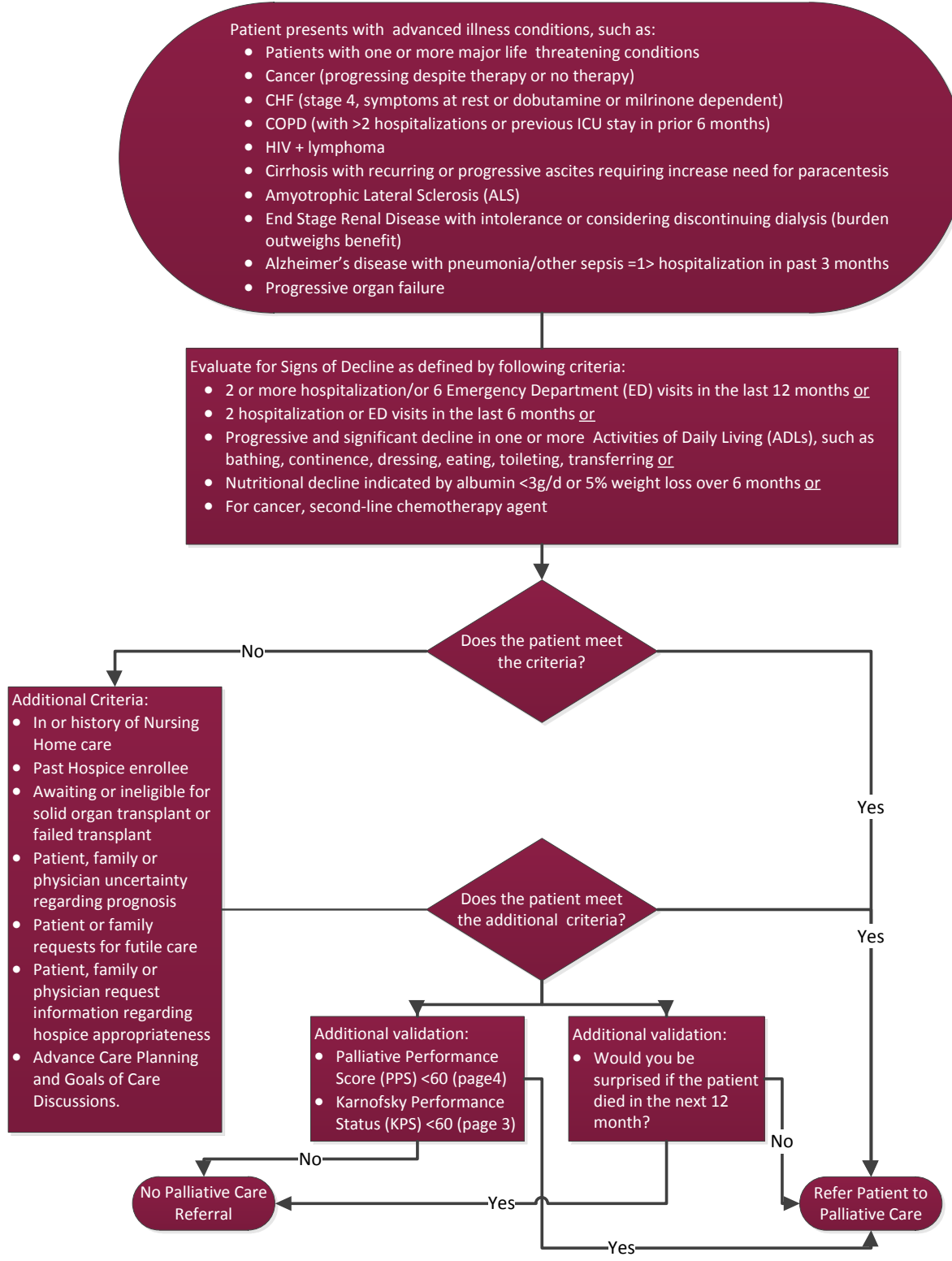


Definition: Palliative Medicine is specialized medical care for people living with serious illnesses. Regardless of the diagnosis, the focus is on providing patients with relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team comprised of doctors, nurses, and other skilled care providers who work with a patient's other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatments.



**This guideline will provide recommendations for initiating steps in the outpatient setting to address patients with progressive or recurrent advanced illness or chronic debilitating conditions as well as provide criteria to warrant specially palliative service consultation. Benefits of palliative service consultation may include discussion of available resources for improved patient care.*

The World Health Organization defines palliative care as "an approach that improves the quality of life of patients and the family facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." Palliative care is provided by an interdisciplinary team of experts that offer comprehensive care and support systems for patients and their health care providers, both at times of end of life and when they are undergoing treatments for advanced illness. Some patients near the end-of-life are being treated with curative treatments and others face disease process deterioration or exacerbations. Both benefit through outpatient palliative care measures that can be offered in the primary care provider's office and others benefit by inpatient consultation and management.

Three diseases, heart disease, cancer and stroke account for 60% of the deaths in the United States. Most people live with some limitation in their ability for self-care for two to four years before they die. While sudden-death occurs in only 15% of people, the predictable decline in patients with "terminal illness" cases of organ failure (e.g., chronic obstructive pulmonary disease, heart failure, renal failure and other progressive serious medical diseases) is associated with gradual decline with intermittent exacerbations. The time of death for these people with progressive and ultimately fatal diseases is not entirely predictable and often occurs unexpectedly. Additionally, the subset of patients who suffer from gradual decline or "frailty" where dementia is often present is associated with a lingering course. They can extend for many years, stressing and wearing out caregivers and other support systems as decline in functional abilities progress.

Distinction between Palliative and Hospice Care

The specialty of palliative medicine arose as a direct result of the hospice movement. Palliative medicine incorporates the holistic care developed by hospice, focusing on symptom management, supporting and assisting with communication and providing such care to a wider group of patient's including those who are not dying or who cannot receive or choose not to receive hospice services. Palliative care aims to relieve suffering in all stages of disease and is not limited to end-of-life care. Within an integrated model of medical care, palliative care is provided at the same time as curative or life-prolonging disease treatments. In contrast, hospice is palliative care that is offered to patients at the end of life when curative or life prolonging therapy is no longer beneficial or when the burden outweighs the benefit. All care delivered by hospice can be considered palliative care however, not all palliative care is delivered in hospice.

Palliative Care

Palliative care is provided by a specialized team of physicians, nurses and other medical caregivers who address more complex needs administering or oversee ongoing comfort care methods for patients who are seriously ill with focus on symptom management and reducing, refractory pain, stress and suffering as well as aspects of depression, anxiety, grief and existential distress thereby improving quality of life for people of any age and at any stage in a serious illness whether that illness is curable, chronic or life-threatening. Palliative care can be administered in conjunction with continued curative treatment if an individual is not ready or unwilling to discontinue such efforts. Additional assistance with conflict resolution regarding goals of treatment with family, issues between medical staff and families, and among treatment teams can be facilitated by the palliative care team. The goal is to improve quality of life for both the patient and the family. While palliative care can be administered in the home, it is most common to receive palliative care in an institution such as a hospital, extended care facility or nursing home that is associated with a palliative care team. The palliative care team can further assist in defining and addressing cases of near futility.

Hospice Care

Hospice care is care designed to provide support to a patient and their family during an advanced illness and focuses on comfort and quality of life, rather than cure at the end of life. A person must be considered terminal or within 6 months of death to be eligible for most hospice programs or to receive hospice benefits. Hospice programs concentrate on comfort rather than aggressive disease abatement. A patient can therefore, concentrate on getting the most out of life with the time they have left. Hospice can provide supplies and equipment seeking to improve the quality of life for patients while supporting the family helping to care for the patient. A wide range of hospice services including physical, psychological, social and spiritual support and counseling for family members with the goal of enabling a patient to have an alert, pain-free end of life and to live each day as fully as possible. Hospice provides "palliative care".

Both palliative care and hospice care provide comfort but palliative care can begin at the time of diagnosis and at the same time as treatment. Hospice care however, begins after treatment of the disease has stopped and when it is clear that the person is not going to survive the illness.

Primary Care Provider's Role

Studies show a clear benefit when patients are given a chance to discuss end-of-life issues and are more likely to die at home or in a comfortable setting instead of a hospital intensive care unit. Survivors are able to cope better with death and experience less anxiety and stress later.

1. Timing of end-of-life conversations should begin well before a person becomes ill as these discussions can be very difficult for patients and their families once a health crisis occurs. Advanced care planning should be an integral part of a primary care providers routine adult medical care prior to declines in health.
2. Periodic end-of-life planning should be revisited as a disease progresses and before a risky procedure or surgery. If a diagnosis of a terminal disease has been made the patient and their families need to understand the prognosis and make decisions regarding what treatment they want and plan priorities for the life that remains.
3. Determine patient's wishes for interventions at time of crisis. This should be accomplished through written advanced directives or direct conversations with the patient with key family members or their power of attorney present addressing general values and specific management choices. Spiritual, cultural and social and economic are key components of end-of-life discussions. Aspects pertaining to the disease or illness treatment related to cure and expectations should be discussed. Determining if length of life or quality of the remaining time is priority.
4. Functional status is a strong indicator of a patient's prognosis. Eliciting information about the patient's ability to perform activities of daily living can help predict survival. When the patient is not able to spend time out of bed, has reduced appetite or reduced caloric intake and cannot dress or bathe without assistance the patient is likely to be in the last months of life. These patients should be eligible for Medicare hospice benefits. This is the time to involve **specialty** palliative care consultation.
5. Primary care providers or hospitalists caring for patients could provide palliative care services including management of basic pain, depression or anxiety and conducting initial or revisited discussions pertaining to advanced care planning, clarifying prognosis of chronic debilitating illnesses and establishing goals of treatment options as well as determining or confirming **CODE STATUS**.

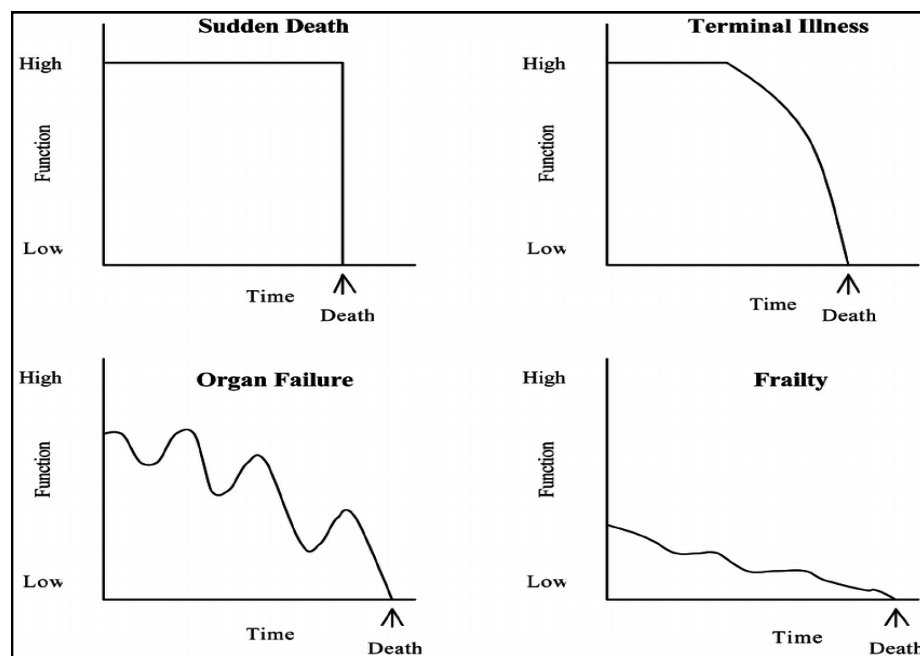
Suggested Questions to Start a Conversation

- Thinking about your death, what do you value most about your life?
- If you were diagnosed with a terminal illness, would you want to pursue every possible cure?
- Do you imagine wanting to stop curative efforts if they were unsuccessful?
- Do you want to die at home?
- How do you feel about an extended hospitalization?
- How much pain is acceptable to you?
- Do you want to be with your family when you die?
- What decisions regarding care do you want to entrust to others?
- What does good death look like to you?

Community Palliative Resources

- Mount Carmel Palliative Care and Hospice Website: <http://libguides.mccn.edu/palliativecare>
- State of Ohio Living Will and Power of Attorney Packet: <http://recorder.franklincountyohio.gov/services/living-wills.cfm>
- Ohio Department of Health DNR forms: <http://www.odh.ohio.gov/pdf/forms/dnrfrm.pdf>
- Center to Advance Palliative Care (capc): <https://www.capc.org/>
- National Hospice and Palliative Care Organization: <http://www.nhpco.org/>
- American Academy of Hospice and Palliative medicine: <http://aahpm.org/>

Theoretical Trajectories of Dying



KARNOFSKY PERFORMANCE STATUS SCALE DEFINITIONS RATING (%) CRITERIA

The Karnofsky Performance Scale Index allows patients to be classified as to their functional impairment. This can be used to compare effectiveness of different therapies and to assess the prognosis in individual patients. The lower the Karnofsky score, the worse the survival for most serious illnesses.

Able to carry on normal activity and to work; no special care needed.	100	Normal no complaints; no evidence of disease.
	90	Able to carry on normal activity; minor signs or symptoms of disease.
	80	Normal activity with effort; some signs or symptoms of
Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed.	70	Cares for self; unable to carry on normal activity or to do active work.
	60	Requires occasional assistance, but is able to care for most of his personal needs.
	50	Requires considerable assistance and frequent medical
Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly.	40	Disabled; requires special care and assistance.
	30	Severely disabled; hospital admission is indicated although death not imminent.
	20	Very sick; hospital admission necessary; active supportive treatment necessary.
	10	Moribund; fatal processes progressing rapidly.
	0	Dead

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Palliative Performance Scale (PPSv2) version 2

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity <i>with</i> Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

Instructions for Use of PPS (see also definition of terms)

- PPS scores are determined by reading horizontally at each level to find a 'best fit' for the patient which is then assigned as the PPS% score.
- Begin at the left column and read downwards until the appropriate ambulation level is reached, then read across to the next column and downwards again until the activity/evidence of disease is located. These steps are repeated until all five columns are covered before assigning the actual PPS for that patient. In this way, 'leftward' columns (columns to the left of any specific column) are 'stronger' determinants and generally take precedence over others.

Example 1: A patient who spends the majority of the day sitting or lying down due to fatigue from advanced disease and requires considerable assistance to walk even for short distances but who is otherwise fully conscious level with good intake would be scored at PPS 50%.

Example 2: A patient who has become paralyzed and quadriplegic requiring total care would be PPS 30%. Although this patient may be placed in a wheelchair (and perhaps seem initially to be at 50%), the score is 30% because he or she would be otherwise totally bed bound due to the disease or complication if it were not for caregivers providing total care including lift/transfer. The patient may have normal intake and full conscious level.

Example 3: However, if the patient in example 2 was paraplegic and bed bound but still able to do some self-care such as feed themselves, then the PPS would be higher at 40 or 50% since he or she is not 'total care.'

- PPS scores are in 10% increments only. Sometimes, there are several columns easily placed at one level but one or two which seem better at a higher or lower level. One then needs to make a 'best fit' decision. Choosing a 'half-fit' value of PPS 45%, for example, is not correct. The combination of clinical judgment and 'leftward precedence' is used to determine whether 40% or 50% is the more accurate score for that patient.
- PPS may be used for several purposes. First, it is an excellent communication tool for quickly describing a patient's current functional level. Second, it may have value in criteria for workload assessment or other measurements and comparisons. Finally, it appears to have prognostic value.

Definition of Terms for PPS

As noted below, some of the terms have similar meanings with the differences being more readily apparent as one reads horizontally across each row to find an overall 'best fit' using all five columns.

Ambulation

The items '**mainly sit/lie**,' '**mainly in bed**,' and '**totally bed bound**' are clearly similar. The subtle differences are related to items in the self-care column. For example, 'totally bed bound' at PPS 30% is due to either profound weakness or paralysis such that the patient not only can't get out of bed but is also unable to do any self-care. The difference between 'sit/lie' and 'bed' is proportionate to the amount of time the patient is able to sit up vs need to lie down.

'**Reduced ambulation**' is located at the PPS 70% and PPS 60% level. By using the adjacent column, the reduction of ambulation is tied to inability to carry out their normal job, work occupation or some hobbies or housework activities. The person is still able to walk and transfer on their own but at PPS 60% needs occasional assistance.

Activity & Extent of disease

'**Some**,' '**significant**,' and '**extensive**' disease refer to physical and investigative evidence which shows degrees of progression. For example in breast cancer, a local recurrence would imply 'some' disease, one or two metastases in the lung or bone would imply 'significant' disease, whereas multiple metastases in lung, bone, liver, brain, hypercalcemia or other major complications would be 'extensive' disease. The extent may also refer to progression of disease despite active treatments. Using PPS in AIDS, 'some' may mean the shift from HIV to AIDS, 'significant' implies progression in physical decline, new or difficult symptoms and laboratory findings with low counts. 'Extensive' refers to one or more serious complications with or without continuation of active antiretrovirals, antibiotics, etc.

The above extent of disease is also judged in context with the ability to maintain one's work and hobbies or activities. Decline in activity may mean the person still plays golf but reduces from playing 18 holes to 9 holes, or just a par 3, or to backyard putting. People who enjoy walking will gradually reduce the distance covered, although they may continue trying, sometimes even close to death (eg. trying to walk the halls).

Self-Care

'**Occasional assistance**' means that most of the time patients are able to transfer out of bed, walk, wash, toilet and eat by their own means, but that on occasion (perhaps once daily or a few times weekly) they require minor assistance.

'**Considerable assistance**' means that regularly every day the patient needs help, usually by one person, to do some of the activities noted above. For example, the person needs help to get to the bathroom but is then able to brush his or her teeth or wash at least hands and face. Food will often need to be cut into edible sizes but the patient is then able to eat of his or her own accord.

'**Mainly assistance**' is a further extension of 'considerable.' Using the above example, the patient now needs help getting up but also needs assistance washing his face and shaving, but can usually eat with minimal or no help. This may fluctuate according to fatigue during the day.

'**Total care**' means that the patient is completely unable to eat without help, toilet or do any self-care. Depending on the clinical situation, the patient may or may not be able to chew and swallow food once prepared and fed to him or her.

Intake

Changes in intake are quite obvious with '**normal intake**' referring to the person's usual eating habits while healthy.

'**Reduced**' means any reduction from that and is highly variable according to the unique individual circumstances.

'**Minimal**' refers to very small amounts, usually pureed or liquid, which are well below nutritional sustenance.

Conscious Level

'**Full consciousness**' implies full alertness and orientation with good cognitive abilities in various domains of thinking, memory, etc. '**Confusion**' is used to denote presence of either delirium or dementia and is a reduced level of consciousness. It may be mild, moderate or severe with multiple possible etiologies. '**Drowsiness**' implies either fatigue, drug side effects, delirium or closeness to death and is sometimes included in the term stupor. '**Coma**' in this context is the absence of response to verbal or physical stimuli; some reflexes may or may not remain. The depth of coma may fluctuate throughout a 24 hour period.

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Correspondence should be sent to Medical Director, Victoria Hospice Society, 1900 Fort St, Victoria, BC, V8R 1J8, Canada

Advance Care Planning Service (ACP) CPT Codes and Descriptions

CPT Codes	Billing Code Description
99497	Advance care planning including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed) by the physician or other qualified health care professional; first 30 minutes, face-to-face with the patient, family member(s) and/or surrogate.
99798	Each additional 30 minutes. (List separately in addition to code for primary procedure.)

Important Advance Care Planning Service Billing Information:

- No limits to the number of times ACP can be reported for a given beneficiary in a given time period. The first 16 - 30 minutes are to be billed under 99497 and if the conversation is 46 minutes or more, both 99497 and 99498 can be billed.
- Billing of these codes is not limited to particular specialties, specific diagnosis, place of service and can be billed by any physician or non-physician authorized to independently bill Medicare.
- Codes can be billed on the same date of service (or different date) as most other Evaluation and Management (E/M) codes, as well as transitional care management services (TCM) or chronic care management services (CCM) or Annual Wellness Visit (AWV). It is important to indicate that the time spent on advance care planning was "separate from and in addition to" the other service(s).
- Appropriate documentation is required which includes an account of the encounter, noting the voluntary nature, who was present, the time spent, what forms were discussed, and the completed form when performed.
- Completion of an advance directive form such as Health Care Proxy, a Medical/Physician Orders for Life Sustaining Treatment (MOLST/POLST), a Living Will, DNR/DNAR/AND or a Durable Power of Attorney for Health Care are not a requirement for billing the service. The service is the explanation and discussion of the form.

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This clinical guideline outlines the recommendations of Mount Carmel Health Partners for this medical condition and is based upon the referenced best practices. It is not intended to serve as a substitute for professional medical judgment in the diagnosis and treatment of a particular patient. Decisions regarding care are subject to individual consideration and should be made by the patient and treating physician in concert.

