



Sharing Your Loved One's End-of-Life Experience

(Family Version)

You had a conversation with your loved one about their ELE, and you wish to share the experience with other family members, friends, or health provider(s). Below are some suggestions and guiding questions that may help you prepare for this conversation.

Getting Permission

ELEs can be very meaningful, but they can also be incredibly private or personal. While your loved one may have chosen to share their ELE with you, it is best to check with them before sharing it with others. Perhaps they would like to share the experience themselves.

Getting Ready – Setting Intentions

Before sharing the ELE, reflect on what your loved one has shared. How does it make you feel? Take the time to process what has happened.

It may also be helpful to understand your intentions for this conversation. Do you want to share how you're feeling or what the ELE was about? Did the ELE bring up other things you would like to discuss with someone other than your loved one? Do you have any particular concerns you want to talk about?

Consider who you want to share with and what you need for this conversation to take place. Do you want to share with individual family members or your family as a group? Do you want to share with your healthcare provider? Your friend? Your faith leader? Where would you feel comfortable talking? Is your loved one okay with you sharing with those individuals?

What do you feel are the important things for others to take away from the ELE?

Understanding Others

After deciding who you're going to share the ELE with, consider what you know about the person. How do you think they would react? In our experience, some caregivers choose to only share with people that they know would be supportive and not ruin the positive experience. Others may choose to go ahead and share regardless of anticipated negative responses.

Sharing this ELE may reveal that you and the person you shared with may disagree. When that happens, you can acknowledge the difference in opinion respectfully without having to feel defensive of what you are feeling. The important thing is to keep open communication. Now finish this sentence:

Even though we do not share the same opinion about ELEs, it is important to me that you know...

Having the ELDV conversation

Here are some suggested ways to initiate the conversation:

- "I was talking to _____, and they were sharing with me some dreams/visions they've been having..."
- "Remember when _____ was really sick, they were seeing _____ . _____ has been having a similar experience. Can I tell you about it please?"
- " _____ had a dream/vision about _____ and it got me thinking. Can we talk about this a little bit more?"

Here are some suggested things to talk about when someone is sharing with you:

- The dream or vision experience content — what happened and when it happened
- How the ELE made your loved one feel
- How the ELE made you feel
- What your loved one has been thinking about or feeling since having the ELE
- Connections to a previous experience of another person you may have known to have ELEs
- Any concerns they may have as a result of ELEs
- How the ELE makes them feel and what they think about it

Remember:

- Exercise patience. You may be excited about your loved one's ELE and have thought a lot about it, but this is the first time the person you are sharing with has heard it. Some people may need a little bit more time to think.
- People may react differently than you to the ELE. This is okay. You may also want to refer your loved one or healthcare provider to the ELE resources on this website. Some people may find it helpful to know the research that has been conducted on this subject matter.
- You ultimately know how the experience was for you and what it meant for you and your loved one. Remember this no matter how others react when you share with them.

This tool is provided courtesy of Hospice & Palliative Care Buffalo.

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