

*Resource Handbook
for the film*

The Last Days of Living

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The Last Days of Living

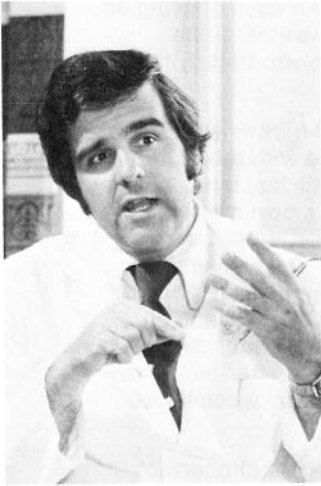
In this film we share in the hardships and the joys of the last days of living as they are experienced by the patients, their families and the staff of the Royal Victoria Hospital Palliative Care Service. We are confronted by the transience of life – the patients' and our own.

We are deeply indebted to the patients, their families and friends who, with extraordinary grace and openness, have allowed us to be with them during some of the most "private" and intimate moments of their lives. It has been observed that in our society personal feelings about one's own mortality are as sensitive as feelings about one's sexuality. In each case, those participating did so in an effort to make a contribution to *us* – the viewers – to show us that there is "another way to die," that when there is excellence of symptom control and an air of honesty and trust, one can usually face all odds. They have given meaning to the assertion of Dr. Cecily Saunders of St. Christopher's Hospice, London, that "dying is that unique period in the patient's illness when the long defeat of living can be gradually converted into a positive achievement in dying."

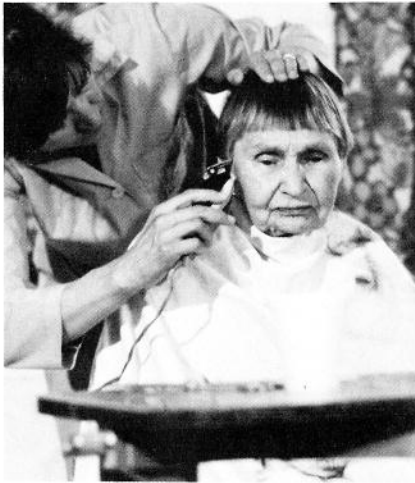
Those filmed do *not* represent a highly select group of people chosen because of their unusual fortitude. *Last Days* was filmed in a single four-week period. This fact gives each of us a measure of hope since, while they are extraordinary in their courage and grace, their achievements are clearly attainable by us all. With fresh insight we can understand the importance of Forster's words and concur with the narrator when he observes "When there's nothing left to hide and no need to turn away, you can make a moment last a lifetime, make a lifetime last a day."

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The Last Days of Living



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Suggestions for Use of the Film and the Book

Like any other creative work, the film *The Last Days of Living* will evoke a highly personal response. The intimacy and immediacy of our contact with the people involved makes them our close acquaintances and our friends. We empathize and identify. We are reminded of a host of personal experiences of our own and are filled with myriad emotions. Some of us may not wish to discuss this film.

With repeated viewing it becomes clear that there is more to learn from these patients and their families than is conveyed in the film's initial emotional impact. They become our teachers. Viewers who do not work in health care will be confronted with the reality of death and the problems and potentials it poses for all involved. For members of the medical and paramedical teams these issues are seen from both personal *and* professional perspectives.

The following notes are intended to serve as a resource for those wishing to use the film for discussion purposes. While some Palliative Care Service patients have non-malignant diseases, all in this film were cancer patients. The discussion in this manual, therefore, centers particularly on issues related to cancer. While they are anything but comprehensive, these quotes, questions and comments are intended to stimulate discussion, thought and action. Experience suggests that discussion is frequently more meaningful if viewers are asked to keep pencil and paper handy and jot down comments or incidents to which they particularly relate (in either a positive or negative sense). Such notes serve to crystallize the memory of specific impressions that are otherwise lost. They often then serve to stimulate dialogue.

Resource Handbook for the film *The Last Days of Living*

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The Palliative Care Service

“Death destroys a man but the idea of Death saves him.”
– Edward Forster

The Palliative Care Service was formed at the Royal Victoria Hospital in January 1975 following a 1973 study at the hospital demonstrating serious deficiencies in meeting the needs of terminally ill patients and their families.

Five clinical arms complement teaching and research activities. They are the Palliative Care Unit (a 12-bed ward), a consultation service, a home care program, a bereavement follow-up service, and an out-patient clinic.

Modelled on the British “hospice” concept, the Palliative Care Service differs from traditional health care services in several aspects.

1. The physical care of the patient and excellence of symptom control are of prime concern. But once these ends are accomplished, psychological, social and spiritual issues are accepted as being of central importance. Whole-person health care is seen as mandatory.
2. The patient and family, not simply the patient alone, constitute the unit of care.
3. Terminal care is viewed as a prelude to bereavement follow-up.
4. Institutional depersonalization is ever-present. It is watched for and minimized while recognizing that efficiency is very comforting.
5. A relaxation of institutional regulations concerning visitors, food, pets and other details of daily life promotes a relaxed atmosphere.
6. The length of life, being beyond control, is seen as a peripheral concern. The focus is not on dying but on the quality of remaining life. The arena of terminal illness is recognized as being a setting of great potential for personal growth, integration, reconciliation of relationships and a heightened sense of purpose and fulfillment.
7. All involved in the therapeutic triad – the patient, family and care-giver – risk significant stress. Each requires clearly defined support mechanisms.
8. The traditional hierarchical, physician-dominated, health care team is inadequate for this task. Such multidimensional care requires contributions from different disciplines by a team with new operational patterns.
9. A blurring of traditional professional roles is accepted – necessitating patience, skilled listening and a minimum of professional insecurity.

General Considerations

Questions:

1. More than 70 percent of us die in institutions. Where do people die in *our* community?
2. We expect doctors, nurses, and the clergy to be at ease and supportive when they help us face death. Are they? We expect them to have answers. Do they? If not, why not?
3. If I were terminally ill would I want to die at home? Would my family want me to?
4. When patients are facing death, their relationships may come under serious stress. Clearly there is potential for disaster. But there is also potential for personal growth and reconciliation. What determines which of these options will occur?
5. How should cultural factors present in our community influence care of the dying and the bereaved?
6. A variety of approaches have been used in attempting to improve the care of the terminally ill. In our community the most reasonable approach would be:
 - a) no need to change or improve services
 - b) consultation teams in our hospitals
 - c) a team to facilitate home care
 - d) a palliative care ward in our hospital(s)
 - e) a free-standing "hospice"
 - f) education of relevant health care professionals within our existing system
7. We have been characterized as a "death-denying society." Is this true? If so, is this significant? Why has this occurred? How can the situation be changed?
8. How can we be most helpful in preparing those involved for the death of a loved one?
9. How can we be most helpful in supporting the bereaved?

Comments:

(See *Canadian Medical Association Journal* 115:119-121, 1976)

Approximately 70 percent of Canadians now die in institutions. There is increasing evidence that these patients and their families experience a wide variety of critical problems that usually go unrecognized by those responsible for their care. The terminally ill patient, instead of receiving sympathetic understanding and expertise in meeting his medical and emotional needs, may encounter isolation and depersonalization.

The hospital staff also find the situation difficult. Lasagna has suggested that the orientation of the medical team may foster a half-hearted approach in seeing to the welfare of the dying. Nurses, for example, do not welcome assignments to dying patients and many are uncomfortable in conversing with them. As death approaches, interaction between patient and staff becomes strained and patient care is affected. This problem is accentuated by the pressures of intrahospital routines that are designed to satisfy efficiency of operation and the needs of the staff. Physicians visit with decreasing frequency the longer a patient is hospitalized, and nursing care decreases as a patient's death becomes imminent. It takes longer for a nurse to answer the bell rung by a dying patient than by a patient expected to recover. Isolation, suspicion, and distrust develop, owing to the lack of communication between patients, family members, nurses and physicians. This is fostered by the physicians' reluctance to inform the patient of the diagnosis and prognosis, a natural preference to treat disease rather than to deal with personal and social problems, and an endemic denial of death.

Deficiencies in our approach to the terminally ill were demonstrated in a study of attitudes to dying at the Royal Victoria Hospital in Montreal. The

General Considerations

data obtained indicated the patients' desire for complete openness and honesty in discussion of diagnosis and prognosis, the physicians' reluctance to be that candid, the residents' relative lack of concern for the patients' emotional needs, and the social workers' tendency to minimize the problem. The physician's attitude towards his own death was found to be an important variable in determining how he perceived his patients' needs: 84 percent of physicians who felt they would want to know their own prognosis if they were fatally ill thought that their patients also desired direct communication of prognosis, while only 45 percent of physicians not wanting to know their own prognosis thought their patients desired honesty of communication. One physician stated that he would not tell a patient that he had cancer unless he asked and that no patient had ever asked him; this tells us more about the physician's inability to hear what his patients are saying than about his patients' fears.

If terminal care is so poor, why is the problem not more generally recognized? The Royal Victoria Hospital study suggested two important factors that limit our perception. First, there is a general tendency to see ourselves as sensitive individuals and consequently we do not recognize our insensitivity to the needs of those around us. In each professional group the proportion who recognized deficiencies in the way in which their colleagues met the needs of the terminally ill was larger than the proportion who recognized that they themselves had deficiencies. Similarly, the proportion who felt that they personally avoided discussions with patients regarding dying was smaller than the proportion who felt that their colleagues avoided such discussions. Second, patients are reluctant to criticize those who care for them.

Why has this deficit in terminal care developed? The isolation and the lack of sensitivity, caring and expertise that these patients encounter cannot be explained on the basis of indifference of the medical team. There are other factors.

As individuals we reflect the attitudes of our death-denying society. It is of utmost importance to recognize the misalignment between the needs of the terminally ill and the four goals of the general hospital: to investigate, to diagnose, to cure and to prolong life. As the rate of accumulating medical knowledge increases, so does the pressure on the medical team to concentrate its efforts in the direction of these four goals. The problem arises when we introduce into this general hospital environment patients for whom the hard-won expertise of the health care team is no longer appropriate. In the management of the dying, skills of investigating, diagnosing, curing and prolonging life are irrelevant. The appropriate goal is treatment aimed at producing the optimal quality of life for the patient and his family. The expertise of the staff and the needs of the patient are therefore mismatched. From the perspective of traditional hospital goals "nothing can be done" for the dying patient. Thus, the medical team feels impotent and may become angry or indifferent. Far from there being an absence of caring and concern, these very qualities often magnify the feelings of guilt and anxiety of members of the hospital staff. To cope with the situation the staff increasingly isolates the patient and family, and so the problem is reinforced.

With respect to malignant disease, there are three admissible goals: to cure, to prolong life and to provide treatment aimed exclusively at enhancing the quality of remaining life. Until now, interest, concern and financial resources have been applied towards improving the effectiveness of our action in curing patients and, if this is not possible, prolonging life. We must now seek ways to improve the lot of those for whom treatment aimed at improving the quality of life is the only appropriate goal.

It isn't that we need to try harder, to do a *better* job. We need to do a *different* job. *Last Days* documents one attempt to do that different job.

The Control of Pain and Other Symptoms

Questions:

1. Are terminally ill patients pain-free and alert in your hospital? Are their other symptoms well controlled?
2. How do you assess the nature of a patient's pain and determine how much of it is "psychological?"
3. When and how should narcotics be used to control pain in advanced malignant disease?
4. Do you feel that psycho-social issues influence symptom control?
5. What roles do physiotherapy and music therapy play in terminal care?
6. When is further treatment to prolong life inappropriate?
7. What are the pros and cons associated with a patient dying at home?

Quotes:

- Mr. Kouri: Even just to turn around, I can't do it alone. Every second, every minute, you can't be asking that much ... and then in the middle of the night if I just want to change my position a half inch I can't do it. Sometimes you ask for death.
- Physio: Now Mrs. Bleau, I'll put your splint on and get you ready for a walk.
- Narrator:
 - Medications can be changed as frequently as every four hours.
 - For most patients a pain-free state can be achieved without loss of awareness.
 - Any device that increases a patient's comfort is welcomed.
 - An ordinary air mattress filled with water does a lot to prevent bedsores and skin ulcers. A lazy-boy recliner on a wheeled platform is a comfortable way to go just about anywhere.
 - Not to prolong life through medical intervention but to help make the last days of life more meaningful and more rewarding for the patients.
 - Physiotherapy not aimed at restoration. It's a battle to make the most of decreasing capabilities.
- Mike: I intend to, when I get home, blow a bit of money that I've saved up for a few years to get married. And one of the things I want to do is get a nice tape recorder. Then I can operate it right from my bed. It'd be fantastic, you know.

Comments:

(From Royal College Lecture, *Annals of the Royal College of Physicians and Surgeons of Canada*, July 1978. See also CMAJ 120:435-438, 1979)

Defining Appropriate Therapy

The current tendency to equate excellence of medical care with aggressive investigation and therapy is a natural outcome of the recent rapid expansion of medical knowledge. The result is a generation of physicians conditioned to see their role exclusively as "employed by the patient to fight for his life." Failure to recognize that further investigation and active treatment may be inappropriate in the presence of advanced disease has frequently resulted in unnecessary suffering. We have too often failed to recognize that the capacity to act does not, in itself, justify the action.

There are three acceptable therapeutic goals in the treatment of malignant disease: to cure, to prolong life and to improve the quality of the remaining life. When therapy to prolong life is still appropriate, unproven therapeutic modalities are justifiable only with informed consent as part of carefully designed and supervised clinical trials. Accepted forms of treatment may be justified only after a consideration of attendant morbidity, probability of response and mean duration of response, in consultation with the patient and family.

When enhanced quality of life becomes the only appropriate goal, further investigations should be carried out only if they lead to improved symptom control. Investigations for research purposes are justifiable in this setting only when informed consent has been obtained from the patient.

The Control of Pain and Other Symptoms

The decision that therapy should be restricted to palliative care is made more easily if the physician's perception of his mandate embraces the broader concept of alleviating suffering rather than simply "fighting for life." The treater's need to treat, and the family's need to have treatment continued are unacceptable rationales for further therapy.

A decision that further "active therapy" is inappropriate should be associated not with a pessimistic attitude that "nothing more can be done," but with a positive statement that while therapy can no longer be expected to make an impact on the disease process, much can be done to control symptoms and assist the patient in living as fully and as comfortably as possible. It may be helpful to remind both patient and family that many medical problems, such as diabetes, arteriosclerotic vascular disease and multiple sclerosis cannot be cured but that patients can lead a worthwhile life within the situation, in the face of decreasing resources. The patient and family are left with the concept of an appropriate shifting in therapeutic goals by a physician who remains interested and actively involved. The statement "nothing more can be done" reflects a tragic ignorance of the multidimensional needs of these patients and their families and the creative therapeutic responses to those needs that are now possible.

The Nature of the Need

Our traditional preoccupation with pathophysiology alone is woefully inadequate in the setting of advanced disease. While the medical needs may be undeniably complex and will be of great concern, added to them are the complicating factors of psychological stress for the patient and family, strained interpersonal relationships, frequent financial problems and the ever-present metaphysical questions which these patients face. "Why me? Why this suffering? Why is this allowed? Is this all there is?" Experience suggests that intervention must be directed at all these levels – physical, psychological, metaphysical (or spiritual) and social – if suffering is to be successfully alleviated.

Chronic Pain: Its Nature and Management

When the intractable pain of malignant disease is present, its treatment is the central focus in palliative care.

I – The Nature of Chronic Pain

It is important to recognize the significant difference between acute and chronic pain. Acute pain has a beginning and an end. It may be classified as mild, moderate or severe and has a "purpose" in that it draws attention to the offending member so that corrective therapy may be introduced. Chronic pain, however, can be characterized as a vicious circle with no set time limit. The fearful anticipation of its perpetuation leads to anxiety, depression and insomnia, which in turn accentuate the physical components of the pain. Leshan suggests that meaninglessness, helplessness and hopelessness are characteristic of the unreal nightmare world in which the patient with chronic pain lives. Pain forcefully reminds the patient with advanced malignant disease of his prognosis, thus increasing his distress. Saunders has coined the term "total pain" to describe the multiple components of chronic pain – physical, psychological, spiritual and social.

II – Aims of Treatment

The goals in treating chronic pain should be:

a) to identify the etiology: clarification of the cause is an essential first step in pain control since it may lead to specific therapy, such as focal irradiation for a bony metastasis, extraction of a carious tooth, or bowel care for pain due to constipation.

The Control of Pain and Other Symptoms

b) to prevent pain: the aim is to anticipate and prevent pain rather than treat it. This requires the regular administration of appropriate amounts of analgesic, at a dose titrated against the patient's current needs. There is no place for "prn" medication orders as the standard for the treatment of chronic pain since the resultant pattern of recurring pain results in unnecessary suffering and escalation in analgesic dose.

c) "to erase" pain memory: as the anxious anticipation and memory of pain is lessened by successful pain prevention, the dose of analgesics required may frequently be decreased.

d) an unclouded sensorium: many patients feel trapped between perpetual pain on the one hand and somnolence on the other. A pain-free state without sedation requires careful individual regulation of analgesic dose according to the patient's need.

e) a normal affect: the ability of a patient to relate to his environment will be enhanced if the agents used to control pain do not inappropriately elevate or depress mood.

f) ease of administration: oral administration of analgesics can allow a patient to retain a degree of independence and mobility that is impossible when analgesics are given parenterally. Cachexia may also make regular intramuscular injections difficult and painful.

III – The Management of Chronic Pain

If the pain is localized, radiation therapy, nerve block or some form of ablative neurosurgical procedure may provide excellent control.

With moderate to severe chronic pain, only the narcotic analgesics provide adequate control. Milder analgesics should always be tried for less severe pain and may be helpful in combination with more potent drugs. A wide variety of agents is available; Catalano has provided a helpful review.

In the past the use of narcotics for chronic pain has been widely considered "bad management." Recent studies have demonstrated, however, that all the above treatment goals may be achieved using oral narcotics, without the danger of tolerance and attendant dose escalation. An oral narcotic solution has provided excellent pain control in 75 to 80 percent of patients with intractable cancer pain in general hospital accommodations and in 90 percent of patients in the Palliative Care Unit. The remainder, with very few exceptions, had excellent pain control with regularly given parenteral narcotics.

While early studies used a variant of the traditional "Brompton Mixture" (containing cocaine, ethyl alcohol and a flavouring syrup in a chloroform water vehicle) it is now recognized that a simple aqueous solution of morphine is equally effective.

The psychological distress of the patient with cancer is multiplied many times if symptom control is poor. The shifting symptom complexes and diminishing resources noted earlier require regular and frequent reassessment if symptoms are to be adequately controlled. Such a practice will pay rich dividends in the avoidance of potentially serious problems and unnecessary hospitalization. The implied message that the physician has a continuing interest in the patient's welfare reassures both patient and family.

Conspiracy of Silence

Questions:

1. What should a patient be told about his diagnosis and prognosis?
2. What should family members and close associates be told about the diagnosis and prognosis of a loved one?
3. Who should do the telling?
4. Reasons given for *not* disclosing matters relating to diagnosis and prognosis include:
 - a) You can't tell who can take it.
 - b) The family doesn't want the patient to know.
 - c) The patient didn't ask.
 - d) Uncertainty is better than knowing.
 - e) It is wrong to deprive the patient of hope.Are these reasons valid?
5. Studies suggest that the dying patient is often isolated and visited less frequently by medical staff, family and friends. Why does this occur? How can we decrease or avoid such isolation?
6. We tend to hide death from children. What is the best approach?
7. It has been observed that we should never take away a patient's hope. What do terminally ill patients hope for?
8. What effect does openness concerning diagnosis have on those involved?

Quotes:

- Mike: My mum has seemed to be pretty strong this time about accepting it, 'cause she knows it's final. It's not something that's going to drag on and on and on. So I think perhaps that helped her to accept it a little more. Whereas with the previous incident with the tumor there was a continuing hope and you were always left in the air.
- Dr. Mount: Did you find it easier, as your mother did, when the outcome was certain as compared to when you thought you'd be cured?
- Mike: The rollercoaster! Definitely. We were all living on hope. This time we all know that we are going to die... We accept it differently.
- Mike's Mother: But I think what she would like to know is how you brought yourself to the point where you were able to go into the room and talk to Michael... whereas at the very beginning it was difficult for you to do.
- Mike's Father: Simply when I found out that when I did it the first time it was very pleasant.
- Mike's Mother: Some people are afraid to come to visit Michael. They say that it's too painful and that they love him too much. They couldn't bear to see him in the state that he's in now because they know he's dying. It's not like it was before when they thought that he might survive. Now they know for sure and it's scaring them away...
- Mike's Father: Just think how you would feel... how you would feel faced with his situation if everybody, or *anybody* said they don't want to see you because you're dying. But that's when he needs you really.
- Home Care Nurse: We've left all the information for the death certificate and the death certificate is at home and they have even made some tentative arrangements with the funeral home.

Conspiracy of Silence

Head Nurse: You were going to ask a doctor to come and talk to Mr. Mlot because he was asking about his prognosis.

Consult Nurse: I found him very depressed and withdrawn. That was Monday morning. Monday afternoon (after talking to the doctor) he said, "I just feel like a new person" and it's obvious he is... He's up walking now. He smiles. When you come in he greets you very warmly. Now he knows what's ahead of him. He can cope a little bit easier.

Mr. Mlot: They seemed to have the answers but thing is, I have to ask the questions. But if I don't know the questions...

Discussion between Sheila Bergevin and her son:

- You OK?
- Yes... I'm OK...
- For ever and ever?
- For ever and ever.
- Ah, John's happy Mamma's OK for ever and ever.
- You... OK?
- Yes...
- You... you never sick?
- I'm never sick. Never never sick, John.
- I love you.
- I love you too.

Comments:

(See *Cancer*
45:1985, April 1980)

Cassell suggests that the issue is not "to tell or not to tell," but what we want the transfer of information from physician to patient to accomplish. He proposes that such an exchange should improve the patient's ability to act on his own, now or in the future, reduce uncertainty, and improve and strengthen the patient-physician relationship of trust.

The usual arguments offered against open discussions of diagnosis and prognosis include the physician's inability to predict "who can take it," the probability that the patient would lose hope and the premise that uncertainty is better than knowing the diagnosis of cancer. As Cassell has observed, however, to name a fear is to confront it and in some fundamental way to control it. We are most vulnerable to uncertainty: a fact clearly documented in animal experiments, brain-washing techniques, clinical experience, literature, and in every Alfred Hitchcock thriller. Uncertainty breeds anxiety and leaves us unable to mobilize defenses. The attempts of well-meaning physicians to protect and give hope to their patients by presenting a blurred and purposefully incomplete picture of reality simply enhance the patient's fear. In the film, the consult nurse (of the consultation team of the Palliative Care Service) finds Mr. Mlot a changed person when the doctor levels with him concerning his grave prognosis. His uncertainty gone, he can muster effective coping mechanisms. The same is true for Mike and his family. Interestingly, Mike projects, "This time we *all* know that we are going to die."

The policy of answering only those questions directly posed by the patient leaves the onus of broaching the most highly sensitive issues on the patient. Mr. Mlot put it well: "They seemed to have the answers but the thing is, I have to ask the questions. But if I don't know the questions!..."

Conspiracy of Silence

The physician's inability to talk easily and with reassurance betrays his sense of uneasiness when the prognosis is not favorable. As one patient commented to her care-givers, "I sense your fear and it enhances mine." Another patient observed, "I never really saw what fear was until I looked at everybody else looking at me."

Our experience supports the observations of others that an honest yet supportive approach to questions concerning diagnosis and prognosis leave the patient most able to mobilize psychological defenses. There is always a need for hope, but the hope should be based on a realistic appraisal of the situation. Therapeutic goals, whether to cure, to prolong life, or to improve the quality of remaining life, should be made clear.

Sheila's touching conversation with her son John suggests how easily we fall into compliance with the conspiracy of silence, particularly with children. She later commented that she wishes she had handled John's question some other way but "before I knew what I was saying it was out." She asked that the scene be left in the film.

It is appropriate for patients to begin active therapy with determination, but for many there comes a time when body and mind can fight no more. At this stage, a desire for longer life often gives way to other hopes: hope for absence of pain and other disabling symptoms, for skilled nursing care, and for a family and physician who will support the patient until the end.

This transition becomes more difficult if the patient has been given false hope, if he has been led to believe that the outcome depends on him and that he must continue to fight, or if he has to contend with a physician who is reluctant to discontinue therapy. Clinging to unrealistic hope of cure or longer life in the face of increasing debility breeds anxiety and an enhanced sense of insecurity and fear. As the incontrovertible evidence of reality accumulates, the denial of the truth saps emotional energy, leaving the patient less able to be reflective, receptive, and empathically interactive. On the other hand, acceptance of the inevitable can lead to a sense of peace and frees energy for sharing life with loved ones.

Discussions concerning diagnosis and prognosis should be in person (not over the telephone), in private, and unhurried. The prognosis should never specify anticipated length of survival. Appropriate advice may be offered when necessary concerning "getting affairs in order" for all eventualities. Specific estimates of survival time can only enhance anxiety and are always highly speculative in any event. An attitude of confidence, concern, and quiet optimism should be conveyed.

It is helpful to discuss what will happen at the time of death, anxieties about what will happen to the family after death, and funeral arrangements, well in advance, with family and patient. The film demonstrates how such discussions assisted the Charettes, diffusing anxieties about Mike's death and facilitating the making of arrangements for the funeral and his staying at home until the end.

Psychological Issues: Communication and Active Listening

Questions:

1. What do the terminally ill fear?
2. Does the understanding of these fears equip us to better meet their needs? How?
3. Kubler-Ross suggested that the patient, the family and the care-givers *all* go through a series of mental adjustments in coming to terms with the fact that they are finite. She observed that this included denial, anger, bargaining, depression and acceptance. Do you think her observations are valid? What evidence of these reactions is seen in the film or in your personal experience?
4. There is a danger that Kubler-Ross' "stages" may become *perscriptive* rather than *descriptive*, that preoccupation with psychodynamics by a group of amateur psychologists may not be helpful, and that the "diagnosis of a patient's stage" may become an end in itself rather than a means to an end. Was there any evidence of this problem in the film? (e.g. Mike: "more and more people want to talk to me about dying.") In other situations you have encountered?
5. What effect does it have to group dying persons together? Does it ghettoize death? How does it influence the thinking of patients, family members, staff? Do you feel the film was representative in this regard or only showed those who responded favourably?
6. The film suggests that the Palliative Care Service (PCS) approach has a favorable impact on the psychological response of patients, family members and staff. What factors contributed to this? Is this reproducible? What are the essential ingredients?
7. What factors assisted the patients, family and care-givers in recognizing and expressing their feelings?
8. Is it necessarily helpful to express feelings?
9. In the film, did patients and family members appear to want to "say the right thing?" If so, why? If they need to patronize those caring for them, does this imply they have an inability to criticize inadequate or insensitive care? If so, how do we (as care-givers) recognize when psycho-social care is deficient?
10. If the film is an example of "a need to leave a legacy," does this suggest the significance of finding meaning in life? How can we assist the terminally ill and their families find greater *meaning* in each day?
11. It has been stated that seventy to ninety percent of communication is non-verbal. The film demonstrated sensitivity, and, at least once, insensitivity to non-verbal communication. What factors influence listening? What is "active listening?"
12. The use of humor can reflect many things, including anxiety, avoidance, an ability to "celebrate life," an easier way to say difficult things. What roles did it play in the film?
13. Many profess an interest in "quality of life." What produces quality? The narrator asks "How can you measure the worth of a song, or the richness in a smile?" Can a "quality of life index" measure such things?
14. Confronting death can lead to new perspectives and possible personal as well as interpersonal growth. How can we facilitate such changes?
15. What factors add stress in relationship for:
 - the patient?
 - the family member?
 - the care-giver?

Psychological Issues: Communication and Active Listening

16. Two support systems are in general underutilized in health care:
 - the support between patients with similar problems;
 - the support from family members to patients *other* than their loved one.How can these relationships be fostered?
17. What additional stresses occur if the patient dies at home? What steps can be taken to assist the death at home?
18. Are there things that can be done at the time of death to minimize the difficulties inherent in the situation and to assist subsequent grief work?

Quotes:

- Mike's Mother: She would like to know how you brought yourself to the point where you could go into the room and talk to Michael whereas at the very beginning it was difficult for you to do.
- Mike's Father: Simply when I found out that when I did it the first time it was very pleasant... When I faced him I realized that he's not leaving anywhere. I mean we brought him into the world and we're willing to let him leave it gracefully, with us as a part of it.
- Mike: When I first found out I was going to die it was very traumatic. I was hit by so many feelings and thoughts that I couldn't comprehend what was really happening... after going through a lot I still always had hope. I was thinking about living, not dying. But I find myself very adaptable. So it didn't take long for me to start thinking about dying rather than being afraid of it. Once you start thinking about it then you start to accept it, you know. It's for me the highlight of living, the ultimate gift. When we're all born everybody knows and they all say "we're all born to die." We're all going to die but how and when no-one knows. So I don't want to attach any importance to the time of dying. What is the right age to die? There is no right age. Any age is right if God determines it that way. I say God because I don't know of any other word to use to describe the unknown...
- Madelaine: I was very frightened when I went into the unit because I thought palliative meant I was going to die right away. But of course it doesn't necessarily mean that. It meant I needed help. Mostly initially I needed help with pain control... I don't feel as frightened as I used to feel because I know that they're (the PCS team) behind me now.
- Madelaine: I know that when the day comes when I can't cope anymore that the unit will be there for me. I know there's some place I can go when the time comes. I hope it's a long way away! I'm sure going to as hell going to do my best to try and make it a long time away.
- Head Nurse: ... because it has happened before: patients dreamt about seeing themselves dead and they actually did die very shortly after.
- Madelaine: "My mirror and I are face to face,
We study each other and share the disgrace,
Together we see a most painful sight:
No breast on the left, just one on the right.

Psychological Issues: Communication and Active Listening

We see our one breast, with its head sadly down,
It misses the other one being around,
And there's something so weird, and so ugly wrong
About having just one:
It's just wrong! It's just wrong!
We want to be as we were before,
But we both know the hurt that for ever more
What we see now will never be changed –
Just the one on the right will grow sadder with age.”

Mrs. Bleau: I felt ashamed. I felt ashamed even to talk about it. (Turning away).
Volunteer: Well you shouldn't feel ashamed. I think it's terrific.

Mrs. Bleau: Very nice dream.
Head Nurse: Did you call your husband, after that?
Mrs. Bleau: Yeah, I called him last night around 12 o'clock. I didn't tell him that.
Head Nurse: You didn't?
Mrs. Bleau: No, I didn't tell him.
Head Nurse: Why didn't you?
Mrs. Bleau: I didn't tell him, and I didn't tell my daughter either.
Head Nurse: Is that right?
Mrs. Bleau: No. I didn't tell anybody – I've dreamt a good many dreams about my mother.
Head Nurse: Did you?
Mrs. Bleau: Yeah about my mother. I dreamed that my mother wants to see me, wants to see me. I've had quite a few dreams like that.
Head Nurse: Oh?
Mrs. Bleau: You know, my mother's dead, eh?
Head Nurse: I see.
Mrs. Bleau: And I've woke up and I've thought to myself, you know, "My mother wants to see me." You know.
Head Nurse: What does that mean?
Mrs. Bleau: I don't know what it means –
Head Nurse: Do you ever think about dying?
Mrs. Bleau: Yes. -- I do.
Head Nurse: How does that feel? What do you think?
Mrs. Bleau: I don't feel nothing.
Head Nurse: Yes?
Mrs. Bleau: Some days I feel, you know, gloomy. Some days I feel "It's going to be, it's going to be."
Head Nurse: You're quite a person, you know!
Mrs. Bleau: Eh?
Head Nurse: You're quite a person!
Mrs. Bleau: (Smiles with a little sigh).

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- Dr. Ajemian: You say all this with a smile. I sense that you kind of cover a lot of things with a smile as you go along.
- Mrs. Mlot: Dr. Brox came in yesterday and he said that he had been speaking to you and that we expressed that we wanted to go home, and he's going to try and arrange it for us. So – it – he sort of brought home the meaning of it all – and of course my husband had to ask again -- "how much time?"
- Consult Nurse: In what way did you mean he "brought home the meaning of it?"
- Mr. Kouri: Just to even turn around, I can't do it alone.
- Music Therapist: We don't mind coming to help.
- Mr. Kouri: I know, but – every second – every minute – you can't be asking that much! And then, in the middle of the night – if I want to – just change my position a half-an-inch – can't do it.
- Music Therapist: Can't do it. Discouraging, eh?
- Mr. Kouri: More than discouraging. Sometimes you... you ask for death.
- Music Therapist: Mmmmmm. It's understandable.
- Narrator: Celebrating time not merely marking it.
- Nurse: René – he's dieting, you notice.
- Madelaine: You dieting? You naughty man!
- Nurse: I offered her a bed in here with you fellows but she passed it up.
- René: Oh, you passed it up.
- Madelaine: I did not. I wouldn't pass up an offer like that!
- Mike: I wouldn't start any long novels.
- Mike: It would have to be day by day.
- Mr. Mlot: One day at a time.
- Mrs. Mlot: Yes – we told him we'd live one day at a time –
- Mr. Mlot: There's no other way of living it, right now.
- Mike: It (his illness) has made me more aware of people and their feelings. Before it used to be "get what you can while you can", whereas now it's "enjoy what you have while you can – with people you care about."
- Madelaine: I don't think I'm the same person since I went in there. It's an experience to spend two months, day and night with people who really care about how you feel. Day and night. They really care.
- Narrator: When there's nothing left to hide
And no need to turn away
You can make a moment last a lifetime
Make a lifetime last a day.

Psychological Issues: Communication and Active Listening

Madelaine:	I remember when you had a bottle of Dubonnet and we had a little celebration. Remember? That was nice wasn't it? We sang a long time that day, didn't we?
Group:	Row, row, row your boat.....
Pastoral Associate:	82 years old! Isn't that marvelous? Happy Birthday, Veronika. Blow out the candles!
Mr. Bleau:	It's hard for me – breathing – you know – I have breathing difficulties.
Mrs. Bleau:	He's not sick or anything. It's just that he has breathing difficulties.
Mr. Bleau:	It's chronic asthma!
Dr. Ajemian:	Do you find that there are still ways that you can relate to the kids?
Sheila:	I find that my role has dwindled.
Consult Nurse:	What has this done for you as a couple?
Mrs. Mlot:	Well, I think it's drawn us closer together. We were always close as it was, but now I want to be with him and I don't care if anybody else is around or not, we can say a lot more to each other than we ever did before. We used to feel it and know it. But now it's very open.
Sheila:	No? Do you want to sit on Mummy's knee?
Mr. Bergevin:	Do you want to sit on Mummy?
Lisa:	No!
Sheila:	Do you want to smell the flowers – – be careful she don't fall off! Put her on my knee.
Mr. Bergevin:	Do you want to sit on Mummy?
Sheila:	No? You're afraid? Afraid you're going to fall off?
Lisa:	Yes – – –
Sheila:	Aw!
John:	I like you!
Sheila:	I like you too, John! My gosh!
Mike's Father	A week before, I had told Mike, in his room... "If you want to die at home, in your bed, it's alright with me" and he stopped for a few seconds and he said "are you sure about that, Dad?"
Mike's Father:	The day he died, at 11 o'clock in the morning I gave him a bath, for the first time, from head to foot, you know. And it sounds so phoney that I hate to mention it, but it really happened. As I finished bathing him he – he – hugged me and he kissed me on my neck, and he said "Daddy, I love you" – and – and that you know – a twenty-two year old – you don't tell your father!
Ann:	That's true.
Mike's Father:	But he told me – and – you know – it's just – it's wonderful!
Mike's Mother:	"Love is like the ocean, It's vast and unlimited, But, sorrow – is like a shadow, Cast over the sea." (John Gray)

Psychological Issues: Communication and Active Listening

Comments:

(See *Cancer*
45:1985, April 1980)

Psychological Response of Patient and Family

A great many factors have been shown to influence the psychological response of patient and family to malignant disease. The nature of the presentation of the illness may dictate early coping responses. Ill-defined initial symptoms suggesting a functional disorder may lead to anxiety, reactive depression, anger and, when the diagnosis is finally confirmed, a sense of relief or resentment. Fear, modesty, or a sense of guilt may lead to patient-initiated delays in seeking medical attention.

Other variables influencing the psychological impact of malignancy include the type and stage of the tumour and the anticipated outcome of therapy, the personality of the patient, the perceived stigma of malignancy in the patient's social setting, the patient's pattern of reacting to previous stress, relationships and communication patterns with family and other key persons, the pre-existing relationship of patient to physician, the sensitivity of the physician as he guides discussions with the patient and family, and the effectiveness of management of non-psychological stresses.

Two further factors, the potential for change in, and the uncertainty of, the patient's clinical status, add their oppressive weight to the equation, making it inestimably more difficult for both patient and family to perceive, integrate, and cope with reality. Mike Charette, his family, the Mlots, all suggest the importance of discussions that lessen uncertainty and therefore anxiety, thus facilitating coping.

Patients with incurable disease face four major tasks. They must deal with the symptoms and altered physiological state of advanced disease. They must confront the impending separations from loved ones and cherished things. They have to consider the prospect of a transition to an unknown state. They must ponder their past life in light of how they had wanted to live in it. Struggle with these issues provides many of the most meaningful moments of the film.

Kubler-Ross has suggested that there are a series of mental adjustments that we may go through in coming to terms with life-threatening disease. These may include denial, anger, bargaining, depression and acceptance. In the film these responses are clearly seen. In a given patient, however, one can usually find a subtle balance between a realistic acceptance on the one hand and simultaneous rejection on the other.

Vaillant has presented a recent helpful summary of defense mechanisms used in coping with psychological distress. Denial and repression are commonly employed in life-threatening situations and may represent a valid coping mechanism. This does not, however, justify supporting the patient's denial with false information or otherwise reinforcing his "unreality" orientation.

The well-documented tendency for patients to "hear" only as much dispiriting information as they can tolerate will alert the attentive physician to the need to go slowly in imparting information. One patient's comment, "Thank you for talking to me last night doctor, I'm glad it isn't serious," following a careful explanation that he had metastatic renal carcinoma rather than the "flu" as the cause of his six-month illness, communicated admirably both his appreciation of an interested physician, and his need, at that time, for denial.

In caring for the patient who uses denial, our response may be more helpful if we evaluate the nature and quality of the patient's denial. Hyland has suggested that differentiation should be made between "adaptive" (healthy) and "brittle" (global) denial. He has observed the former to be characterized by an awareness of the diagnosis but a conscious refusal to dwell on the implications of it.

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Such individuals de-emphasize the limitations imposed by the illness and underline their remaining strengths. The patient may recognize that he is being unrealistic but feels, "maybe I can beat the odds." Hyland suggests the physician align himself with the patient's emphasis on his remaining strengths in this setting.

"Brittle" denial, Hyland suggests, is characterized by a near-total refusal to acknowledge one's illness or the seriousness of that illness. In this state, the patient is psychologically paralyzed and thus unable to take appropriate actions. He suggests that such denial should be challenged, but at the same time a clear offer of support towards a more appropriate way of coping should be made.

To cope with any cancer, irrespective of outcome, the patient and family must deal with loss. Experience suggests that the clinical manifestations and coping mechanisms first described by Lindemann and Parkes in the setting of acute grief also characterize response to any loss and are found in all cases of life-threatening illness. At the very least, the patient must deal with the loss of the concept of being "healthy." For most patients with cancer, there is not one, but a series of losses to be sustained, understood, reacted to, and compensated for. Such losses may include body image, income, career goals and other plans for the future, mobility, strength, physical and mental capacity, and ultimately existence itself. The reactions to each of these threats may overlap, resulting in an apparent quicksand of continuously changing emotional responses for patient and family members.

Losses, which include an alteration in self and body image, are particularly significant. Madelaine's song "My Mirror and I" speaks of the "disgrace" following mastectomy; of the "most painful sight, no breast on the left, just one on the right." She exclaims, "It's just wrong! It's just wrong!" and is clearly speaking for all cancer patients when she emphatically states "We want to be as we were before!"

The impact is particularly devastating when there is loss of sexual and/or excretory function. Urinary and fecal diversion carry with them a particular risk of guilt, shame, and a host of new anxieties. All therapeutic procedures entailing such changes in body structure and function should be preceded by a careful preparatory discussion outlining the nature and psychological implications of the proposed operation and the subsequent adaptive techniques available. In general, it is important to include the patient's sexual partner in such discussions. A pre-operative visit with a stoma therapist, and, where feasible, with patients who have undergone similar procedures are useful in lowering the anxiety of all concerned.

The importance of communications between patients and those whom they love deserves emphasis. The presence of a life-threatening illness imposes enormous stresses on the existing frailties present in all relationships. In the film, the Mlots relate how their relationship was stressed by his illness. "I could hardly talk to him." Mrs. Bleau reassures the nurse regarding her husband's incapacitating breathlessness. "He's not sick or anything!"

While the potential for stress is great, so is the opportunity for reconciliation and growth, both in relationships and as individuals. Sheila finds that her role with her children has dwindled. Her little daughter withdraws, but, with remarkable sensitivity to his mother's feelings, her young son sees what is happening and rushes in to heal the hurt - "I love you!" Mrs. Mlot comments with feeling, regarding her husband's illness, "It's drawn us closer together" and in a touching testimonial to a new-found ability to express depth of feeling in human relationships, Mike's father recounts the intimate details of the sharing he and Mike experienced a few hours before Mike's death. What happened can hardly be looked on as other than monumental in signif-

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icance! With such potential available to us, can we continue to justify, tolerate, foster and permit the perpetuation of health care services that stifle such growth?

For the first time, material things and events may be recognized as ultimately of limited value, while the significance of time, feelings, and relationships may be seen in a new perspective. In reflecting on his disease, Mike observes, "It's made me more aware of the importance of people and their feelings... you know before it used to be 'get what you can while you can', whereas now it's 'enjoy what you have, while you can'... by that I mean, with people that you care about." The poet Ted Rosenthal, when dying with leukemia, noted the difference between "living for the moment" and "living in the moment" and commented "I'm changed; I'll always be changed. I'll always be happier for what I have gone through." As Smyth has observed, "It is when we are down and experiencing a time of adversity that we may be most willing to open the doors of our personalities and expose our needs." The physician's unique opportunity to act as a catalyst enabling communication, integration, and growth is awesome, particularly when measured against the cost of failing to use this potential.

Family meetings with care-givers are useful for ventilating feelings and avoiding tensions related to blocked communications. The elderly and the young should be included in such meetings. In the Royal Victoria Hospital Palliative Care Service experience, the elderly parents of adult, terminally ill patients were found to have particular difficulty during bereavement. This may have been related to the recognized impact of losing a child at any age, but may also relate to the fact that the elderly are frequently "protected" from the knowledge of serious family illness and are thus unprepared for the loss of a loved one.

A physician's visit will be remembered as being longer in duration and of greater meaning if the physician sits down at the bedside so that there is eye contact on the same level. Concern is often best conveyed nonverbally by taking a hand or touching an arm. However, physical contact may represent an invasion of privacy to a few. It requires sensitivity to meet patients as they are, respecting their individuality.

The presence of caring people who are good listeners, a positive cheerful environment, and the availability of diversional activities, have been found to be further variables that may significantly lessen cancer-related stress.

Active listening is a learned skill. It is difficult. The startled volunteer misses the depth of Mrs. Bleau's feelings following her "out of body" experience. It has *just* happened as the filming started, Mrs. Bleau is overcome, uncertain, frightened, confused. She turns her back in withdrawal and says "I felt ashamed... I felt ashamed even to talk about it." But in the intensity of the moment as she recognizes what has just happened the volunteer *reacts* rather than *listens*. "Well, you shouldn't feel ashamed! I think it's terrific!" Opportunity missed. To actively listen is to work. It requires energy. It involves listening to all forms of communication, verbal and non-verbal. It recognizes that feelings and ideas may be conveyed through direct and through figurative language. It demands that the listener be aware of not only what *is* said, but what is *not* said; the things that are implied, alluded to, hinted at. It picks up meanings that the speaker may not entirely be aware of. It should always convey interest, respect, and support. We see the head nurse listening with every fibre of her being as Mrs. Bleau describes her "out of body" experience. Active listening par excellence! The consult nurse catches the significance of a passing phrase and asks "In what way did you mean he 'brought home the meaning of it?'" Her relaxed manner and the absence of fear, her willingness to confront painful issues with calm openness speaks volumes. The MIots are re-inforced in their courage. Dr.

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Ajemian "listens" to the person behind the words and gently observes to Sheila, "I sense you cover a lot of things with a smile as you go along." The comment is supportive, not confrontational. Sheila is helped to examine her feelings.

Two patient support systems are recognized too infrequently. When persons with shared experiences are placed together, patient-to patient support may be a highly significant factor in lessening a sense of "aloneness" and the feeling that "no-one understands." A further source of psychological support frequently seen is that of the family of one patient to other patients in the room, ward, or clinic. Both these support mechanisms are fostered by a sense of community and openness and are hindered by single-room accommodations and an exaggerated attention to privacy. The impact of "community" on the experience of all concerned is seen throughout the film. It is sensed in the warmth of the exchange between Madelaine, Jacques, and René as she returns to the floor. A warmth that overcomes language barriers. They recall a shared bottle of Dubonnet and some earlier moments together.

The impact of community is perhaps seen most memorably, however, in the scene in the women's room when the music therapist sings *Le Canadien Errant* with the initially reluctant Mme Allard. In a magical moment, decades of defences, fears and barriers melt away and with a radiance not previously seen in months of illness she shyly sings. It is only on re-seeing the film that one sees why it is that she had the courage to express herself on this occasion, for in the earlier sequence, as the therapist is singing "row-row your boat" with her elderly neighbour, Mme Allard is seen in the corner of the screen intently watching. She has been drawn naturally into the experience of the community and the camera records for us the new milestone in communication that results!

At the Time of Death

Most patients do not fear death itself but pain in dying. In reality, when death comes, it is usually painless and peaceful for a patient dying of malignant disease. Mental and physical pain commonly recede during the last few days and almost always in the last hours. The reassurance that this will be the case may encourage a family to keep their loved one at home when their anxiety would otherwise necessitate hospitalization. The family will need particular support and guidance if the patient is to die at home. Enabling the patient to die at home may pay rich dividends as has already been seen with Mike and his parents. The assistance of a home care nurse during the final days is invaluable. It is also important that the family be aware of the community resources available to them. A social worker may be of great assistance in this regard. Anxieties are often lessened if the family has discussed funeral arrangements before the death as was done in Mike's case.

It is often expected that the physician will come to the bedside when the patient dies. While this is not always possible, it should be a definite goal for the physician primarily involved in the case. He can make an important contribution towards the resolution of the family's immediate problems and future "grief work," if he is present at that critical point.

On the Palliative Care Unit, a brief commemorative ritual on the part of the physician or nurse present at the time of death declares that something of significance has happened. A prepared statement or memorial prayer can be useful in this regard. This tends to ease the tension of the moment and has invariably been meaningful, regardless of the family's religious background. It has been suggested that subsequent grief work will be facilitated if family members are encouraged to be present at the time of death. The

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unobtrusive touching of the body by a member of the nursing team will signify that there is nothing frightening or “wrong” in doing so. In general, the discrete presence of a staff member will lessen anxiety as the bereaved family looks at the body.

Bereavement

It is now recognized that serious psychological morbidity also occurs among the bereaved. The evidence suggesting that the bereaved represent a high-risk population is now convincing. The studies of the last three decades suggest that bereavement is a period of increased somatic, psychological, and social vulnerability. It is one of the most trying times in life. With their resources depleted and in disarray, the bereaved are called on to find a new balance in their emotional economy. In recent years, society has been particularly ill-prepared to assist them in this task.

A variety of intervention models has been examined in an attempt to assist the bereaved. The programs developed have included intervention at the time of bereavement, intervention by professionals in the bereavement period and self-help, widow-to-widow programs. While further studies are needed to determine those most in need of follow-up and the structure of optimum intervention programs, results of studies to date suggest that support during the early weeks of bereavement effectively reduces morbidity.

On the Palliative Care Service, bereaved family members are given a prepared handout describing commonly experienced features of the grief reaction and problems that may be encountered. Bereavement follow-up includes a monthly memorial service (referred to in the film by the Pastoral Associate, Sister Brenda Halton, as she recalls meeting Mike’s mother at the service), personal visits and telephone contacts by trained personnel, particularly during the first six months of bereavement, the regular monthly listing and recall by the team of those dying on the service the previous year, and a personal note of greeting sent to the bereaved to mark the anniversary of the death.

The Multidisciplinary Team

Questions:

1. Are you, personally, sensitive to the emotional needs of patients and their families? Are other health care professionals around you?
2. Do you regularly turn to other members of the medical and paramedical team for assistance? If not, why not?
3. Do you feel comfortable in dealing with the terminally ill and their families?
4. What are the most common causes of interpersonal stress among health care professionals?
5. What re-structuring of the traditional medical team is necessary to enable excellence in whole-person medical care?

Quotes:

Narrator: The rewards of palliative care flow both ways.

Bereavement Counsellor: Your need as well as hers?

Dr. Mount: You put together people of different disciplines and expect them to listen to one another. It is very difficult. Then you say to them, OK, we want you to meet the physical, psychological, social and spiritual needs of this family – and that's terrific because that's impossible! You put together highly motivated people, to do an impossible task. People who have difficulty setting limits. There's little wonder there's stress.

Dr. Mount: When you take down the traditional hierarchical model and have physicians who are at least supposed to be listening, when you understand that any team still has to have a quarterback, there still has to be a clear decision-making process. A democracy doesn't mean you have a referendum on every topic. What key issues these were to think through if we are to practice whole person medicine! It's a different sort of – it's a surprisingly different sort of task.

Dr. Mount: Any team that can have Kitty and Brenda and Susan and Ursula and you and Pierrette all on one team – of course I'm not a problem – but the rest of you!! – It's amazing.

Dr. Ajemian: You're in a special category, as captain. We don't deal with that until later on!

Dr. Mount: You just decide on your own, do you?..... OK, that's fair.

Comments:

(See *Cancer*, 45:1985, April 1980 and *CMAJ*, 119:303-304, 1978)

A 1975 Royal Victoria Hospital study demonstrated a marked discrepancy between the attitudes of patients and care-givers toward life-threatening illness. Deficiency in the care-givers' perception of patients' emotional needs was equally pronounced in physicians of various faiths, whether "committed" Christian or Jew, or agnostic. Care-givers of all professions tended to rate themselves as being highly sensitive to their patients' emotional needs and, in general, more sensitive than they were rated by their colleagues (and vice versa). This lack of personal awareness of insensitivity to the emotional needs of patients tends to perpetuate the depersonalization endemic in our institutions. A discussion of the impact of institutional depersonalization and suggestions for its elimination have been presented elsewhere.

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Other factors are known to influence the attitude of health care professionals towards the cancer patient. These include the endemic societal denial of death, the physician's often inordinate personal fear of cancer and possible death, the highly focused orientation in health care delivery towards pathophysiology and skills in investigating, diagnosis, prolonging life, and curing (to the usual exclusion of psychological considerations), the physician's age, and the frequently held perception of a universally poor prognosis for cancer patients.

Uncertainty breeds anxiety among health care professionals, as it does for the patient and family. It is clear that care-givers use the same coping mechanisms as do their patients when faced with the possibility of the patient's death. Withdrawal, physically or emotionally, from the patient and depersonalization (seeing the patient as a problem in evaluation and therapeutics, rather than as a person) are frequently seen.

Poor communication among members of the team concerning the details of diagnosis and prognosis and the patient's awareness of such inadequacy hinder patient care. The failure of the physician to inform the nurses involved commonly neutralizes their effectiveness and ability to support patient and family.

Klagsbrun reported his observations working as a psychiatric consultant in a cancer research unit where patients frequently complained of "uncaring doctors" and "unavailable nurses." He comments, "We became aware of the tremendous strain the patients placed on the medical and nursing staff. To a great extent, the staff saw these patients as walking dead: and since 'one should not speak ill of the dead,' the staff felt constrained to keep their feelings about the patients to themselves." Weekly meetings between Klagsbrun and the nurses served as an effective forum for expressing feelings. They also helped the nurses understand why the oncologists involved felt a need for distancing, and clarified the centrality of the nursing role in patient care. The weekly psychiatrist-led meeting on the Palliative Care Service (held outside when filmed for *Last Days*) has aims similar to Klagsbrun's. These meetings effectively monitor staff stress and also act as a safety valve for its expression.

Staff stress and "burnout" among members of oncology teams have recently received increasing attention. Signs to watch for include physical complaints (fatigue, dyspnea, backache, headaches, gastrointestinal complaints, weight gain), psychological complaints (depression, anger, irritability, cynicism, loss of libido, insomnia), increased use of depersonalized terms ("case load") or derogatory terms ("old crock") for patients, increased distancing (more time with charting and less with patients), increased job dissatisfaction and increased stress in relationships in personal life.

Experience suggests that those with a "high need to serve" function most effectively in this form of health care. It must be remembered that such individuals frequently have difficulty in setting limits on their "giving." This carries with it a high risk in a clinical setting in which the stated intent is to meet the physical, psychological, social and spiritual needs of patients and family – an impossible goal.

The possibility of interpersonal stress on a multidisciplinary team is ever-present. Questions concerning the meeting of spiritual needs of these patients and their families have been particularly contentious for the PCS team. Saunders has commented: "The special needs of a terminally ill patient and his family make the question of religious and philosophical belief a central issue," yet this is a question which most health care professionals feel poorly equipped to handle. They are sensitive issues. There is always the risk of misunderstanding and of inappropriate proselytizing. In

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this, as in other areas of holistic care, there is the risk of the care-giver acting to meet his own needs rather than the patient's. Patience, tolerance, openness to meet others where they are and a clear understanding of goals are required. On the PCS these issues are continuously being re-addressed. The need to do so and the sensitivity involved are both suggested by the passing comment of the bereavement counsellor "Your need as well as hers?" as Mike's mother explained that the home care nurse had asked to say a prayer when Mike died and that it seemed to meet a need.

Methods that effectively deal with staff stress include:

1. care in staff selection,
2. clarification of goals, accountability, the role of team members, communication channels and decision-making patterns,
3. regular meetings between staff and a consultant psychiatrist,
4. the development of other interests (hobbies, physical activities),
5. regular vacations,
6. increased use of part-time staff.

A sense of humor helps.

Spiritual Concerns

Comments:

The central theme of existentialism is that to live is to suffer and to survive is to find meaning in the suffering. Nietzsche commented, "He who has a *why* to live can bear with almost any *how*." Clearly, finding a sense of meaning in existence is a variable of key significance in determining what "quality of life" one experiences. It is this fact that prompted one young patient whose brief life had been marked throughout by extraordinary achievement to comment shortly before dying, "This last year has been the best year of my life." In his final illness he had found new meaning to life. In the film, Sheila, Mike, the Mlots and others speak of new meaning that they have experienced in the presence of life-threatening illness.

Confrontation with death demands a total reassessment of previous perceptions about life, death, and existence beyond death. Once symptoms have been controlled, the patient finds that the question of the meaning of existence is paramount. Invariably life's ultimate questions are raised. What are the implications of Sheila's comment "We don't know why we are selected to get the disease?" One patient observed "It's the time when the mind's own camera is forever turned on self." To ignore the significance of metaphysical issues in this setting is to miss the boat. If we are to meet the needs of patient and family we must be willing to stand with them in front of questions.

At a point where we can no longer alter the circumstances affecting our destiny we still have one last choice – one area in which we can yet exercise control. Viktor Frankl has commented, "the last of human freedoms is the ability to choose one's attitude in a given set of circumstances." In ministering to the metaphysical or spiritual needs of a patient and family in the arena of death, therefore, we are attempting to act as catalysts to their attempt to find their own meaning.

While the care-giver may feel a need to tell patients of his particular faith or system of beliefs the aim in this, as in other dimensions of "total care" should be to meet them where they are not where we think they "should" be.

In the film, the pastoral associate is seen giving Communion to René. She speaks to him in language filled with religious symbolism; language that was very meaningful to him, a man who had had a sustained faith. To meet Mike where he was, was to listen to him as he described all religions as "man-made," while asserting his belief that "some supernatural being created us and the earth, and the universe... I say God because I don't know of any other word to use to describe the unknown."

Helen Keller wrote "I cannot understand the poor faith that fears to look into the eyes of death. Faith that is vulnerable in the presence of death is a frail reed to lean upon. With steadfast faith I follow sight beyond all seeing, until my soul stands up in spiritual light and cries, 'Life and death are one'." While a deep personal faith may be sustaining in life's darkest hours, it is also important to remember that *along with our* belief we bring a host of other determinants that will modify our response to tragedy. Parkes has suggested that these modifiers may include childhood and later experiences, previous mental illness and other life crises, our relationships to others, the nature of the present crisis, our age, sex, personality, socio-economic status, nationality and cultural expectations, our support systems, secondary stresses and our emergent life opportunities. We must not be surprised, then, when as stalwart a man of faith as the Christian writer and thinker C. S. Lewis says, in his hour of acute bereavement, "In which sense is my faith a house of cards? Because the things I am believing are only a dream, or because I only dream that I believe them?" Crises of faith may be particularly bitter if they are unexpected. It should be reassuring to all to know that even a C. S. Lewis can have doubts. It is of further support to know that in time his reassurance came through his faith.

Spiritual Concerns

Questions:

1. A terminally ill patient who happens to be your age and sex unexpectedly asks you if you believe there is a life after death. In this setting would you:
(a) turn the question back to the patient asking his beliefs while remaining non-committal yourself?
(b) refer the question to a chaplain or rabbi?
(c) speak candidly about your beliefs?
2. Considering that only a minority of our society are close adherents to any specific religious faith, what relevance do you feel spiritual questions have for the terminally ill?
3. Whose job should it be to meet the spiritual needs of patients and their families?
4. How do you assist an agnostic or atheist in answering life's metaphysical questions?
5. How can you help someone of another faith find greater meaning in the midst of suffering?
6. How can you reconcile the concept of a good and all-powerful God with the existence of unmerited suffering?
7. Does the existence of a personal faith support a person facing death? Is the absence of a meaningful faith a detriment to coping with terminal illness?
8. What does "faith-healing" mean to you?

Quotes:

Mike: What is the right age to die? There is no right age. Any age is right if God determines it that way. I say God because I don't know of any other word to use to describe the unknown... There are so many different religions. They're all man-made though and they all seem to boil around the same idea. Some supernatural being created us and the earth and the universe. I mean it's so gigantic something had to start it.

Mike's Father: He doesn't think of his impending death as the end of it all. It's the beginning of it all.

Sheila: Physically we may not be cured but physical is just temporary anyway – for all of us – even those in the best of health. It's only temporary. We're only meant to be here for a little while. Our eternity is waiting for us.

Chaplain: C'est le corps du Christ...

Sheila: We don't know why we are selected to get the disease.

Mike: My Dad is hoping that some supernatural thing will overcome this if the doctors can't. He's still got that thread of hope.

Mike's Mother: Aileen asked if she could say a prayer and I said "Certainly" because I felt that was – a need – at the moment...

Bereavement Counsellor: Your need as well as hers...

Mike's Mother: Yes... as hers...

Spiritual Concerns

When we face death, then, metaphysical questions are reconsidered. One's belief system is re-examined. Through it, one may find meaning and solace, a greater awareness of our essential aloneness, or heightened anxiety if it leads to feelings of guilt and fear of punishment. Whatever the impact, the questions are asked. Thus adequate support can only be given if we permit and assist their surfacing and support patient and family in their quest for meaningful answers. Given the uncompromising reality of the setting, the potential for personal and interpersonal growth for the patient and family is unparalleled. Having assisted in the realization of this potential, the care-giver may find that he or she has shared in the growing process.

The Last Days of Living

Film Credits

Research, Direction and Editing:
Malca Gillson

Photography:
Robert Humble, Barry Perles

Location Sound:
Bev Davidson, Michael Hazel

Re-recording:
Hans Peter Strobl

Producer:
Tom Daly

Executive Producers:
Arthur Hammond, Barrie Howells

**Produced by
National Film Board of Canada
with the help of a grant from the
Richard and Jean Ivey Fund,
London, Canada**

**16 mm Color
Screening Time: 57 minutes 52 seconds**

**Distributed by
National Film Board of Canada**

**16 mm: 106C 0180 002
Videocassette: 116C 0180 002**

The Last Days of Living

Selected Bibliography

- Ajemian, A. and Mount, B. M. **The McGill Manual on Palliative/Hospice Care.** New York, Arno Press, 1980 (in press).
- Benjamin, Alfred. **The Helping Interview.** Boston, Houghton Mifflin Co., 1974.
- Duff, R. S. and Hollingshead, A. B. "Dying and Death," in **Sickness and Society.** New York, Harper and Row Company, 1968.
- Feifel, H. **The Meaning of Death.** New York, McGraw Hill, 1959.
- Frankl, Victor E. **Man's Search for Meaning.** Beacon Press, Boston, 1959.
- Fulton, R. et al. **Death and Dying: Challenge and Change.** Reading, Mass., Addison-Wesley, 1978.
- Garfield, C.A. **Psychosocial Care of the Dying Patient.** New York, McGraw Hill, 1978.
- Hinton, J. M. **Dying.** Baltimore, Penguin Books, 1967.
- Holland, J. "Psychological Aspects of Cancer", in **Cancer Medicine.** Holland, J. F. and Frei, E. Philadelphia, Lea and Febiger, 1973.
- Kubler-Ross, Elizabeth. **On Death and Dying.** New York, MacMillan Company, 1969.
- Lewis, C. S. **A Grief Observed.** New York, Bantam Edition, 1976.
- McIntosh, J. **Communication and Awareness in a Cancer Ward.** London, Croom Helm, 1977.
- Melzack, R. M. **The Puzzle of Pain.** Harmondsworth, Eng., Penguin Books, 1973.
- Munro, S. and Mount, B. "Music Therapy in Palliative Care," **Canadian Medical Association Journal** 119: 3-7, 1978.
- Parkes, Colin M. **Bereavement Studies of Grief in Adult Life.** London, Tavistock Publications, 1972.
- Saunders, Cecily M. **The Management of Terminal Disease.** #1 in the Management of Malignant Disease series. London, Edward Arnold Ltd., 1978.
- Swift, V.K. "The Chaplain's Role in Care for the Dying: Toward a New Understanding." **Canadian Medical Association Journal** 115: 181-185, 1976.
- Wyse, H. et al. **Making Health Teams Work.** Cambridge, Mass., Ballinger Press, 1974.

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