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Palliative Care:  
a human right  
and moral  
imperative

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# Palliative Care: a human right and moral imperative

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Daniel Nuzum & Marie Murphy

Palliative care is the term used to describe care provided when cure is no longer possible. It is a term that evokes an emotional response in most people. When introduced for the first time, for many, it can be a time of uncertainty and misperception. It usually signifies a serious and progressive illness personally or in a loved one; and the mention of palliative care may evoke fear about impending death. The diagnosis of a life-limiting illness – especially at an early age – is a devastating experience and often unexpectedly we come face to face with our own mortality. It is in this context that we may hear about palliative care for the first time. End of life care is one aspect of palliative care. The introduction of palliative care does not necessarily mean death is imminent but it may trigger conversation about end of life care and concerns. Public awareness about palliative care is diverse, however a 2010 published study amongst the general Irish population commissioned by the Irish Hospice Foundation suggests that most Irish people are concerned about the quality of their dying and moreover that religious beliefs may influence end-of-life decision making.<sup>1</sup>

Coupled with broad confusion generally, there is much inaccurate and irresponsible social commentary about palliative care, related ethics and moral theology which at best sows seeds of doubt for patients and loved ones when faced with incurable illness; at worst, incorrect understanding can lead to unnecessary physical, social, emotional and spiritual suffering and pain. At the

1 McCarthy J, Weafer J, Loughrey M. 'Irish views on death and dying: a national survey', *Journal of Medical Ethics* 2010;36:454-458.

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heart of inaccurate commentary – which can be explicit at times or more often subtle and indirect – is the fear that palliative care somehow equates with hastening death which in turn is really euthanasia cloaked in respectability. This is the theological, ethical and social ‘elephant in the room’ concerning palliative care from a faith perspective. Some of this commentary is informed by a genuine desire to reflect theologically and ethically on life, dying and death which is the call of every responsible person of faith and is to be encouraged. However, there is also ill-informed and inaccurate commentary that does not reflect the position of major world faiths and the place of palliative care declared as a human right in 2011 by the United Nations.<sup>2</sup>

This article seeks to set out some of the principles of palliative care from a pastoral and theological perspective and in doing so will face some of the hard questions that have sometimes been posed as concerns about whether palliative care is in keeping with Catholic Church teaching.

### VALUE OF HUMAN LIFE

For members of the Catholic Church there is clear and unambiguous teaching that all human life is sacred from conception to natural death.<sup>3</sup> Therefore it is perfectly reasonable that anything that pertains to our dying is worthy of prayerful, social, theological and ethical reflection. The intentional ending of the life of another, euthanasia, is always wrong and this is expressed clearly in *Evangelium Vitae* by Pope John Paul II and reaffirmed consistently in subsequent teaching by Pope Benedict XVI and Pope Francis. It is right therefore to have a natural and well-placed caution towards anything that might impinge on this core and inviolable principle of the value of all human life and the dignity of the human person, after all we profess from a Christian anthropological perspective that every human person reflects the *Imago Dei*. Indeed the value of human life is the most basic of all human rights and all world faiths profess the sacredness of human life. Palliative care holds the value of human life at its core, celebrating, and *enabling* through skilled care, the uniqueness of each individual. ‘*You matter because you are you and you matter until the last moment of your life. We will do all we can, not only to help you die peacefully, but also to live until you die*’.<sup>4</sup>

Although the protection of human life is a basic human right, it is also a simple fact of life that illness can cause suffering and pain

2 <http://www.ifhhro.org/news/un-advocacy-on-palliative-care-as-a-human-right/>

3 Vatican, *Catechism of the Catholic Church*, Vatican: Libreria Editrice Vaticana, 1993, 2258.

4 Cicely Saunders, ‘*Care of the Dying*’, *Nursing Times*, 72 (1July 1976): 1003-5.

and that treatment of this suffering and pain is also a human right. Not to respond to suffering or pain is a form of torture and a gross violation of human rights and dignity. Palliative care attends to the suffering of the person rather than focussing on disease and does so within a robust ethical framework. So, where does palliative care fit into the wider healthcare model when most healthcare endeavours are focussed on curing illness and preserving life?

WHAT IS PALLIATIVE CARE?

Palliative care is defined by the World Health Organisation as

“an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”<sup>5</sup>

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.<sup>6</sup>

As is illustrated by this comprehensive definition, palliative care as a discipline attends to the needs of the whole person and his/her family unit. It is not a narrow ‘symptom response unit’ but rather a dedicated and specialised medical discipline.<sup>7</sup> The preface to *The Oxford Textbook of Palliative Medicine* states that ‘Palliative

5 <http://www.who.int/cancer/palliative/definition/en/>

6 *ibid.*

7 Clark, D. *To comfort always. A history of palliative medicine since the nineteenth century*, Oxford University Press, Oxford 2016.

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medicine asserts, boldly and optimistically, that even in the face of overwhelming illness, suffering can and must be relieved'.<sup>8</sup>

### HISTORY OF PALLIATIVE CARE

Palliative care is formally considered to be a relatively new medical discipline originating from the work of Dame Cicely Saunders who founded St Christopher's Hospice, London in 1967. Saunders is recognised as bringing together in one place a focussed approach to clinical expertise and symptom management, compassionate care, teaching and research. However, here in Ireland we also need to recognise that religious orders such as the Religious Sisters of Charity were providing highly valued end-of-life care and founded two of the world's oldest hospices, St Patrick's Hospital (now Marymount University Hospital and Hospice) Cork in 1870 and Our Lady's Hospice Dublin in 1879.<sup>9</sup> The contribution of Irish religious, medical, nursing and pastoral care to the broader palliative care discipline in Ireland and beyond is a story yet to be fully told.

### A BIBLICAL VIEW

For people of faith there is no need to rehearse here the centrality and value of all created life in the Judeo-Christian biblical texts and traditions. As Christians, we hold dear to the belief that God's supreme expression of our human life is in the person of Jesus Christ. In the life, ministry, death and resurrection of Jesus, God embodies the fullness of life where pain, struggle and suffering are transformed. At a surface reflection the life of Jesus can point to a redemptive value in suffering, however to remain there is to become stuck in a one-dimensional and less than faithful view of the fullness of life to which we are called. Jesus demonstrates over and over again God's abundant mercy and grace to alleviate, to palliate the suffering of human pain – physical, emotional, social and spiritual. In fact Jesus – par excellence – expressed healing as complete healing, (shalom) and never compartmentalised pain into mere physical, mere emotional, mere social or the mere spiritual: pain is pain. The life of Jesus Christ, which for this purpose can be summed up in his words *I have come that you may have life and have it abundantly* (John 10:10) is in many ways a charter for palliative care. In them are held the core ethical value of palliative care which is that of dignity and quality of life. This brings us from a Biblical perspective to the core of palliative care: palliative

8 Cherny N, Fallon M, Kaasa S, Portenoy R & Currow D (eds), *Oxford textbook of palliative medicine (5th Ed)*. Oxford University Press, Oxford, 2015.

9 McCarthy K, *A dream unfolding: portrait of St Patrick's Hospital and Marymount Hospice*, St Patrick's Hospital/Marymount Hospice, Cork, 2004.

care is about living as much as it is about dying. To state so boldly that palliative care is about living may come as a surprise, but to suggest otherwise is to undermine the professional integrity of healthcare professionals and more importantly to deny the profound experiences of patients and their loved ones who treasure each moment of life when earthly life is limited in timespan by incurable or progressively degenerative illness. In her book *Hospice and Palliative Care* Cicely Saunders refers to the aim of palliative care as being to enhance the quality of living and relationships for patients and families for whatever time is left.<sup>10</sup> This requires care delivered by a team of highly skilled professionals of many disciplines working together.

#### CATHOLIC MORAL TEACHING AND PALLIATIVE CARE

Catholic moral teaching views matters pertaining to the end of life through the lens of the value of life, the naturalness of death and that humankind is created in the image of God.<sup>11</sup> This approach is further experienced liturgically and pastorally in the Christian expression of eternal life and the non-finality of death. This is supremely expressed as an eschatological reality through funeral liturgies and through the celebration of the Eucharist. In *Sacrosanctum Concilium* the Second Vatican Council stressed the importance that funeral rites 'should express more clearly the paschal character of Christian death'.

The common thread that is woven through Scripture and Church teaching is that of the value and dignity of human life. While by virtue of being human suffering exists, the Church has consistently affirmed in her social and moral teaching that care for those who suffer is a *sine qua non* for all. The watershed documents of the Second Vatican Council and subsequent papal encyclicals explore and develop our approach to illness, suffering, pastoral care, and healthcare ethics and each, supported by addresses of successive Popes provides a congruent and clear message about the appropriateness and essential character of palliative care.

Drawing on the definition of palliative care as outlined above from the World Health Organisation, palliative care seeks to identify, assess and relieve symptoms of distress caused by illness or disease. It is important to highlight a fundamental principle of palliative care that the process of dying, once diagnosed, is neither hastened or prolonged. The responsibility to diagnose dying remains that of the responsible physician and requires medical skill and wisdom. Once dying is diagnosed the focus of care becomes

<sup>10</sup> Saunders C, *Hospice and palliative care: an interdisciplinary approach*, E Arnold, London, 1991.

<sup>11</sup> Corkery P., *Bioethics and the Catholic moral tradition*. Veritas, Dublin, 2011.

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comfort. Unnecessary and futile interventions cease. This approach to care is entirely consonant with Catholic moral teaching as expressed in magisterial teaching. The Catechism of the Catholic Church when discussing the discontinuation of medical procedures states that in discontinuing futile treatment ‘one does not will to cause death; one’s inability to impede it is merely accepted’.<sup>12</sup> Developing this further, palliative care is not a passive approach where unnecessary medical treatment is not pursued but rather it is an active endeavour to intentionally alleviate or ‘palliate’ distress, pain or discomfort. This approach demands a high level of clinical, psychological and spiritual care where healthcare professionals are working closely with a patient and his/her family.

One area of common discussion is how medication is used to alleviate symptoms. In some quarters there is a thinly veiled belief that medication used in palliative care may shorten life. It is perfectly reasonable that medication would be used (as one of a myriad of approaches to alleviating distressing symptoms). Much casual and often ill-informed conversation arises about the use of strong opioids (ie ; morphine and others). For example pain and breathlessness may both occur in advanced illness. These symptoms can be relieved by the judicious use of strong opioids e.g. morphine. This is a safe and validated practice. Good symptom control results in improvement to the patient’s quality of life and ability to function independently. It is not uncommon to hear it said that when morphine is used that the recipient will die soon! However, such assertions are NOT supported in the published medical literature and more importantly are not evidenced in clinical practice. There is an expanding body of evidence that early palliative care improves quality of life and, in the case of advanced cancer, is also life prolonging. Thus medications prescribed in palliative care, including morphine, when used correctly are life enabling, with the purpose of relieving suffering including that which may emerge once a patient enters the dying phase of their illness. The myths surrounding the use of morphine and other medications in palliative care reflect an ignorance on the part of commentators. Ill-informed statements by well-meaning bystanders can cause much personal distress to both patients and family members at a very vulnerable time in their lives.

At a recent international palliative care congress (2018) in Rome hosted by the Pontifical Academy for Life, hospitals and healthcare centres were enjoined to ‘ensure affordable access to basic palliative care medicines, particularly to opioid medications

12 Vatican, *Catechism of the Catholic Church*, Vatican: Libreria Editrice Vaticana, 1993. 2278

like morphine...'.<sup>13</sup> In a message to the conference, the Vatican Secretary of State, Cardinal Pietro Parolin reminds us that Pope Pius XII addressed this very ethical dilemma in 1957 when he asserted that 'Pope Pius XII clearly legitimized, by distinguishing it from euthanasia, the administration of analgesics to alleviate unbearable pain not otherwise treatable, even if, with death imminent, they cause life to be shortened'.<sup>14</sup>

Another myth is that palliative care will shorten life or hasten death. This can be colloquially heard in phrases like "is he at the palliative stage yet?" or "it's too early to call in the palliative care team". This lack of understanding is more common than we would wish -even in the medical world and healthcare chaplaincy. As cited above, the general population is also uninformed about palliative care.<sup>15</sup> Palliative care is more than end-of-life care. In palliative medicine, the evidence points to improved outcomes and longer lifespan with the early introduction of palliative care.<sup>16</sup> It is illness that brings about death in palliative care, not medication. When faced with the reality that a patient can not be cured, it is not an option to abandon the patient at what is arguably their point of greatest need. There should never be a situation where the fatalistic words "there is nothing more we can do" are uttered. In the face of incurable illness, palliative care keeps the focus of the whole healthcare team on the needs of the patient and his/her family. Archbishop Vincent Paglia, President of the Pontifical Academy for Life addressing the 2018 International Congress of Palliative Care described palliative care as helping 'the medical profession rediscover its humanistic vocation'.<sup>17</sup>

Palliative care is not an alternative to curative treatment but rather should be seen as working alongside medical or surgical care. For example many patients continue with their chemotherapy or radiotherapy while also receiving palliative care for symptoms related to their illness. Such patients will receive the benefits of both teams in an integrated way thereby providing optimal care through the early identification and relief of distressing symptoms and improved quality of life.

13 White Paper for Global Palliative Care Advocacy, PAL-LIFE advisory group, Pontifical Academy for Life, Vatican City, 2018.

14 cf. *Acta Apostolicae Sedis XLIX* [1957], 129-147, as cited in a letter from the Cardinal Secretary of State to the International Palliative Care Congress, Rome, 2018.

15 <http://jme.bmj.com.ucc.idm.oclc.org/content/36/8/454>

16 <http://www.nejm.org/doi/full/10.1056/NEJMoa1000678>

17 <http://www.academyforlife.va/content/dam/pav/documenti%20pdf/2018/Greetings%20from%20the%20President%20to%20the%20PAL-LIFE%20ConventionRome%202028.pdf>



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### PALLIATIVE CARE AS A MORAL IMPERATIVE

Approaching palliative care in this way there is a strong moral argument that palliative care affirms human life, protects the dignity of the human person and safeguards a profoundly theological understanding of each person embodying the image of God. After all, to return to the Biblical narrative, Jesus articulates unequivocally that pastoral care (and by extension medical care) is an intentional enterprise. Humanity is called to intentionally and actively reach out to those who suffer ‘For as much as you did it to one of the least of these you did it to me...’ (Matthew 25:35-40). Pope Francis in a message to a meeting of the World Medical Association in 2017 wrote

‘even if we know that we cannot always guarantee healing or a cure, we can and must always care for the living, without ourselves shortening their life, but also without futilely resisting their death. This approach is reflected in palliative care, which is proving most important in our culture, as it opposes what makes death most terrifying and unwelcome – pain and loneliness’.<sup>18</sup>

In this year of the *World Meeting of Families* it is important to note that palliative care sees the family unit as the focus of care. This communal focus of palliative care recognises the systemic and often far-reaching impact of incurable illness. We do not live, suffer or die in isolation from those we love or who love us even when our family structures and relationships may be strained or fractured. It is often of great comfort to patients in our palliative care services to know that the palliative care team will continue to care for and support their loved ones after their death. If a patient’s suffering was ameliorated by good symptom control, their loved ones witnessed experience of care may positively influence their bereavement. The reverse is also true...memory of a patients suffering at the end of life causes distress for loved ones left behind. Thus good palliative care for patients at end of life is important not just for the patient but also their loved ones.

### RECENT DEVELOPMENTS FROM THE PONTIFICAL ACADEMY FOR LIFE

The Pontifical Academy for Life [PAL] has long debated issues of bioethics and healthcare. The PAL-LIFE project was initiated by the PAL in 2017 as an ‘international advisory working group on diffusion and development of palliative care in the world’. This group made up of global palliative care experts had its initial

18 [http://www.academyforlife.va/content/dam/pav/documents/papi/papa-francesco/MESSAGE%20end\\_of\\_life\\_en.pdf](http://www.academyforlife.va/content/dam/pav/documents/papi/papa-francesco/MESSAGE%20end_of_life_en.pdf)

meeting in Rome in 2017 and developed a global palliative care strategy for the Pontifical Academy of Life.<sup>19</sup>

In early 2018 the Academy held an important international palliative care congress entitled “Palliative Care: Everywhere & by Everyone” to present the work of the PAL-LIFE project to the public. This international congress had three dimensions 1) Identifying, analysing and discussing the value of palliative care; 2) the diffusion and development of palliative care throughout the world; 3) what religions say about pain and suffering. During this congress the importance of palliative care as a human right was asserted with conviction by the Church. In addition the Pontifical Academy for Life presented a White Paper for global palliative care advocacy with recommendations for thirteen stakeholders.<sup>20</sup>

On the global stage it is a matter of profound urgency to address the lack of access to palliative care and to pain control medication such as morphine. A recent study in *The Lancet* highlighted the enormity of this global challenge where in many low and middle income countries access to palliative care can be as low as <1%. Surely this is an affront to the dignity of humanity.<sup>21</sup> It is to this context that the Pontifical Academy for Life has an important political and advocacy role to play in bringing together world leaders in palliative care. The PAL-LIFE project in no small way seeks to progress global access to palliative care as a basic human right. In this regard the work, ministry and mission of the Pontifical Academy of Life has an important role in shaping the *Sensus fidelium* of popular discourse to affirm palliative care as being an active gospel initiative. Archbishop Vincent Paglia speaking at the PAL-LIFE congress in 2018 proposed that this accompaniment of those who are dying should be seen as an eight act of corporal mercy.

#### CONCLUSION

The place of palliative care as a human right for all who experience physical, psychological or spiritual suffering and pain as a result of illness deserves our wholehearted support. To provide palliative care is to live out the teaching of Jesus Christ so that all may experience life in abundance where quality of life no matter how fragile is a benchmark of our compassion and charity. Palliative care cherishes at its heart the dignity of every person and their loved ones. Through skilled medicine, compassionate care and exquisite attention to the holistic physical, psychological and spiritual care,

19 <http://www.academyforlife.va/content/pav/en/projects/pallife/pallife-project.html>

20 <http://www.academyforlife.va/content/pav/en/news/2018/whitepaper13reccomendations.html>

21 [http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736\(17\)32513-8.pdf](http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(17)32513-8.pdf)

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palliative care should not be a luxury but a central part of our healthcare, available to all. To appropriate the title of the recent Vatican congress, 'Palliative Care: Everywhere & by Everyone' is the call and the clear message of not just of the Catholic Church but all major world faiths .

In the words of Dame Cicely Saunders '*You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die*'.

In summary for the Christian, Palliative Care: a Christ-like expression of dignified love.

### **Christ Comes Disguised as a Stranger**

I saw a stranger yesterday  
I put food for him in the eating place,  
drink for him in the drinking place,  
music for him in the listening place;

And in the Holy Name of the Trinity,  
he blessed myself and my house,  
my possessions and my family.

And the lark said as she sang:  
It is often, often, often,  
Christ comes disguised as a stranger.

– GARETH BYRNE, *Love One Another as I Have Loved You*,  
Veritas, 2016, p. 34.