On the Front Line

# 'A Good Death': One Hospice Chaplain's Approach to End-of-Life Care



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#### Abstract

When doctors determine patients' life expectancy to be six months or less, patients are considered palliative. Hospice offers care for the terminally ill patient's body, mind and spirit. As part of the hospice team, chaplains support the spiritual needs of the patient and their family – a challenging and rewarding role. Dr Madison Cawdor shares his extensive experience as a United States-based hospice chaplain and explains the role's demands, including the importance of both being present with and listening to patients while also employing an interdenominational approach (i.e. supporting regardless of religious practice). Dr Cawdor explores the role's personal impacts, including being on call, sustained exposure to death and grief, and also the satisfaction of supporting patients. The demand for hospice care is projected to increase dramatically in the coming years, making understanding the demands of and approaches to this work crucial to facilitate both the recruitment and the retention of hospice chaplains.

#### **Keywords**

chaplain, death, dying, family, hospice, interdenominational, listening, presence, sustainability

# Introduction

The study of death, dying and bereavement is a continually evolving, multi-disciplinary field that includes psychology, history, anthropology, media, policy, organization studies, religion, medicine and, of course, sociology (e.g. medical, clinical, social, health and illness, etc.). Though death is the most common human experience, death and dying varies

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heavily by geographic location and the associated socio-cultural norms and practices, as 'dying, death, and bereavement do not occur in a social vacuum' (Thompson et al., 2016: 173). Beginning with Durkheim (1893[2012]), the debates in the death studies literature include death taboo or ambivalence (Paul, 2019), the denial of death (Kubler-Ross, 1970; Tradii and Robert, 2019), the social or familiar avoidance or distancing from death (Elias, 1985), the good death discourse (Cain and McClesky, 2019; Lang, 2020) and the medicalization (Prior, 1989), institutionalization (Lang, 2020) or professionalization of death (Kellehear, 2007) more recently. It has been posited that the advances in medical technologies have both prolonged death and drawn more emphasis on the end of life as a life stage (Carr and Luth, 2019), while also making death and dying less familiar or depersonalized for family (Paul, 2019).

Patients with 'a projected six-month survival period' can be referred to hospice for palliative care, which focuses on symptom relief rather than curative medical treatment (Carr and Luth, 2019: 525). Patients can be offered or can elect to receive hospice care when curative medical interventions have been exhausted, a terminal diagnosis has been given or when the patient elects to discontinue treatments because they are 'no longer realistic or appropriate' (Lopez, 2018: 46). Hospice offers holistic care for terminally ill patients by addressing the entire person: body, mind and spirit. Hospice care also supports the families of patients throughout the dying process and may extend to post-mortem support to assist in the grieving process. Working with an interdisciplinary team, hospice provides pain management and emotional and spiritual support. Hospice chaplains, who focus on the spiritual needs of patients, are an important part of this team. Given the importance of and sharply increasing need for hospice care (Technavio, 2021), and the relative short tenure of most chaplains (Zippia, 2022), the aim of this On the Front Line (OTFL) article is to illuminate the challenges and rewards hospice chaplains face and how one can manage these challenges -a gap in the literature identified by Lindholm (2018). Hospice worker burnout and poor well-being appears to be 'leading to significant long-term staffing problems in the field' (Schneider et al., 2022). This article aims to spur research exploring on how to make the hospice chaplain role more sustainable by learning from one hospice chaplain's lived experience.

Therefore, this OTFL article highlights the voice of Dr Madison Cawdor, an experienced hospice chaplain, to contribute to our understanding of the day-to-day work demands and the nuance between the challenges and benefits of the role. This article is divided into three main sections: defining hospice and the role of the hospice chaplain; a brief introduction to Dr Madison Cawdor; followed by a narrative from Madison about his long career as a hospice chaplain. Researchers sometimes mistakenly discuss death without recognizing the global variance of death and dying traditions, practices and norms (Walter, 2008). Therefore, given this OTFL piece is highlighting the experiences of one hospice chaplain living in the United States, the discussion here is focused in this socio-demographic context.

# The hospice industry: United States of America

In the United States, the sum total of hospice services delivered equated to USD32.1 billion in 2021 (Grandview Research, 2022). Owing to the increase of chronic

disease, the size of the aging population, and age-related diseases (though not only for the elderly) (Grandview Research, 2022), the need for hospice services could balloon to USD78.81 billion by 2025 (Technavio, 2021). This projected increase in demand will be driven by the 'high prevalence of cancer, dementia, respiratory, cardiovascular, and kidney diseases among the geriatric population' (Grandview Research, 2022: para. 1).

Hospice services can be delivered in several settings: routine home care, continuous home care, inpatient respite care and general inpatient care (Lopez, 2018), but 90% of hospice services are offered in patients' homes (Grandview Research, 2022), which is often preferred by patients (Carr and Luth, 2019; Fereidouni et al., 2021). This choice likely results from the efficacy of managing acute symptoms at home, the increased comfort home offers (Grandview Research, 2022) and the comfort of having family and pets around, but may also be influenced by financial or insurance factors.

The multidisciplinary palliative care team consists of hospice physicians, nurses, chaplains, social workers, certified nurse's aides, dieticians, home health aides, bereavement workers and volunteers (Cramer and Tenzek, 2012; Lopez, 2018). Teams work collaboratively (Lopez, 2018) and meet regularly to review each patient's individualized care plan, which requires high levels of coordination and cooperation (Wittenberg-Lyles et al., 2008).

## Hospice chaplains

Hospice chaplains are an integral part of the hospice team. In the United States, there are roughly 8000 hospice chaplains. Sixty-six percent of chaplains identify as men, 20% are members of the LGBT community and are on average 51 years old (Zippia, 2022). Seventy-two percent of American hospice chaplains are White, 10.8% are Black and 8.5% are Latino (Zippia, 2022). Chaplains are highly educated with 42% holding a bachelor's degree, 42% a master's degree and 7% a PhD. The average chaplain's annual income is \$52,000 (Zippia, 2022).

Chaplains focus on the spiritual needs of patients (Cramer and Tenzek, 2012) and families. Hospice chaplains can work part-time, full-time, as employees or as volunteers. Primarily, the chaplain's role is to be present with and listen to patients and their families, but the job also requires regular team meetings and documentation (Lopez, 2018). In some cases, funeral services are conducted as part of their role. Chaplains may be on call 24 hours a day and, if visiting patients at home, may require substantial time driving (Lopez, 2018); therefore, receiving per-mile reimbursement. Some hospice organizations require chaplains to complete a clinical pastoral education programme as part of seminary training (Zippia, 2022), but this is not universally required.

Hospice care intends to be 'spiritually inclusive' (Williams et al., 2004: 638); however, the vast majority of chaplains are Christian (Wright, 2001). The chaplain must be able to offer spiritual care to atheists or agnostics as well as those from a variety of faith traditions (Williams et al., 2004). As such, chaplains may seek assistance from a community parish, synagogue, temple or mosque (Lopez, 2018). The focus must be on meeting the patients and families where they are (Lopez, 2018) and the chaplain's own needs and issues are secondary (Lindholm, 2018). 'Not everyone in hospice wants to meet the chaplain' (Lopez, 2018: 51). Patients' and families' perceptions of chaplains can be unclear or loaded. Important are the 'images that the chaplain represents for the patient and family' (Reed, 2017: 111) because they influence receptivity to care. Patients may assume chaplains will take a hard-sell approach or aim for conversion, but this should never be the case. Patients who receive good spiritual care report greater quality of life, better coping mechanisms, greater well-being and reduction of despair (Soroka et al., 2019). When patients are educated about the inclusive hospice approach they are more likely to accept chaplain services, which affords them the benefits of end-of-life spiritual care (Soroka et al., 2019).

# Demands of the role

The work of a hospice chaplain requires being present and listening to patients, but there are also some challenges that face those who perform this work. Lopez (2018) discusses the cornerstone of effective work as presence, listening and patience. He defines presence as simply 'being with a person' (p.46). Whereas medical team members focus on treating physical issues, the 'heart of spiritual care for the hospice chaplain is presence, some say, empathetic presence, the exact opposite of "fixing it" (Lopez, 2018: 46). The aim is for the patient to feel heard, as this is a time when many patients and families might feel alone, angry, despair or abandonment. They may have significant emotional challenges as they seek to understand their suffering (Lopez, 2018). Being present does not always include conversation, but may be sitting with or just being available to a patient.

Chaplains must hold space for and listen to patients with an uncritical ear to ensure the patient feels heard but without feeling judgement or rejection (Lopez, 2018). At the end of life, people often focus on forgiveness, gratitude and affection (Bryock, 2013, as cited in Lopez, 2018). Though not easy, chaplains must set aside their own thoughts and feelings in order to listen well (Bryock, 2013, as cited in Lopez, 2018), which requires deep focus, extensive effort and emotional labour and intelligence.

Chaplains' regular engagement with death and dying can be draining and research highlights the need for supports to reduce stress (Williams et al., 2004). Developing relationships that will certainly end is very stressful (Lindholm, 2018), and is compounded by the frequency of this experience. However, a genuine relationship between patient and chaplain is necessary to foster a climate of acceptance and peace (Lindholm, 2018). So, chaplains must be open and vulnerable in order to create a relationship, but the loss of connections can result in grief (Lindholm, 2018). In contrast, as chaplains face their own mortality they may re-evaluate their lives, work roles and relations with others and with organizations to use their limited time to the best of their ability (Reedy and Learmonth, 2011).

Research addressing ways to make this role sustainable is limited. In fact, 34% of hospice chaplains stay in the role for two years or less, 26% remain for 5–10 years and only 13% remain for 11 years or longer (Zippia, 2022). The literature suggests future research is needed to explore in depth the challenges facing hospice chaplains and how they manage these challenges (Lindholm, 2018).

## Introducing Dr Madison Cawdor

To better understand how hospice chaplains effectively provide inclusive spiritual care and how they cope with the challenges of the role, we speak with Dr Madison Cawdor. He was recruited for a larger research project, but after hearing about his role and approach to his work we felt his story needed to be highlighted here. He eagerly agreed to co-author this article, under a pseudonym, and was therefore not included in the original research project. Following an interview with Dr Cawdor, drafts were written by the first author and provided to Madison for his review and editing to ensure we accurately captured his voice.

We begin by describing Madison and his unique background, given there are no universal qualifications for hospice chaplains. Madison is 81 years of age and is a cisgender, White man, married, and father of four and grandfather of seven. He earned a Bachelor of Divinity, Master of Arts in Theology, and PhD in the New Testament. Madison began his career as a professor and then moved to several ministerial roles in a variety of churches. As a pastor, Madison was particularly interested in death and dying, as he regularly supported members of his congregation and their families through the dying process.

Madison had experienced death extensively in his formative years, including the death of his father when he was 12. In rural Virginia in the 1940–1950s, death was a family and community experience, with bodies of loved ones being brought into the home for three days after death to allow for visitors and viewing; therefore giving Madison experience with both proximity to and familiarity with death that is not experienced today in the United States. When he retired from the pastorate in his early 60s, he was hired by a hospice programme seeking a part-time chaplain and served in this role for over 16 years. He retired from his paid hospice role in 2020, but continues his hospice work today as a volunteer at the local hospital.

## The reflections of Dr Madison Cawdor

Death is inevitable: 'none of us will get out of this life alive!'. We hear comments like this a lot, but until I worked with death day in and day out, it hadn't really sunk in. On one level I knew that everyone eventually died. But hospice work and the constant presence of death forced me to accept the truth intellectually, emotionally and spiritually.

There is so much denial of our frailty. Even getting old can be a negative: wrinkles are frowned upon, being infirmed is not understood. We have a difficult time understanding that death is simply a part of living. We are afraid of it and don't know what to do with it. We try and ignore it until we have to face it. We so often say, 'The person passed', rather than say, 'He died'.

In hospice work, we tried to normalize that we all are going to die. We all have a path, and I sought to make it as gentle and as easy as it can be for everyone without denying what was going on. I often began talking with a patient by asking, 'What was your reaction when you were given a fatal diagnosis?'. Then we would try and talk about it. Talking about feelings was very helpful.

Death doesn't have to be scary. The unknown can be frightening. If we've never gone through something before, if we're facing something huge and imposing for the first time, we can be sacred. And the 'big' unknown for humans is death. We don't know what to expect and we don't get to practise it. So, for many people death carried a lot of 'natural' baggage. But not for everyone! I witnessed instances in which death was not a negative and wasn't something to avoid. Instead, it meant freedom. I worked with people who were suffering terribly, and their quality of life was not good. For them death wasn't an escape from reality, it was a release from pain and unhappiness. It was freedom from significant limitations. I've come to balance the frightening prospects of death with this positive, hopeful expectation. Perhaps my vision is skewed, but I think I've come to view death in a broader, richer way.

In hospice, we often talked about 'a good death'. A good death was when a patient realized that death was near, and they accepted it. I've had many people tell me, 'I'm done, I'm ready to go'. They visibly relaxed. In these cases, we had worked also with the family to help them face their own fears and understand what was happening. In these cases, the family acknowledged that their loved one was at peace and was not afraid. Many times, the family would tell the person, 'It's OK to die. We're going to be fine.' Family permission often meant a lot.

# View of my role

The chaplain is part of the whole hospice team. Every hospice programme in this country has a hospice chaplain. Patient care starts with comfort care. Nurses first addressed the patients' pain issues. The social worker focused on family systems and resources. I did the spiritual piece. The goal was to bring hope, a sense of hope without healing, which often required redefining 'hope'.

As a chaplain, I tried to be as honest as possible. Early in our relationship, I would tell a patient that I was not a 'medical professional'. I clarified that I couldn't answer questions about their medications or procedures but that I would pass on questions and concerns. I always tried to be who I was without any illusion to being more. That is, I worked hard to be honest with patients and families. I would be asked time and again, 'How long do I have to live?'. I would say that that was not my decision, but I assured them that they would be surrounded by hospice care and support for the entire journey. 'Will I die?'. The answer was, 'Yes', and then we would try and discuss how that makes them feel. 'What will happen to me when I die?'. I wasn't absolutely sure, but I was willing to share my thoughts and opinions. We would not downplay their disease and we would not pretend that the journey ahead would be easy. The patients had a right to know what was going on with them. They likely knew the answers before the questions were asked, and perhaps they simply needed confirmation from someone with experience with the dying process. Sometimes families weren't as honest with their loved ones as we tried to be, which occasionally created interesting dynamics.

Families were clearly part of our work. They had some of the same issues and emotions as their dying loved ones. I had the honour of being asked to conduct many funerals. Conducting a funeral was not stressful for me. The funeral would provide a sense of closure and completeness to my work. My local hospice programme held an annual memorial service to remember those who had died in the past year. There were years we remembered as many as 200+ people. Many family members were present.

A lot of people think that my job was a difficult one. Honestly, I could not have worked as a kindergarten teacher, but I could do hospice. I'm not anything special. I simply had the ability to work with death and dying.

#### Interdenominational spiritual care

My work did not subscribe to any one particular branch of faith or theology. If spiritual care is done well, it will be inclusive. If it's not done well, it will not be inclusive. It will be judgemental. I did not discriminate. One of the driving forces in my life is inclusive spirituality. My own religious tradition is only part of a much larger whole. There's no one religious tradition that is any better than any other. All the religious traditions, unless they become abusive or harmful, are worthy. I appreciate the great diversity of spirituality.

I attempted to be kind and to bring to patients and families a sense of peace, presence and the grace of God. The concept 'God' had to be understood in broad terms. I had a lot of people who said they were not religious, that is, they didn't belong to an established religious body, but they claimed to be spiritual. They had a basic spirituality that can be defined as thinking of themselves as part of a larger whole, a part of something greater than themselves. I met them where they were. I did not try to make anyone conform to my own ideas, notions or theology. And, if a patient was Catholic and wanted specific rituals or sacraments performed, the patient would give me permission to reach out to a local Catholic priest to ensure that their spiritual needs were met in a way I was unable to do. I did the same for anyone in any other tradition or theological system.

I often called God the 'Holy Other', or simply the 'Holy' or the 'Sacred Reality'. 'Great Creator' was a familiar name. If a person was feeling abandoned by or cut off from their 'Sacred Reality', one of my tasks was to try and bridge that gap. I had people say that they were too old or too bad to be loved. I had some people say, 'I just don't know how something greater than me could love a person like me'. Part of my job was to bring a sense of spiritual peace and calm while all the other dynamics were at play. They needed to hear: 'You do matter'; 'You are important'; and 'You belong'.

We could make a real difference when we were permitted into a family's life, but some families didn't let us in. Patients from two specific religious systems rarely let the chaplain in. Sometimes families had a preconceived notion of what a chaplain is or what a chaplain does. Patients could not easily refuse a nurse, but they could refuse to see a social worker or a chaplain. I took that rejection personally. I know I shouldn't have, but I did because that's who I am. If I could get in, I could do my work.

## Reflecting on the work of the chaplain

I was with a person to listen. I wasn't visiting to work on my own agenda, to have someone recognize how smart I was, or to offer any sage advice. I would often ask, 'What are you worried about today?'. Or, 'How is your day going?'. I never asked how they were feeling. I wanted to listen to the person, whatever he/she wanted to say, and however, she/he wanted to state it. I discovered how powerful it is when we simply listen. I tried very hard not to be thinking about what my next comment would be. My comments were not as important as what the person wanted to talk about. Sometimes, I just said nothing, and I tried to nurture the presence of silence. It takes a lot of practice to do that.

While there were mental and social and spiritual differences among my patients, there were at the same time a lot of similarities. The approach I used for one patient would not necessarily work for the next person I'd visit. Yet, the basic needs were not all that varied. There was the need for meaning, for a sense of personal integrity, to feel loved, and often a desire for forgiveness, to accept that they were not alone. In my non-judgemental approach, I tried to be honest and to hold a sense of integrity. I would not sit in judgement over any of my patients. But, if I could listen and invite them into a space that was freeing and peaceful, what a gift to them. More than a few times I had the privilege of helping people experience the forgiveness that only comes from God.

It was my task to be present with the patient. I was with a person sometimes just to be with them. Sometimes, especially in the nursing home or at the hospice house, there may have been no conversation at all. Perhaps the person was awake but unable to speak. Perhaps the person was in a coma. Perhaps the person could speak but chose not to on that occasion. Many other people might leave the room. I often sat in that space in silence. My personal presence was a demonstration of the fact that the person was important enough for me to take the time to spend with them without demanding anything from them.

I would seek to bring God into that space through meditation and focus. It was a time to be open to and invite God's presence with me and the patient, sometimes through silent prayers, silent recitation of scripture, or silent reading of sacred literature. I sat with a lady for a couple of hours one afternoon who was slowly dying. Her daughter could not be there. It was one of the most powerful hospice experiences I had, being there with her, inviting God into that time and place, honouring her and her journey, and never saying a word.

We were building relationships. So much of the work of the social worker and the chaplain was based on the relationships we formed with patients and families. To deliver the messages 'you are not alone' or 'you are cared for' or 'you are loved' or 'you are important', I needed time to develop a relationship. In some circumstances, if a person was admitted to hospice and died quickly, I was unable to offer a lot. But, if I had the time, we could normally do good work together. If the point was reached for a patient where not much more could be done medically, the nurse and other staff would take a step back and I would step forward. It was not uncommon near the end of the patient's life that I would visit more than the nurse. One of the signs that it was time for me to retire from hospice was that I began to grieve too much the death of a friend. It seemed that I no longer had the 'professional distance' needed to be appropriate.

A challenge in building these relationships is that it demanded that we ourselves be vulnerable. You are putting yourself out there. You can't be closed off. At the same time, you cannot predict with whom you will connect. Still, I couldn't be closed off when I walked into a house or a room. Many times, I became good friends with patients because they came to trust me. We might be able to talk about stuff they at first were reluctant to tell their family. I was honoured. I tried very hard not to take that for granted.

Sometimes the demands of dealing with death as an everyday occurrence can take its toll. We had a support group where we would talk, cry or laugh together. We might share

stories about the people we knew who had just died. In this work, one has to face one's own issues and personal concepts of mortality and one's personal faith. I didn't always have a fixed schedule. It was often not a 9 a.m. to 5 p.m. job. Sometimes, at any time, I could get a call from an actively dying patient that I was needed. I could also make death calls with a nurse.

Each time before I entered a house or a patient's room, I asked God to help me and guide me. I could not do this alone. I depended on God's presence and guidance and strength to do my work.

There are certainly also blessings. I believe in the value of hospice and what it can do for people. I believe this is the most important work I have done in my career. The work has made me more appreciative of everyday life. I no longer take beauty in another person or beauty in nature for granted. I don't take everyday life for granted. I see life as a gift much more than I ever did before. Everyday life becomes more precious. I learned from one of my earliest patients three things: to live in the moment, to be thankful for what I have and don't focus on what I don't have. I learned a lot. I gained a lot.

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Madison Cawdor (pseudonym) earned a Bachelor of Divinity, Master of Arts in Theology, and PhD in the New Testament. Madison's career began as a professor, which then was followed by almost 30 years in ministerial roles in a variety of churches, and after that by over 16 years as a hospice chaplain. He retired from his paid hospice role in 2020, but continues to volunteer for a hospice program at the local hospital.

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