

# Supporting Hope

## KEY POINTS

- ➔ Patients and families are adapting and adjusting to the changes that occur with progressive illness, as they shift from a goal of cure or life prolongation to comfort
- ➔ Patients and families require time to adjust and cope with each change
- ➔ Hope is about possibility and is a common effective coping mechanism
  - ➔ Hope builds strength, and is critical to the psychosocial well-being of patients and family
- ➔ Feelings of hope and hopelessness may occur at the same time
- ➔ Healthcare professionals can influence hope, helping to support specific hopes
  - ➔ Supporting hope involves providing patients and families with adequate information about the disease so that they can develop personal goals and participate in decision making about their medical care
  - ➔ Providing honest information about prognosis does not take away hope, instead it allows patients and families to adjust their hopes to their current situation
  - ➔ Evidence shows that honest communication reduces patients' feelings of hope (see References below)
- ➔ Hope will evolve and change over time and circumstance
- ➔ Hopes expressed by patients and family/caregivers may be very different from that of the healthcare team
  - ➔ It is important to find a balance between being honest and providing hope

Examples of hopes in seriously ill individuals and their families:

- ➔ For a cure

- ➔ For comfort, through control and management of pain and symptoms associated with the disease
- ➔ For quality of life and relief of suffering
- ➔ For dignity
- ➔ For continued connections and for maintaining social relationships
- ➔ For reconciliation of interpersonal conflicts or issues
- ➔ That they are not a burden on their family
- ➔ That family will be okay after they die
- ➔ For spiritual connection or peace or an afterlife (depending on the patient's beliefs)

#### STRATEGIES FOR HEALTHCARE WORKERS TO SUPPORT HOPE

- ➔ Be honest and authentic
  - ➔ Effective communication through active listening and showing empathy will support hope
  - ➔ After breaking bad news (using SPIKES), in a follow-up conversation you can ask patients: "Given what you know about your diseases, what do you hope for at this time?"
- ➔ Facilitate care relationships
  - ➔ Be physically present in times of crisis, so that the patient does not feel abandoned
- ➔ Encourage determination and courage
- ➔ Engage in remembering, reflecting back on life with the patient and family, journaling
- ➔ Listen attentively
- ➔ Help patients and families to establish short-term, attainable goals
- ➔ Support spirituality and connections to family and others who are important to the patient
- ➔ Manage pain and other symptoms

## Coping with Serious Illness

### Tools for Coping with Serious Illness:

- ➔ The following ideas are helpful for people facing a serious illness (either as a patient or a family member)
- ➔ Everyone of us is unique, so if some of the ideas don't now work for you, ignore them; take only what fits
- ➔ Use these ideas to stimulate more of your own

<b>Enlist the support of others</b>	Studies show that a support network can be helpful in coping with this situation. Because your friends and family may not be able to support you as often, or in the way you would like, or may be struggling to cope as well, it may be helpful to utilize additional resources such as religious or community supports, healthcare staff, etc.
<b>Eat healthy</b>	This is tough when you don't feel like eating. When you are stressed, your appetite is affected. Follow any guidelines given to you by your doctor or healthcare professional, but eating small amounts more often is usually better than trying to face a big meal
<b>Take a deep breath</b>	When under stress we tend to breathe very shallowly, which doesn't allow enough oxygen to the brain. Breathing deeply every so often helps to maintain that balance and give you an edge
<b>Use your sense of humour</b>	Humour will go a long way to carry you through this stressful time. Laughter creates a release of tension and releases endorphins into the system to give you a sense of well being. This will help to cope with the stress of dealing with serious illness
<b>Write down your thoughts</b>	A journal is one way of sorting through your experiences. Sometimes ideas and thoughts run around in your mind and it is hard to get a handle on what really is happening for you. Writing is one way to help with this. You cannot write as fast as you think and, as a result, your mind is forced to slow down
<b>Personal coping kit</b>	Based on what gives you energy; put together a kit. This kit may contain pictures, mementos, videos, letters, crossword puzzles, a good book, magazines, etc. – whatever you think would help you through the difficult times.

## Common Reactions When Coping with Serious Illness

<b>Inability to focus or concentrate</b>	Things which may have been routine in your daily life are now difficult, such as reading, etc.
<b>Poor memory</b>	Even such things as a familiar phone number may be a challenge to recall
<b>Physical reactions</b>	Reactions such as tight muscles, headaches and exhaustion may also be a part of this experience. If you are experiencing these symptoms, it is a good idea to check with your family doctor
<b>Increased irritability</b>	Your tolerance level may not be as high as it used to be. This may be particularly true within your own family, or with those you care about
<b>Confusion/ disorientation</b>	You may find yourself losing track of place/time.
<b>Less self-confidence than usual</b>	This incident has turned your world upside down and has shaken up your beliefs, including what you believed about yourself
<b>Difficulty in making decisions</b>	Sometimes what once seemed the simplest of decisions becomes a challenge
<b>Difficulty sleeping</b>	When you try to sleep or rest, your thoughts may run all over the place
<b>Sense of unreality</b>	"This can't really be happening to me!"
<b>Feelings of helplessness</b>	The feeling that there must be something you could do to make a difference to the situation
<b>Feelings of being "on alert" at all times</b>	You may find that you are easily startled and that it is hard to settle yourself down, particularly at night
<b>Being on an "emotional roller coaster"</b>	You may feel that you are never quite sure what is going to happen day by day as you deal with the situation

## REFERENCES

- Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES A six-step protocol for delivering bad news: application to the patient with cancer. *Oncologist*. 2000;5(4):302-11. doi: 10.1634/theoncologist.5-4-302. PMID: 10964998.
- Beng KS. Malaysian Family Physicians COLLUSION IN PALLIATIVE CARE [Internet]. [cited 2023 Sep 18]. Available from: [https://www.e-mfp.org/old/v1n2-3/palliative\\_care-printcopy.htm](https://www.e-mfp.org/old/v1n2-3/palliative_care-printcopy.htm)
- Bernacki RE, Block SD. Communication About Serious Illness Care Goals: A Review and Synthesis of Best Practices. *JAMA Intern Med*. 2014 Dec 1;174(12):1994-2003.
- Cairns M, Thompson M, Wainwright W, editors. *Transitions in Dying & Bereavement: A Psychosocial Guide to Hospice and Palliative Care*. Victoria Hospice Society. Baltimore: Health Professions Press, Inc.; 2003.
- Chaturvedi SK, Loiselle CG, Chandra PS. Communication with Relatives and Collusion in Palliative Care: A Cross-Cultural Perspective. *Indian Journal of Palliative Care*. 2009 Jun;15(1):2.
- Downing GM, editor. *Medical Care of the Dying*, 4th ed. Victoria Hospice Society; 2006.
- Evans WG, Tulsy JA, Back AL, Arnold RM. Communication at Times of Transitions: How to Help Patients Cope with Loss and Re-Define Hope. *The Cancer Journal*. 2006 Oct;12(5):417.
- Hancock K, Clayton JM, Parker SM, Wal der S, Butow PN, Carrick S, et al. Truth-telling in discussing prognosis in advanced life-limiting illnesses: a systematic review. *Palliat Med*. 2007 Sep 1;21(6):507-17.
- Hinds, P. "Trying to Be a Good Parent" As Defined By Interviews With Parents Who Made Phase I, Terminal Care, and Resuscitation Decisions for Their Children. *J Clin Oncol*. 2009 Dec 10; 27(35): 5979-5985.
- Lotz JD, Daxer M, Jox RJ, Borasio GD, Führer M. "Hope for the best, prepare for the worst": A qualitative interview study on parents' needs and fears in pediatric advance care planning. *Palliative medicine*. 2017;31(8):764-71.
- Mack JW, Wolfe J, Cook EF, Grier HE, Cleary PD, Weeks JC. Hope and prognostic disclosure. *Journal of Clinical Oncology*. 2007;25(35):5636-42.
- Mathes Canes P. *Trauma Healing and Transformation: Awakening a New Heart with Body-Mind-Spirit Practices*. Capacitar Inc; 2004. ISBN-10: 0615114849. ISBN-13: 978-0615114842.
- Truog RD, Campbell ML, Curtis JR, et al. Recommendations for end-of-life care in the intensive care unit: A consensus statement by the American College of Critical Care Medicine. *Crit Care Med*. 2008 Mar;36(3):953-963.
- Truog, J. L., Jr., & Blevins, D. (Eds.). *Psychosocial issues near the end of life: A resource for professional care providers*. American Psychological Association; 2006. Available from: <https://doi.org/10.1037/11262-000>.