10 THINGS WE’D LIKE YOU TO KNOW ABOUT WHAT IT MEANS TO BE A LIVING WELL DYING WELL END OF LIFE DOULA

There are different titles for people supporting individuals, in a non-medicalised role, at end of life – Death Doulas, Soul Midwives, End of Life Companions, Carers and so on. What they are called, how they are trained and supervised can differ and cause confusion. We take pride that we are part of the Living Well Dying Well Network and call ourselves End of Life Doulas. We have benefited from an in-depth training and work within a professional and guided framework. We set out here what we do together with what we believe, in some situations, differentiates us. We hope the information is helpful but please do call or email if there is anything more you’d like to know.

1. As End of Life Doulas we can begin our work with the person at any stage - from the diagnosis of an illness, the onset of fragility, through to dying and death. What we do and the time we spend with the person, which may be years or months or weeks, will, therefore, change to meet individual choices and needs. We respect the fact that everyone exists within their own social circle and community. Part of our role is to inform, facilitate and empower those closest to the person who is dying, so they gain the confidence to be involved and to be with dying and death.

2. Our role is extremely flexible and we work in an open-hearted, person-centred way to create an atmosphere of loving support, kindness, respect, dignity and normality for all concerned. We place emphasis on the word normality. We are, like Soul Midwives, trained to work holistically with both the spirit and the soul of the dying person, if that is important to them. We can be alongside the dying person and the people they love to hold a vigil and include spirituality within our work irrespective of our own belief systems. We will go where the dying person wants to go on their own journey at end of life. So in doing this we are respectful that the person we are with may or may not have spiritual and religious beliefs.

We are very practical and can:
- take the time that is needed to sit with the dying person – we are able to hold the space, talk, listen, facilitate conversations, look back together aiming to make sense of it all, read, listen to music or watch films - always responding to their situation and needs
- work with people to make all the decisions that they need to make at end of life
- support them to prepare their Advance Plan including their Advance Decision (or Directive in Scotland)
- help to navigate the health and social care systems being the point of contact
- ‘speak up’ for the individual and those they love when they need help with this
- provide respite care
- within the home environment, support family or those close to the person who are in a caring role, to have quality time together, to rest or have time off. We do this by being practical and hands on, helping with housework, shopping, creating a comfortable environment, making meals and drinks, walking the dog and so on.
3. We try to avoid expressions like a ‘good death’. None of us can say for sure how and when a person will die or what they will experience. We do, however, do all we can to support them to die in the place of their choice, to feel safe and at peace with their own unique death and dying, with the people they love.

4. Living Well Dying Well has pioneered the training of End of Life Doulas in the UK which is the only externally certificated training, monitored by Crossfields Institute. We are the only educational centre for the training of End of Life Doulas in the UK to offer this quality standard.

5. The Diploma Course comprises 20 days of comprehensive learning in the class room (we understand Soul Midwives and some others offer anything from 2 - 5 days). Our training is combined with portfolio work, evidential learning and required volunteer experience. At the time of writing our fees are in comparison are very favourable.

6. All Living Well Dying Well people who are working with a dying person have a mentor made available to them. This individual has the knowledge and skills to take responsibility for overseeing the work of the Doula and act as a reference point. It ensures that the dying person and the people they love are held by a safe pair of hands, the work is monitored by another person and high standards are maintained.

7. As an End of Life Doula or a Doula in training there are regional networks currently in London, the South West, the North and Scotland (being developed). These networks provide an ongoing connection with Living Well Dying Well, continuing professional development, peer supervision and a foundation for ongoing support during training and afterwards.

8. We work in our Communities running events and festivals to raise awareness and workshops. In the last year these have included the Pushing Up Daisies Festival in Todmorden; Advance Planning for End of Life, Care of the Body Workshops; training Volunteers to be End of Life Sitters. Many of us host Death Cafes throughout the UK.

9. Some of our Doulas have worked or continue to work within associated fields for example as Funeral Directors; Celebrants; End of Life Coaches and Counsellors; complementary and alternative health therapists, Reiki, Reflexology, Aromatherapy, Homeopathy, etc; Palliative Care and Community Nurses; Managers and Employees working within the Hospice Movement and so on. This knowledge is shared and is available within our network. A few of our Doulas started their training as a Soul Midwife and decided to continue their journey with Living Well Dying Well to become an End of Life Doula.

10. Our Patron is Professor Allan Kellehear, Bradford University 50th Anniversary Professor (End of Life Care). He is a leading academic in the field of death and bereavement and is the author of Compassionate Cities which is a ground-breaking work taking end-of-life care beyond traditional boundaries (and a medicalised model) to involve whole communities; adopting a compassionate approach to dying, death and loss.

See links below...
In reaching out to the public Hermione Elliott, the pioneer of Living Well Dying Well, has spoken about our work with Joan Bakewell on Radio 4 *We Need to Talk About Dying* and to Radio 4 PM Programme; we have also had articles about our work in The Guardian, Financial Times and The Independent. Doulas have been featured in a short film project associated with the Wellcome Trust.

https://www.youtube.com/watch?v=5EfgMmhituo
http://www.bbc.co.uk/programmes/b084ys5v
https://www.ft.com/content/cbae3d14-f158-11e3-9161-00144feabdc0
https://www.theguardian.com/lifeandstyle/2014/may/04/death-doulas-helping-people-face-up-to-death