in care home more homely & personal
- Ensuring religious minorities wishes are met
- Giving people with a history of mental health issues space and time to explore complex family relationships

# Supporting Children

- Helping them before and after the death of a parent or sibling
- A doula may create a picture book or use dolls to explain illness and death to a 5-year-old whose mother is dying, allowing the child to ask questions safely and at their own pace.
- Memory boxes, scrapbooks, interviewing
- Involving them in end of life rituals
- a Doula may offer storybooks about loss, simple mindfulness exercises, or grief play sessions to help them express what's hard to put into words.





# Supporting adults of all ages

## ■ DEATH CAFES

- ❖ Started in Hackney in 2010
- ❖ over 17,000 held worldwide last year
- ❖ Attendees of all ages
- ❖ Opportunity to share fears and hopes - breaking the taboo around death and dying
- ❖ [www.deathcafe.com](http://www.deathcafe.com)
- *thought-provoking, life affirming, blissful, helpful and oddly calming*



## Poll time: Supporting people to plan ahead

Where would you ideally like to be when you die?

# Some figures for context

Public Health England 2022

<b>Where we want to die</b>	<b>Where we died</b>
<b>Home: 63%</b> Dying Matters Research 70%	28.7%
<b>Hospice: 28%</b>	4.7%
<b>Hospital: 8%</b>	43.4%
<b>Care home 15%</b>	20.5%
<b>Other places</b>	2.6 %

# Planning Ahead for later life

- **Advance Care Planning** - 77% of patients with a recorded advance care plan achieved their preferred place of death.
- **Is your home appropriate for old age?**
- **Are you sharing your passwords?**
- **What support is in place and what is lacking (physical, mental, creative, spiritual, financial, nature, dreams)**
- **What is your broader legacy?**
- **What kind of end of life celebration is right for YOU?**







# Companion Voices

- **Founded in the UK in 2014**
- **Singing at the bedside of the dying**
- **Beneficial for both the dying and their families**
- **Exploring partnerships with Kings Hospital, London**

# Contact me

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# Thank you

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[www.eol-doula.uk](http://www.eol-doula.uk)

Find us on Facebook, Twitter, Instagram & LinkedIn



**End of Life Doula UK is a Charity. Wherever we can we provide support to people who do not have monies available to pay for a Doula. If you would like to donate, please go to <https://eol-doula.uk/support-our-work/>**

# Questions

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