Creating and Leading a Village Share Interest Group (SIG) on Aging, Death, and Dying

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I started the BMAV Aging Well SIG (shared interest group) in February 2017, five years ago.

I called it the Aging, Death, and Dying SIG, but after a couple of years, the BMAV Board suggested the name might be off-putting to potential new BMAV members (because of the words "death and dying"), so we changed the name to the Aging Well SIG.

The Aging Well SIG met monthly at my house for the first three years. I invited outside speakers to talk about advance directives, decluttering, hospice care, keeping fit, death doulas, how to be a superager, reinventing retirement, cremation versus green burials, leaving a legacy, finding meaning in old age, dying with dignity, and many other topics relating to aging well and end-of-life issues. The meetings were well attended, and the Aging Well SIG soon became the most popular SIG in our village.

To encourage people to attend, I would write personal emails to virtually all our members, warmly inviting them to attend. I'm sure this individual attention helped to bolster the audience numbers.

Another thing my wife Gail and I did was to offer hot cider, wine, and small eats to people who came. This helped to give the event a social and fun atmosphere. People enjoyed coming to the meetings at our house because they were enjoyable (even though I asked them to take off their shoes before coming in!)

To build more community spirit, I sent out a weekly e-newsletter to SIG members about aging with quotes from scientists, authors, and poets, as well as humorous material. This has evolved into a monthly e-newsletter to members in which I promote the upcoming Aging Well SIG meeting, give my reflections on some aspect of death and dying, and include a carefully curated selection of humorous cartoons relating to aging, death, and dying.

When the pandemic hit in March 2020, we began to meet by Zoom. Instead of having outside speakers, I decided to pose questions to the group so we could get to know each other better. The questions included:

- What are the most important lessons you learned from your parents or grandparents?
- What are some intriguing aspects of your family history?
- What brings you joy?
- What are the best ways to age successfully?

- What advice would you give the next generation about dealing with old age?
- What are the silver linings for older people in the pandemic?
- What are some of your most unusual life experiences?
- What are your favorite holiday traditions?
- When do you feel most alive?
- What are your most treasured memories?

Typically over 30 members would participate in these discussions. I asked people to write down their answers ahead of the meeting because I found this significantly increased the quality of the Zoom discussions. I was constantly delighted by the diversity and compelling nature of what members wrote and discussed, which reflected the fascinating life experiences of our members.

After each meeting, I collected and edited all the contributions and created a report (usually about ten pages long) which I then shared with everyone (so even those who couldn't get to the Zoom meeting could enjoy what people wrote). Our executive director, Elizabeth Haile, would post the report on the BMAV website, where only village members could read it (for privacy reasons).

About six months ago, I decided to refocus the Aging Well SIG on aging and end-of-life issues. I sent the following email on October 14, 2021, to BMAV members

Dear friends in BMAV's Aging Well SIG,

This email might be the most unusual invitation you have received from another village member.

I would be honored if you would take one hour this coming Sunday (October 17) at 4 pm to join me on Zoom and engage in a conversation about death and dying and, more specifically, how to achieve a good death.

I warmly welcome those who want to come to listen and not say anything.

This will not be a morbid conversation but a very human one where we consider what we want, both in life and during its closure.

Through sharing our thoughts and feelings on this subject, we can more readily confront our fears, talk more openly, and forge a deeper understanding and connection with our loved ones.

The reason to have this conversation is simple: our lives will be better, and so will the lives of our loved ones.

Our reluctance to talk about death and dying can cause us all manner of pain. Moreover, the denial of death leads us to postpone doing things we know we need to do.

As I say, we will meet on Sunday at 4 pm by Zoom, and aim to end by 5 pm.

Talking about death and dying may seem like a challenging conversation, but it can be constructive and valuable (and not dour and gloomy).

So many people die badly -- in fear, in pain, hooked up to tubes and ventilators, being overtreated, intubated, and in an ICU instead of being surrounded by loved ones at home.

We can do much better, but to do better (i.e., die peacefully, gently, painlessly, and with life tasks completed) requires planning and forethought. Unfortunately, it does not happen "naturally" (that is, without planning) these days.

Would you please let me know if you'd like to join this conversation on October 17? Simply showing up on Sunday at 4 pm is excellent, too. You don't have to let me know in advance. Elizabeth will send out the Zoom link on Sunday morning.

I'm delighted that six BMAV members have already decided to come.

We'll consider and discuss questions like:

- a. What are the elements of a good death?
- b. What would an ideal end of life be for you?
- c. On a scale of 1 to 5, where do you fall on this continuum? "1" is "let me die without medical intervention." And "5" is "don't give up on me no matter what, try any proven and unproven intervention possible."
- d. Would you prefer to die at home or in a hospital if there were a choice?
- e. Could a loved one correctly describe how you'd like to be treated in the case of a terminal illness?
- f. Is there someone you trust whom you've appointed to advocate on your behalf when the time is near?
- g. Have you completed any of the following: written a living will, appointed a healthcare power of attorney, or completed an advance directive?
- h. What are some of the tasks we might consider completing before dying? Examples might include telling a family member you love them, apologizing to someone you hurt, and spending time with loved ones.
- i. What do family members need to do immediately after death?
- j. What do you want done with your body?

Please let me know if you would like to join this Zoom meeting on Sunday, October 17 at 4 pm. As I say, coming to listen is fine.

Thank you.

Best, Chris

The meeting that followed the above email led to an excellent discussion of people's concerns in the area of death and dying. Since then, we have held the following meetings:

- A couple of our members talked about the dying and deaths of loved ones they had experienced.
- Author and journalist Steven Petrow talked about his latest book on aging well.
- I gave a workshop on writing a legacy letter (also called an ethical will) and a presentation on how to age well.

I am planning upcoming meetings on the Final Exit Network, the vexing challenges of dementia, death cleaning, working with a death doula, and the best way to plan a funeral.

In terms of our future plans, I am planning on a more systematic examination of the following topics:

- 1. **"The conversation."** Studies have demonstrated that when people discuss their goals and wishes with loved ones and their doctors for the end of their lives, the outcomes are far better. They suffer less, are more physically capable, and are better able to interact with others. They enroll in hospice sooner, but they do not die sooner. On average, they live longer. The goal is to give members the tools they need and the courage to have "the conversation" with their families and doctors about the death they want.
- 2. Live well so as to die well. The evidence is overwhelming that when people live well, feel fulfilled and purposeful, have rich and loving relationships, and lead meaningful lives, they die with less angst, fear, and suffering.
- 3. **Complete an advance directive, including a dementia coda.** Research shows that when people do this, they are more likely to have a good death and die peacefully. So the goal is to help members complete an advance directive, including a dementia coda.
- 4. Write a memoir as a legacy project. We will continue to offer workshops on memoirwriting to help people make progress with telling their stories.
- 5. Compose an "ethical will" (sometimes called a "legacy letter"). An ethical will is a letter or statement created for heirs that communicates feelings, intentions, values, perspectives, or essential information seen as too important to be left unsaid or that could otherwise get lost over time. It will likely include expressions of love and gratitude, perspectives on what is important in life, an articulation of values and your vision for the future, lessons learned in life, and messages of support and encouragement.
- 6. Update will and estate planning documents. For example, we want to make sure members' accounts name the intended beneficiaries to simplify the administration of their estates.
- 7. **Declutter and "death clean" our homes** so that our children are not left with an overwhelming and insuperable mess to clean up after we die. For example, it's a good idea to find mementos and letters that are precious and prepare a guide for our heirs so that they can find them, appreciate them, and hold on to them.
- 8. Work with a death doula (sometimes called an end-of-life doula or midwife). We will educate our members (for example, by speakers, videos, articles, etc.) about death doulas. In addition, we will search for death doulas, interview them, and keep an updated list, so we have help available for our members as the need arises.

- 9. Explore the right to die. This issue is controversial, so we must be sensitive to everyone's views. The essential idea is to help those who want advice on controlling when and where they will die. Maryland has not yet passed a "medical aid in dying" bill, although it has become close to doing so.
- 10. **Provide care for caregivers.** Caregivers are engaged in vitally important work. Yet, they often experience exhausting and grinding schedules, as well as burnout. Our members who are caregivers need help in getting the self-care that they need to endure.
- 11. Work with hospice and take advantage of what hospice offers. We plan to bring in expert speakers and take other actions so our members can become more familiar with the concept of hospice and how it could help them when the time comes.
- 12. Explore and encourage green burials and cleaner, less-polluting ways of body disposal.

Closely allied to the Aging Well SIG's activities are the three-part workshops I give on behalf of BMAV on leading a meaningful and successful life and on how to write a memoir.

The Aging Well SIG is valuable because of the learning that occurs, especially around breaking the taboo on conversations about death and dying. But, more importantly, the Aging Well group helps members get to know each other and bond.

The group is as much about community and connecting as it is about death and dying. By coming together in monthly meetings where members discuss matters that are important to each of us, members make a genuine connection to others and a sense of meaning, togetherness, and community. It truly exemplifies the goals of the village movement.

Aging Well SIG talk to WAVE June 13 2022