

End-of-Life Care: Processing the Experience

*A workbook to support reflection and
integration for end-of-life doulas and
caregivers*

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May these pages remind you that what you experienced is important, that the care you offered made a real difference, and that you don't have to carry any of it alone.

CONTENTS

How to use this workbook — 3

Part One: The time spent with the client

Chapter 1: What is staying with me — 4

Chapter 2: My part in the care of the client — 5

Part Two: The people and places around the death

Chapter 3: Family, Chosen Family, and Absence of Family — 6

Chapter 4: The team — 8

Chapter 5: When the client is in a facility — 10

Part Three: Different experiences of dying

Chapter 6: A short visit or vigil — 11

Chapter 7: When the person chose VSED — 12

Chapter 8: When the person chose medical aid in dying — 15

Chapter 9: Other circumstances — 17

Part Four: After the death

Chapter 10: Grieving someone in our care — 18

Chapter 11: Continuing on with this work — 20

Chapter 12: Integrating the experience into daily life — 21

Part Five: Being with others

Chapter 13: A death circle — 22

Note from Valerie — 25

Helpful resources — 26

How to use this workbook

A client's death can affect us whether we spent months with them or only a few hours. Processing what we experienced is necessary; it helps us understand what affected us and what we may need after the death. Yet there may be little opportunity to talk, and others who shared the care may be unavailable or prefer to process in their way. We may be left to make sense of the experience on our own.

This workbook provides a space for you to process and write at your own pace. Think of it as a journal with prompts to help get you started. If you're new to journaling or struggling to express your feelings, start with whatever comes up first. That's where the prompts may help.

This is about your experience. These pages are for what you valued about the care you gave, as well as what has been difficult to process on your own. This workbook is here to help you feel less alone as you put your thoughts and experiences into words.

Part One: The time spent with the client

Chapter 1: What is staying with me

After someone passes away, a single moment might keep coming back to you over and over. It could be their last breath, last words, the sound of a room, a conversation, or, if not present at their death, the moment you heard they had died. If it feels right, start here.

Some writing prompts

The moment(s) that keep returning to me are...

What I remember about them before the final days is...

Something I saw or heard that has stayed with me is...

When I think about their death, I...

Space to write

Chapter two: My part in the care of the client

The care we give each day can mean a great deal to the client and their family, even when we barely notice all we do. Some parts of caring may have come naturally, while others may have been difficult. We may remember a time that took more from us than we realized, tough questions we wished we could have answered, or a decision we are still thinking about. This chapter is for all of it: what felt natural, what was difficult, and what you offered, without comparing your care to someone else's.

Some writing prompts

During my time with this person, I offered...

A small thing I did that mattered to me was...

I felt most connected to the person when...

I found it hard to be present when...

Something I wish I could say to the person now is...

Space to write

Part Two: The people and places around the death

Chapter 3: Family, Chosen Family, and Absence of Family

When we are introduced into someone's life, we enter relationships that began long before us. Family may include relatives by birth, marriage, or adoption, as well as friends and others the person considers family. Some are close; others may be distant or estranged. We may see people caring with tenderness and love, or in ways we do not immediately understand. We are seeing only part of their history together.

Sometimes no family is present. We may not know whether that absence reflects distance, circumstance, the person's wishes, or something else. Being the only one in the room can affect us deeply, but we cannot assume what the absence means to the person who is dying. This chapter offers a place to reflect on the relationships you witnessed, the people who were not there, and how both affected your care.

You may feel protective of the client and still recognize that you saw only part of the family's experience.

Some writing prompts

What I came to understand about the people close to this person is...

I felt drawn toward one person when...

I noticed myself judging someone when...

That feeling affected how I was with the client by...

A way I saw love expressed, even if it looked different from what I usually see, was...

When no family or chosen family was present, it felt like...

Space to write

Chapter 4: The team

People can share a person's care and still have very different views of the experience. We work different hours, hear different conversations, and have different relationships with the client and family. When there is tension in a team, we may carry it into a visit even when we are not aware of it, or when we are trying not to.

Some writing prompts

A time I felt supported by someone on the team was...

A time I wished someone had checked on me was...

The part of the experience I think others may not have seen is...

A difference between us that was hard for me was...

I noticed team tension affecting the way I was with the client or family when...

Space to write

If I was leading the team

A person leading a team can make room for more than clinical updates about the client. During a long period of care, especially VSED, a regular text, call, or a few minutes in person can give each team member a chance to say how they are doing and whether they need a break. That check-in matters while the person is still alive, not only after their death.

If you were leading the team, write about how you stayed in touch with the people doing the care. Include the personal check-ins that happened, the ones that were missed, and what you would want to offer a team next time.

Space to write

Chapter 5: When the client is in a facility

When someone lives in residential care, assisted living, a skilled nursing facility, or a hospital, the place and its staff become part of the experience of dying. We may see care that moves us. We may also see something that troubles us and stays with us after the person dies. A doula is present for only a portion of the person's life there.

Some writing prompts

What I noticed about the person's daily life in that place was...

An act of care from staff that I remember is...

Something I witnessed there that still troubles me is...

Being an outside caregiver in that setting felt like...

My relationship with the staff affected my time with the person by...

Space to write

Part Three: Different experiences of dying

Chapter 6: A short visit or vigil

A vigil shift may be your only time with someone. You may know very little about their life and still remember the hours clearly. Being with a person briefly can bring its own kind of sadness, particularly when you learn later that they died and you were not with them.

Some writing prompts

When I entered the room, I noticed...

I found my place with this person by...

During our time together, there was a moment when...

When I left, I felt...

Learning that the person had died brought up...

What I remember about this person, even from our short time, is...

Space to write

Chapter 7: When the person chose VSED

VSED, voluntarily stopping eating and drinking, is a choice to end one's life by no longer taking food or fluids. For the people caring for someone through it, this is often a period of many days rather than one defining moment. The person's needs will change. Family members and caregivers will tire at different times. Feelings about the choice can also change as the days go on.

You may have respected the person's decision and still found the process difficult. You may have felt close to the family and, at times, needed distance. You may have wondered what was happening during the hours you were not there. Take time with the different parts of the experience rather than trying to sum it up all at once.

At the beginning

Write about how you came into the person's VSED experience. Include what they shared with you about their wishes and what you felt as the process began. If you joined after it had started, begin with your first day.

Some writing prompts

I understood the person's choice in this way...

When I first arrived, the situation was...

At the beginning, I thought I was prepared for...

What I kept to myself then was...

When there was a question about decisions, I answered...

As the days went on

Choose a day that stood out. Write about what it was like to be with the person that day and what it was like to go home afterward. Then write about how the days added up for you.

Fatigue, closeness, irritation, uncertainty, relief during a break, and concern about the person can all be part of caring.

Some writing prompts

A day I keep remembering began with...

Something I found hard to witness was...

A moment of connection and comfort was...

Going home while the process continued felt like...

As the days went on, I noticed a change in myself...

Family and team during VSED

The length of VSED can bring out different needs in everyone involved. Family members may show their love in different ways. Team members may have very different experiences depending on their shifts. Regular personal check-ins can give people room to voice their needs before they reach the point of exhaustion.

Some writing prompts

What I saw happening among the people close to the client was...

A feeling I had about the family that was hard to admit was...

What I needed from the team during those days was...

A check-in that helped, or one I wish had happened, was...

If I were leading the team, I made room for people to tell me how they were doing by...

After the death

When the days of care end, your response may not be what you thought. Write about the moment you learned the person had died or, if you were with them, the moment they died. Then return to the longer experience. Notice what is still with you from the beginning, the middle, and the end.

Some writing prompts

When the person died, I felt...

What I miss about those days is...

What I am relieved is over is...

What I still want to say to someone who shared this care is...

Space to write

Chapter 8: When the person chose medical aid in dying

Medical aid in dying, or MAiD, can bring a planned date, people preparing to gather, and many conversations before the death. The day itself may move quickly. Once the planning and attention to others have ended, feelings may arise that you had no time to notice while you were there.

You can support a person's choice and still feel unsettled by something from that day. You can feel relief and sadness together, or find that your response differs from the family's or another caregiver's. As with the VSED chapter, write about your experience before, during, and after the death — what you anticipated, what it was like to be there, and how you felt in the days that followed.

Begin with the moment you remember most clearly if that is easier than beginning at the start.

Before and the day

Some writing prompts

What the person told me about their choice was...

How I felt about their choice was...

A feeling I had before the day, whether or not I shared it, was...

What was reassuring or confirming was...

The day of

Some writing prompts

Before the medication was taken, I remember...

When the medication was taken, I remember...

As the day went on, I found myself attending to...

A moment when I noticed my feelings was...

After the day

Some writing prompts

Once I left, I felt...

A feeling that came later was...

The part of the death I have found hardest to talk about is...

Something I want another person who was there to know is...

If I were present for another MAiD death, I would want...

Space to write

Chapter 9: Other circumstances

Some deaths do not follow the path we imagined. A person may die sooner than expected. You may have kept a vigil for many nights, been absent when the death came, or cared for someone with no family at the bedside. A disagreement about care may have occurred in the room. Choose the part of this page that fits your experience.

No family present. Write about what it was like to be with this person and who, if anyone, seemed to know them well.

A long vigil. Write about returning to the room over many shifts and how it felt when the vigil ended.

Conflict around the person. Write about how being near a disagreement affected you and your connection with the person who was dying.

Something else about this death that I need room to write about...

Space to write

Part Four: After the death

Chapter 10: Grieving someone in our care

Feelings can change after a death. You might feel sadness, relief, anger, gratitude, exhaustion, or several of these at once. An unexpected memory may return. An earlier loss may be part of what you are feeling now.

Grief for someone in our care is not always recognized. Others may not know how close we became to the person, or may assume that death is something we are used to because of our work. This is sometimes called *disenfranchised grief*: grief that is real but has little space to be acknowledged. We may share sadness with a family while remaining mindful that they cannot be responsible for helping us through our own grief. That can leave us wondering where to take it.

If you shared this person's care with others, you may want to reflect on what it would be like to speak with them after the death. Would you want to remember the person together, talk about a difficult moment, or simply hear how someone else is doing? You may also prefer to speak with another doula or caregiver who was not involved. There is no single or right/wrong way to grieve.

Return to this page another day. Begin with "Since I last wrote, something has changed..." or "I am still stuck on..."

Some writing prompts

Today, the feeling I notice most is...

A feeling that surprises me is...

A memory that comes up when I am doing something ordinary is...

This death has touched an earlier loss in me by...

A moment when I felt I had to keep my feelings to myself was...

What I wish someone understood about my relationship with this person is...

Something I am having trouble saying aloud is...

What I need from another person right now is...

Space to write

Chapter 11: Continuing on with this work

After this experience, what moments would you want to carry into your next experience? What worked? What didn't work? What or how would you do things differently if you had the chance? What happened may continue to shape the way you care for someone else. You may also want some time away and to simply remember the person outside their death.

Some writing prompts

What I want to remember about this person is...

Something this experience taught me about my own limits is...

A part of the care I felt good about is...

The support I would welcome before doing similar work again is...

I would like to talk with someone about...

How might I carry on a tradition after their death?

If this death continues to affect your sleep, relationships, daily life, or ability to work, please ask someone you trust to sit with you or help you find more support.

Space to write

Chapter 12: Integrating the experience into daily life

The end of care does not always feel like the end of the experience. You may think of the person while doing the laundry, notice that you need more rest, or find yourself in a more contemplative way. Integration can begin by noticing what has stayed with you and what you need as you return to daily life. You do not have to make meaning of everything; just making it meaningful counts.

Some writing prompts

Since this person died, I have noticed a change in my daily life when...

A part of the experience I am still trying to understand is...

Something I have been doing that helps, even a little, is...

I notice I need more of... and less of...

This experience has affected how I relate to others by...

A conversation I would welcome, if the opportunity came, is...

As I return to ordinary life, I would like to remember this person by...

Space to write

Part Five: Being with others

Chapter 12: A death circle

A death circle gives people who shared the care a chance to remember the person and speak about what the experience was like for them. It can happen soon after the death or later, with the care team, the family, or both, if they wish to gather. Some people may want to speak; others may prefer to listen.

Allow enough time for each person to speak without being rushed. One person can guide the circle. Begin with a few moments of quiet, then invite people to remember the client. Let each person finish without interruption, and listen to understand what the experience was like for them.

For a VSED death, allow room for the length of the process: the days that stood out, the repeated care, the personal check-ins people needed, and what it felt like when the days ended.

For a MAiD death, allow room for the preparation, the planned day, and the feelings that may have come after everyone went home. People may have experienced that day differently.

Remembering the person

Invite each person to speak from one of these beginnings or chose your own:

A moment I remember with this person...

Something I came to know about them...

A small act of care I remember from one of us...

What I experienced

What being there was like for me...

A part of the experience I have not talked about...

Something about the family, the setting, or our team that affected me...

What I appreciated about the way we cared for this person...

A time I needed more support from the team...

Closing the circle together

Each person can share something they want the others to remember, or simply pass. The circle is meant to have made time to listen to one another.

Closing your own circle

Whether or not others gather, you may need a way to acknowledge what this death has been like for you. Think about what you want to remember, what has been difficult, and what you may still need. You can return to these questions whenever you are ready.

Writing prompts

Did your care begin with an opening circle? If so, would you want to gather again?

Would the family or others who shared the care want to gather? How might you find out?

What would you want to share or hear from others?

If no one can gather, who might you speak with one to one?

What would you like to remember about this person and the time you spent with them?

What do you need for yourself as you close this workbook?

Space to write

Note from Valerie

I started writing this workbook after a recent VSED death. I was having trouble finding words for what I had experienced, the care I had given, what had been difficult for me, and how I was processing my grief. I needed a way to reflect.

I looked for resources to help me process and integrate my experience after a client's death, but found very few. So I began writing prompts and scenarios drawn from experiences I've had over the years. Creating this workbook helped me put words to my own experience. I hope it gives you a place to reflect on yours, in your own words and in your own time.

Helpful resources

The writing in this book is personal. These resources offer further reading about VSED, MAiD, the doula role, and support among people doing end-of-life work.

End of Life Choices California offers information about VSED, medical aid in dying, and other end-of-life choices.

Website: endoflifechoices.org

Compassion & Choices offers information about VSED for people considering it and those caring for them.

Website: compassionandchoices.org/vsed

Compassion & Choices' California resources provide information about medical aid in dying. Readers elsewhere can look for resources where they live.

California: compassionandchoicesca/in-your-state/california

Other states: compassionandchoices.org/in-your-state

VSED Resources Northwest offers advocacy, support, and resources for those choosing VSED.

Website: vsedresources.com

National End-of-Life Doula Alliance describes the doula's role and ways of connecting with others in this work.

Website: nedaalliance.org

Center to Advance Palliative Care offers resources for care teams dealing with the emotional demands of their work.

Website capc.org/toolkits/health-care-professional-well-being/

A local hospice or grief support organization may also offer a place for caregivers and volunteers to talk after a death.

