

END OF LIFE DOULA SCOPE OF PRACTICE

End-of-life doulas will work with a dying person, their family, friends, and caregivers in the last months of life to support them emotionally, spiritually, and physically. The end-of-life (EOL) doulas will also provide information to help the dying person and others make choices about, or understand the nature of, the dying process. One of the primary areas of focus for the end-of-life (EOL) doulas is exploring life meaning through life review that helps a dying person and those close to them look at what has been important to them over the course of their life, what they have learned, the values they have come to hold, their impact on the people they have lived among, and what they consider to be their legacy. The EOL doulas will help a dying person and family extract from this life review the legacy they want to concentrate on as they create a memory book, box, scroll, audio or video that can capture and express that legacy.

The EOL doula will help the dying person and family plan for how they want the last days of life to look, sound, and feel. This involves reviewing and explaining the choices they have in how the space is set up around them; the kinds of interaction they want with caregivers, family, and others in the last days of life; as well as the kind of sounds, reading, smells, light, and touch they would find comforting and helpful as they go through the dying process. The EOL doulas will also help create and demonstrate the use of guided imagery and ritual for the dying person and family.

When the dying person is in the last days of life, the time we refer to as the “vigil,” the EOL doulas will attend him or her and the family or caregivers around the clock as much as possible. Their primary focus in this stage of the EOL doula approach is maintaining and advocating for the plan and wishes the dying person and family worked out earlier. If no such planning work occurred prior to the EOL doula involvement, the EOL doulas will work on the choices and options with those involved as the vigil begins. The EOL doulas will make sure that the choices about the atmosphere in the space around the dying person will be carried out, and use sound, readings, touch, guided imagery, and ritual to deepen the sense of meaning and bring greater comfort to everyone involved.

The EOL doulas will also assist in the physical care of the dying person by providing simple mouth care, assisting the caregivers in repositioning the dying person or changing the bed sheets, applying a cool or warm compress, or wiping sweat from the person’s face and neck.

When providing physical care in in-patient settings, the doulas will abide by the rules and regulations of that setting for the kinds of physical care assistance that is acceptable.

When hired privately doulas will discuss physical care with the dying person, family, and other paid caregivers to determine the kinds of physical care they will provide. This may include changing the dying person’s incontinence undergarment, if all the parties are comfortable with this. If the family wishes the doulas to provide medication, and the doulas are comfortable with that, they can do so under the guidance of the primary caregivers and/or the nurse involved in overseeing care. It is in the best interests of the doulas to obtain a written agreement to this effect with very clear delineation of the circumstances under which this can occur and a waiver of personal liability

The EOL doulas will inform family and caregivers about the signs and symptoms of the active dying process and imminent death, discussing how and when to address these symptoms, as well as what to expect as the process continues to unfold. If the family or caregivers need further clinical understanding, or events and issues suggest the need for greater professional involvement, the EOL doula will reach out to the appropriate clinician to help the family or caregivers.

The EOL doulas will not perform any medical assessment or intervention, regardless of their background or licensure, which lies outside of the EOL doula training and scope of practice as stated in this document.

Following the death, the EOL doulas will help family to reprocess the dying experience through one or more sessions. The focus of these sessions will be to uncover recurring images, sounds, or other experiences, as well as things said or not said, things not done, or wishes unmet. The EOL doulas will try to reframe those experiences that have negative emotional content. The EOL doulas will also share their experiences of the more positive and touching moments they witnessed to help family hold on to those moments as well.

The EOL doulas will discuss the nature of bereavement and encourage the processing of some of the emotions grief brings up. The EOL doulas will also refer family to bereavement services offered through the organizations the dying person and family had been involved with, or detail community resources available to assist in bereavement. The post death processing the EOL doulas do may also involve the use of music, guided imagery, and ritual to deepen the meaning of this part of their work and bring closure to their involvement.

Following the end of formal services, the EOL doulas will not establish an intimate relationship with any of the people directly involved in the case, according to the specifications in the INELDA Code of Ethics. Nor will the doulas solicit business or provide services unrelated to the doula work in a way that would take advantage of or be exploitive of the relationship that was created in the EOL doula