

## How a Death Doula Assists with VSED

by VSED Resources Northwest



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A death doula, sometimes called an end-of-life guide or death midwife, is a non-medical person who serves the dying person and their family. Her work is part case-manager and part godmother as she maintains a holistic perspective of the mental, physical, and spiritual needs of the client and family. Her tasks include educating the client and family members about the VSED process, helping them navigate conversations with their health care provider and assisting them in gathering a supportive group of caregivers. Her ability to coordinate with physicians, hospice staff, visitors, pharmacy and caregivers, allows family members the option of supporting their loved one as well as taking good care of themselves during this time of transition.

A death doula collaborates with hospice staff, if they are involved, by supporting family members and caregivers in following hospice directives. Unlike hospice staff, who have a caseload of clients to visit, a death doula has only one client. While a hospice nurse has specific time constraints and focuses on the immediate medical needs of the patient, the doula is available 24/7 to respond to family dynamics, anticipate needs for information and support, manage guest visits, and guide the family through each step of the dying process. And because the death doula has the time and intention to be with and know the family well, her insights can be helpful in collaborating with hospice staff.

It is a sacred and intense calling for the death doula to be consistently present as the VSED client completes their life's work—saying “I love you,” asking for and receiving forgiveness, and saying goodbye.

## Death Doula Responsibilities in Preparation for VSED

### Prepare client and family

#### **Speak initially with client or his/her representative**

Determine how best to consistently reach him/her (phone, email, message)

Describe role of Death Doula (what it is and what it is not)

Discern what the client & family want and need

Determine if this will be a good fit for all concerned

Offer contract and individualize it as needed

#### **Meet with client and point person to begin discussing VSED process**

Meet with other family members to answer questions, share concerns

Who are the medical professionals involved with this family?

Has client spoken with PCP re desire to do VSED?

Who will be the family's point person for client?

Send VSED resources to client & family and review them in person; assess understanding

Offer names and phone numbers of other families who have witnessed VSED

**Talk about selection of a Start Date for VSED and what needs to be in place beforehand**

Determine what medications are currently being taken

Ask about significant medical history, including mental health, trauma

Ask about normal daily routine: waking, toileting, meals, quiet time, social time, bedtime

Review with client (and family) the responses to “List of things that comfort me”, discuss significance

**Determine what preparation has been done in advance**

Determine status of Advance Care Plan and POLST

Determine who is Durable Power of Attorney (DPOA) for Healthcare

Determine status of legal preparation: DPOA for Finances, Release and Assumption of Risk document for caregivers and family members, Will

Discuss usefulness of preparing two videos - one on iPhone for quick reference and a longer one on thumb drive for legal protection

Assist in making videos, if desired

**Explain physical preparation for VSED – diminished calories, diminished intake, cleanse**

Explain medications that might be used: what they are, what they do

Talk w/ family and client about level of sedation wanted, anticipated by physician, client, family

Talk about fears (death, pain, suffering, separation, regrets, goodbyes, etc.) of both client & family that may influence this EOL experience

**Discuss with client and family plans for disposition of the body**

Cremation/burial/green-burial

Assist family with completing paperwork re disposition of the body

**Offer an intention-setting ceremony before VSED begins**

Gather family, friends, and caregivers to offer support for what is about to happen

Talk about the coming transition in caring, supportive terms

Celebrate the person getting ready to embark on their VSED journey

**Encourage client and family to document the VSED journey**

Encourage family members to journal, draw, photograph during VSED days as important outlet

Talk about significance of photos

Talk about significance of ceremonies or rituals

**Help family anticipate preferences/needs for the immediate days after death**

Self-care, comfort, sitting *shiva*, asking for help, asking for quiet; distraction

**Request family complete intake with EOLWA for data collection**

Introduce idea of legacy work: (if time permits or if family can be engaged in doing so)

## Coordinate external agency support, supplies and equipment, and records

### **Coordinate with Physician**

Have client sign communication release document for PH-associated providers

Notify physician of Death Doula (DD) assistance with their client

Give or email information about VSED

What medications are currently being taken and when to stop them

Request, if appropriate, liquid medication for pain, anxiety, hallucinations as well as discussion of ways to do cleanse prior to start VSED

Determine physician's willingness to collaborate and communicate w/DD, family point person, and family during process

Determine physician's willingness to make a home visit

Communicate with physician during VSED process, as determined from earlier communication

Communicate with physician after death, as determined from earlier communication

### **Coordinate with Hospice**

Discuss with family the importance/advantages of being on hospice

Ask family to call Hospice and request an intake appointment

Have client sign Communication Release Document for Peace Health (PH)

Call/email hospice about DD involvement with participant's VSED & request intake appointment for client

Introduce self to each hospice staff person who comes to the home; offer card

Thank hospice staff at every opportunity and after death for their collaboration and care

### **Oversee caregiving logistics**

Coordinate with Death Doula colleague(s) so there is 24/7 Death Doula coverage and accessibility

Discuss with family the need for caregiving - safety, medication, comfort, continual assessment

Determine need for non-family care-givers vs family involvement: how & when is family available

Discuss with family the advantages/concerns of being the caregiver for their family member

Hire caregivers so there is 24/7 coverage for client

Introduce caregivers to client and family so compatibility is assured

Review with caregivers, and teach/demonstrate if necessary, the expected skills for the VSED process

Prepare schedule for 24/7 caregiving through 14 days

Distribute copy of schedule to family and caregivers

### **Maintain records**

Create a notebook of all paperwork:

- Phone numbers for everyone involved
- Business cards and phone numbers for additional social resources
- Caregiver log sheet for each caregiver to track hours worked, date, time
- Medication sheet for meds given
- Progress notes for caregivers to document progress, family concerns & questions, hospice notes
- Email correspondence with client and family prior to start date

## *How a Death Doula Assists with VSED*

- Client's most current Advance Care Plan with VSED addendum, if appropriate
- Hospice enrollment paperwork
- Signed Release & Assumption of Risk
- Copy of signed Death Doula contract
- Signed Communication Releases with Physicians and Hospice (Peace Health)
- VSED Resources documents for everyone to refer to
- Business receipts associated with this VSED process

### **Coordinate equipment and supplies**

Give family a list of recommended equipment, noting which ones can be borrowed from the group's Lending Bank of Supplies

Give family a list of necessary and helpful non-equipment supplies (lip balm, eye drops, lotion, incontinence supplies, etc.)

Have equipment and supplies on hand by start date of VSED

## **Death Doula Responsibilities During and After VSED Process**

### **During VSED**

The death doula will be on-call 24/7 to family and caregivers. She sets the energy of love and compassion wherever client is located and makes a home visit each day to do the following:

1. Offer anticipatory guidance to family about what the client is/will experience
2. Offer anticipatory guidance to family about what changes they are/will see in client
3. Assess how client is progressing in VSED process
4. Observe how family members are adjusting, managing, maintaining self-care
5. Assess how caregivers are working, adjusting, collaborating, maintaining self-care
6. Determine how records are being maintained by caregivers
7. Record any new change in medications, input from Hospice, use of resources
8. Send updates to healthcare provider, if desired
9. Invite family to look through notebook anytime and to add comments!
10. Strive to be present for visits from hospice staff, especially Hospice RN visits

### **Following Death**

Offer ceremony for last breath; washing body; leave-taking of the house

Continue to help family assess their emotional and physical health

Discuss realities of grieving

Share grief resources that may be helpful

Refer family members to area support groups and VSED Support Group

### **Final financial responsibilities**

Assess family's ability to engage in business-aspects of the death

Prepare time-sheets based on caregiver log-in sheets

Have stamped envelopes prepared so checks can be immediately mailed

Mail checks or deliver to caregivers

**Final evaluation responsibilities**

Assess family's ability to engage in this final processing

Review what happened and what was helpful

Review what was challenging and how things could have been better

How could the Death Doula been more attuned to the needs of client and family

**Follow-up with caregivers**

Discuss with caregivers (as a group) what went well and what was challenging

Help each caregiver identify their individual strengths and what they'd like to learn & expand

Ask for feedback re DD role and responsibilities; did they feel supported

Have conversation about caregiver self-care and anticipatory grief