

# Hope near the end of life

Rod MacLeod

# What is hope?



# Hope

“is the most beautiful of all affections and does much to the promulgation of life if it be not too often frustrated, but entertain a fancy with an expectation of good”

*Francis Bacon*

*1561–1626*

# Hope

- is not desire nor optimism, nor merely expectation, nor wishful thinking, nor even stoicism, although some of these emotions do play a part
- is active and not passive, an ethic which would seem to be a process of both conscious and unconscious reasoning
- “to entertain expectation of something desired”
- “the highest degree of well founded expectation”
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# Hope

- Reflect for a moment what hope means for you
- Where is your hope and hopefulness right now on a scale of 1 to 10?
- What is the smallest thing that could happen to increase your hope?
- What helps your hope generally?

# Hope

We ridicule those who have too much of it. We hospitalize those who have too little of it. It is dependent on so many things yet indisputably necessary to most. Those who have it live longer. Words cannot destroy it. Science has overlooked it. A day without it is dreadful. A day with an abundance of it guarantees little



*Ronna Jevne. The Hope Foundation*

What do you hope for?



# Comparison of foci of hope by non-terminally ill and terminally ill people

## Non-terminally ill people

- Cure of disease or remission of disease
- Getting better
- Relief of pain
- Living longer
- Surviving

## Terminally ill people

- Living day to day
- Feeling better
- Relief of pain
- Not suffering more
- Peaceful death
- Life after death
- Hope for families

Wendy Duggleby. Hope at the end of life  
*Journal of Hospice and Palliative Nursing* 3; 2,  
2001



# Hope in newly diagnosed cancer patients

- Hope decreases with age – those aged 65 and older report the least hope
- Hopelessness associated with feelings of despair and desire for hastened death
- Men were found to have significantly higher levels of hope than women
- Staging of cancer wasn't a significant factor in influencing hope
- Relationship between hope and pain was not significant
- Minimal relationship between depression and hope
  
- Data collated from health records

Duggleby W, Ghosh S, Cooper D, Dwernychuk L.

Hope in newly diagnosed cancer patients.

*Journal of Pain and Symptom Management*

2013

# Four central attributes of hope

- an experiential process
  - as part of ‘being’
- a spiritual process
  - acceptance that there is a higher being (faith)
- a rational thought process
  - setting of goals, establishing a sense of one’s past present and future, a degree of control
- a relational process
  - a feeling of connectedness to others

# Developing hope

- A realistic assessment of the predicament or threat
- The envisioning of alternatives and the setting of goals
- The bracing for negative outcomes
- A realistic assessment of personal and external resources
- The solicitation of mutually supportive relationships
- The continuous evaluation for signs that reinforce the selected goals
- The determination to persevere

# Herth Hope Index

- The presence of a meaningful relationship
- The ability to feel light-hearted
- Personal attributes of determination, courage and serenity
- Clear aims
- Spiritual beliefs
- Ability to recall positive moments
- Having one's individuality accepted and respected

Physicians (75%) and nurses (63%) were most frequently identified by participants as contributing to their hope. Participants reported that 'being present', taking time to talk and interact with patients was the most effective way that health care professionals inspired hope

Koopmeiners et al 1997

Interviewed 32 oncology patients to explore how HPs influence or inspire hope

# Hope inspiring strategies (Herth)

- To provide comfort and pain relief
- To facilitate a sense of sustained connectedness with others
- To help redefine goals (when specific hopes were not attained)



# What fosters hope during palliative rehabilitation?

- Active interaction
- Diversion
- Unity and wholeness
- Feeling valued as an individual
- A comforting environment
- A sense of wellbeing
- A positive change in attitude
- Challenges
- Achievable goals
- Incentives
- Normality

# Examples of hopeful language

## The language of options

- “how can we help?”
- “what is the worst possible outcome for this situation?”
- “what is the best possible outcome for this situation?”
- “whose example would you follow if you decided to behave in a hopeful manner?”



# Examples of hopeful language

## The language of hope and change

- “what is the smallest change that could increase your hope?”
- “what would a hopeful person do in your circumstances?”
- “what would you do differently if you were more hopeful?”



# Examples of hopeful language

## Use words of possibility

- The use of 'when' instead of 'if'
  - “when this difficult time passes”
  - “when you find a remedy for this
  - pain”
- The use of 'could' instead of 'should'
  - “I could try that now”
- The use of 'yet' instead of 'but'



# Hope fostering strategies

- Facilitating caring relationships
- Humour and play
- Encourage determination and courage
- Patients and families to set short-term goals
- Facilitate the environment and resources for spirituality
- Reminiscing
- Physically present in a crisis
- Listening attentively
- Pain and symptom management

# Factors that influence hope in the terminally ill

## Decrease

- Feeling devalued as a person
- Abandonment and isolation
- Lack of direction
- Uncontrolled pain and discomfort

## Increase

- Feeling valued as a person (reminiscence)
- Meaningful relationships (humour)
- Realistic goals
- Pain and symptom relief

# Strategies to enhance hope

- Care and communicate your care
- Hear patient stories – really listen
- Make something happen – pain relief
- Share stories of hope with patients
- Hope images (pictures/symbols)
- Hope models (who is your model/example of hope – real person or story book character)