



# Amaranth Foundation

## *Existential Distress*

### What does this have to do with a life-threatening illness?

The word '*existential*' describes experiences related to existence and experience; with emphasis on human existence and human dealing with experience and existence. From a philosophical stance it describes those elements that exist and are identified as known by an experience rather than that known by reason.

An *existential crisis* is provoked by a significant event in one's life and may stem from the new perception of life and existence. (Wikipedia) Living with a life-threatening illness brings decline in health, withdrawal from social networks, loss of normal roles, and the utter aloneness with the confrontation of the end of one's existence.

([www.caresearch.com.au](http://www.caresearch.com.au))

*Existential Distress or suffering* at the end of life has been defined as hopelessness, futility, burden to others, loss of sense of dignity, profound loneliness, intolerable emptiness, remorse, sadness, loss of meaning, desire for death or loss of will to live and threats to self identity. It is not relieved by the treatment of physical symptoms, and can occur in the absence of such symptoms. It is distinct to *Spiritual Distress*, which is a disruption in one's beliefs or value systems, is independent of religion, and upsets the basic beliefs of a person's life. (Hospice and Palliative Nurses Association)

*Existential Suffering* is associated with advanced and progressive illnesses and Kissane (2012) states that this is an 'inevitable consequence of the disease and its treatment'. The maintenance or reestablishment of meaning is a central goal in the existential care of those with a life-threatening illness.

*Existential Loneliness* "is understood as an intolerable emptiness, sadness, and longing, that results from the awareness of one's fundamental separateness as a human being." (Ettema E, Derksen LD, van Leeuwen E. Existential loneliness and end-of-life care: a systematic review, *Theor Med Bioeth.* 2010 Apr;31:141-69.)

Kissane et al (in Ed. Chochinov & Breitbart *Handbook of Psychiatry in Palliative Medicine* 2009 p325) identifies four key domains to guide an understanding of existential concerns for people with a life-threatening illness. These are: the self (suffering must be seen within the context of the person's whole life); free choice (taking responsibility for the manner in which we live); meaning (having a sense of accomplishment) and anxiety (the impermanence of life emerges as fear and dread when illness threatens life and is sometimes referred to as 'death anxiety').

There is no such thing as a natural death ... for every man his death is an accident, and, even if he knows it and consents to it, it remains an unjustifiable violation.

Simone de Beauvoir, 1966

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# Existential Distress or Suffering

The importance of the patients' existential concerns in end of life care was described by Cicely Saunders in the 1960s when she introduced the term *total pain*, including the physical, psychological, social, and spiritual dimension. Existential needs are linked to the wish to maintain a meaning in life, to infuse life with freedom and relations as well as sustain purpose and hope.

'Suffering' has been described as a psychological or spiritual state that can diminish an individual's capacity to find solace or peace in their present situation. (Williams, 2004) It is a dynamic experience; it changes constantly as the life-threatening illness progresses and death approaches.

Kissane (2012) states that an important goal of medicine is the relief of suffering but that *existential suffering* needs a biopsychosocial response, nurturing courage and maintaining each person's sense of meaning, value and purpose.

(Kissane, D. The Relief of Existential Suffering *Arch Intern Med*/ Vol 172 (No 19) Oct 22 2012 )

Suffering in an existential framework develops from the threat to life or injury to the self, with resultant distress, grief at loss, emerging helplessness, and likelihood that this situa-

tion will endure... "pain can become overwhelming when its source is uncertain, its meaning dire, its treatment difficult, and control perceived as unlikely". Kissane continues (2012, 1501) that a [life threatening] illness challenges the usual assumptions that underpin our very existence, it challenges our 'life schema' (the belief we have about ourself, about others, about the world, about the way 'things' should happen). For the person coping with a life-threatening illness Kissane maintains that "an existential gaze can lead to despair and demoralization about the value of continued life". (p1502)

Associated with this realization is "inadequate symptom control, undiagnosed depression, unaddressed existential angst, unrecognized family distress, communication breakdown, burnout, and demoralization." (Kissane 2012, 1502)

The major forms of existential challenge include :

- Death anxiety
- Loss and change
- Freedom with choice or loss of control
- Dignity of the self
- Fundamental aloneness
- Altered quality of relationships
- Search for meaning, and
- Mystery about what seems unknowable.

(Kissane, 2012)

By focusing on the unachievable long term goals, people with life-threatening illness face feelings of futility and distress. Cherny (2009) states that a reestablishment of purpose can be facilitated by the "identification of unfulfilled aspirations, incomplete tasks, and unresolved issues that the patient can productively pursue." He continues, "remorse can provide the motivation for achievable constructive pursuit." It is important that non-redeemable issues are identified so that they do not distract from the more achievable and thus maximize productive use of time and energy. Patients can be helped "acknowledge that there are meaningful and fulfilling tasks to be done, joys to be shared, things to be said or completed, relationships to be savoured, and animosities to be resolved."

(Cherney, N. , in *Psychiatry in Palliative Medicine* Ed Chochinov & Breitbart 2009 p300-323)

Common Symptom Cluster	Nature of Existential Challenge	Adaptive Adjustment	Maladaptive Response
Fear of process/state of being dead, uncertainty of future	Death anxiety	Courage, open awareness of dying	Panic, dread, angst, anxiety disorder
Waves of tears, sadness, and emotionality	Grief at loss and change	Mourning, continued focus on living	Complicated grief, chronic anger, depression
Obsessive need for control, fear of dependence	Freedom and autonomy	Responsibility, acceptance of caregivers, treatment adherence	Nonadherence to treatments, fear of being a burden
Shame, body image concerns, embarrassment	Dignity	Robust self-esteem, self-confidence, acceptance of frailty, feeling respected	Feeling stigmatized, agoraphobic, avoidant
Social withdrawal, loneliness	Fundamental aloneness	Secure with one's self, personal integrity, connectedness	Feeling insecure, isolated, alienated
Family conflict/dysfunction	Quality of relationships	Well-functioning family, mutual support	Feeling fractured, chaotic, having unsupportive family, poor supports
Pointlessness, hopelessness, futility, desire to die	Meaning of life	Fulfilled life, with accomplishments and legacy	Demoralization, clinical depression
Guilt, loss of faith, loss of connection with the transcendent	Mystery and the unknowable	Peacefulness, religious faith, contentment	Spiritual doubt, anguish, despair

Kissane, D. The Relief of Existential Suffering *Arch Intern Med*/ Vol 172 (No 19) Oct 22 2012

# Dignity, Meaning and Demoralization

## Dignity

Dignity is defined as “the quality or state of being worthy, honoured, or esteemed” (Merriam-Webster Dictionary). For patients coping with living with a life-threatening illness a sense of dignity is the feeling that they are respected, and worthy of respect, despite the physical and psychological distresses they are coping with. Expanding on these concepts of self-worth and self-respect are notions of being able to maintain feelings of physical comfort, autonomy, meaning, spiritual comfort, interpersonal connectedness, belonging and courage in the face of impending death. A broken sense of dignity for those coping with living with a life-threatening illness is associated with feelings of degradation, shame and embarrassment and is linked to depression, hopelessness and desire for death. (Kissane et al in Ed. Chochinov & Breitbart *Handbook of Psychiatry in Palliative Medicine* 2009 p330)

## Dignity Therapy

Designed by Chochinov (2002), *Dignity Therapy* addresses existential distress among terminally ill patients. The therapy provides patients with the opportunity to address issues, memories, and reflections that they would wish to offer to those they are about to leave behind. Following a framework of questions, tape-recorded conversations guide patients in sharing life stories that highlight their values, address how they would like to be remembered, identify their most important accomplishments, hopes and dreams for loved ones, and advice or guidance for important people in their lives. A ‘generativity document’ is created, a legacy document which aims to summarize the value and meaning of the life lived, a document that can be reread and shared by successive generations thus reinforcing the notion of generativity, yet focusing on themes that affirm and engender a connection with an individual’s core sense of self. (Kissane et al in Ed. Chochinov & Breitbart *Handbook of Psychiatry in Palliative Medicine* 2009 p335)

## Demoralization

Demoralization has been described as the loss of meaning, purpose, and hope that sustains the will to live or the loss of any potential for future joy. (Kissane, Clarke & Street, 2001) Proposed by Jerome Frank (1970), it indicates a state of perceived incompetence, inability to

cope, hopelessness, existential despair, and meaninglessness. It involves a sense of ‘giving up’ as the individual feels hopeless and that the amount of energy used to accomplish a goal does not translate into a tangible result.

Demoralization becomes a morbid mental state when its distress is persistent rather than transient. It has been hypothesized that untreated demoralization can expose individuals to chronic distress, MDD (Major Depressive Disorder), social withdrawal, impulsive suicidal behavior and requests for physician-assisted suicide. Kissane (2009) states that “suicidal thinking develops not from anhedonia per se but from hopelessness and meaninglessness—profound existential despair”. (in Ed. Chochinov & Breitbart *Handbook of Psychiatry in Palliative Medicine* 2009 p327)

## Demoralization Syndrome

Hopelessness, loss of meaning, and existential distress are proposed as the core features of the diagnostic category of *demoralization syndrome*. This syndrome can be differentiated from depression and is recognizable in palliative care settings. It is associated with chronic medical illness...fear of loss of dignity, social isolation and, where there is a subjective sense of incompetence, feelings of greater dependence on others or the perception of being a burden. Because of the sense of impotence or helplessness, those with the syndrome predictably progress to a desire to die or to commit suicide.

## Meaning Centered Therapy

Developed by William Breitbart (2004), “Meaning Centered Therapy” is based on Viktor Frankle’s (a Holocaust survivor and psychiatrist) belief that the three main sources of meaning in life are derived from creativity, experience and attitude. “Through a mixture of support, reflection, and directed focus on issues of meaning and purpose in life, patients with a limited prognosis are helped to reclaim their hopes and enhance their quality of life”. (Kissane et al in Ed. Chochinov & Breitbart *Handbook of Psychiatry in Palliative Medicine* 2009 p334)

The new emphasis on meaning-centered therapy has confirmed the benefit in asking patients what matters most about their life. What goals, roles, values, and pursuits sustain the continuity of meaning in their lives? ...reframing the value of the patient’s life and the patient’s continuing opportunity to sustain a meaningful life with family, thus creating goals that sustain purpose, value relationships, express gratitude, and focus on living until death intervenes. (Kissane, 2012)

...patients can be greatly reassured by the fact that [the] existential framework for distress does not involve psychiatric disorder per se but rather arises from universal challenges that are givens in our human existence.

Kissane, 2012

# “HOW PEOPLE *Live* MATTERS”

... it really does.

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## Existentialism and Grief

Existentialism is a philosophy that emphasizes individual existence, freedom and choice. It is the view that humans define their own meaning in life, and try to make rational decisions despite existing in an irrational universe... It emphasises action, freedom and decision as fundamental, and holds that the only way to rise above the essentially absurd condition of humanity (which is characterized by suffering and inevitable death) is by exercising our personal freedom and choice .

[http://www.philosophybasics.com/branch\\_existentialism.html](http://www.philosophybasics.com/branch_existentialism.html)

The feelings of grief, of being deprived of something that was of importance, often leaves the person who is grieving as feeling that they are a passive player in their own life after suffering the loss. The role of existentialism places ‘freedom’ into the life of the person—freedom that evolves by learning that they have the capacity to make choices, to make decisions. Field (1996) states that uncertainty around prognosis for chronic conditions means that even at end-stages these conditions are often not acknowledged as “terminal”, affording patients little opportunity to be active participants in the shape and control of their dying. The experience for many grieving people has been described as ‘re-learning the world’. Barnard (1995) discusses how people with chronic and terminal illness may develop unrealistically positive views, to the point of illusion, of their condition as a means of preserving hope.

Patients that are dying are not just dying ; they are also living.  
Whether or not they have the opportunity to live this final human experience to the fullest – each in their own way,  
is influenced in great measure by those that take care of them.

## GF Chocolate Quinoa Pancakes

### Ingredients:

3/4 cup of milk of choice (dairy, coconut, nut, goats)  
1 Tablesp lemon juice  
2 Tablsp coconut oil or butter, melted  
1 - 2 tsp cinnamon  
Pinch of salt  
1 egg  
1/2 cup quinoa flakes  
1/2 cup almond or hazelnut meal (or alternative flour such as rice flour, buckwheat)  
1 –2 Tablsp rapadura sugar  
1/2 tsp baking soda  
1/2 tsp baking powder  
1/4 cup cacao melts, chopped  
Butter or coconut oil for cooking  
Raw honey to drizzle on top.

### Method:

1. mix dry ingredients together in a bowl
2. mix wet ingredients together in a separate bowl until well combined
3. Preheat frying pan on a low-medium heat
4. Mix wet & dry ingredients together
5. Add some butter or coconut oil to pan and allow it to melt and coat the pan entirely
6. Do a test pancake; if the mix is too runny just stir through a little more flour
7. Add more butter or coconut oil to the frying pan if needed and cook 2–3 pancakes at a time; cook on each side until golden, then remove and place on a plate
8. Continue cooking the mix, adding butter or coconut oil in between as needed.
9. When serving, drizzle with a touch more honey, perhaps some fruit and yoghurt