



Death and the Maiden
Chavannes Pierre Puvis 1872

Understanding and working with fear and anxiety when facing death

Jayne Huggard
Mercy Hospice Auckland - Te Korowai Atawhai
School of Nursing, University of Auckland



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When working with the dying, two of the emotions causing distress and pain in patients and their families are fear and anxiety

Both need to be recognised and understood

However, fear and anxiety often cause distress for health professionals working in these areas



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Illness and the care it entails
comprise an experience laden
with anxiety, anguish, sorrow, and
frustration for the patient and
their family

Dunhamel & Dupuis (2003)



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People who have cancer lose their
sense of security, of being
protected from danger.

Fear becomes their constant
companion

Parkes, Relf & Couldrick (1996)



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Most people newly diagnosed with
cancer are frightened,
anxious, and sad

They will do their best to
conceal these feelings



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The fear that accompanies a
new diagnosis of cancer is usually
worse than the fear of needing
palliative care

Parkes, Relf & Couldrick (1996)



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Fear is a natural adaptive response to
a stimulus which poses a threat to
well-being, safety or security

Apprehension, tension, uneasiness,
worry, edginess, and difficulty
concentrating are features of fear

Carr (1999)



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Anxiety increases with a cancer diagnosis, peaks prior to surgical interventions, and frequently remains high, declining gradually during the first post-operative year

Maguire (1978)



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Anxiety associated with radiotherapy
may not decline as treatment
progresses because of the fear
associated with the cessation of
treatment; this psychological distress
may exceed the physical distress
resulting from the treatment

Chochinov & Breitbart (Eds.) (2000)



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Anxiety experienced during chemotherapy may also increase when treatments are completed, as patients feel “unprotected”, see their oncologists less often, and worry about the effectiveness of the chemotherapy



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The thinking style of the anxious patient is characterised by overgeneralisation and catastrophising, negative outcomes seem inevitable, patients see themselves as helpless in a hopeless situation – the instinct is to flee



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Sharing the experiences of illness helps caregivers come to terms with the impact of critical illness. It helps remove feelings of isolation and reduces anxiety and fear. In other words, health care professionals need to be able to help patients and relatives share their experiences and tell their story

Parkes, Relf & Couldrick (1996)



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Health professionals should not over-protect patients by concealing from them information that will worry them

However, we need to acknowledge different cultures' beliefs about this

Parkes, Relf & Couldrick (1996)



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A person who finds no one willing to take the time and offer the help necessary to bring forth speech, will protect himself by saying nothing. But the time when I cannot put something into words is usually the time when I need to express myself ...The problem is finding someone who will work out the terms of that expression

Frank (1991)



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It is in silence and in listening to the
silence that we begin to get insight
into the questions

Sister Dervilla Byrne rsm



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Health professionals need insights and new understandings from a range of human experiences including such complex phenomenon as suffering, loss, disfigurement, fear and grief

Breslin (1996)



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Our own loss and grief

Past:

Working in palliative care gets us in touch with our past loss and grief – this can be both positive and negative

Present:

Emotional pain experienced by bearing witness to the grief of others can intensify our own feeling of helplessness and sense of failure

Future:

Concerns about our own feared losses–personal identification



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Reasons health care professionals may use to distance themselves from asking the hard questions:

Fear of harming patients psychologically

Inadequate training (own fears and anxiety)

Lack of available practical and emotional support

Maguire (2000)



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206 doctors and nurses taped during
patient interviews

High percentage of blocking strategies
used

Few questions were asked that
encouraged patients to disclose their
concerns

Maguire, Booth, Elliot & Hillier (1996)



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Blocking strategies observed in health professionals communication with frightened patients:

- Deliberately interrupting
- Avoiding answering direct questions
- Using technical language when answering questions
- Failing to provide opportunities to talk about health status with the patient

Zanchetta & Moura (2006)



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Psychological studies of physicians suggest that their own unacknowledged fears of loss and death serve as a barrier to emotional engagement with patients facing death and dying

Kvale et al (1999)



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In a longitudinal study of 186 women
who had had a mastectomy, no
doctor or nurse asked any woman
how she felt about losing her breast

Maguire (1985)



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It is fear that keeps us silent about
difficult topics;

It is courage and compassion that
allows us to begin to speak

Kuhl (2003)



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Being aware of our own mortality
generates terror, not as an intense
fear of death, but rather a profound
and usually unconscious dread of
death as absolute annihilation

Solomon, Greenberg & Pyszczynski (1991)



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We cope with such terror by
developing an “anxiety buffer”,
denying or repressing the terror
in the unconscious

This is the genesis of spiritual pain

Solomon, Greenberg & Pyszczynski (1991)



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Spiritual pain appears somatically,
emotionally, religiously or socially, and
is recognised as suffering

Kearney & Mount (2000)



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Spiritual pain includes feelings of
isolation, terror, meaninglessness
and hopelessness



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Attending to a patient's spiritual
distress has to do with alleviating
suffering and healing in its
deepest form

This is holistic care in it's
truest sense



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Managing fear and anxiety in dying patients

emotional support listening fully

guided imagery art therapy

image work muscle relaxation

dream work music therapy



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massage

meditation

reminiscence
and biography

hypnosis

psycho-education

cognitive-behavioural
therapy (CBT)

medication



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Family members of dying patients need to be encouraged to express their concerns and their fears. In the year before the death of cancer patients:

- 50% had problems sleeping
- 46% reported high levels of anxiety
- 39% were depressed
- 33% had lost weight

Ramirez, Addington-Hall and Richards (1998)

Fear and anxiety (along with symptom management) was the most severe problem reported by patients and families

Ramirez, Addington-Hall and Richards (1998)



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Fear aggravates pain
and
pain aggravates fear



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In palliative care, a common cause of anxiety is uncontrolled pain

Patients with breakthrough pain report significantly more anxiety and depression than patients who do not report these episodes

Payne (1995)



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Suicidal ideation is common in patients with uncontrolled pain

Massie, Gagnon & Holland (1994)



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Anxiety is lessened when
patients feel they have a sense
of control over their pain levels

Payne & Massie (2000)



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Factors affecting pain threshold:

fear

anxiety

sadness

depression

discomfort

insomnia

fatigue

anger

boredom

mental isolation

social abandonment

MacLeod (2007)



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It is helpful for health care professionals
to understand that any anger expressed
by dying patients and relatives
may be masking fear



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Fear is the normal human reaction to
any danger, and grief is the normal
reaction to loss

If we are to be helpful to the dying,
then we need to recognise and
understand these two emotional
responses

Parkes, Relf & Couldrick (1996)

We all have anxieties and fears

We will worry about the process of dying,
the potential loss of control, the increase in
suffering, and the blackness of death

Fear of losing our dignity however
may be our worst fear

MacLeod (2007)



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Death is a less acceptable topic of
conversation than sex,
and denial and fear of it are
still the norm

Beevar (2003)



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Is death a failure of medicine?



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If death is the only true certainty in life,
yet most people continue to fear it, is
fear of death itself a rational pre-
occupation?

Nyatanga (2005)



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How possible is it to fear death when we
have not experienced it ourselves?

Nyatanga (2005)



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What exactly do people fear
when they fear death?

Nyatanga (2005)



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If fear of dying is justifiable, is it
actually the fear of going to hell?

Nyatanga (2005)



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Death anxiety is a phenomenon
associated with being human,
it is the fear of non-being, the
ultimate existential concern



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For those without a faith in the after
life, the greatest fear is that when we
die we become nothing

We are filled with the fear of
annihilation

Hahn (2002)



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Fears about death arise from concerns about the dying process, what happens the moment death occurs, and about the loss of our only life on earth

Neale (1973)



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Further fears are related to awareness
of a lack of meaning in one's life, to
negative associations regarding the
decay of our body, to apprehension
about Judgement Day, and dread of
the unknown

Stiller (2001)



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In palliative care, exposure to
death is inevitable

Daily confrontation with life-threatening
illness and death can push emotional
buttons and make us fear mortality

Failure to confront and resolve this
leads to avoidance behaviours for health
professionals working with the dying

Radziewicz (2001)



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The fear that accompanies moments of intimacy in palliative care is a fear of entering intimately into another person's agony and the fear of being overwhelmed by suffering, chaos and disintegration

The tension is between the promise of intimacy and the fear of our own undoing

Barnard, Towers, Boston & Lambrinidou (2000)



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We are afraid that talking
about death beckons it

Kuhl (2002)



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One of the most valuable ways to form connections with our dying patients is to acknowledge and understand their reality without conveying a sense of helplessness, despair or defeat



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Dying patients are less worried
about tasks being performed on
them than they are for a desire to
have close and meaningful
relationships



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Therefore, providing a nurturing,
caring, and supportive relationship
with the dying patient
is paramount



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Enabling people to deal with their
fears about dying requires a
relationship of trust

Trust needs to be earned

Lloyd (2000)



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The communication process described
as most helpful for the terminally ill,
and their significant others, includes
an empathised awareness of the
patient's need to talk about death
and dying

Reynolds (2000)



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Most people are more afraid of dying
than they are of being dead



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Exploring the patient's fears and apprehensions about the progression of the disease, treatment procedures and psychological difficulties often serves to alleviate a substantial degree of the patient's anxiety

Chochinov & Breitbart (Eds.) (2000)



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The process of detoxifying and
demystifying the experience of death
leads to reduced levels of anxiety, fear,
and psychological distress

Chochinov & Breitbart (Eds.) (2000)



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Dying patients want to share their fears, hopes and expectations with staff, they want to be listened to, understood, and accepted as themselves

Saunders (1978)



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The real presence of another person is a place of security. We have to give all patients that feeling of security in which they can begin, when they are ready, to face unsafety

Saunders (1978)



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Anxiety increases if patients become aware of both the relative ineffectiveness of medical treatments in halting the disease progression, and consequently, their limited life expectancy

Payne & Massie (2000)



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The presence of one who is willing to be a companion and remain steadfast when there are no answers, is a form of powerful communication that goes beyond words

Kearney & Mount (2000)



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Presence is defined as “being with”
the patient, rather than “doing for”.
It involves the capacity to engage with
another person, often within the
tension of unknowing
This sharing of uncertainty between
the patient and the health professional
allows us to be fully present

Benner (1986)



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Psychological treatment of anxiety in terminal illness focuses on helping patients contain the anxiety associated with their impending death, and to deal with practical concerns and fears around the issue of dying

Payne & Massie (2000)



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Frank, open and honest discussion
about patients fears and anxieties
concerning their dying have been
shown to be effective in alleviating
their distress

*Blake-Mortimer, Gore-Felton, Kimerling,
Turner-Cobb & Spiegel (1999)*



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People want a peaceful, dignified,
comfortable death, but in reality, they
don't want it yet

They prefer life-prolonging care
in the hope that their peaceful,
dignified, comfortable death will occur later

Hinshaw (2003)



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Denial serves a very useful function
in protecting against distress and
anxiety, and can vary in the patient
from moment to moment –
acknowledgement of the seriousness
of the condition in the morning can be
followed by considerable denial in the
afternoon

Chochinov & Breitbart (Eds.) (2000)



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Patients with anxiety usually report
subjective feelings of foreboding,
apprehension and dread,
intensifying when death is
imminent



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When dying patients ask
“how long have I got?”
the underlying unspoken question is
often
“what will happen to me?”

Murray, Kendall, Boyd & Sheikh (2005)



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Routinely explore both symptoms and
worries with the terminally ill and
their families

Research with bereaved families about
their perceptions of their loved one's
worries show a fear of:

being a burden (39%)

being dependant (40%)

loss of bodily function (44%)

Hickman & Tilden (2004)



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For many patients and their families,
death is a new experience and they
will have no idea what to expect.
Fear and anxiety fill the space, unless
they are given accurate information,
and their fears are named



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Further causes of fear in the terminally ill

separation from loved ones, home, job,
roles

abandonment

being a burden

losing control, feeling helpless

leaving family behind

pain, or uncontrolled symptoms



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being unable to complete life tasks or
responsibilities
body disintegration
loss of dignity
dying
being dead
fears of others (reflected fear)



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Sitting alongside the patient's and
family's anguish

“allows the unspeakable to
be able to be spoken”

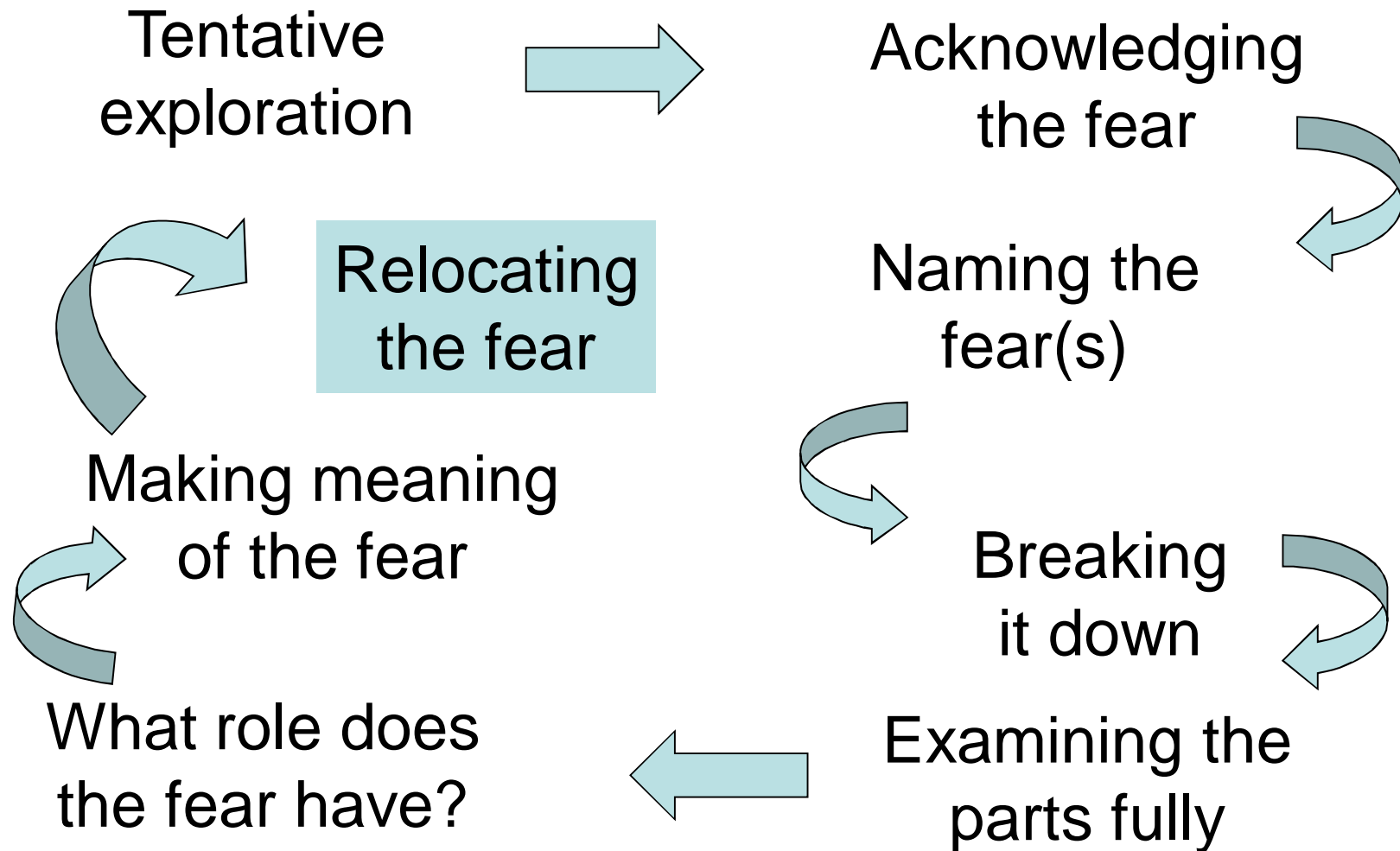
Stanley (2002)



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Deconstructing Fear



Jayne Huggard



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Self care is a necessary component to
being healthy and providing quality
care to patients and families

Dealing with the challenge of handling
frightened, dying patients while also
walking intimately with a family in the
face of suffering is one of the truest
measures of compassion

Radziewicz (2001)



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Don't listen with your ears, listen with
your mind. No, don't listen with your
mind, listen with your spirit

Listening stops with the ears, the mind
stops with recognition, but spirit is
empty and waits on all things

Chuang-tau
Taoist philosopher



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What our patients and families need from us in the therapeutic relationship

Being listened to fully

Feeling understood



Safety and
Trust

Being accepted as themselves

Not being criticized or judged

Treated with dignity and respect

Honesty about what we know and don't know



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How is hope kept alive
in the face of death?



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For patients with a terminal illness, hope provides meaning, direction, motivation and a reason for living

Dunhamel & Dupuis (2003)



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Hope for the dying

There is always something to hope for:

relief of pain and symptoms
to maintain dignity and respect
to complete unfinished business
to not be abandoned
to be listened to and understood
to see another sunrise
to last until
a good death



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When you walk to the edge of all the light
you have and take that first step into the
darkness of the unknown, you must
believe that one of two things will
happen:

There will be something solid for you to
stand upon, or you will be taught how to fly

Overton (1975)



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Hans Baldung-Grien

Death and the Maiden

1510

oil/panel, 15.75 X 12.75

Kunsthistorisches Museum
Vienna, Austria



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Der Tod und das Mädchen

Hans Baldung Grien 1517



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P J Lynch 2010



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La jeune fille et la mort

Nancy Levy 1900



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Death and the Maiden

James C. Christensen



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jayne.huggard@mercyhospice.org.nz



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