

HELP!

I'M LIVING WITH TERMINAL ILLNESS



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TERMINAL ILLNESS

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INTRODUCTION

I began writing this booklet the same week Jenny¹ returned home to Northeast Tennessee from Florida after her release from a medical trial. Participation in the trial was dependent on her cancer responding to treatment, so her discharge from the program said everything that words could not verbalize and that many hearts did not want to believe. Less than a week after my wife and I, with several friends, welcomed her home at the airport, Jenny died.

Jenny had been diagnosed with pancreatic cancer five years earlier and had endured chemotherapy, surgery, and several clinical trials in efforts to minimize the effects of living with what was, in her case, an inoperable disease. But the reactions of her and her husband, Stan, to God's ways and timing assured everyone who witnessed their suffering that divine grace is sufficient.

1 Names have been changed to protect the identities of those concerned.

They both knew the truth of these words:

*My Father's way may twist and turn,
My heart may throb and ache,
But in my soul I'm glad to know,
He maketh no mistake.*

*My cherished plans may go astray,
My hopes may fade away,
But I'll trust my Lord to lead
For He doth know the way.*

*Tho' night be dark, and it may seem
That day will never break,
I'll pin my faith, my all in Him,
He maketh no mistake.*

*There's so much now I cannot see,
My eyesight's far too dim;
But come what may, I'll simply trust
And leave it all to Him.*

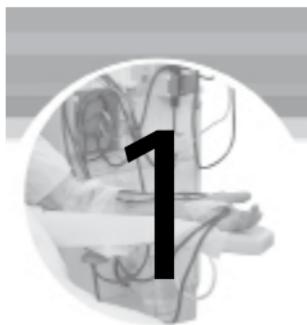
*For by and by the mist will lift
And plain it all He'll make,
Through all the way, tho' dark to me
He made not one mistake.²*

There are many ways the subject of terminal illness

could be approached. The title of this booklet says a lot about my personal perspective on living and dying and how I plan to engage with the issue of terminal illness. It is not *Help! I'm Dying from Terminal Illness* but *Help! I'm Living with Terminal Illness*. This perspective is, I believe, beneficial to anyone suffering with—or concerned about someone suffering with—terminal illness. My hope is to encourage any dying person, or such a person's family member or friend, with a singular hope which the dying process cannot diminish and death cannot extinguish.

Eighteenth-century preacher John Wesley once said, "Our people die well because they live well."³ Jenny lived and died with grace, dignity, faith, and joy. Given the time and opportunity, Stan and Jenny could easily have written this booklet. It is to Stan and to Jenny's memory that this booklet is lovingly dedicated.

- 2 A. M. Overton, "He Maketh No Mistake," quoted in Lee Roberson, *The Gold Mine* (Murfreesboro, TN: The Sword of the Lord, 1996), 109–110.
- 3 Quoted in Leon O. Hynson, *Through Faith to Understanding: Wesleyan Essays on Vital Christianity* (Lexington, KY: Emeth Press, 2005), 141.



Life and Death Are Personal

Death is very personal to us all. I well remember receiving the news of my grandfather's impending death. His prognosis was twelve months and he died within weeks of that prediction. Only a few days before his death my family traveled to see him. Although bedbound, he held my first child and laughed with her when she was a mere six months old. But it grieved my heart that my grandfather never enjoyed my children as he had the children of my older cousins.

A similar grief has probably motivated you to read about terminal illness. Grief is a real, God-given, necessary emotion and should not be denied. Grief has its purposes, but in the battle of emotions it should not win the day. This booklet is really about grieving with joy and hope.

My parents had anticipated a life of leisurely travel

in their retirement years, but my father's illness permanently canceled those plans. He suffered from a decade-long fight with Chronic Obstructive Pulmonary Disease (COPD), a debilitating respiratory illness which inhibits breathing. As the disease progresses, less air flows in and out of the airways. For many years he was unable to walk the length of a room without intermittent stops. His inability to breathe often required him to live dependent on an external supply of oxygen. Visits to the local hospital emergency room became so habitual and lengthy that my mother routinely dropped him off at the ER, returned home, and awaited the call to retrieve him.

Dad never complained about his illness, but he worried about how and when he would die. A defibrillating pacemaker often reminded his heart to beat, but not without great physical pain. I vividly remember my sister's phone call encouraging our family to make our way to San Antonio as my dad entered an ICU for the last time. The inevitable had become unavoidable—as it does for us all, sooner or later.

Many things can be said about death. It is universal and is perhaps the most conspicuous thing that is wrong with this world. The mortality rate is 100 percent. For this reason, no one profits from

denying the inevitability of death. Yet any discussion about it is difficult. My most important counsel to you is to find your strength, joy, and hope in God and in his Word, the Bible. God's Word is true, sufficient, and relevant to everything about us. God does not avoid the difficult issues of life. The Bible explains life, suffering, and death, and in particular speaks clearly and directly to end-of-life concerns. This is one of the reasons I most appreciate the Christian gospel. It is a very powerful anchor of truth and rationality for anyone in any kind of storm. We'll turn our attention to these important matters in the next chapter.

There are, however, other, practical matters to consider in this process. While it is not my intent to address medical concerns regarding end-of-life care, I would encourage you to consult with your pastor, family, friends, and physician and to do so in timeliness and candor. If you are a Christian you can speak directly and honestly about death, because you know that for the Christian, death is God's release from the curse of sin. In addition, please do not ignore the advice of those who are further along this path or the wisdom of professionals who have walked through this valley with others.

The following action points were derived from

conversations with health-care and mental-health professionals as well as friends enduring the dying process.

Planning Care

- ▶ Death is an extremely emotive issue. The people around you may not know how to begin talking with you about it. Take the initiative to openly and candidly speak about end-of-life concerns. It is also important to gain your family's agreement on essential issues. Conduct private conversations if disagreement exists. You will not want to spend this important time in estrangement from those closest to you. Take the necessary time to encourage everyone to respect your decisions.
- ▶ Do your best to be open and clear about your wishes regarding medical care, financial concerns, your will, your funeral, and life after your death. Explain what caused you to make certain decisions. How do your decisions give meaning to your life and death?
- ▶ Share your end-of-life concerns. Do you desire independence? What will happen if or when you

cannot remain independent? If this happens, with whom or how will you live? Would you prefer to die at home?

- ▶ Is there a hospice care facility in your vicinity?⁴ If so, I would encourage you to use their services. As a former board member of a local hospice and the husband of a former hospice nurse I know that hospice personnel combine professionalism and compassion in a unique way as they care for patients and families.
- ▶ If you currently have no ongoing Christian influence in your life, I recommend that you contact an evangelical minister of the gospel. He will certainly be willing to visit with you and your family to offer biblical counsel. Ask someone you love to call a Bible-believing, Bible-teaching church in your area to inquire for a pastoral visit.
- ▶ Do you have a living will or advanced directives that detail your medical preferences? Both will speak to the specifics of your medical care if you are unable to speak for yourself.
- ▶ Consider creating a durable power of attorney.

⁴ For a very helpful discussion of the benefits of hospice, see Deborah Howard, *Help! Someone I Love Has Cancer*.

It allows someone else to act on your behalf when you are unable to do so. A durable power of attorney can go into effect as soon as you sign it, when you deem it appropriate, or when a doctor confirms you are incapacitated. As long as you are mentally competent, you can revoke a durable power of attorney anytime you wish.

- ▶ Of course, every decision is subject to change. Maintain open lines of communication and keep the conversation going with your family and other significant people in your life. Your openness and frankness will encourage the same from others. Many important and meaningful discussions can be held during this time. You and everyone around you will benefit from the transparency you exhibit.

Funeral and Business Arrangements

- ▶ Have you written a final will? A will enables you to retain control about what remains of your life even after your death. It protects those you love. A will can also ensure that your last wishes are fulfilled.
- ▶ What about funeral arrangements? Nothing

adequately prepares us for the death of someone we love. Feelings of panic can paralyze those who remain. A prearranged funeral can serve many purposes. If you are a Christian it can share your faith, and it provides closure for loved ones, relieves your loved ones of the responsibility of its planning, honors your last requests, and enables those you love to exert their energy and emotion on the care of one another.

- ▶ Consider writing your own obituary. You know best what is important to be said about you. Your obituary is a history of your life and a lasting legacy of your values, priorities, triumphs, and joys.
- ▶ Take time to locate and share important documents. Your family may need your birth and marriage certificates, divorce decrees, car and property titles, life insurance or health insurance policies, summary of pensions or benefits, and death certificates of any loved ones who have preceded you in death.
- ▶ It is important that you and your family understand in advance what your insurance will cover for your care. Have you researched this?
- ▶ Make a financial inventory of all your assets and

debts. Write down all important information such as bank account numbers and passwords, e-mail addresses and passwords, the deed of trust to your home, the location of safety deposit boxes, and the name of your attorney. Gather your bills and give someone the oversight of paying your monthly expenses, such as your utilities.

- ▶ If applicable, it is imperative that someone notify the Social Security department, Medicare or other governmental agencies of your death. Who will assume this responsibility?

Emotional and Relational Needs

- ▶ You may notice that life tires you more easily each day. To recuperate and ensure you enjoy time with family and friends, consider time limits for visits from those outside your immediate family, take naps throughout the day, and discover new activities that do not require as much energy.
- ▶ You are also going to experience emotional changes, such as denial, anger, fear, and grief, if you are not already doing so. Don't hesitate

to discuss your feelings with your pastor or family. In reality, your family members want to talk to you about their grief and fears. Talk with someone else who has a terminal illness for mutual encouragement.

- ▶ Consider writing down all the difficult experiences of your life in the past and how you coped with them. Doing so may encourage you about your illness. You may also remember something of value that will help you now.
- ▶ Is there anyone in particular whom you want to contact soon? Consider calling old friends to rejoice in your relationship or to say goodbye. Death has a way of helping us get over former grievances. Perhaps you could heal a broken relationship or become reconciled to those with whom you have had disagreements.
- ▶ Make a list of people you want to be contacted when you die. This list could include the phone numbers or e-mail addresses of extended family, friends, social acquaintances, or former coworkers.

I trust that these suggestions will give you mental,

emotional, and physical rest as you handle the dying process, and will enable you and your family to concentrate on loving one another rather than being distracted by peripheral issues.