

SUFFERING

At the Australian Palliative Care Conference in Canberra last September, I was privileged to attend two sessions at which Prof Eric Cassell (from New York) spoke about ‘personhood’ and ‘suffering’. I had long been a fan of his writing including his well-known book “The Nature of Suffering” first published in 1991. He is not a palliative care physician but his ideas on “illness” are so relevant to our work in palliative care.

His first session dealt with the importance of “illness as a story” and how each individual person’s response to illness differs according to that person’s “goals, purposes and change of function”. Illness (as opposed to ‘disease’) changes every part of a person’s function from the molecular or pathophysiological level, right through to psychological, social and spiritual domains. He contends that by encouraging the step-by-step telling of the person’s “narrative” of their illness, we can then understand their priorities, beliefs, fears and hopes, leading to appropriate interventions to improve the illness experience by reducing suffering. Thus, he believes, interventions can always alter the illness regardless of any change in the disease. Interventions at any stage of the story change the rest of the story, and interventions can lead to a change in outcome of the illness even though the patient still dies. In other words, healing can still occur within an illness despite progression of the disease process and the ultimate death of the person. As he puts it “Just because you are dying doesn’t mean you have to be sick.”

Cassell’s second talk was more about suffering and about how it is still, by some authorities in medicine, divided into “physical” and so-called “existential” types. This ancient and discredited distinction between mind and body finds voice in some palliative care circles when the issue of palliative sedation is considered. It is argued by some that it is acceptable to use palliative sedation for intractable ‘physical’ suffering near the end-of-life, but that its use in a patient with ‘existential’ suffering is ethically more tricky and, to some, unacceptable.

To put this into perspective, I can do no better than to quote from a recent paper by Cassell and bioethicist, Ben Rich (see ref below):

“...suffering is a specific distress that occurs when an impending destruction of the person is perceived and continues until the threat is gone or the integrity of the person can be restored.”

“A person is an embodied, purposeful, thinking, feeling, emotional, reflective, relational human individual existing through time in a narrative sense. Generally all of these parts are consistent and harmoniously accordant. Suffering, in which all of these parts are affected, variously destroys the coherence, cohesiveness, and consistency of the whole. It is in this sense that the integrity of the person is threatened or destroyed.”

“Bodies do not construct meaning and do not have a sense of future, only persons do. Suffering is an affliction of persons not bodies. Suffering is personal, individual, lonely, and marked by self-conflict.”

“It is not valid to make a distinction between suffering whose source may be physical, such as pain, and suffering coming from the threat to the integrity of the person from the very nature of the person’s existence.”

“For medicine and science persons are of a piece; whatever happens to one part happens to all and whatever takes place in the whole person has an impact on every single part.”

“In thinking about this problem of palliative sedation, we must remember that we are talking about very sick, terminally-ill patients. What is called existential distress arises from the impact of their sickness on their existence; helplessness, isolation and loss of control that characterize severe illness, and which is brought on by symptoms as varied as pain or profound weakness. When these things are seen by the person as threatening their destruction as the persons they have known themselves to be, they start to suffer. Their suffering then becomes the problem. Their suffering, as suffering, is no different than the suffering that comes about because of pain. To see such suffering as somehow not as real as (say) vomiting or as “just emotional” is not true of severe illness as any clinician knows it to be.”

Thus, I believe, Cassell makes a clear case for not artificially separating suffering into two separate types. Palliative sedation for the relief of severe suffering in the terminal stage of illness should depend on “the patient’s needs and wishes without regard to what is believed to be the originating source of suffering.”

Reference:

Cassell EJ, Rich BA. Intractable End-of-Life Suffering and the Ethics of Palliative Sedation. *Pain Medicine* 2010; 11: 435-438

Dr Greg Mewett

Palliative Care Physician

Grampians Regional Palliative Care Team

PALLIATIVE CARE VICTORIA LIFE MEMBERSHIP AWARD



Dr David Brumley was awarded life membership at this year’s Palliative Care Victoria Annual General Meeting. David was awarded life membership for his significant and sustained contributions to the objectives of PCV and its mission and vision. David has dedicated his life’s work to palliative care, and has achieved great accomplishments in the Grampians region. He was instrumental in the founding of Ballarat Hospice Care Inc and became Medical Director from 1987-88 and then from 1992 to the present. He was also influential in the establishment of Gandarra Palliative Care Unit at Ballarat Health Services and went on to hold the position of Clinical Director of Palliative Care at Ballarat Health Services. David’s commitment to local services, to the Grampians region and to the speciality of palliative care is a credit to him. His legacy to palliative care and our region will be the sector’s commitment to education and better communications skills for clinicians.

Congratulations David!

CONTACTS

Grampians Regional Palliative Care Team

Ph 5320 3553	Fax 5320 6493
Dr David Brumley	davidb@bhs.org.au
Dr Greg Mewett	gregm@bhs.org.au
Dr Maziah Fahandej	maziahf@bhs.org.au
Jade Odgers	jadeo@bhs.org.au
Regina Kendall	reginak@bhs.org.au
Lawrence Habegger	lawrenceh@bhs.org.au
Bernadette Matthews	bernadette@bhs.org.au

Ballarat Hospice Care Inc

Ph 5333 1118	Fax 5333 1119
Carita Potts	eo@ballarathospice.com

Central Grampians Palliative Care

Ph 5352 9328	Fax 5352 9425
Jane Bourman	jane.bourman@eghs.net.au

Djerriwarrh Palliative Care

Ph 5367 2000	Fax 5367 9641
Pam Ryan	pamr@djhs.org.au
Jane Cape	janec@djhs.org.au

Gandarra Palliative Care Unit

Ph 5320 3895	Fax 5320 3763
Dr David Brumley	davidb@bhs.org.au
Dr Greg Mewett	gregm@bhs.org.au
Maree Kewish	mareek@bhs.org.au

Wimmera Hospice Care

Ph 5381 9363	Fax 5381 9170
Melanie Hahne	mhahne@whcg.org.au
Jennifer Noonan	jnoonan@whcg.org.au
	hospice@whcg.org.au

Grampians Region Palliative Care Consortium

Peter Marshall	gpalcareconsort@gmail.com
----------------	---------------------------

JAN/FEB 2014