



## Review Article

### Planning for Death

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#### Abstract

Death and birth are inevitable events in all human lives. Although it is common practice to plan for birth, death is something that is rarely planned for in the hospice environment. The development of a death plan provides patients with the opportunity to ensure that their wishes are followed throughout the dying process. In a three-part series of articles, death planning and supportive services during and after the death process will be presented. In our first article, development of a death plan will be presented. In the second article, supportive services during the dying process will be discussed. The final article of this series will focus upon supportive services that may be provided to caregivers of the deceased after death.

**Keywords:** Death planning; Hospice; Supportive services

#### Part One: Planning for Death

##### Introduction

Birth and death are two inevitable events that every human being is guaranteed to experience in a lifetime. Throughout the birth process, parents are encouraged to create a birth plan to help ensure that their desires throughout the labor and delivery process are known. Why do we not approach death with the same reverence as birth? Should we not also establish a plan designed to outline our desires throughout the death and dying process? While there are extensive hospice interventions designed to address a patient's pain management, it is also important to fully address the patient's supportive needs and desires. Within the framework of this three-part series of articles, the following will be presented:

- Part one: Planning for death
- Part two: The Sherpa of death: support services in the dying process

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- Part three: What happens after death? How do we better support caregivers that have experienced the death of a loved one?

#### On death and dying

The mere mention of the word death invokes a myriad of emotions in people. For many, death is something to be feared. In fact, some cultures go so far as to forbid the mention of the word death or the name of the deceased person after death [1]. In the western culture, the fear of death is prevalent enough to warrant its own term: Thanatophobia or death anxiety [2]. The term thanatophobia was first coined by Sigmund Freud in 1915 in thoughts for the time on war and death [2]. Freud believed the fear of death to be tied to the unconscious desire for immortality [2]. When confronted with the concept of mortality, the individual experiences disruption to the ego sense of self-identity and anxiety arises [2]. A great deal of research has been conducted on thanatophobia and some researchers have even theorized that it is the innate fear of death that guides many human motives and actions throughout life. Greenberg, Pyszynski, and Solomon [3] first presented the terror management theory which postulates that many human actions are guided by an innate fear of death itself. The theory further hypothesizes that humans initially seek meaning in life predominantly out of the awareness of mortality [3].

The next question then becomes, why would one want to prepare for something so terrifying? Research suggests that what we fear most may not be so bad after all. In fact, studies involving patients near death have found the feeling of those facing mortality were predominantly positive versus negative [4]. While the public narrative of death may be negative, the personal experience of the dying process was found to be quite positive in numerous research studies [4].

#### Development of a death plan

Although planning for the dying process may sound morbid initially, patients and families that have been allowed to plan for death have expressed immense gratitude for being able to make such decisions [4]. Planning for the dying process allows patients and their families to process feelings of grief and closure [5]. Secondly, the creation of a death plan allows patients to clearly verbalize their desires regarding the dying process before they find themselves unable to make such decisions [6]. Thirdly, the creation of a death care plan gives family members the opportunity to verbalize their desires ahead of time so that they fully focus upon their dying loved one. This becomes particularly important when the patient is in a care facility or hospital so that the appropriate accommodations may be made to support the patient and their family. This article is designed to address supportive services that may be provided to end of life patients and their families. Pain management has not been formally addressed within the framework of this article, as a separate pain management plan should be utilized to adequately address the patient's needs.

Jessica Hanson, a nurse and national spokesperson of project 660, has been educating health care professionals across the US about how to orchestrate a better death narrative [7]. After the tragic death of

her toddler aged son, Jessica became passionate about assisting families to create a death story that allows them to grieve and heal the loss of their loved one. The most recent National Institute for Health and Care improvement (NICE) guidelines for end of life care stress the importance of shared decision-making and the development of an individualized care plan to meet the patient's needs at the end of life [8]. Additionally, health care workers report increased satisfaction when caregivers have been allowed to proactively participate in the dying process [7]. In her presentation, "Orchestrating Death", Hanson [7] discusses the need to allow family members to take charge of the death. Hanson [7] outlined five major stages to orchestrating a better death including:

1. Invite
2. Saturate
3. Empower
4. Prepare
5. Heal

Inviting loved ones into the death narrative is crucial [8]. This allows family members to become active participants in the death process. For example, family members may find themselves escorted out of the room during code situations or after a patient has died. Sadly, this does not allow family members to adequately grieve the loss of their loved one. More importantly, by doing so, we rob family members of the opportunity to say goodbye and experience full closure within the death process. Allowing family members to be a part of the death process may be as simple as allowing a family member to hold the foot of their loved one during code situations or to hold their loved one after death.

Hanson [7] refers to saturate the senses as a means of allowing caregivers to fully experience the death of their loved one. Through the engagement of the five senses (sight, hearing, taste, smell, and touch), humans formulate memories of events [9]. Galizio [9] suggested that olfaction may be closely tied to memory formation. In many cultures, the practice of bathing and dressing of the body after death is a responsibility reserved for the loved ones. By allowing family members to engage the five senses and experience the death process, we allow them to fully grieve and recognize the death.

It is equally important to empower family members to actively participate in the death process. Simple acts like allowing a family member to lay next to the body of their loved one and hold them or brush the hair of their loved one allow them to orchestrate a better death story. In the hospice environment, we have the unique opportunity to fully empower patients and family members to direct their death story. For example, patients may want to wear a favorite dress or suit at the time of their death. Patients may want to listen to a certain type of music while dying. Family members may want to be left alone with their deceased loved one for a period of time after death. They may desire to hold or dress their loved one.

Opening the door to a discussion on death planning allows patients and their families to make these decisions and to become an actor in their death story and not simply an observer. As health care providers, we may open this discussion by allowing patients and their families to formulate a death plan. Just as we prepare for the labor and delivery process for nine months, we should also prepare for death. This requires health care workers to essentially overcome their own thanatophobia and to initiate the discussion of death and dying. It is crucial

that patients and family members be allowed to write their own death story. In this sense, patients and families become the writer, director, and lead role in their death story versus the observer. Langton-Gilks [10] speaks to the importance of creating a plan for death and dying well in advance that allows patients and their families to have their wishes honored in the death process. Additionally, the author discusses how she was able to fully grieve the loss of her son through the attainment of his wishes in the last three months of life [10]. Dr. Harvey Chochinov [11] and the Dignity in Care project highlight the importance of patient involvement in decision making as a key dignity-conserving measure [11]. The author further discusses how health care workers may positively impact the patient experience through good communication and open dialogue [11]. Development of a death plan is a means of facilitating communication and beginning the dialogue around death and dying. A sample death plan has been included in Appendix 1 with questions designed to initiate a discussion of death with patients and their caregivers. The sample death plan presented in Appendix 1 of this work is meant to provide a means of opening the discussion of death planning. While there are many other questions that may be included in the death plan, it should be individualized to the patient and caregiver's needs.

For some individuals, it may be important to tell the death story. For others, this may take the form of writing about the death in a story format. Others may prefer to express their grief through artistic media such as painting or drawing. One woman reported that she went home and baked several pies after the death of her mother as a tribute to her because her mother was such a wonderful cook. Regardless of the methodology, we must encourage family members of the deceased to open the door to the discussion of death for them to fully experience closure.

The door to healing may be opened through the creation of a death story. In the beautiful Mexican tradition of *dia de muertos* (Day of the Dead), the deceased are celebrated once a year in hopes of supporting their loved one's spiritual journey. During these fiestas, the deceased are given offerings of their favorite foods, flowers, and beverages. In many ways, the *dia de muertos* represents a beautiful death narrative for caregivers of the deceased. The deceased are remembered and celebrated in the lives of their loved ones. In so doing, the process of death may be accepted, and healing may be fully embraced.

In part two of this series, guidance through the death process will be discussed. We will review the important role that medical providers and staff play throughout the death process. As such, the importance of support systems for patients and family members in the hospice environment will be discussed in greater detail. A birth doula is a person trained specifically to assist a birthing mother and their family before, during, and after birth [12]. In like manner, a death doula could be utilized to assist patients at the end of life before, during and after death. The role of the death doula and other mechanisms designed to support patients throughout the dying process will be presented. Additionally, the concept of the care provider as a death midwife will be reviewed. It is important to open a framework for a new death narrative ushered in by acceptance and not fear.

## Conclusion

In conclusion, death is an inevitable part of the human existence. Planning for death provides patients and their loved ones with the unique opportunity to ensure that their wishes are realized before,

during and after death. Death planning allows patients to become the director of their death story. Patients that have been given the opportunity to orchestrate their death stories have reported higher levels of comfort with the dying process [4]. Family members report increased sense of closure and comfort with the death of their loved one when allowed participating in the death process [7]. In the next article in this three-part series entitled, “The Sherpa of death”, we will discuss support services that may be provided to patients and their families during the dying process.

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## Appendix

### Sample death plan

A sample death plan has been included below. Questions included

in the sample death plan have been classified into the following categories: Patient questions, questions for caregivers, and any special consideration that may need to be made based upon the given responses [13].

Questions for Patients	Questions for Caregiver after Death	Special Requirements
Would you like to listen to a certain type of music during the dying process?	Would you like to lay next to your loved one after their death?	
Is there something special that you would like to wear when you are dying?	Do you want to hold your loved one in your lap after their death?	
What would you like to have others do for you when you are unable to do so?	Would you like to dress your loved one after their death?	
How would you like to have the lighting in your room?	Do you want to take a picture of your loved one after their death?	
What would you like to have around you in your room? (family photos, photos of pets, flowers, a special piece of artwork, etc..)	Do you not want to be present during your loved one’s death?	
What gives you comfort? (blankets, pillows, having your hand held, having your hair brushed, etc..)	Would you like to have a gathering with other family members in the room with your loved one after they have died?	
Would you like to have a party before your death to talk about your life and to say goodbye to the people that you loved?	Do you want to have a grief counselor available to you immediately after death?	
Is it important for you to have your pet with you while you are dying?	Do you want to gather your loved one’s belongings, or would you prefer that someone else do this for you?	
Where would you like to die?	Do you feel prepared for what to expect in the dying process? If not, what would help you to feel more comfortable?	
Is there something special that you would like to experience before your death?	Is there something special that you would really like to experience with your loved one before death?	

Appendix 1: Sample Death Plan Questioner.