fraserhealth

Better health.
Best in health care.

☐ Hospice Palliative Care Program
Symptom Guidelines

Psychosocial Care

Psychosocial Care

☐ Rationale

This guideline is adapted for interprofessional primary care providers working in various settings in Fraser Health, British Columbia and any other clinical practice settings in which a user may see the guidelines as applicable.

☐ Scope

This guideline provides recommendations for assessing and addressing psychosocial issues of adult patients (age 19 years and older) who are facing a progressive life limiting illness. It is designed to provide some general considerations and information about psychosocial care, support and interventions to assist all health care providers within their scope of practice and to enhance their engagement with patients and families.

This guideline is not intended to be prescriptive. While medically oriented clinical practice guidelines tend to focus on specific disease sites and describe "which particular treatment is most effective for which particular symptom"(1), psychosocial care is contextually and historically based in the unique experiences of patients and their families. This guideline is intended to assist all health care providers to look beyond the physical aspect of a patient's illness and explore the patient's perception of their illness and its impact upon them. The goal is to assist patients and their families to find meaning within their situation using a holistic approach.

☐ Definition of Terms

Advance Care Planning is an ongoing process of reflection and communication in which a capable adult makes decisions with respect to future health care in the event that they become incapable of giving informed consent. The process should be placed in the context of one's values and beliefs and involve discussions with health care providers and significant others with whom the person has a relationship.(2)

Burnout is a process in which one's attitudes and behaviour change in negative ways in response to job strain(3) arising out of work environment triggers such as frustration, powerlessness and an inability to achieve work goals.(4)

Coping refers to unique and personal strategies used to manage stressful situations that could be perceived by others as being positive or negative.(5)

Comfort Care refers to both a philosophy of care and a program of services aimed at relieving suffering and improving the quality of life for persons who are living with, or dying from, a life limiting illness or who are bereaved.(6)

Compassion Fatigue refers to emotional residue of exposure to working with those who suffer. Natural consequent behaviours and emotions resulting from knowing about a traumatizing event experienced by a significant other, the stress resulting from helping or wanting to help a traumatized or suffering person.(7)

Complicated Grief is marked by the presence of symptoms such as intrusive thoughts of the deceased, yearning and/or searching for the deceased and excessive loneliness since the death, experienced daily or to a marked degree, for at least 6 months, causing clinically significant impairment in social, occupational or other areas of functioning.(8)

Culture is not a single variable but is comprised of multiple variables, affecting all aspects of experience. It is inseparable from economic, political, religious, psychological and biological conditions. Cultural processes frequently differ within the same ethnic or social group because of differences in age cohort, gender, political association, class, religion, ethnicity and even personality. It is highly desirable for health care providers to be sensitive to cultural difference by engaging in an ongoing process of exploring the patient's lived experience of an illness, trying to understand the illness as the patient understands, feels, perceives and responds to it.(9)

Cumulative grief is the occurrence of multiple deaths, either at the same time or in serial fashion. This often occurs in a hospital unit or hospice residence, and may lead to bereavement overload, or what has been called cumulative grief. Cumulative grief is the caregiver's emotional response when there is no time or opportunity to completely or adequately grieve for each person who has died.(10)

Disenfranchised grief is when a person experiences a sense of loss but does not have a socially recognized right, role or capacity to grieve.(11)

Employee and Family Assistance Program offers confidential assessment, counselling and referral services designed to assist with resolving problems that affect an individual's personal life and, in some cases, job performance. The service is provided at no cost to eligible employees and their family members.(12)

Family is a term that is used to describe those who are closest to a patient. It is not exclusive to those who are related by blood or by marriage. It is a term used to describe someone that a patient considers to be "like" a family member, regardless of blood relations.(13)

Life Review is a progressive return of the memories of past experience in search of meaning and in striving for emotional resolution.(14)

Quality of Life refers to an acceptable, if not desired, state of living that suggests fulfillment for an individual. Quality of life is individually defined by each patient. The goal of hospice palliative care is to "provide the best possible quality of life for the terminally ill by ensuring their comfort, care, and dignity at their end of their lives."(15)

☐ Standard of Care

Recommendation 1: Care for the Health Care Provider

- Reflective Practice
- Self-Care

Recommendation 2: Care Considerations

- Understanding and Assessing Patient and Family Experience
- Understanding Grief and Loss
- Understanding Children’s Grief
- Understanding Culture

Recommendation 3: Caring for the Patient and their Family

- Psychosocial Support
- General Strategies
- Communication
- Fostering Hope
- Helping Children
- Desire to Die Statements

Recommendation 4: Help for Challenging Care Situations

- Indicators for Specialized Consultation

Recommendation 5: Evaluation

Recommendation 1 Care for the Health Care Provider

Reflective Practice

To provide effective, compassionate and comprehensive end-of-life care, health care providers must develop a level of comfort with death and dying. Unfortunately "clinicians often do not have the skill, comfort level, and experience needed to care for dying patients."(16) As a result, health care providers may end up avoiding uncomfortable or difficult conversations with patients and family members and direct their attention towards more technical aspects of care. Consequently, health care providers as well as patients and families may lose out on an important opportunity to clarify their understanding and expectations of the current medical situation with a view towards developing effective end of life care. Self-reflective practice is a proactive process which seeks to overcome this reluctance and to enhance relationships with particular people, events, or situations.

Reflection can take place not only retrospectively in thinking about an experience after it has occurred, but also simultaneously as it is occurring, and even proactively before it occurs (or is anticipated to occur), thus, critical reflection before, during and after the experience. Being a reflective health care provider requires an "in-the-moment" awareness of our own issues, attitudes, feelings, values and beliefs, both personal and professional, around death and dying. Reflective practitioners are willing to explore and challenge their assumptions of themselves and others where appropriate.(16) It may help to engage in this process with others on the team rather than exclusively on an individual basis. How does one become more critically reflective in their practice around end of life care?

Think about the following questions:

- What are the assumptions, feelings, values, and beliefs guiding my current actions and behaviours?
- How are my actions and behaviours influenced by these assumptions?
- What do I know about the assumptions, feelings, values and beliefs of the patients and families with whom I am working?
- How might their actions and behaviours be influenced by these assumptions?
- What strategies have been and/or are working, and which strategies are not?

By developing and using reflective practice consistently, you will be able to bring forward ideas to help improve and enhance end of life practice. Effective professionals continually reflect on their work and continue to do so throughout their careers.

Self-Care

Although providing care to palliative patients and their families can be extremely rewarding, it can also be stressful and emotionally draining. The chronic exposure to related stresses and human suffering can lead to adverse physical, emotional, social and psychological effects.(17) This is commonly referred to as burnout or compassion fatigue.

"Working with the dying and the bereaved touches caregivers in profound ways…it makes them painfully aware of the losses in their own lives; it increases anxiety regarding their potential and future losses…and it arouses existential anxiety in terms of their own death awareness."(8) Over time, as health care providers are exposed to multiple deaths, they can become vulnerable to experiencing cumulative or disenfranchised grief. It is not uncommon for this grief to be denied, displaced and/or distorted.(10)

Without adequate coping skills to deal with the exposure of working with patients and families at end of life, health care providers may begin to withdraw, have difficulty communicating and avoid emotional involvement with patients and families, all of which affect the quality of care they are able to provide.(18)

Burnout may be experienced as a variety of symptoms including:

Physical	Emotional
• Headache	• Depression
• Nausea	• Isolation and/or social withdrawal
• Dizziness	• Emotional exhaustion
• Insomnia	• Discouragement
• Skin problems	• Oversensitivity
• Gastrointestinal problems	• Irritability
• Physical exhaustion	• Anger(19)

It may be difficult to find encouragement to access outside forms of support due to the generalized culture of health care. However, it is essential that health care providers have the ability to identify the impact of their work and engage in efforts to recognize and address any negative consequences. The use of self-reflective practice, as described in Recommendation 1, can assist us in clarifying or identifying the source of any 'burnout' or 'cumulative grief'. This can be done through a combination of self-reflection, education about the effects of caring, development of effective coping skills, and the creation of a work culture that supports self-care.(10,20) It may mean that we need to take more time for ourselves, debrief with a trusted co-worker around a specific patient, or utilize an Employee Family Assistance Program for counseling.(12)

Types of self-care activities:

- Basic Needs – nutritious food, exercise, adequate sleep.
- Balance – between personal life and work life.
- Relaxation and Self-reflection – taking time to assess personal feelings, might include meditation, prayer and journaling.
- Informal Support – family and friends.
- Formal Support – peers, supervisor, debriefing, might include access to counseling and support groups.
- Ritual – memorial services or other forms of remembering and providing closure.
- Education and Training – aimed at understanding issues regarding dying and grief, effects of providing care, communication techniques.(10)

Recommendation 2 Care Considerations

Understanding and Assessing Patient & Family Experience

Living with a life limiting illness and awareness of approaching death creates unique stressors and new challenges. Patients and families are faced with having to manage the new demands associated with the illness while maintaining quality of life and meaning within their relationships.

Some of the unique stressors of living with a life limiting illness for patients and families may include:

1. Coping with remission and relapses associated with the often uncertain course of the illness.
2. Experiencing grief associated with adjusting to multiple losses prior to the death.
3. Dealing with the demands of living with and caring for someone who, while is still living, is slowly dying.
4. Managing and meeting the increased demands in all areas of living: financial, social, physical and emotional.
5. Having to address long term family disruption and working at family reorganization to cope with illness.
6. Feelings of loss of control. Witnessing the progressive decline of a loved one and not being able to stop it.
7. Managing psychosocial conflicts, emotional exhaustion, physical debilitation, social isolation, family tension, and commonly experienced emotional reactions to loss (guilt, anxiety, sorrow, depression, anger and hostility).
8. Managing intensive treatment regimens and their side effects.
9. Becoming familiar with health care systems, language, and professionals.
10. Confronting dilemmas regarding decision making and treatment choices.(21)

Understanding the factors related to a patient's quality of life is paramount in providing comfort care to patients and their loved ones. The provision of psychological support for patients and families confronted with a life limiting illness is one that is often overlooked and can be even more undermined when physical pain becomes the main focus of the treatment plan.(15)

The psychosocial assessment is focused more on the significance and functioning of the patient in relationship to themselves, others and their environment. The assessment should ascertain how quality of life is defined and experienced by the patient. Ideally it should identify their goals, barriers to achieving those goals and strengths available to overcome and/or adapt in the presence of constant change.

Assessment serves the purpose of understanding the illness from the perspective of patients and families as well as articulating goals of care. A comprehensive assessment helps clarify and identify strengths, challenges, areas of support and overall functioning. It is the groundwork for planning interventions, addressing needs, assisting with informing decision-making, facilitating care planning and delivery as well as contributing towards team functioning.(5,22) If applicable, the use of professional interpreters should be utilized so as to not place family members (especially children) or even health care providers in the role of mediating decision making or translating difficult or 'bad' news.

Questions which can help to obtain the patient and family's perspective:

1. What is your understanding of the illness?
2. What do you think caused the illness?
3. What kind of impact has the illness had on you and your family?
4. How have roles and relationships changed within your family?
5. How would you describe your communication style?
6. What do you fear the most?
7. Who do you turn to for help?
8. Who should be involved in decision making?
9. What is most important to you?
10. What would be most helpful to you at this time?(9,23,24)

The assessment may include patients and families' competencies, interactions and environmental influences that could hinder one's abilities to adapt. The assessment is not a diagnosis. The psychosocial assessment is an empowering and ongoing collaborative process of moment by moment interactions that begins upon first contact.(5)

An effective assessment is guided by theories rooted in cognitive and behavioural therapy, ego-psychology, family systems and social sciences.

Considerations for a comprehensive assessment within the context of the patient's life limiting illness may include but is not limited to:

- **Ecological factors** – marital status, status of children, family, social support systems (e.g., kin, co-workers, friends, and neighbors), pattern and style of communication, family structure, roles, dynamics, abuse and/or violence, sexuality.
- **Psychological factors** – self-concept, self-esteem, coping abilities, affect, attitude, mental status, substance abuse, developmental stage, defense mechanisms, cognitive abilities, response to previous losses, social skills.
- **Cultural factors** - beliefs, identity, practices, rituals and values.
- **Social factors** – education, employment, housing, financial and/or legal status, leisure activities, physical environment and health care experiences.
- **Spiritual factors** – meaning applied as to what gives purpose, hope.

There is no single, standardized instrument for psychosocial assessment currently being used within the Fraser Health Hospice Palliative Care Program. However, through the use of various techniques such as interviews, family meetings, questionnaires, and specific validated tools such as the Beck Hopelessness Scale, Caregiver Burden Scale, Distress Thermometer, Fam-Care, Herth Hope Index and the McGill Quality of Life questionnaire, the patient and family perspectives can be elicited and shared with all involved interprofessional team members.(25,26)

Understanding Grief and Loss

Patients and family members, in their own way and in their own time, may be grieving many different aspects associated with expected and actual losses. These losses go beyond changes in health status and can include loss of capabilities, roles and responsibilities, employment and income, residence of choice, leisure activities, social connections, sense of self, innocence, faith, and expectations for the future.

Grieving can begin at the time when an individual is first diagnosed with a life limiting illness and arises from an awareness that 'the world that is' and 'the world that should be' are different.(27) Since this "should be world" is a unique construction of each person, the reactions to losing it can be unique.(27)

Grief and mourning are terms which are often used interchangeably. However, "grief" can be defined as "the personal experience of loss", while "mourning" is "the process which occurs after a loss."(28) "Mourning" can also be applied to more formal ways in which the larger community (family, society and culture) addresses and expresses the experience of loss.

Grief is the emotional, physical, intellectual, behavioural and spiritual process of adjusting to loss.(27) It is an active process which can be experienced as the result of a loss or prior to a loss, known as anticipatory grief.(29) There have been many different models for describing and understanding the grief experience. One of the most familiar is the 1969 work of

Elisabeth Kubler-Ross which describes five stages of grief.(30) These include denial, anger, bargaining, depression and acceptance. Although the stages were not proposed to be sequential and mutually exclusive, they were seen to be progressive with 'acceptance' as the goal or resolution of grief.(30)

In more recent years, grief models describe grief as a whole life process which varies in its intensity(16) rather than a single experience or series of stages. The concept of 'denial' has been re-conceptualized to recognize the griever's experience of 'setting aside reality' while "...body, mind, and soul adjust to the distressful situation by closing down to protect and rebuild in small increments".(31) Various emotional states are described as the reality of the loss is fully experienced including searching, yearning, anger, disorganization, detachment and apathy. The outcome of grief work is not so much about 'acceptance' as it is about exploring and adjusting to life without the person who has died. For the griever this involves taking on the changes the loss has created, developing a new sense of self and investing in new roles and relationships. Rather than being a progressive series of stages these various emotions and experiences can be concurrent, cyclical and overlapping. It is the hope that things will get better in time, that there is a life after the death of a loved one, "...that all of this must have some meaning..."(30) that enables grievers to heal, rebuild and begin focusing on future possibilities rather than past losses.

An important part of working with people who are grieving is to help "normalize" the experience. Normalizing grief can provide reassurance and give people permission to acknowledge some of their difficult feelings (i.e., anger and guilt).(32) "Although grief can become prolonged or complicated it is not an intrinsically pathological state, but rather a normal and needful adjustment response."(31) It is important to remember that each grief experience is unique and individual. Each person will experience the above factors differently, so what may be very difficult for one person to experience may not be as difficult for another.

The length of time required to move through these processes varies with each individual. Although there is no "correct" time frame for mourning, an overly lengthy process may indicate complications in grieving that should be addressed.

Factors that may contribute to complicated grief:

- Sudden and unexpected death.
- Loss of a child.
- Death after a lengthy illness.
- Death that the mourner perceives as having been preventable.
- A relationship with the deceased that was markedly angry, ambivalent, or dependent.
- Multiple losses (past or present) or additional stressors.
- Mental health concerns.
- A mourner's perception of lack of support.(25)

When grieving becomes more complicated, a referral for more intense grief counseling may be required to help the person manage his and/or her grief.

Understanding Children's Grief

Much has been written on children's grief but it is still an area that may be difficult for people to address. As adults, we want to protect children. We may try protecting the child from pain by trying to hide the reality of death. Research indicates that children grieve in a healthier way if the adults around them are open, honest, and available to talk when the child is ready.(31) Children need an opportunity to say goodbye and can benefit from participating in funeral rituals. It is important to answer children's questions as honestly and age appropriately as possible because children can imagine things that are often far worse than the truth. Children learn through example. If the adults in their lives are open with their feelings, the children may feel more able to express their feelings as well.

Children's grief is greatly influenced by their age and developmental stage.(33) A chart from The Hospice at the Texas Medical Center shows how concepts of death and grief responses change as children age(64) (*see Appendix A*).

As children grow up they may re-grieve a loss that occurred at a younger age. With their new understanding, knowledge, and sense of self, they may take another look at the loss and how it affects them at each developmental stage. It is important for a parent to realize this may happen because it can be stressful for the parent (who may also be grieving) to revisit the loss themselves.

It is important that we encourage family members of all ages to share stories and to talk with one another, to the person who is dying, and to professional caregivers (re: questions, concerns and requests). Knowing that someone you love is dying, gives you the opportunity to address any "unfinished business" and to say good-bye. It can be a very rich time for families, as members do their grief work together and spend time with their loved one who is dying.

Understanding Culture

Culture refers to commonalities around which a group of people have developed values, norms, family styles, social roles and behaviours in response to the political, economic and social realities they face.(34) Culture is an important factor in determining how individuals experience and express pain, maintain hope in the face of a poor prognosis, make end-of-life care decisions, and respond to illness, treatment, grief and loss. However, culture is not limited to ethnicity and may include categories such as age, gender, spirituality, faith, religion, ablement, sexual orientation, gender identity, lifestyle, national origin, linguistic transition and socioeconomic status.(35,36)

Health care providers are likely to care for persons with very different explanatory models about illness, as well as different expectations about care and views regarding death. Given this diversity, the process of assessment and intervention can present a challenge, and we, as health care providers, may be tempted to steer patients and their families toward choices that suit us instead of trusting and empowering them to make their own choices.

Health care providers need to anticipate and address institutional barriers to caring for patients with a life limiting illness. These barriers often include a lack of trained medical interpreters and the predominance of the western biomedical explanatory model in the health care service delivery with its inherent individualistic values and beliefs. These encourage health care providers to, for example: openly disclose the diagnosis to the dying patient, ask that an advance care plan be developed and minimize physical suffering through symptom management.

While these measures are generally very helpful to the patient, they may be inappropriate for patients from a culture in which:

- Pain and suffering are expressed differently.
- A serious diagnosis is not disclosed to the dying patient.
- Dying is not talked about openly.
- It is understood that the family, and not the patient, makes the final health care decisions as instructed by the patient.(36)

Knowing the cultural formula does not always predict clinical success. Culture is most meaningful when interpreted in the context of an individual's unique history.

It is, therefore, helpful to meet with the patient privately and ask what she or he wants to know about her or his condition; whom to talk to about her or his treatments and potential outcome; and whom she or he wants to make health care decisions for her or him.

Health care providers must remember to ask questions which elicit the patient's own perspective toward their illness and expectations for care. They should offer to make all the information available to the patient first, but allow her or him to decide. They should use professional interpreters to facilitate communication with the patient and family and accommodate all reasonable requests of the patient and their family to build a trusting relationship.

Cultural competence encompasses a set of values, behaviours, attitudes, knowledge and skills which enable health care providers to offer patients the kind of care that is respectful and inclusive of their cultural backgrounds.(36) Understanding how to cope with differences in a comfortable, skilled and competent way allows patients to receive the holistic care they need as the end of their life approaches.

Recommendation 3 Caring for the Patient and their Family

Psychosocial Support

Psychosocial support of a patient and their family is a responsibility all health care providers share. Supports are aimed at enhancing overall well-being for the patient and their family, strengthening their own skills and abilities, and using their own resources for overcoming challenges. Psychosocial support involves attending to the emotional, psychological, social, spiritual, practical needs and wishes of the individual within the context of their community of family, friends, neighbors and associations with others, such as pets.(37) To fully appreciate and provide support, health care providers must attempt to comprehend all significant factors influencing patients and their families' life progress.

Psychosocial interventions are implemented with specific goals in mind and often involve health care providers with specialized knowledge and skills, such as Social Workers, Clinical Counsellors and Mental Health providers. Interventions are agreed upon, ideally, with the patient and their family, with the goal of overcoming barriers, resolving, stabilizing and/or bringing meaning to what is causing distress.(38) Intervention is distinct from diagnosis in that it is viewed as being a 'process' that is put into effect as an ongoing outcome of our observation.(37) Some interventions may be tangible or information based, such as requiring information about different systems, benefits or resources that impact a patient and their loved ones.

General Strategies

Exploring internal and external resources - Internal resources can include resiliency, one's honesty in facing challenging situations, having awareness of one's limitations and ability to express them, ability to cope.

External resources include tapping into patient's supportive network, if one exists such as: family, friends, organization and/or spiritual affiliations, work colleagues. It may include connecting with new resources to assist with coping – counseling, spiritual care, and massage and/or therapeutic touch. Exploring one's internal and external resources can be helpful in assisting with addiction issues and in crisis. Practical tips and suggestions, that is found in patient information handouts, can be helpful to assist patients and families in coping with a life limiting illness (*see Appendix B*).

Enhancing the existing strengths of the patient and family - Through the assessment, one can identify the history and current functioning of the patient and their family, areas of strength, competence and skill. Discuss and explore ways these strengths can be maximized.(32) Familiarize the interdisciplinary team with patient and family strengths and make clear to each team member roles in supporting optimal patient and family functioning.

Providing information – Gain understanding of what the patient and/or family already understand or how much they want to know about their diagnosis, prognosis or other matters related to their quality of life.

Assist with decision making – Identify patient's goals of care and end of life plans. If having difficulty in ascertaining information, asking patients' what is most meaningful to them or what their biggest fears are can help prioritize needs. Utilizing communication tools such as the Advance Care Plan, can help to promote discussions (*see Appendix C*).(2)

Teamwork – Good supportive palliative care is delivered by interdisciplinary teams.(40) The Hospice Palliative Care model is designed on the premise of providing interprofessional care in order to approach each client in a holistic manner and provide "whole person" care. Each member of a team will have a range of overlapping roles, some medical and some non-medical, each focused on a specific state of patient needs. Even if a particular patient or family may choose to not have a specific discipline involved, it can be helpful to include them in the discussion of providing care to patients. Each discipline has their own approach to working with patients and families which can be helpful in gaining a holistic perspective on the patient and their situation in context.

Advocacy – Advocate for the needs, choices, decisions and rights of patients and families in palliative and end of life care. Advocacy should address clinical and social issues that are affecting the life of the patient and foster human dignity and self-worth.(25)

Resources – Utilizing community resources can play an integral part in stabilizing and/or maintaining functioning of a patient and/or family. Social Workers are often familiar with existing resources in the community as it relates to housing, financial benefits, guardianship for children, food programs, and other means that can provide support and guidance for families.

Communication

Supportive/Adaptation Counseling - Counseling is a goal-oriented process which involves employing active listening skills, reflection and exploring inner and external resources all of which can lead to a powerful experience.(25) Often, people are not looking for their problems to be solved, but for someone to deeply hear and be present to the depth of the pain they are experiencing.(40)

Companioning – An intention to bring a respectful, nonjudgmental presence to the dying while liberating them from self-imposed or popular expectations to say or do the right thing. The companioning model, adapted from renowned grief educator Dr. Alan Wolfelt's model of caring for mourners, offers a refreshing departure from traditional counseling formulas and prescriptions.(41)

Active Listening - Listening and talking to patients is one of the key tasks in hospice palliative care.(40) Active listening is a valuable skill because it enables us to demonstrate that we understand what another person is saying, through empathy, and how he or she is feeling about it. Additionally, it also allows the health care provider to check whether their current understanding is correct. Active listening does not mean the same as agreement but rather a demonstration that you intend to hear and understand another point of view. Skills in active listening include: restating, paraphrasing, reflecting back to confirm and ensure understanding of what is being expressed, responding to feelings, summarizing, checking perceptions and allowing for silence.

Normalizing – Discussing common and expected outcomes and responses to situations can be helpful to decrease anxiety about the unknown, apprehension about what "comes next" and for minimizing the common response that their feelings are not "healthy".

Creating a safe space for the "telling of their story" – A life review can be an effective way of allowing a person to have closure in their life, review life's accomplishments and/or achievements, highlight unresolved issues, and to provide an opportunity for forgiveness of self and others.(40) Telling of one's story can also be a useful tool to explore previous coping skills (that were either helpful or not effective), when faced with hardship.(42)

Family Meeting - In hospice palliative care, the family meeting can be an effective way to allow for all members of the family to be heard and understood, allow for observations of relationships among family members, and provide a forum to voice and acknowledge feelings.(43) It is important to prepare for family meetings and to decide, often with the patient, who should be there and who should facilitate. In the presence of family conflict, the family should do most of the talking as the aim is to help them solve the problem, not to solve it for them.(40)

Fostering Hope

Learning to live with a life limiting illness involves patients, their loved ones and health care providers in a continuous process of 'meaning making' and adaptation as they transition:

- From goals of cure to comfort care.
- Through shifts in hopes and expectations.
- With personal, psychosocial and spiritual issues.
- Possibly between care settings (home, hospital, residential care facility and/or hospice residence).(44)

Patients and families require time to adjust and cope with each change. At any stage it is possible that a patient's expressed understanding or disease experience may be different from others, including family members and/or care providers. Identifying and appreciating the 'truth' about an illness within the context of the patient's experience and from the perspective of their loved ones helps to ensure that their values, goals, priorities and preferences will be heard and respected. Throughout the progress of their illness, patients and families may even express hope for outcomes that appear to be unrelated to what is expected based on test results and physical functioning.

While health care providers have an obligation to provide patients and families with accurate information about their disease, prognosis, treatment and/or care options (to the degree desired by patient and family) it is not their responsibility to ensure that hope is 'realistic.'(45)

If hope is defined solely in terms of cure or remission of disease, the hopes of terminally ill patients might be viewed as a form of denial or false reality.(46) Hope for palliative patients needs to be understood and supported as a dynamic process that shifts from hope for a cure to: (46,47)

- Hope for survival.
- Hope for comfort.
- Hope for the energy to keep going.
- Hope for dignity.
- Hope for intimacy, reconciliation with what gives meaning.
- Hope for a better day or better moments.
- Hope for a peaceful death.
- Hope that surviving family will not suffer after patient's death.
- Hope for an afterlife.

For those in the terminal phase of an illness, hope can be a powerful coping mechanism, an inner resource necessary to endure life circumstances. Hope can provide the psychological and physical energy required to endure suffering and achieve goals. It can help people find meaning and direction, "...to stay engaged in the living while shouldering the burden of an uncertain future."(46) It is crucial to approach each patient as a living human being who has the need and the right to maintain a sense of hopefulness, and to be cared for by those who can maintain a sense of hopefulness, however changing this may be, until the moment of their death.(48)

Health care providers can foster hope by:

- Being authentic.
- Facilitating caring relationships.
- Using humour and play.
- Encouraging determination and courage.
- Assisting patients and families to establish short-term, attainable goals.
- Supporting spirituality.
- Engaging in reminiscing.
- Being physically present in crisis.
- Listening attentively.
- Managing pain and other symptoms.(47)

It is through these types of activities that health care providers can sustain their own sense of hope while supporting the evolution of patient and family hope from a curative focus to one that transcends the illness experience.

Helping Children

Adults often struggle while talking with children about sickness, changes in the family and the possibility of death. Adults often don't want children to worry, become upset or they themselves may not be comfortable with giving information because they may still be coming to terms with the diagnosis of a life limiting illness, as well as feeling distracted by the emerging decisions.(21) Despite these fears and feelings, adults can help children by knowing how to provide them with information and support in healthy meaningful ways that respects their experience of grief.

It is not an easy task to talk with children about death and dying and teaching them how to grieve requires the adults supporting them to face those very issues and venture into the unknown themselves.(49) Adults are often in the position of role modeling for children and that happens with one's response to loss and grief as well. Children will often take cues of expressing emotion and behaviour from the adults around them. Consequently, it is important for health care providers to provide education, guidance and support to all of the adult caregivers involved with the children, for their own grief as well as for understanding the developmental stages of children as it relates to grief, loss, intellectual and emotional limitations.(50)

The value of talking with children about the diagnosis, its implications and possible changes in the family will increase their trust, lessen anxiety, promote their feeling of being a part of the family and dispel any false imaginings as to what they may think is happening from what they may have heard.(51)

It is always good to begin with a plan before talking with children and some things to consider are:

- What is known about the illness, treatments, and effects?
- Decide who will talk with the children and when.
- Decide what emotional support is needed.
- General knowledge of available age appropriate materials and community resources.(51)

Suggested guide for talking with children:

1. Ask what they know so far.

- Clarify further by asking what the words mean, i.e., cancer.
- Clarify any misinformation or misunderstandings.

2. Encourage them to ask questions or share worries, reassuring that all are 'okay.'

- This includes information such as location of care, treatments, procedures, possible side effects, physical appearance, etc.

3. Avoid minimizing fears or concerns.

- Tell them who will be there to take care of them and where.

- Let them know of any changes to their day-to-day routine.
- Tell them that you will give regular updates as to what is happening.

4. Answer honestly, be clear and concrete. When you don't have an answer, say so.(49,50)

Desire to Die Statements

Expression of wanting to end one's life of living with a life limiting illness is not uncommon.(52,53,54) Every individual adapts to the inevitability of death in many ways. When we are young, we deny death through parental reassurance, transform death through personification, engage in daredevilry, and when we are older; we transform it into a positive experience, "going home".(53) It is imperative for health care providers to distinguish between patients who contemplate suicide due to fears or questions that can be addressed by an interprofessional hospice palliative care team and those who will, and have the means, to actively take their own life.

Expressing the desire to die surfaces from the need to find meaning within suffering and find reason to live.(56) Meaning is found within relationships which bring life, hope, strength and a sense of completeness.(56) A goal of psychosocial care within hospice palliative care is to support and assist patients and their families in achieving a peaceful awareness of death, life that has been lived and life as it is by helping to sustain meaning.

Statements made by patients with a life limiting illness that either explicitly or implicitly suggests a desire to die can have a variety of meanings. Some thoughts about death and dying are appropriate and do not necessarily indicate suicidal ideation or depression.(57) Typical concerns may include fears around the dying process, contemplation of an afterlife, and other existential issues.(57) More simply, statements made by patients that they have a desire to hasten their death may only be a request to be heard and to be understood.(52)

The most common factors associated with patients expressing a desire to die include:

- Guilt.
- Being a burden to others.
- Loss of autonomy and control.
- Uncontrolled physical symptoms and/or discomfort.
- Depression and hopelessness.
- Existential concerns.
- Fear of the future.(22,54)

Most of the reasons commonly associated with a patient's desire to die can be addressed, however many health care providers often feel inadequately prepared to respond to such statements.(52) Seeking to understand the meaning behind a patient's desire to die is crucial to formulate a professional response and appropriate intervention.(58)

Health care providers can engage in meaningful communication when responding to a patient's statement of a desire to die by: inquiring about the patient's emotional state, conveying a willingness to talk about their distress, and helping them to identify their motivations for the request to die. The very fact that there is communication and expression of wanting to die, suggests the expectation of an interaction with the physician or health care team.(59) The approach to respond to patients, who express a desire to hasten their death, should be guided by a principle that seeks to understand, rather than to act.

Suggested questions and phrases for responding to desire to die statements:

1. Exploring their current feelings and/or fears:

- "Sometimes people feel so overwhelmed by things that they feel everything is just 'too much.' Would you say that you have felt that way?"

2. Assessing their state of suffering and distress (physical, emotional, spiritual):

- "What do you feel could be improved in your care and treatment?"

3. Exploring their specific reasons and plan for suicide, if present:

- "Have you thought about or decided how you would end your life?"
- "If we could relieve the problem, would you still be interested in ending your life?"

4. When they are seeking health care providers assistance with hastening death:

- "Can you tell me how you've come to feel like this and why you want to take this action?"(52)

Through a thorough assessment, a health care provider should ascertain if the patient is an immediate threat to themselves or to others. Health care providers must be careful not to stigmatize their thoughts as suicide but to provide validation of a patient's distress and a commitment to respond to their suffering. If it is determined that there is an imminent threat, one should contact an emergency response team (911 or local Mental Health Unit/Hospital) or the patient's Family Physician for direction.

Recommendation 4 Help for Challenging Care Situations

Indicators for Specialized Consultation

There may be instances where psychosocial intervention is not necessary, but a hospice palliative care Social Worker or Counsellor may be helpful (*see Appendix D*). Based on assessment, some of the following factors may be present that could indicate a greater likelihood of a need for psychosocial support/intervention:

- Emotional anguish experienced by the patient and/or family.
- Feeling overwhelmed and/or unable to make decisions.
- No caregiver in home, caregivers' ability is compromised or patient is primary care provider for another.

- Language, cultural considerations.
- Change in family function e.g., tension, conflict, new roles and responsibilities taken on reluctantly by family members.
- Guardianship with children, young children in the home.
- Unresolved grief from previous and/or traumatic losses (date of identified loss may not be relevant).
- Thoughts of meaninglessness, suicide (either passive or active).
- Concerns regarding active or historical use and/or presence of: alcohol, substance abuse, physical or emotional abuse.
- Concerns regarding physical, psychological and/or financial abuse, neglect and/or self-neglect of adults age 19 and older (*see Appendix E*).
- Absence of advanced end of life planning (i.e., such as personal, health care, financial, legal).
- Spiritual needs, concerns or questions. See *Fraser Health Hospice Palliative Care Symptom Guideline for Spiritual Distress.*
- Educational needs related to community resources and methods to access.
- Mental Health concerns and/or maintenance of mental health wellness.
- Presence of cognitive impairment, learning disability.
- Financial and practical stressors.

Recommendation 5 Evaluation

Palliative and end of life care situations are complex and marked by ongoing changes in patient and family needs, goals and priorities.(61) It is important to have a process that supports the continuous evaluation of interventions and outcomes to ensure that needs are clearly identified and responded to as effectively as possible.(61) Monitoring the efficacy of selected interventions and the progress towards stated goals of care can:

- Enhance and assure consistent quality of care.(5)
- Recognize successes.
- Indicate when a redirection of efforts may be needed.
- Assure that health care providers remain accountable to patients.
- Facilitate hope.
- Help patients mark the completion of important end of life tasks.

A collaborative process for assessing and reassessing interventions recognizes patients and families as "their own best experts"(62) and actively seeks their guidance and feedback. Evaluation processes might also include the use of open-ended interviews, formal assessment tools to monitor pre-and-post intervention changes and clinician self-reflection.

Questions that can help guide evaluation processes include:

1. Was the desired goal of care reached? (Effectiveness)
2. Was the goal of care reached in the most direct way? (Efficiency)
3. Was the patient's autonomy ensured? Were others' autonomy ensured? (Impartiality)(63)

Opportunities may also arise during the course of evaluating outcomes for a specific patient to identify themes, issues or patterns on a global level that can be useful in looking at program policies and procedures for working with the palliative population.

References

Information was compiled using the EBSCO Gateway (up to January 2009) which included Biomedical Health Reference Collection, CINAHL with full text (nursing and allied health), Medline, PsycINFO and PsycArticles. Articles and research were also obtained using the snowball method for finding related articles. Key words included: psychosocial care, self-care, reflective practice, children's grief, grief, telling of a patient's story, hope, expressions of desire to die. Database specific subject headings, if available, were used for these concepts as well. Palliative care textbooks and Kubler-Ross's grief model mentioned were hand searched. Articles not written in English were excluded.

1. Stephen J, Boyle M. The development of clinical practice guidelines for psychosocial oncology: actions and reflections leading to the formation of a national collaborative approach. Vancouver (BC): Provincial Rehabilitation Network, BC Cancer Agency; 2003.
2. Fraser Health. Advance care planning [homepage on the Internet]. Surrey (BC): Fraser Health; 2008 [cited 2009 Jan 30]. Available from: http://www.fraserhealth.ca/Services/HomeandCommunityCare/AdvanceCarePlanning/Pages/default.aspx.
3. Leiter MP, Harvie P, Frizzell C. The correspondence of patient satisfaction and nurse burnout. Soc Sci Med. 1999;47:1611-7.
4. Valent P. Diagnosis and treatment of helper stresses, traumas, and illnesses. In: Figley CR, editor. Treating compassion fatigue. New York: Brunner-Routledge; 2002 [cited 2009 Jan 30]. p. 17-37. Available from: http:// www.paulvalent.com/publications/helper_stress/helper_stress_03.pdf.
5. Hepworth D, Larsen J. Direct social work practice theory and skills. 4th ed. Pacific Grove (CA): Brooks/Cole Publishing Company; 1993.
6. Fraser Health. Hospice palliative care/end of life care [homepage on the Internet]. Surrey (BC): Fraser Health; 2002 [cited 2009 Jan 30]. Available from: http://www.fraserhealth.ca/Services/HomeandCommunityCare/HospicePalliativeCare/Pages/default.aspx.
7. Figley CR. Compassion fatigue: coping with secondary traumatic stress disorder in those who treat the traumatized. New York: Brunner-Mazel; 1995.
8. Gibson L. Complicated grief: a review of current issues [monograph on the Internet]. White River Junction (VT): Research Education in Disaster Mental Health; 2003 [cited 2009 Jan 30]. Available from: http://www.redmh.org/research/specialized/grief.html.
9. Kleinman A, Benson P. Anthropology in the clinic: the problem of cultural competency and how to fix it. PLoS [serial on the Internet]. 2006 [cited 2009 Jan 30];3(10). Available from: http://medicine.plosjournals.org/perlserv/?request=get-document&doi=10.1371/journal.pmed.0030294&ct=1.
10. Marino PA. The effects of cumulative grief in the nurse. J Intraven Nurs. 1998;21(2):101-4.
11. Doka KJ. Disenfranchised grief. In: Disenfranchised grief: recognizing hidden sorrow. Lexington (MA): Lexington Books; 1989.
12. Fraser Health. Employee and Family Assistance Program [homepage on the Internet]. Surrey (BC): Fraser Health; 2002.
13. Service Canada. Unemployment benefits: compassionate care benefits definition [homepage on the Internet]. In: Employment Insurance Act – Part I – Unemployment Benefits. Ottawa: Service Canada; 2008 [cited 200 Jan 30]. Available from: http://www.hrsdc.gc.ca/eng/ei/legislation/ei_act_part1_7.shtml#a23_1.
14. Sadoavoy J, Lazarus L. Individual psychotherapy. In: Sadock BJ, Sadock VA, editors. Comprehensive textbook of psychiatry. 8th ed. Philadelphia (PA): Lippincott, Williams and Wilkins; 2005.
15. Green A. A person-centered approach to palliative care nursing. J Hosp Palliat Nurs. 2006;8:294-301.

16. Wessel, E, & Garon, M. (2005). Introducing reflective narratives into palliative home care education. Home Health care Nurse. 23(8), 516-22.

17. Keidel GC. Burnout and compassion fatigue among hospice caregivers. Am J Hosp Palliat Care. 2002;19:200-5.

18. Egan K, Labyak M. Hospice palliative care: a model for quality end-of-life care. Oxford (England): Oxford University Press; 2006.

19. Sardiwall N, VandenBerg H, Esterhuyse K. The role of stressors and coping strategies in the burnout experienced by hospice workers. Cancer Nurs. 2007;21(2):488-97.

20. White D. The hidden costs of caring: what manager need to know. Health Care Manag. 2006;25(4):341-7.

21. Cairns M, Thompson M, Wainwright W. Transitions in dying and bereavement: a psychosocial guide for hospice and palliative care. Baltimore: Health Professions Press; 2003.

22. Johansen S, Holen JC, Kaasa S, Loge JH, Materstvedt LJ. Attitudes towards, and wishes for, euthanasia in advanced cancer patients at a palliative medicine unit. Palliat Med. 2005, 19, 454-60.

23. Kleinman A. Culture, illness and cure: clinical lesions from anthropologic and cross-cultural research. Annals Int. Med. 1978;88:251-8.

24. Kleinman A. Patients and healers in the context of culture. Berkley (CA): University of California Press; 1980.

25. Culberson R, Brandt K, Cody C. Guidelines for social work in hospice. Alexandra City (VA): National Hospice and Palliative Care Organization; 1980.

26. Kelly B, McClement S. Measurement of psychological distress in palliative care. Palliat Med. 2006;20(8):779-89.

27. Martin K, Elder S. Pathways through grief: a model of the process. In: Personal care in an impersonal world: a multidimensional look at bereavement. Amityville, (NY): Baywood Publishing; 1993. p. 73-86.

28. Worden W. Grief counselling and grief therapy: a handbook for the mental health practitioner. New York: Springer; 2002.

29. Rando T.(1986).Loss and anticipatory grief. Lexington (MA): Lexington Books; 1986.

30. Kubler-Ross E. On death and dying: what the dying have to teach doctors, nurses, clergy and their own families. New York: Macmillan; 1969.

31. Bruce C. Helping patients, families, caregivers and physicians in the grieving process. J Am Osteopath Assoc. 2007;107(7):33-40.

32. Rando T. Treatment of complicated mourning. Champaign (IL): Research Press; 1993.

33. Reeves N. Understanding loss: a parents' guide. In: Taking a closer look. Vancouver: British Columbia Council for the Family; 1991.

34. Christensen CP. Cross-cultural awareness development: a conceptual model. Couns Educ Superv. 1989;28:270-87.

35. National Hospice and Palliative Care Organization. Social work guidelines. Alexandria (VA): NHPCO; 2007.

36. Shakeri Shemariani F. Culturally competent practice in hospice palliative care. Perspectives: BCASW newsletter. 2004.

37. Fraser Health. Hospice Palliative Care. Exploring the journey, psychosocial perspective in hospice palliative care. Surrey (BC): Fraser Health; 2008.

38. Intervention (counseling). In: Wikipedia, the free encyclopedia. San Francisco: Wikimedia Foundation; 2007 [updated 2009 Jan 17; cited 2009 Jan 30]. Available from: http://en.wikipedia.org/wiki/Intervention_(counseling).

39. Turner FJ. Social work diagnosis in contemporary practice. Oxford: Oxford University Press; 2005.

40. Monroe B. Social work in palliative care. In: Doyle D, Hanks G, MacDonald N, editors. Oxford Textbook of palliative medicine. 2nd ed. Oxford: Oxford University Press; 1998. p. 867-79.

41. Wolfelt A. Beyond the medical model of bereavement caregiving. Fort Collins (CO): Centre for Loss and Life Transition; 2007.
42. Jenko M, Gonzalez L, Seymour MJ. Life review with the terminally ill. J Hosp Palliat Nurs. 2007 May/Jun;9(3):159-67.
43. Boyle D, Miller P, Forbes-Thompson S. Communication and end-of-life care in the intensive care unit: patient, family and clinician outcomes. Crit Care Nurs Q. 2005;28(4):302-16.
44. Duggleby W, Berry P. Transitions and shifting goals of care for palliative patients and their families. Clin J Oncol Nurs. 2005;9(4):425-8.
45. Alberta Cancer Board. Alberta hospice palliative care resource manual. Edmonton (AB): ACB; 2001.
46. Johnson, S. Hope in terminal illness: an evolutionary concept analysis. International J Palliat Nurs. 2007;13(9):451-9.
47. Duggleby W. Hope at the end of life. J Hosp Palliat Nurs. 2001;2(2):51-64.
48. Kessler D. The needs of the dying: a guide to bringing hope, comfort and love to life's final chapter. New York: Harper; 1997.
49. Russell C. Living dying: a guide for adults supporting grieving children and teenagers. Toronto (ON): Max and Beatrice Wolfe Centre for Children's Grief and Palliative Care; 2008.
50. Rando T. Strategies for the classroom [summary of guidelines on how to reach and treat the bereaved child within the classroom]. In: Rando T, editor. Loss and anticipatory grief. Toronto (ON): D.C Health and Co.; 1986. p. 170-2.
51. Slakov J. Reaching out to your children when cancer comes to your family: a guide for parents. Vancouver: BC Cancer Agency; 2007.
52. Hudson P, Schofield P, Kelly B, Hudson R, Street A, O'Connor M, et al. Responding to desire to die statements from patients with advanced disease: recommendations for health professionals. Palliat Med. 2006;20:703-10.
53. Van Loon RA. Desire to die in terminally ill people: a framework for assessment and intervention. Health Soc Work. 1999;24(4):260-8.
54. Hudson P, Kristjanson L, Ashby M, Kelly B, Schofield P, Hudson R, et al. Desire for hastened death in patients with advanced disease and the evidence base of clinical guidelines: A systematic review. Palliat Med. 2006;20:693-701.
55. Yalom I. Staring at the sun: overcoming the terror of death. San Francisco (CA): Jossey-Bass; 2008.
56. Kimble M. Victor Frankl's contribution to spirituality and aging. J Relig Gerontol. 2000;11(3/4):1-6.
57. Pessin H, Olden M, Jacobson C, Kosinski A. Clinical assessment of depression in terminally ill cancer patients: a practical guide. Palliat Support Care. 2005;3:319-24.
58. Mak Y, Elywn, G. Use of hermeneutic research in understanding the meaning of desire for euthanasia. Palliat Med. 2003;17:395-402.
59. Muskin PR. The request to die: role for a psychodynamic perspective on physician-assisted suicide. JAMA.1998;279:323-8.
60. Vancouver Coastal Health. Re:act adult abuse and neglect response flow chart. In: Re:act - act on adult abuse and neglect [quick assessment guide] [monograph on the Internet]. Vancouver: VCH; 2005 [cited 2009 Apr 6]. p. 5.
    Available from: http://www.vchreact.ca/attachments/guide.pdf.
61. Saleebey D. The strengths perspective in social work practice. White Plains (NY): Longman; 1992.
62. Cadell S, Wainwright W, Abernethy N, Feron A, Kelley,M, Nelson F, et al. Draft – Social work competencies in hospice palliative care. Ottawa: Heath Canada; 2008.
63. Miley K, O'Melia M, Dubois B. Generalist social work practice: an empowering approach. Boston (MA): Allyn and Bacon; 1995
64. Levetown,M.(2008).Communicating with Children and Families: From Everyday Interactions to Skill in Conveying Distressing Information. Pediatrics, 121:5,1441e-1460.

Children and Death – The Hospice at the Texas Medical Center(64)

Age	Development State / Task	Concept of Death	Grief Response	Signs of Distress	Possible Interventions
2-4	Egocentric. Believes world centers around them. Narcissistic. No Cognitive understanding. Pre-conceptual – unable to grasp concepts.	Seen as abandonment. Seen as reversible, not permanent. Common statements, "Did you know my daddy died – when will he be home?"	Intensive response, but brief. Very present oriented. Most aware of altered patterns of care.	Regress: eating and sleeping disorders – bedwetting.	Short interactions. Frequent repetition. Comforting. Touching.
4-7	Gaining sense of autonomy. Exploring world outside of self. Gaining language. Fantasy thinking/ wishing. Initiative phase seeing self as initiator. Concerns of guilt.	Death still seen as reversible. Great personification of death. Feelings of responsibility because of wishes, thoughts. Common statements, "It's my fault; I was mad at her and wished she'd die."	Verbalization. Great concerns with process. How? Why? Repetitive questioning.	Regression: nightmares, sleeping and eating disturbances, violent play. Attempts to take on role of person who died.	Symbolic play. Drawing/stories. Allow/encourage expression of energy/ feelings of anger. Talk about it.
7-11	Concrete-operational. Industry vs. Inferiority. Beginning of socialization. Development of cognitive ability. Beginning of logical thinking.	Death as punishment. Fear of bodily harm; mutilation. This is a difficult transition period – still want to see death as reversible, but beginning to see it as final.	Specific questioning. Desire for complete detail. Concerned with how others are responding. What is the right way? How should they be responding? Starting to have ability to mourn and understand mourning.	Regression: problems in school, withdrawn from friends. Acting out. Sleeping and eating disturbances. Overwhelming concern with body. Suicidal thoughts (desire to join one who died). Role confusion.	Answer questions. Encourage expression of range of feelings. Encourage/allow control. Be available but allow alone time. Symbolic play. Talk about it.
11-18	Formal operation problem solving. Abstract thinking. Integration of ones own personality.	"Adult" approach. Ability to abstract. Beginning to truly conceptualize death. Work at making sense of teachings.	Depression. Denial. Regression: more often willing to talk to people outside of family. Traditional mourning.	Depression. Anger. Anger towards parents. Non-compliance. Rejection of former teaching. Role confusion. Acting out.	Encourage verbalization. Do not take control. Encourage self-motivation. Listen. Be available. Do not attempt to take away grief.

Tools for Coping with Serious Illness

The following are ideas that you may find useful in assisting you while coping with a serious illness, whether it is for yourself or a loved one. These ideas/tools may trigger or reinforce some of your own. They are not all inclusive nor do they corner the market on truth. If some of these ideas do not work for you, ignore them. Take only what fits. Each of us is unique in how we handle difficult situations. Use these ideas to stimulate more of your own.

- **Deal with your emotions:** Allowing ourselves to deal with our emotions, whether they are up or down, is a part of the healing process. When we have a lot of stress in our lives, our defences are down and emotions are closer to the surface.
- **Drink water:** Dehydration occurs when we are under stress of any kind. This can affect our energy level, etc.
- **Eat healthy:** 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 health care professional, but eating small amounts more often is usually better than trying to face a big meal. Food replacements such as Ensure® or Boost® may be helpful.
- **Enlist the support of others:** 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, health care staff, etc.
- **Take a deep breath:** 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.
- **Personal coping kit:** 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.
- **Write down your thoughts:** 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.
- **Utilize your sense of humour:** 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.

Also….for family and friends:

Being there for someone who is ill is difficult work at any time. However, when faced with a life-threatening situation, things are even more complex, and events may take on a different meaning. While the ideas above may apply to you, also remember the following:

- **Time out:** Take breaks to allow your body time to rejuvenate. Take short walks, get some fresh air, even if only for 5 minutes at a time. A change of scenery gives you a break from the intensity of the situation and can give you renewed energy to continue to be present.

Common Reactions when Coping with Serious Illness

Information for individuals, friends and family

There are a wide variety of feelings and reactions that come into play when you are facing a serious illness either yourself or of someone you love. It is important to note that no two people react in the same way to a crisis like this. Everyone is unique and, as a result, will handle the situation somewhat differently.

As you go through this experience, you may find yourself reacting in ways that are very uncharacteristic for you. This does not mean that you are "losing it"; it does mean, however, that your reactions are "normal" or can be "expected" given these unusual circumstances. Be gentle with yourself, give yourself permission to take breaks, and ask for support from those around you.

You can expect that there will be some emotional reaction to this situation. Some of the common reactions you may experience include:

- **Inability to focus or concentrate:** Things which may have been routine in your daily life are now difficult, such as reading, etc.
- **Poor memory:** Even such things as a familiar phone number may be a challenge to recall.
- **Physical reactions:** 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.
- **Increased irritability:** 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.
- **Confusion / disorientation:** You may find yourself losing track of place/ time.
- **Less self-confidence than usual:** This incident has turned your world upside down and has shaken up your beliefs, including what you believed about yourself.
- **Difficulty in making decisions:** Sometimes what once seemed the simplest of decisions becomes a challenge.
- **Change in sleeping patterns or difficulty sleeping:** When you try to sleep or rest, your thoughts may run all over the place. (A health care professional may be able to give you some suggestions to help deal with this).
- **Sense of unreality:** "This can't really be happening!"
- **Feelings of helplessness:** The feeling that there must be something you could do to make a difference to the situation.
- **Feelings of being "on alert" at all times:** You may find that you are easily startled and that it is hard to settle yourself down, particularly at night.
- **Being on an "emotional roller coaster":** You may feel that you are never quite sure what is going to happen day by day as you deal with the situation.

This is not a complete list and you can add many other things that you experience. Use only what works or fits for you.

Advance Care Planning

• Respect • Trust • Caring

Advance Care Planning is an on-going process that involves encouraging capable adults to have meaningful discussions about personal values, beliefs and possible future medical decisions with their loved ones and physicians/health care team.

Fraser Health Authority in British Columbia has developed an Advance Care Planning program that promotes:

- Advance Care Planning conversations throughout the continuum of care,
- standardized education for health care professionals,
- information and education for the public in community settings, and
- development of systems that honours wished.

A variety of tools and materials are available at: www.fraserhealth.ca (search "Advance Care Planning") and include:

- My Voice Workbook©
- Information Booklet for Advance Care Planning Brochure
- Making Informed Decisions About Cardio-pulmonary Resuscitation Brochure
- Let's Talk DVD
- Planning in Advance for Your Future Health Care Choices e-book
- Posters
- Wallet card

For further information, please call: 1-877-825-5034 (toll free within BC)
or email: advancecareplanning@fraserhealth.ca

1-877-825-5034

fraserhealth Better health. Best in health care.

When to Call the Hospice Palliative Care Social Worker and/or Counsellor...

Fraser Health Hospice Palliative Care Consultation Services

For consultation on any aspect of psychosocial assessment &/or care planning regarding the provision of care to hospice palliative care patients & their families/caregivers.

For information & resources (i.e., pamphlets, books, referrals) for clients and families/ caregivers regarding palliative care, grief & bereavement, financial & community resources.

For collaboration with primary care staff in a joint visit or family meeting to:

- Assist with assessing psychosocial needs.
- Discuss goals of care.
- Provide support with challenging psychosocial situations.
- Describe the hospice palliative care program to a patients and/or family members.

For specialized support & counselling in complex situations where assistance is needed regarding:

- Difficult family dynamics and/or adjustment to illness.
- Exploring and/or assisting patients and their family/caregivers in the expression of emotions such as anxiety, anger, depression, meaningfulness and hope.
- Financial and/or legal planning options related to end-of-life.
- Ethical dilemmas including conflicting expectations regarding treatment and/or care planning.
- Cultural issues.
- Caregiver issues (i.e., Protection concerns of young children or dependent and/or vulnerable adults including issues of abuse or neglect).
- Advance Care Planning or discussions regarding end-of-life decision making.

To facilitate case reflections (staff 'debriefings') regarding complex and/or challenging hospice palliative caregiving situations, current or recent.

To discuss any personal/professional challenges you may be experiencing in working with hospice palliative care patients & families — including grief or boundary issues.

***Please contact your local Hospice Palliative Care Team Social Worker and/or Counsellor:**

http://www.fraserhealth.ca/Services/HomeandCommunityCare/HospicePalliativeCare/Pages/ContactUs.aspx

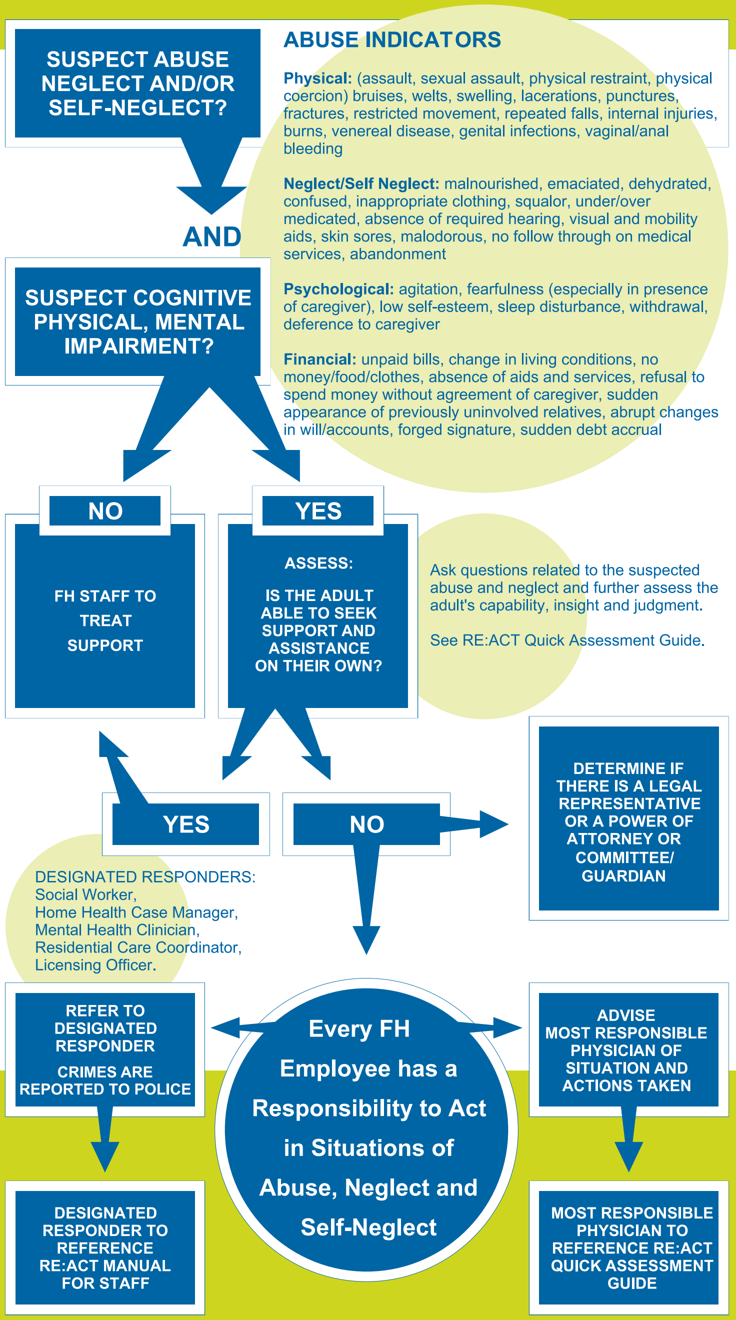
Approved by: Hospice Palliative Care, Social Work/Counsellor Committee, April 2009

re:act

Adult Abuse and Neglect

Response Flow Chart

For Fraser Health



SUSPECT ABUSE NEGLECT AND/OR SELF-NEGLECT?

AND

SUSPECT COGNITIVE PHYSICAL, MENTAL IMPAIRMENT?

ABUSE INDICATORS

Physical: (assault, sexual assault, physical restraint, physical coercion) bruises, welts, swelling, lacerations, punctures, fractures, restricted movement, repeated falls, internal injuries, burns, venereal disease, genital infections, vaginal/anal bleeding

Neglect/Self Neglect: malnourished, emaciated, dehydrated, confused, inappropriate clothing, squalor, under/over medicated, absence of required hearing, visual and mobility aids, skin sores, malodorous, no follow through on medical services, abandonment

Psychological: agitation, fearfulness (especially in presence of caregiver), low self-esteem, sleep disturbance, withdrawal, deference to caregiver

Financial: unpaid bills, change in living conditions, no money/food/clothes, absence of aids and services, refusal to spend money without agreement of caregiver, sudden appearance of previously uninvolved relatives, abrupt changes in will/accounts, forged signature, sudden debt accrual

NO

FH STAFF TO
TREAT
SUPPORT

YES

ASSESS:

IS THE ADULT ABLE TO SEEK SUPPORT AND ASSISTANCE ON THEIR OWN?

Ask questions related to the suspected abuse and neglect and further assess the adult's capability, insight and judgment.

See RE:ACT Quick Assessment Guide.

YES

NO

DETERMINE IF THERE IS A LEGAL REPRESENTATIVE OR A POWER OF ATTORNEY OR COMMITTEE/ GUARDIAN

DESIGNATED RESPONDERS:
Social Worker,
Home Health Case Manager,
Mental Health Clinician,
Residential Care Coordinator,
Licensing Officer.

REFER TO DESIGNATED RESPONDER

CRIMES ARE REPORTED TO POLICE

DESIGNATED RESPONDER TO REFERENCE RE:ACT MANUAL FOR STAFF

Every FH Employee has a Responsibility to Act in Situations of Abuse, Neglect and Self-Neglect

ADVISE MOST RESPONSIBLE PHYSICIAN OF SITUATION AND ACTIONS TAKEN

MOST RESPONSIBLE PHYSICIAN TO REFERENCE RE:ACT QUICK ASSESSMENT GUIDE

DOCUMENT AT EACH STEP

CONFIDENTIALITY:

A person must not disclose or be compelled to disclose the identity of a person who makes a report or offers collateral information.

POLICE REPORTS:

FH is required by law to report to the police suspected crimes committed against adults that are unable to seek support and assistance on their own.

EMERGENCY IDENTIFICATION:

It is necessary to act without delay in order to preserve the adult's life, prevent serious physical or mental harm, or to protect assets from significant damage or loss.

re:act
Adult Abuse & Neglect - Response Resource

fraserhealth Better health. Best in health care.

Adapted from Vancouver Coastal Health.[60]