

# Bury me in white, and other advance care planning

Making end-of-life decisions before they're necessary helps our loved ones to have the information they need as they make decisions for us



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**PLANNING FOR CARE** at the end of our lives due to old age, illness, or accident is often something overlooked until it is necessary. Unless death comes suddenly, many end-of-life decisions are made while coping with the crushing grief that comes with facing the imminent loss of a beloved family member.

As believers, we can face death with a deep and peaceful hope. We can anticipate seeing our Lord Jesus face to face and trading our earthly bodies made of dust for our heavenly bodies that will never wear out, get sick, hurt, break down, or die. Jesus promised to never leave us—ever, not in sickness or death—but assured us that He has gone to prepare a place for us (John 14:2-3). Though death is still an enemy, it has been defeated. Jesus is coming again for us, His bride, just as He promised: “I will come again and will take you to myself, that where I am you may be also” (John 14:3). In the tenderness of saying goodbye,

we must remind ourselves of this truth so that we may feel the peace of God that passes understanding, which guards our hearts and minds in Christ Jesus, especially in those last months, weeks, or days (Philippians 4:7).

We typically approach end-of-life care by thinking about medical realities before spiritual ones. But it is our theology that determines how we live and how we die, how we should use medicine, and when we can decline further treatment, doing “medicine in a theological context rather than doing theology in a medical context.”<sup>1</sup>

End-of-life care thus begins in the day-to-day life of the Christian community and not simply within the hustle and bustle and technical expertise of the medical ward at the end of our lives. End-of-life care begins where we are right now. As we concentrate on our spiritual formation in the present time, we begin to prepare ourselves for that time when suffering and pain form the tragic garland that crowns our final experience.<sup>2</sup>

Those spiritual considerations give shape to practical consid-

erations, which allow us to give guidance to our loved ones as they make decisions for our care or as they give us guidance for their care. The following recommendations may help you organize your thoughts and make your wishes known. Doing so will bless those overseeing your care.

## Do first

Staying organized is always helpful in bringing peace of mind to all concerned. Contacts, important policies, bank accounts, assets, and prepaid arrangements for funeral and burial should be collected into a notebook as they become part of life.

Start now. This is one task that you will not want your loved ones to have to manage later when they are in the middle of making end-of-life decisions or when you face a difficult diagnosis.

Three-ring binders are great, with a table of contents to note which divided section holds what. This should also include a list of contacts to be notified in case of emergency or death, subscriptions for magazines, newspapers, account numbers and passwords, workplace contacts, pet care information, and the name of the



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attorney who holds your will (if you have one).

### **You first**

Before you attempt to help someone else make their plans for end-of-life care, set aside time to think through your own wishes and answers to the questions provided in these resources. Not only will this make you more familiar with the decisions that need to be made, you will also find yourself more tender-hearted toward those you wish to assist.

### **Questions to ask**

Critical medical decisions are often made in a rush at the end of our lives by people who barely know us. Discussing our wishes with

loved ones ahead of time provides the best opportunity for the care we desire. Some decisions are technical, and some are not. The following questions are good to ask yourself and/or your loved ones when beginning an end-of-life plan:

- Who will be your health care advocate?
- What are the most important things to you about your care?
- If your heart stops, do you want cardiopulmonary resuscitation (CPR)?
- Under what circumstances would you want a feeding tube and for how long?
- Under what circumstances

would you agree to be put on a ventilator?

- Do you want to be an organ donor?
- Would you like to be at home for your last weeks or days?
- How would you like to spend your last weeks or days?
- Who do you want with you if you are in critical condition?
- What will your plans for burial and funeral be?

### **Naming your advocate**

Choosing your health care advo-

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cate will be the most important decision you make. Your health care advocate or surrogate will be responsible for carrying out your decisions related to these situations, so it's important to spend some time discussing them. All the wishes you have can be insisted upon by your advocate when you are unable to advocate for yourself. This is not the person you designate to care for your personal effects and belongings, such as your home, car, bank account, and pets. That's your "power of attorney." It is best to select two different people to handle health care decisions and financial affairs. Choose one for each responsibility. For example, asking two or more siblings to share a responsibility will complicate your care and their relationship.

### **Do you want a DNR?**

A "do-not-resuscitate" (DNR) or "do not attempt resuscitation" (DNAR) order directs your care should your heart stop for any reason. This decision begins a "conveyor belt"<sup>3</sup> of more decisions to be made. If CPR is successful, and you decide to be "full code" and have everything possible done for your condition, you will likely be placed in an intensive care unit. Depending on your circumstances and location, you may wish to be given all help available to keep you breathing and keep your heart beating.

However, if you instead decide that you wish for your family and physicians to "let you go" if you go into cardiac arrest, you will need to sign a DNR order.

It will take courage to ask your doctor to be clear with you about

## **You can begin end-of-life care right now and bless those who will be overseeing that care.**

what you can expect if you sign a DNR and if you do not. It's always best to make these decisions ahead of time for the sake of all involved.

### **Tools to help**

There are many conversation starters to choose from when making advance care plans. Whether you are the one making plans, or the one encouraging a discussion, time is a gift and these decisions even more so as they can prevent distraction from the precious last moments you spend with your loved one. Considering the complexity of your current or future circumstances, outlining the specifics for your medical wishes may seem impossible. Speaking rather of what is important to you, who you want with you, where you want to be, and how you want to live your last days will give direction to those supporting you at that time.

Patty Webster with The Conversation Project notes that speaking of "what matters to you" instead of "what's the matter with you" will lead to a better-quality care plan.<sup>4</sup> The success of such a plan begins with when and where to have that conversation. This is not just about having a legal document, Webster reminds us. Conversations carry

far more value than words in black and white as you or your loved one advocates for care.

Here are some specific tools that can help guide your planning:

**Prepare for Your Care (PrepareForYourCare.org):** Using this tool, you will be able to designate your Medical Decision Maker and note your preferences for treatment, location of your last days, who you desire to be with you, and what kinds of decisions you would like made for you in case of an emergency. For example, would you want CPR administered if your heart stopped, or would you want a DNR order? Specific wishes can be noted within these pages, and they offer rules by state for how to legalize your written wishes. (Note of caution: "Right-to-die" laws are different in each state. While Prepare for Your Care does not directly advocate for the option of physician-assisted suicide, it recommends that you write your wishes on page 10 of the Directive and let your loved ones and medical provider know what you would consider a "not-good quality of life" for you.)

**The Conversation Project (TheConversationProject.org):** As mentioned above, quality of life is the focus of this tool, setting aside the technical complexity of medical and clinical wishes. A big-picture plan rather than a specific medical scenario is the approach for what matters to you. Once begun, this is meant to be a tool that encourages updates over the years with changing circumstances. Anyone age 18 and older should have a plan in place in case of accident or illness. You will find guides to selecting

or serving as a medical advocate and tools for having an organized conversation through a small workbook called “What Matters to Me” to help navigate serious illness. “The Conversation Starter Guide” is also very helpful to begin a conversation with mom or dad. Their quick guide for what to do now has been updated to include a little information about COVID-19. (Keep in mind, their recommendations follow CDC guidelines for masks and distancing.)

**Five Wishes (FiveWishes.org):**

With two pages of introduction available on their website, Five Wishes at Home is a project of Aging with Dignity. Their tools begin with an assumption of compliance for “stay-at-home” orders and compliance with “social distancing” as well. They begin by asking who you trust to make your decisions for you and what treatments you want for life support or comfort. This is a more specific tool to navigate important aspects of the process of wrapping up a life on earth. Not only does it encourage discussion of your treatment, it also asks who you want with you and what items bring you comfort, what conversations you want to have, and important things loved ones need to know from you—last words, forgiveness, words of love.

**Good To Go: A Guide to Preparing for the End of Life:** Jo Myers’ book outlines “The ABCs of Death and Dying” in a practical and humorous way. With a refreshing perspective on the normal things people face when helping loved ones say goodbye, she provides a thoughtful, step-by-step guide.

**Saving your documents**

Once you have created advance-planning documents, you’ll need to make sure they’re saved and accessible. Here are two practical solutions for that.

- Make copies and give to your physician and family members and tape a well-marked one to an obvious place (like your fridge).
- Select an online service such as MyDirectives.com to upload your paperwork to. Provide the login information to the appropriate loved ones. Revisit this document once a year. Make sure it still reflects your wishes or those of mom or dad. Be sure to share any updates and changes with physicians, loved ones, and those most likely to be with you in the case of an emergency.

As you plan and prepare for the inevitable, no matter what brings your last days to pass, many things will be unimportant in the end. Little things may matter more than

you realize. The bride of Christ must be ready for His return or His calling us home.

Faithfulness to Him is most important. As for me, please bury me in white. ♦♦♦

1Swinton, J., Payne, R., & Hauerwas, S. (2009). *Living Well and Dying Faithfully: Christian Practices for End-of-Life Care* (1st ed.). Eerdmans.

2Ibid, xxiv

3A fabulous book on this subject is *Extreme Measures, Finding a Better Path to the End of Life*, by Dr. Jessica Nutik Zitter. Spanning two decades of work in the intensive care unit and then palliative care, after realizing she was overtreating patients to the point of abusing them. With a kindness toward her patients, their stories, and her profession, she gives an inside look at the medical mindset to “cure no matter what” she often found in the ICU.

4“Psychology of Aging” podcast with Dr. Regina Koepp, (Accessed August 24, 2021).

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