

Clearly Defined: Matching Our Terminology to Our Intentions

By Lee Webster

Many of us who are committed to the concept of family-led after-death care realize that there has been growing confusion over what we call ourselves, and what the public is hearing and understanding. This concern has come to the attention of the NHFA from several directions, suggesting that, as the umbrella organization in the US, we take the lead in grappling with defining the many-faceted aspects of the vocation of end of life, dying, and after-death care.

What we call ourselves is both a reflection of our own self-worth and a way of advertising to the world what we offer. In a field as “new” and unknown as this, at least to those who have no memory of the ancient practice of caring for our own dead without professional assistance, presenting a clear, consistent message is crucial for many reasons.

As the pioneers who are shaping the national conversation about after-death care, it is up to us to unite in spirit and intention. Our words and the terms we use to describe ourselves and what we offer matter. We must find common terminology for what we do in order to be understood by those we seek to serve.

Getting Started

While we understood that no one term would be satisfying to all of our constituents who provide services, our first and foremost goal was to meet the needs of the public. A public with no relationship to a concept will not respond to shocking or uncomfortable terms, leaving our providers without an audience. In meeting the needs of our members, it behooves us to bring our terms into alignment, if for no other reason than to ensure our own future success.

We began by polling our members, both through a formal online survey and by calling and writing to a large variety of involved persons. The results were unambiguous, giving us sure footing in developing an understanding of what end of life care advocates of all interests call themselves and how they see their involvement in the big picture. We also felt strongly that it was up to us to evaluate the effectiveness of current terms and imagine a fresh outlook.

Survey Results

The thirty people who responded met the criteria for survey results relevance. The following charts reflect the results of the study. In addition, we reached out to individuals by phone and email to comment and give recommendations.

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Asked to choose one definition that best described a person who helps a family with after-death care of the body, 76.6% selected home funeral guide, with 13.3% selecting death midwife.

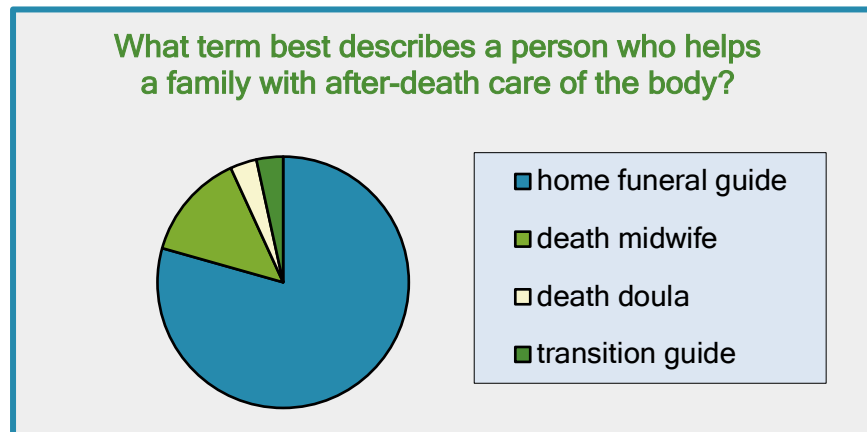


Figure 1
Home Funeral Guide

When asked what best describes a person who works with a dying person to help facilitate a smooth or conscious death, 63.3% chose death midwife, with death doula a far second at 16.6%. Though death midwife is used commonly in some parts of the country, many people felt strongly that the early term Transition Guide might be better recognized, less threatening, and more readily accepted in public and medical spheres.

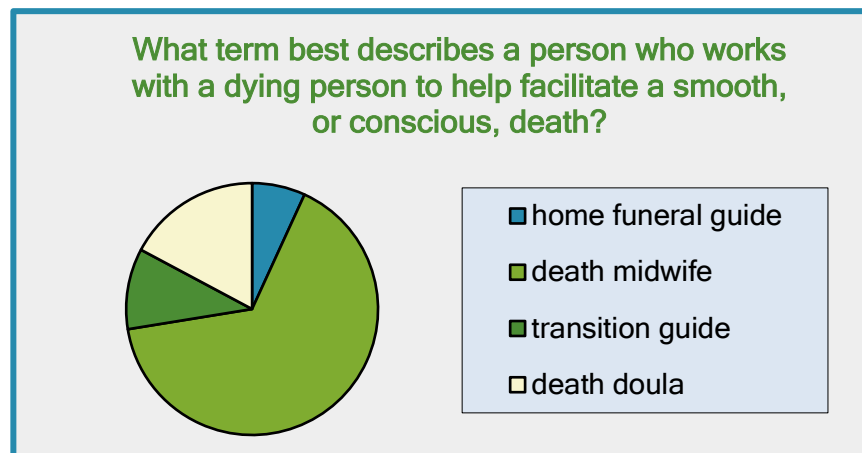
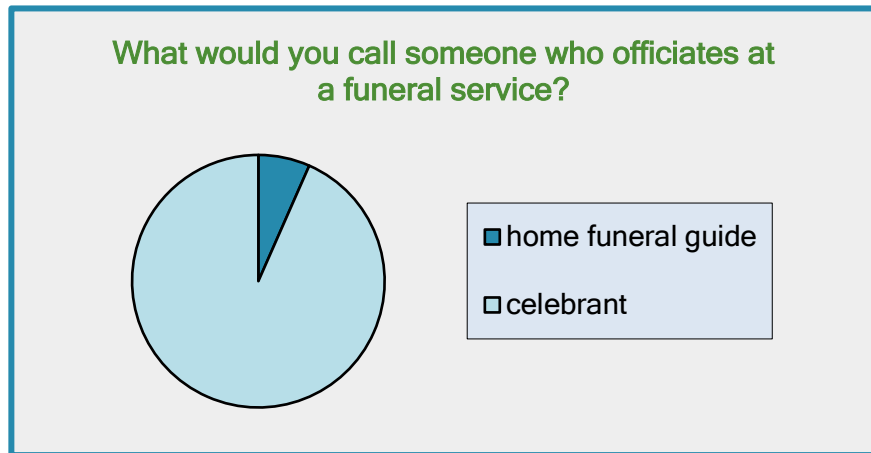


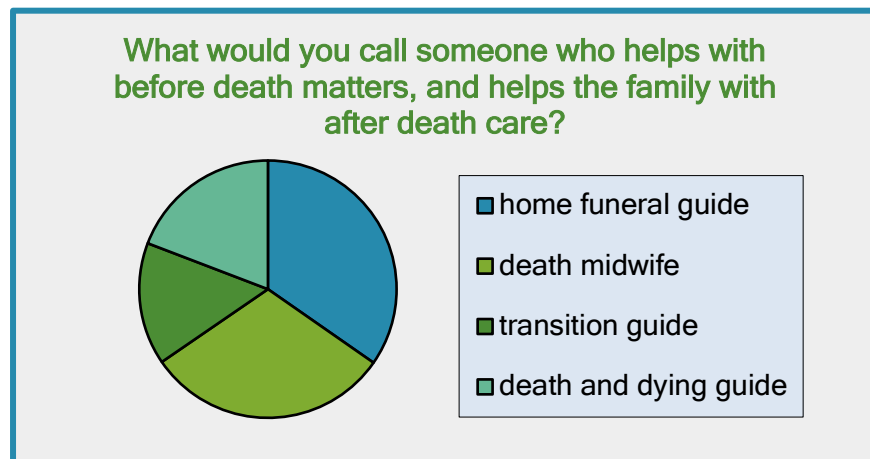
Figure 2
End of Life Transition Guide

The term celebrant was the easy choice for someone who officiates at a funeral service at 93.3%.



*Figure 3
Celebrant*

The hardest term to determine was for when one both aids the dying person and stays to help the family with after-death body care. Home funeral guides edged out death midwives at 30% and 26.6% respectively, but death and dying guide and transition guide were still in the running at 16.6% and 13.3%. Due to the strong and relatively even split between the terms, many members voiced that a fresh, more universal term might better serve to describe someone who provides a full spectrum of death and dying services.



*Figure 4
Death and Dying Guide*

Defining the Problem

Results of the survey, along with many and varied discussions, helped answer some questions while bringing up new trains of thought. As we explored, more terms were discovered that individuals were using to satisfy their perceptions of their own unique offerings. Several concerns were identified through this process.

Establishing Credibility

There is a lack of consistency in terminology distinguishing those who provide before and after-death care. This may create a perception from those we seek to serve that we are disorganized, unprofessional, or on the fringe. Since people are trying to wrap their heads around new concepts, having multiple, hazy usage may make it even harder for the public to envision and adopt these new ways in lieu of conventional practices that rely on a professional industry that has a well-established language and marketing brand.

Creating Our Own Brand

Without a clear understanding of what end of life educators offer based on their title, the people we are trying to reach will not know who or what to ask for if they want a specific service. Clearly separating what we call ourselves when providing before or after-death care offerings is one step toward clarity. Someone who provides a fuller range of services also needs a term that is easily recognizable.

For those trying to raise awareness about their services, undefined or misunderstood terms make it difficult to help educate and inform the public. This includes having a thoughtful, coherent and consistent reply for members of the media who are in a position to expand our reach. And since the internet is one of our major tools in getting the word out, search engines must be able to find us easily with a few succinct key words.

Our own members in this fast-growing movement are clamoring for consistent and understandable terminology for 'what we do'. Clear role definitions will inspire confidence by reflecting our ability to market ourselves effectively and deliver on our promises of quality care in whatever area we feel we are qualified.

Choosing Wisely

So what was the criteria for choosing titles that adequately convey a consistent message and have a chance of becoming instantly recognizable? We developed the following set of considerations to guide us:

- Titles must sound mainstream, be non-threatening, and be easy to understand.
- Descriptors need to get the idea across in everyday language.
- Terminology needs to easily integrate into a medical environment and language lexicon.

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- Terms must translate well across regional cultures and generations, faiths and worldviews.

The role of the NHFA is to educate, not regulate, but it is also to provide leadership. We recognize that we will never reach 100% agreement about what terms to use. What we do agree on is that this proposal does not require others to use a specific term – we simply define the terminology that the National Home Funeral Alliance will be using going forward, and encourage our members to do so as well. This approach also gives us the freedom to grow, change and redefine as this movement matures.

Terms and Definitions for End of Life Service Providers

After careful consideration of the data and research from a wide variety of resources and individuals, the NHFA has chosen to employ the following terms:

Death and Dying Guide

One who works with the dying person and family to accompany them throughout the death experience, facilitates family-led after-death home or facility care, and may attend to spiritual and ceremonial needs as requested

End-of-Life Guide

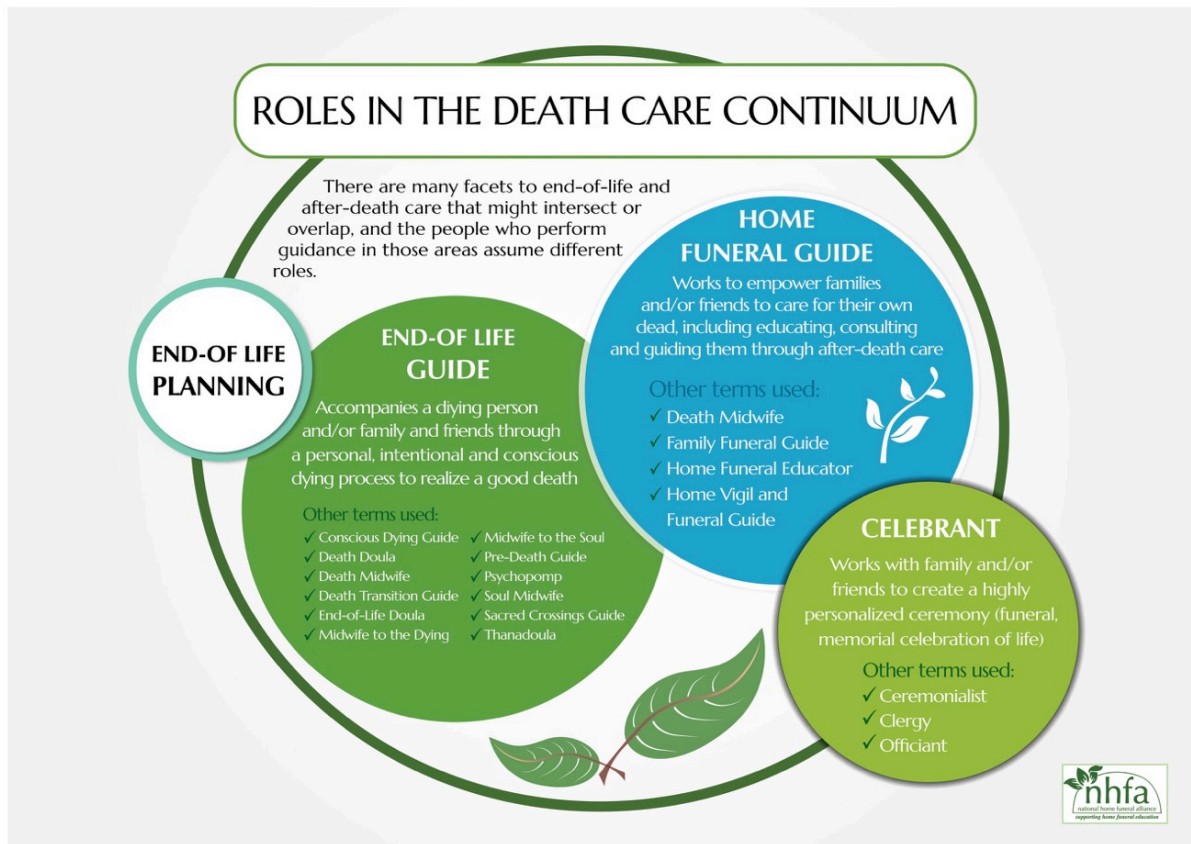
One who accompanies a dying person and/or family and friends through a personal, intentional, and conscious dying process to achieve a conscious death

Home Funeral Guide

One who empowers families and/or friends to care for their own dead, including educating, consulting, and guiding them through after-death care

Celebrant

One who works with family and/or friends to co-create a highly customized ceremony (for funeral, memorial, celebration of life)



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Figure 5
Death and Dying Terminology Graphic

Terms and Definitions for Advocates and Educators

Home Funeral Advocate, Home Funeral Educator

While not included in the lexicon of end of life care providers who educate families through consulting, coaching, demonstration and myriad other means *privately*, home funeral advocates/educators do vitally important work by educating *publicly* through presentations, workshops, local tabling opportunities, and other events aimed at developing a global understanding of the home funeral movement.

Glossary of Related Funeral and Disposition Terms

Home Vigil — (also known as *lying in honor*, *visitation*) the period between death and final disposition that may include family and community visitation in the home or place of rest for the purpose of acknowledging the death, supporting the family, and validating grief while offering the opportunity for private goodbyes

Community Care Group — often called *threshold groups* or *threshold circles*, community care groups are trained to care for and support others within their group or the larger community during the home funeral period (death to final disposition)

Conventional Burial — final disposition by full body burial in the earth in a casket or, which is usually buried in a concrete, plastic or fiberglass vault for purposes of maintenance of the lawn cemetery

Crematory — (aka *crematorium*, *cremator* or *retort*) a place where cremation takes place

Green Funeral — after-death care that employs environmentally-responsible practices, that may include organic, noninvasive preservation techniques of the body; use of locally sourced materials such as native pine caskets or hand sewn shrouds made by regional craftspeople; wildflowers; natural burial; or other regional opportunities or practices

Green or Natural Burial — final disposition by full body burial in a hybrid cemetery, natural or conservation burial ground or preserve that allows decomposition processes to occur naturally; eschews embalming fluid, concrete or plastic vaults, rainforest wood and metal caskets, pesticide or herbicide use

Home Burial — final disposition by full body burial in the earth on private family property

Disposition — the final step in after-death care where the remains of the deceased are either buried in the ground or entered into a cremation retort (*legal place of disposition in a cremation is the crematory*)

Home Funeral — family or community-directed after-death care from the time of death through final disposition; may occur in home or other setting; may or may not include professional assistance; may or may not include a vigil, ceremony, or memorial service

Interment — the act of burying a dead person

Inurnment — the act of placing cremated remains in an urn; may also refer to placing the urn in a location such as the ground or in an above ground columbarium

Scattering — when cremated remains are released to the air, sea or earth without burial

Threshold Choir — chapter of a national non-profit organization choir that sing to people on the threshold of dying, to soothe and reassure the dying, their family, friends and caregivers

Summary

There is clear evidence of rapid growth of the home funeral movement throughout the US since the inception of the National Home Funeral Alliance in 2010. In a seemingly brief period of time, a culture that encourages open conversation and engagement with death has emerged, both adding to the strength of the movement and illuminating a need for consistency and clarity in the words we use and the ways we identify ourselves to one another and to the public.

It is the fervent hope of the NHFA that its members embrace a changing lexicon of terms early in the growth of the movement that best reflect our collective intentions. Failing to come to agreement on this issue may lead to fracturing of this courageous yet fledgling culture. We urge you to adopt the terminology that best describes your services and intentions within the framework of this united front.

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Ways You Can Support This Initiative

Find and use opportunities to explain the terms as part of your educational mission.

When people wonder what a term of any kind means, it is your opportunity to explain in clear, positive language more about end of life and home funeral care in ways that resonate with you. Family-centered, peaceful, meaningful, noninvasive, home-based, compassionate, privilege, responsibility, taking charge, last act of love, home vigil are all words we often use to describe why it matters to keep a loved one home for the period and before final disposition. Find yours and make it your consistent message.

Update your own websites, brochures, documents, etc., to include definitions.

When plugging in your choice of terms, you might consider adding a brief derivative of the definition. For instance, Home Funeral Guide (*one who educates, guides or consults with families*). Feel free to lift the terms above and post them to your website or printed materials, adding, “As defined by the National Home Funeral Alliance, homefuneralalliance.org”.

Blog about the terms

Use FaceBook, Twitter, and blogs, anywhere you frequent to find ways to highlight the terms and explain them. Every message helps, especially when it comes from your heart. In a cultural movement such as this, everything you do and say has value, and your support of consistency will be heard, your actions seen.