



# *Be Not Afraid*

THE GIFT OF PALLIATIVE CARE



RESPECT LIFE



## STEPHANIE'S JOURNEY

*"You see life differently when death is imminent."*

In 2012, Stephanie Packer, a 32-year-old wife and mother of four was diagnosed with scleroderma (a chronic connective tissue disease) and told she had three years to live.

Yet far from letting the terminal diagnosis define her, Stephanie has found new purpose in leading and participating in support groups for fellow scleroderma patients. Stephanie has also actively worked to combat proposed assisted suicide legislation in her home state of California.

A powerful advocate for proper treatment and care for those ill and vulnerable, Stephanie sees no dignity in taking her own life.

"Terminally ill people need to know they're valuable and worthwhile. We don't hand a gun to someone who's suffering from depression, so we shouldn't give the dying a handy tool to end their lives. It's important instead to give terminally ill patients the tools to live. There is beauty in their lives; perhaps more even than before their diagnoses. You see life differently when death is imminent."

Stephanie's 10-year-old daughter Scarlett believes that her mother's advocacy for terminally ill patients and her fight against physician-assisted suicide is her mission. Of her mother's work she said, "We all have a purpose in life. Giving people faith and hope is her purpose."

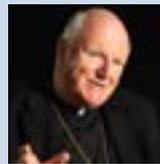
Watch this video to hear more of Stephanie and her family's powerful story:  
[www.stephaniesjourney.org](http://www.stephaniesjourney.org)

## WATCH THE *BE NOT AFRAID* VIDEO

- When someone we know is facing death, how do we respond?
- Are high doses of pain relief at the end of life a form of euthanasia?
- What harm would allowing terminally ill people to take their own life do?

See experts in medicine, law, aged care and Catholic teaching address these questions and more.

## FEATURING:



ARCHBISHOP DENIS HART  
CATHOLIC ARCHDIOCESE  
OF MELBOURNE

"God has given us our life, he loves us passionately all through our life, and he loves us just as passionately at the moment when our life is ebbing away."



ASSOCIATE PROFESSOR  
NATASHA MICHAEL  
PALLIATIVE CARE  
PHYSICIAN

"We accompany people when they enter the world ... and death is also a time that you accompany somebody as they leave the world. It's a time of accompaniment."



JULIAN MCMAHON  
BARRISTER

"Once we allow the state, or people, to kill other people for whatever reason, we're crossing a line, a fundamental line about how society works ... and looking at how other countries work, the idea of crossing the line is really so dangerous and so worrying for me that I'm confident it's a line we shouldn't cross."



SR ANGELA BURNS  
ST JOSEPH'S HOME FOR  
THE ELDERLY

"It's not euthanasia to give a person adequate pain control ... that's not trying to hasten a person's death. ... You're trying to control the pain so that they're comfortable and that their family is comfortable too."

Watch at: [www.cam.org.au/lifemarriagefamily](http://www.cam.org.au/lifemarriagefamily)



## 1. PEACE AT THE END OF LIFE

*“If it is understood as the end of everything, death frightens us, it terrifies us, it becomes a threat that shatters every dream, every promise, it severs every relationship and interrupts every journey. This occurs when we consider our lives as a span of time between two poles: birth and death; when we fail to believe in a horizon that extends beyond that of the present life; when we live as though God did not exist.”<sup>1</sup> – Pope Francis*

Dying and death are a part of every human life. Although many of us find it difficult to speak about death, faith gives reassurance to those in their final days as well as their family members. We are given the opportunity to actively and intentionally love and care for those within our communities when the death of a family member or someone we are close to, draws near. By responding with Christian solidarity to these challenging circumstances, we help to ensure that physical, psychological, emotional, social and spiritual supports are in place to accompany those who are dying with reverence and care.

The unpredictability of how our lives will end can make the approach of death difficult. Both the person dying and those around them can feel anxiety, fear and loss. Much can be done to ease these feelings when compassionate support is available.

## 2. A CRUCIAL TRANSITION: FROM CURE TO COMFORT

As well as care that seeks to cure or treat medical conditions, a patient may be given care aimed at comforting and relieving pain. Sometimes this comfort care can assist a patient for a long time, even years, as they live with painful conditions.

However, as the end of life draws near, there can be a transition from curative treatment to palliative care. Recognising and being able to accept this transition is important for patients and their families. It represents an opportunity to adjust psychologically and spiritually to the nearness and sacredness of death. This transition also makes it possible for patients to make choices about how they wish to live out their final days in the most fulfilling way.

Continuing to treat to cure when a person has entered the final stages of life is in essence a denial of the reality of the situation, and is often detrimental to the patient and their family members. It can contribute to a sense of false hope and deprive them of the opportunity to transition to the stage of accepting and preparing for death. Patients approaching the end of life need to experience peace, presence and solidarity from those around them.

The transition from cure to comfort is not something that should be viewed as a failure or give rise to undue fear. Nor should it be confused with neglect or the desire to hasten the death of the patient. For people of faith, palliative care represents a safe, supportive and comforting way to ease loved ones into their new life.

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<sup>1</sup> Pope Francis, General Audience Address, 27 November 2013.



### 3. PALLIATIVE CARE: TREATING THE WHOLE PERSON

Palliative care embraces an interdisciplinary approach which aims to provide holistic care to people living with terminal illness or who are close to death. It maximises comfort and support while also seeking to address the needs of family members and carers. With roots in religious care and nursing,<sup>2</sup> palliative care draws from a broad spectrum of disciplines, calling on a variety of specialists and a multitude of therapists to provide the best care – addressing each patient’s individual psychological, social, emotional, cultural and spiritual needs as well as attending to distress and relieving pain.

Family members, friends, doctors, nurses, allied health workers, pastoral carers and priests (or ministers of religion) can gather around those living out their final days. In seeking to reflect our love of God and neighbour by accompanying those who are dying, we are able to give our nearest and dearest the comfort and confidence that will allow them to die in peace.

Palliative care also supports family members during their loved one’s illness and aims to help people live as fully as possible until the very end.<sup>3</sup>

In the State of Victoria, many agencies operate palliative care services providing in-hospital or hospice care and palliative care services in the home.

Catholic health and aged care services in Australia strongly support the provision of excellent palliative care, currently operating more than 70 hospitals as well as 630 aged-care facilities – some of which are specialist palliative care hospices.

Pope Francis reaffirmed long standing Catholic teaching and practice in this area in a recent

address to the Pontifical Academy for Life when he said:

*“Palliative care is an expression of the truly human attitude of taking care of one another, especially of those who suffer. It is a testimony that the human person is always precious, even if marked by illness and old age. ... This is why, when their life becomes very fragile and the end of their earthly existence approaches, we feel the responsibility to assist and accompany them in the best way.”<sup>4</sup>*

### 4. LETTING GO WHEN THE TIME IS RIGHT

Catholics cherish and celebrate life but we do not advocate preserving life at all costs. In the interest of achieving the best possible care for people with life-limiting illnesses, it is best if treatments for cure and comfort overlap. In making the transition from curative treatment to palliative care, it can be a great relief to patients and their family members when they understand and acknowledge that there is no requirement to try every possible treatment when the end is near and recovery seems unlikely. Patients and their families are not bound to request or accept ‘extraordinary treatment’ which would be overly burdensome at the end of life.

In order to determine what constitutes overly burdensome or ‘extraordinary treatment’ the patient’s condition, age, disposition and a range of other factors need to be considered. When treatment is deemed to be futile, patients and their family members may choose to let the disease take its natural course and allow palliative care treatments to focus on providing comfort. This decision, when made in the best interests of the patient’s well-being, can help them to make choices

<sup>2</sup> Allan Kellehear, ‘The changing face of dying in Australia’, *Medical Journal of Australia*, 2001, 175: pp.508-510.

<sup>3</sup> *To Love to the End*, Respect Life Sunday Resource, Catholic Archdiocese of Melbourne, 2011.

<sup>4</sup> Pope Francis, Address to the Pontifical Academy for Life, 5 March 2015.



about how best to live out their final days and die a good death.

As the end of life approaches difficult decisions will need to be made with the assistance of family members and health care professionals. These decisions can be made with confidence when the focus remains on cherishing life, while at the same time accepting the inevitability of death.

It must be noted that it is never ethical to refuse a patient basic nursing or comfort care. Assistance with feeding and antibiotics for infection, for example, are almost always ordinary care.

“Nutrition and hydration should always be provided to patients unless they cannot be assimilated by a person’s body, they do not sustain life, or their only mode of delivery imposes grave burdens on the patient or others.”<sup>5</sup>

## 5. PLANNING FOR THE END OF LIFE

Decisions to refuse overly burdensome treatment should be made where possible by the patient if he or she is competent. If the patient is no longer able to make decisions for themselves, the responsibility will fall to the next of kin, unless an alternative representative has been specifically appointed by the patient. In this decision-making role the person appointed is responsible for requesting or refusing treatment in the patient’s best interest and advising health care staff of the patient’s wishes for end of life care. It is important for the appointed person to know the patient’s values and beliefs as well as what their loved one would consider to be overly burdensome.

In many hospitals and aged care facilities, patients are asked to sign advance care directives or plans. While these documents seem to represent a positive step toward greater patient autonomy, in some jurisdictions, they may prevent health care professionals from acting in the best interests of the patient. They can make it difficult and sometimes impossible for nurses and doctors to adapt treatment in response to changing or unexpected circumstances.

Advance care plans should be descriptive, rather than prescriptive with the best outcome attained when developed in conjunction with reliable medical advice and a trusted substitute decision maker is appointed. A patient’s representative will only assume decision making responsibilities when the patient is incapable of making the decisions stipulated in the advance care document.

## 6. EUTHANASIA

Euthanasia intentionally ends someone’s life rather than accompanying and comforting them while relieving their pain and suffering.<sup>6</sup> It also takes us away from seeing death as a natural part of life. Euthanasia is not compassionate. It is the admission of a society’s inability to provide proper care to those at the end of life. “True compassion ... helps vulnerable people with their problems instead of treating them as a problem.”<sup>7</sup>

Euthanasia is committed by a deliberate act or omission which, of itself and by intention causes death to eliminate suffering.<sup>8</sup> This can take the form of active euthanasia or assisted suicide.

It is not euthanasia to give a patient adequate pain control. The aim of pain management is to treat the pain so that the patient and their family members

<sup>5</sup> *Code of Ethical Standards for Catholic Health and Aged Care Services in Australia*, 2001, part 2, section 5.12.

<sup>6</sup> *Catechism of the Catholic Church*, 2277.

<sup>7</sup> *To Live Each Day with Dignity: A Statement on Physician Assisted Suicide*, United States Conference of Catholic Bishops, p.6.

<sup>8</sup> Pope John Paul II, *Evangelium Vitae (The Gospel of Life)*, 1995, section 65.



are comfortable. Treating someone's pain is not the same as seeking to hasten the patient's death.

Euthanasia crosses a line. It seeks to overthrow long held medical maxims which would fundamentally change the practice of medicine and strip the patient-physician relationship of the absolute trust that is so crucial to the practice of medicine.

In the past 20 years, 30 proposals to legalise euthanasia have been put to Australian parliaments. Only one has passed, however, this was later repealed. Since that time the lived experience of Belgium, the Netherlands, Switzerland and Luxembourg have shown that once approved, laws cannot contain the abuses that stem from such a radical departure from traditional medical ethics. In just over a decade since the introduction of euthanasia, Belgium now allows euthanasia for children,<sup>9</sup> patients with autism, anorexia, borderline personality disorder, chronic-fatigue syndrome, partial paralysis, bi-polar disorder, and people who are "tired of life".<sup>10</sup> Almost 30 per cent of cases of euthanasia in Flanders now occur without explicit consent<sup>11</sup> and only half the euthanasia cases are reported as legally required.<sup>12</sup>

It is not simply a question of individual rights or the autonomy of a patient who requests euthanasia. The effect on families, communities left behind, health care professionals involved in decision making and society at large must be

considered. As it becomes harder for people to care for the sick and elderly at home,<sup>13</sup> illness and death are being increasingly institutionalised. Many die in hospitals and aged care facilities despite the majority wishing to be able to die at home. As a result of these changes in society, people can become more ignorant about illness and suffering and fearful of the inevitability of death.

It is important for Catholics to take seriously the pain and isolation that sick and terminally ill people suffer, and faithfully accompany them with our care, compassion and prayer as they cross from this life to the next.

*"What is the Christian meaning of death? If we look at the most painful moments of our lives, when we lost a loved one – our parents, a brother, a sister, a spouse, a child, a friend – we realise, even amid the tragedy of loss, even when torn by separation, the conviction arises in our hearts that everything cannot be over, that the good given and received has not been pointless. There is a powerful instinct within us, which tells that our lives do not end with death."*<sup>14</sup> – Pope Francis

<sup>9</sup> Dan, B., et al. 'Self-requested euthanasia for children in Belgium', *The Lancet*, 2014, volume 383, issue 9918, pp.671-2.

<sup>10</sup> Aviv, R., 'Who has the right to a dignified death?', *The New Yorker*, 22 June 2015.

<sup>11</sup> Chambaere, K., Bilsen J., Cohen J., et al. 'Physician-assisted deaths under the euthanasia law in Belgium: a population-based survey' *Canadian Medical Association Journal*, 2010, 182(9), pp.895-901.

<sup>12</sup> Smets, T., Bilsen, J., Cohen, J., et al. 'Reporting of euthanasia in medical practice in Flanders, Belgium', *British Medical Journal*, 2010, 341:c5174.

<sup>13</sup> *Palliative Care*, Victoria Auditor General's Report, 2015.

<sup>14</sup> Pope Francis, General Audience Address, 27 November 2013.



## RESOURCES

### **The Life, Marriage & Family Office**

*A wide range of end of life care resources – including online copies of this resource and accompanying videos – can be found on the LMFO website and social media pages.*

Website: [www.cam.org.au/lifemarriagefamily](http://www.cam.org.au/lifemarriagefamily)

Facebook: Life, Marriage & Family Office

Twitter: LMFO Melb

YouTube: Life, Marriage & Family Office

### **My Future Care**

*It is important to reflect on one's future health care needs. This resource from Catholic Health Australia provides information for people considering their future health care needs, and guidance for health care professionals.*

Website: [www.myfuturecare.org.au](http://www.myfuturecare.org.au)

### **Advance Care Plans**

*Advance care plan guidelines for patients and medical practitioners can be found on the website of Catholic Health Australia.*

Website: [www.cha.org.au/publications](http://www.cha.org.au/publications)

### **Real Love, Care & Compassion**

*Produced by the Australian Catholic Bishops' Conference, this resource provides useful information on the dangers of euthanasia and assisted suicide.*

Brochure: [www.goo.gl/6wGDyg](http://www.goo.gl/6wGDyg)

### **Stephanie's Journey**

*Stephanie Packer is a terminally ill wife and mother of four fighting against assisted suicide with a powerful story to tell.*

Video: [www.stephaniesjourney.org](http://www.stephaniesjourney.org)

## WHAT YOU CAN DO:

### BE INFORMED

Develop an understanding of palliative care and how it is different to euthanasia and assisted suicide. Encourage others to become more informed. Access the Respect Life Sunday resources on the Life, Marriage & Family Office website.

### TALK ABOUT IT

Talking is the most important thing you can do to prepare for the death of someone you love. Have a conversation with loved ones about how you would like to be cared for at the end of your life. Also, ask them about their plans and wishes for care.

### PRAY ABOUT IT

Pray that life continues to be protected from birth until natural death. Pray especially for those with sincerely held beliefs about the taking of human life. Ask friends and parishioners to pray too.

### TAKE ACTION

Encourage and support politicians who are committed to protecting life. Also be ready to challenge misleading descriptions of euthanasia such as 'dying with dignity,' as well as assertions that pain management methods used during palliative care are similar to euthanasia.

## PRAYER FOR THE END OF LIFE

Jesus Crucified!

I always carry you with me,

I love you above all things.

Thank you for my life, and for the gift of life  
in every human being.

Be with infants in the womb, the newborn,  
and all whose life is challenged.

Be with the elderly and the sick as they share in your suffering.

May our love of life be a light to the world  
so that all may know you are near.

Be my defence in life, and my comfort and confidence  
when death approaches. Amen

+ *Dennis J. Rost*

*Life Marriage  
and Family Office*

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