

INTERNATIONAL END-OF-LIFE DOULA ASSOCIATION | SCOPE OF PRACTICE |

End-of-life doulas will work with a dying person, their loved ones, and paid caregivers at any point following a terminal diagnosis, and especially in the last months of life to support them emotionally, spiritually, and physically. The end-of-life (EOL) doula 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 EOL doula is exploring life meaning through life review that helps a dying person and those close to them look at what has been important to that person 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 doula will support a dying person and loved ones in extracting from this life review the material they might want to use in creating a remembrance project, often referred to as a legacy project. This project may reflect who the dying person has been and the impact they will leave behind on people and their community.

The EOL doula will help the dying person and loved ones plan for their wishes during the last days of life. This involves reviewing and explaining the choices they have in where they want to die, how the space is set up around them; the kinds of interaction they want with loved ones, caregivers, and others; 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. If there is conflict in the wishes of the dying person and their loved ones, the doula will advocate for the primacy of the dying person's wishes and also explore ways to support the loved ones.

When the dying person is in the last days of life - the time we refer to as the "vigil" - the EOL doula will attend to them and those around them in ways that reflect their wishes and the need for doula presence. The primary focus of the EOL doula in this stage is maintaining and advocating for the spirit of a plan they had worked out beforehand. If no such planning work occurred prior to the EOL doula involvement, the EOL doula will work on the choices and options with those involved as the vigil begins. The EOL doula will do what they can to hold the space for the choices about the atmosphere and the wishes of all involved. The EOL doula will use sound, readings, touch, guided imagery, and ritual to deepen the sense of meaning and bring greater comfort to everyone involved.

The EOL doula might 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 bedsheets, applying a cool or warm compress, or wiping sweat from the person's face and neck. The doula will not administer medication or change wound dressings, or do any other kind of physical care that requires clinical training.

When the doula is providing care in a facility, hospital, or hospice in-patient setting they will only assist with physical care if asked by a clinician to assist and the doula is comfortable in doing so. If assisting with physical care, the doula must abide by the rules and regulations of that setting for the kinds of physical care assistance that is permitted for non-staff people.

The EOL doula will inform loved ones and caregivers about the signs and symptoms of the active dying process and imminent death, discuss how and when to address these symptoms, as well as what to expect as the process continues to unfold. If the loved ones 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 have them provide information or to intervene appropriately.

The EOL doula 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 doula will help loved ones 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 loved ones hold on to those moments as well.

The EOL doula will discuss the nature of bereavement and encourage the processing of some of the emotions grief evokes. The EOL doula will also refer loved ones 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 doula facilitates 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 doula 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 exploitative of the relationship that was created in the EOL doula work.