From: Susannah Duncan - SVPHM on behalf of CCCHE - SVPHM
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Caroline Chisholm Centre for Health Ethics

Chisholm Health Ethics E-Bulletin

June 2017

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Caroline Chisholm...

Inspired by the love of God, Caroline Chisholm (1808-1877) dedicated her life to serving those in need. She was also one of Australia's first social researchers. This Centre is dedicated to her as we hope and pray that our work and research will also be inspired by love of God, and also serve those in need.✠

Contact CCCHE

From the Chair

Julia Trimboli, MA Theology & Bioethics

Caroline Chisholm Centre for Health Ethics (CCCHE) began officially in March 1995. It is interesting to note that in July 1995 we held our first official public event, which was a discussion on Euthanasia. Due to the popularity of this event, it was broadcast on ABC radio - a credit to the centre being recognised as a place of importance in the public debate.

As I write this many years later, the sector faces similar issues discussed at this first public event. Much has changed in the church and our health systems since that time. However, the Centre continues to foster dialogue in the public space in relation to such important issues.

Hence, it is with great pleasure that we have two important contributors to the new online Bulletin. Rev Dr Joseph Parkinson STL PhD and Dr Caroline Ong RSM MBBS FRACGP MA who invite us to face this issue from our tradition with confidence.

In the spirit of Caroline Chisholm may we, as a Catholic health sector, continue to

explore the ethical questions together both robustly and pastorally. ✠

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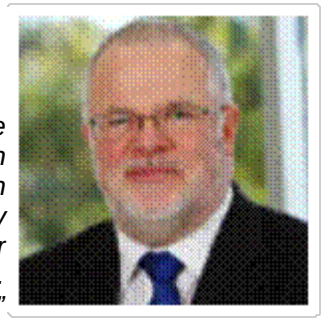
Finding light in darkness



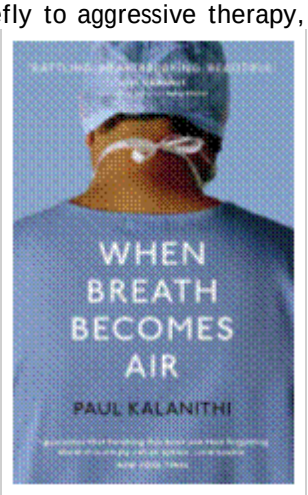
Rev Dr Joseph Parkinson, STL PhD

Near death experiences and the wisdom they produce are the stuff of countless novels, but when the story ends in the author's death, where is wisdom to be found? American neurosurgeon Paul Kalanithi has left an astonishingly eloquent and lucid account of his own dying and his inner journey to find meaning and even peace in that experience. As inspiring as it is tragic, "When Breath Becomes Air" rightly sits on The New York Times list of best sellers, and is a must-read for anyone working in bioethics or health care.

It was the priest in generations past who trod the sacred space between life and death, for he alone could make sense of one in light of the other. For Christians, answers lay ultimately in the mystery of Christ's death and resurrection, the great symbol of our search for ultimate meaning in the face of injustice and suffering – a theological answer to very tangible human questions.

As world views have evolved, so too the answers we seek: in the liminal space surrounding death, previously priestly power has passed to the physician, indeed to the medical professions in general. When confronted with suffering today we instinctively turn first to the empirical – the doctor, the surgeon, the health care system – and often only as last resort to the spiritual.

I came across this observation thirty years ago at an international conference on Catholic health care, and it came back to me while reading the 2015 best-seller "When Breath Becomes Air" by the late American neurosurgeon Dr Paul Kalanithi.[1] The author tells his own story of dying, of confronting in his own case the existential questions he had helped so many others negotiate in his short years of clinical practice. The shelves of airport bookstores are replete with 'doctor-turned-patient' stories, which usually resolve in the author committing to become a better doctor. Kalanithi knew he had no such option: his metastatic lung cancer responded only briefly to aggressive therapy, returning to end his life at the age of 37.



But his story is more than an account of his dying (the final chapter was written by his widow Lucy). Naturally it traces his pathway through university, medical school and specialist training, but Kalanithi takes the reader much deeper than that. Reflections on the doctor-patient relationship give way to age-old questions of time and meaning: in particular the relativity of time at the end of life, and what ultimately gives meaning to a life cut cruelly short. Kalanithi flirts briefly with the answer of the preacher in the biblical Book of Ecclesiastes: "All is vanity". But in the end he discovers meaning in his own way: not in searching the past, but in being present to the present; not in achievement or wealth, but in passing new life to a daughter whose very presence brought him profound peace and joy.

What has all this to do with bioethics? I have noted before that some strands of Catholic bioethics at the end of the Twentieth Century had acquired a tendency to focus so tightly on reasoned principles that it sometimes risked overlooking the unique contribution of personal insight.[2] Dr Margaret Mohrmann pleads powerfully for doctors (and bioethicists) to pay close attention not only to medical data and ethical principles, but also and perhaps especially to the patient's personal experience of illness. A primary question for Mohrmann is not simply "what is the prognosis", but "what does this illness mean to the patient?" A definitive diagnosis of psoriasis does not exhaust the issue: until the doctor knows that the patient experiences the disease as 'humiliation', the doctor has missed its true meaning for the patient and so, regardless

of ethical principles, cannot help the patient heal as a whole person – even in the absence of a cure.

Considering it as a subset of moral theology, Catholic bioethics has a duty to establish its central focus on the person of the patient in all of his/her humanity.[3] The challenge, of course, is how to achieve this without lapsing into a kind of 'situation ethics' that would make everything relative to the individual person and deny the existence of objective values or principles. Relativity has its place, to be sure, but that place isn't here. The Catholic ethical tradition grounds itself instead in our shared human nature which is, as it were, received as 'gift' by each one of us, and it is in honouring the totality of that gift that we honour both one another and the One whom we Christians hold to be the Giver of Life.

Kalanithi makes a similar discovery through reflecting, in light of his terminal disease, on the vocation of the physician. He captures something of the sacred, even sacerdotal nature of his profession:

> All of medicine, not just cadaver dissection, trespasses into sacred spheres. Doctors invade the body in every way imaginable. They see people at their most vulnerable, their most sacred, their most private. They escort them into the world, and then back out. Seeing the body as matter and mechanism is the flip side to easing the most profound human suffering.[4]

In light of his own dying, Kalanithi confronts for himself the kind of existential questions his patients had raised so often: "questions intersecting life, death, and meaning, questions that all people face at some point".[5] These draw him back to reflect on the power of the physician to help patients and their families to make sense – to find meaning – even in the darkest experiences of suffering and death. Musing on his own successes and failures as a physician brings Kalanithi to a realisation that every person – patient, parent, doctor, child – is enmeshed in networks of relationships that sustain and give meaning to their life, and it is in such sacred spaces that true healing can occur even in the face of death.

> Amid the failures and tragedies, I feared I was losing sight of the singular importance of human relationships, not between patients and their families but between doctor and patient. Technical excellence was not enough. As a resident, my highest ideal was not saving lives – everyone dies eventually – but guiding a patient or family to an understanding of death or illness. When a patient comes in with a fatal head bleed, that first conversation with a neurosurgeon may forever colour how the family remember the death, from a peaceful letting go . . . to an open sore of regret. When there's no place for the scalpel, words are the surgeon's only tool.[6]

Today, in many cases, the first care giver admitted to the liminal space around a dying person is not the priest but the doctor. Yet the task remains the same: to help this person, and/or their families and loved ones, to make sense of the tragedy they traverse so that life can go on with some sense of meaning. Kalanithi realises that the caring relationship itself, captured and expressed in words of compassion, has a unique potential to bring healing.

As a writer, Kalanithi has the true artist's gift for evoking deep truths through slight and seamless transitions. At one point the narrative gently moves from past to present tense, heralding something new and momentous, like a symphonic shift from minor to major key. He is dying, and seeking to make sense of his imminent end his thoughts turn to the relationship between time and space, between memories of past achievement and hopes for the future – except that, if he has a future at all, it is utterly tenuous.

> I don't know what I'll be doing five years down the line. I may be dead. I may be healthy. I may be writing. I don't know. And so it's not all that useful to spend much time thinking about the future – that is, beyond lunch. . . . Everyone succumbs to finitude. I suspect I am not the only one who reaches this pluperfect state. Most ambitions are either achieved or abandoned; either way, they belong to the past. The future, instead of the ladder toward the goals of life, flattens out into a perpetual present. Money, status, all the vanities the preacher of Ecclesiastes described hold so little interest: a chasing after wind, indeed.[7]

Denied by illness the luxury of hope, where should he seek such meaning as to bring his life full circle, from searching to finding, from longing to fulfilment, from restlessness

to peace? Kalanithi finds his answer neither in memories of past achievement nor in dreams for the future, but in the present tense alone: in treasuring and contemplating the gift of a life he has helped to create. In breathtakingly honest and beautiful prose, Kalanithi offers us his answer in a single, unforgettable paragraph – the last he ever wrote. I won't spoil it for you: find the book and read it yourself, and see if it doesn't pierce you through and through.

So what might Paul Kalanithi offer Catholic bioethics?

Human life has, in Kalanithi's words, a "visceral nature . . . which is unique and subjective and unpredictable":

> Science may provide the most useful way to organise empirical, reproducible data, but its power to do so is predicated on its inability to grasp the most central aspects of human life: hope, fear, love, hate, beauty, envy, honour, weakness, striving, suffering, virtue. Between these core passions and scientific theory, there will always be a gap. No system of thought can contain the fullness of human experience.[8]

Kalanithi takes us one step further than Mohrmann, who like him pleads greater respect for the meaning-giving stories and focal points of individual lives. Unless we hear their stories, she says, we miss the real human meaning of the patient's illness and so cannot help them weave the next chapter of their life's journey. Kalanithi – perhaps because his life's journey is all but run – pushes us to ask how the patient's experience of proximity to death might impact their perception of absolute value.
From our vantage point outside the unfolding human drama, do we see things as the dying patient sees them? Does the patient see something that we can't? How far can we accommodate the unusual or the unique in Catholic bioethics?

Some years ago I was consulted by a hospital chaplain on behalf of a Catholic woman whose husband of over 60 years was imminently dying. He was an inpatient of a public facility, and on one occasion while she was visiting him (as she did each and every day, for she was devoted to him) a VMO noticed she had symptoms consistent with kidney disease. She was offered treatment at the same hospital, with the suggestion that two or three times a week after visiting her husband it would take little effort to check into the dialysis unit. The woman thought long and hard about the offer, and decided to accept it – but only as long as her husband lived. She decided that once he passed away, she would cease dialysis and allow her illness to run to its natural conclusion.

In the years since I have returned to this woman's choice over and over again. There is no question that dialysis would have been therapeutically beneficial for her, so the technical ethical point seemed to me to be whether her treatment or its effects constituted (in her view) an unreasonable burden. In itself, of course, life is never a burden – but in a particular context it is undeniable that some aspects of life might be experienced as burdensome. This lady seemed to base her choice on an estimation that 'life without my husband of 60 years' would be too psychologically and emotionally burdensome. Does this satisfy the requirements of the Principle of Extraordinary Means of Medical Treatment?

Kalanithi, I suspect, would have said 'yes'. Just as he struggled to find meaning in his dying, she struggled to find meaning after her husband's dying. Kalanithi finally found meaning in his child, but she lost hers when she lost her husband. From her unique perspective, facing the calamitous loss of her life partner, her choice has the kind of "unique, visceral" quality which removes it from the reach of absolute ethical dissection. I am not sure I would make the choice this lady made, but I like to think our bioethics is generous enough, and sufficiently respectful of the sacred liminal spaces surrounding death, to accommodate her. As Kalanithi put it:

> In the end it cannot be doubted that each of us can see only a part of the picture. The doctor sees one, the patient another, the engineer a third . . . . Human knowledge is never contained in one person. It grows from the relationships we create between each other and the world, and still it is never complete. And Truth comes somewhere above all of them ...[9]

Rev Dr Joseph Parkinson STL PhD is a priest of the Archdiocese of Perth and Director of the L J Goody Ethics Centre in WA. ✠

ENDNOTES

[1] Paul Kalanithi, *When Breath Becomes Air*. Vintage Publishing, 2016. Also published in Kindle and iBooks editions.
[2]

See “Medicine as Ministry”: A case for truly theological bioethics. *Chisholm Health Ethics Bulletin* 21:2 (Summer 2015) 9-12.
[3] This agenda is set by the Church itself: see for example Second Vatican Ecumenical Council, “Decree on the Training of Priests *Optatum totius*.” (28 October 1965) 16.
[4] *When Breath Becomes Air*, 73-74 (iBooks edition).
[5] Ibid, 99.
[6] Ibid, 118-119.
[7] Ibid, 247-248.
[8] Ibid, 214.
[9] Ibid, 217.

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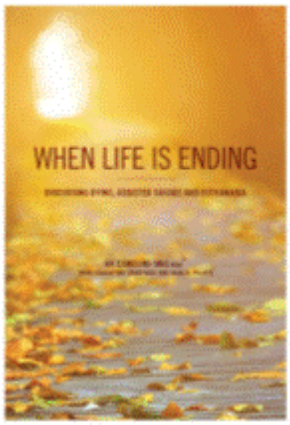
When Life is Ending booklet release

Dr Caroline Ong, RSM MBBS FRACGP MA

Author and GP Dr Caroline Ong explains how her text came about: 'As I began to write this booklet, I asked myself "How did we get to the stage in our society that such a booklet needed to be written?" There are of course many reasons, but two came to mind rather strongly: firstly the medicalisation of our dying and secondly, the move from a paradigm of community to one of individualism.



This booklet was written to remind ourselves that dying does not need to be medicalised and that the only “medicalisation” of our dying lies in the service that palliative care offers.’ Ong says. ‘It reminds us that we have come far enough in our medical knowledge and life-knowledge, to assist each other in the dying process, so as to be able to die peacefully. If that is not happening to us or our loved ones, we perhaps need to ask the person in charge why it isn’t so.

To read the booklet, click here:
When Life is Ending Booklet (pdf) ✠

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