

## Study Guide Materials

### Introduction

The two part document which forms the body of this booklet, includes both *A Draft Statement on Euthanasia*, and a longer section, *Care in Dying: The Report of the Task Group on Euthanasia and Assisted Suicide*. Together, those sections were commended to the church for study by the 1998 General Synod. The task group then prepared the following study guide to accompany the materials that had been prepared earlier in order to facilitate the process of study and response. The reason we felt the need to do this will become clear in a brief account of the history of these documents, and the process by which they were presented to the 1998 Synod.

The issue of euthanasia and assisted suicide was considered by a task group of the Doctrine and Worship Committee towards the end of the life of that committee. Faith Worship and Ministry took up the task in 1997 following a process undertaken by the Canadian Council of Churches which had sought to identify what appeared to be an emerging ecumenical consensus around the issues of euthanasia and physician assisted suicide. Faith Worship and Ministry established a task group and began the period of study and reflection that gave rise to the documents presented to Synod. The first section of the document, the two pages entitled *A Draft Statement on Euthanasia and Assisted Suicide*, was initially proposed by the task group as a pastoral guideline for the Anglican Church of Canada. It attempts to provide a brief statement of what is at stake for Christians seeking to make faithful decisions about medical treatment at the end of life where some appeal might be made to the possibility of euthanasia or assisted suicide. The recommendations offered, which are intended to be pastoral in tone rather than narrowly prescriptive, are explained at greater length, and arguments offered in support of them in the report of the task group which follows, *Care in Dying*. Taken together, the report and proposed pastoral guidelines seek to give further assistance in one of the areas covered by the earlier and more broadly based study, *Dying: Considerations on the passage from life to death*.

In opting to suggest pastoral guidelines rather than a policy statement, the task group sought to recognize both the complexity of the issues at stake in debates around euthanasia and assisted suicide, and the range of opinion that are a part of the life of our church. Guidelines invite thoughtful and prayerful engagement with the realities that people may face at the end of their lives rather than demanding obedience to closely defined teaching. We felt that this more closely accords with Anglican ethos. However, it does not mean that the task group has not taken a position, because it clearly has. What we sought to recognize was that the position taken represents a starting point and not the conclusion of Canadian Anglican reflection on this subject. With this intention in mind, the Council of General Synod decided that there needed to be time and opportunity for the wider church to study both documents and an opportunity to invite and hear responses to them before inviting the Synod to endorse the proposed pastoral guideline. Thus General Synod 1998 was invited to, and chose to, commend the documents contained in this book for study.

This now presented a problem. The work of the task group was directed towards those specifically concerned with decision making around end of life issues, rather than towards the more general audience to which the report was now to be circulated. Therefore, in order to assist the process of reflection we have provided study materials of various kinds that we hope will make this text more accessible to the general reader.

- We have offered some study suggestions to allow individuals or groups to grapple with the definitions which are found on pages 6-9 of the report. These definitions in our view are amongst the most important things that we have to offer. Too much of the discussion in this area reflects confusion of a range of circumstances which, while similar in some ways, may have quite different implications for patient care. We hope these definitions will help people to be clearer about what sorts of decisions they are comfortable with and what sorts of decisions seem to them to be unacceptable, and why.
- We have provided materials for a study session on the guideline. This includes suggested questions for group discussion, cross references to appropriate sections of

the report, *Care in Dying*, and some case studies which seek to give the participants in the discussion some appreciation for the conditions under which requests for euthanasia might be made.

- We have provided questions for discussion and / or reflection throughout the text of the report, *Care in Dying*, which forms the main part of this text.
- Finally, we have provided a response form at the back of this book so that you can let us know whether or not this book was helpful to you. We want to know what you found to be good and useful, and what you found to be confusing, misleading or just unhelpful. We would also like to know if you think the proposed pastoral guideline would indeed be of assistance to Anglicans involved in discussions about the acceptability and appropriateness of euthanasia and assisted suicide in Canada.

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## **Group Study Session**

The materials for group study are divided into two parts. Part 1 deals with the definitions which are drawn from the longer report of the Task Group, *Care in Dying*. Part 2 deals with the draft pastoral guideline. It is possible to do only one part of the study. However, if both parts are done, we recommend that groups work first with the definitions and then work on the pastoral guideline at the second session. Both the definitions (in abbreviated form) and the guidelines are reprinted here for ease of reference.

Both of these study sessions have tried to provide ample material for groups to pick and choose what they find helpful. We do not suggest that you try and accomplish everything suggested, but decide what materials and questions you want to focus on as a group. In the case of the guideline we have provided materials that would probably require two or three sessions to complete if all of the options were followed.

In using the narrative case studies provided for the study of the guideline we suggest that you try to pay careful attention to the perspective from which the stories are told. The storytelling is not intended to be neutral but to suggest how the situation looks from a particular perspective. This does not mean that we endorse or agree with that perspective, but these reactions do take place, and a pastoral approach demands that we have something to say in response to people in the real contexts where decisions have to be made.

## **Group Dynamics**

Before beginning work in groups it would be helpful to set out some general principles to make the experience one in which all members of the group are able to participate freely and comfortably.

Euthanasia and assisted suicide involve decisions about the lives of real people in quite tragic and painful circumstances. Although the actual incidence of request for assistance in dying is very low, many of us will know of people whose dying involved decisions to refuse certain types of treatment (Do not resuscitate orders, decisions not to oppose pneumonia with antibiotics, decisions to withdraw therapy etc.) Often in such

situations the question will have been asked as to whether it would not have been kinder to have ended the patients life. When listening to the experiences and stories of others it is important to seek to understand first the realities that they describe from their perspective. This will make it all the easier to understand those points where we disagree and to be able to express our disagreements in a manner that is accurate, appropriate, and constructive.

In order to facilitate group discussion, contributions should be respectful. That involves careful listening. Listening is not simply a pause while we think what to say next. It is a time to hear and understand as precisely as possible the point of view of another person.

Linked to this, respect involves allowing people to speak for themselves. We need to be careful not to put words into other people's mouths. It is one thing to ask somebody to clarify what they have said. It is quite another thing to tell them what they said.

Respect means responding in a positive way to the views of others. This does not mean that we always agree with them. However, it does mean that we are attentive to the places where we do agree and able to use those points of agreement as the starting point of our discussions.

Respect also means that we seek to put the best possible construction on another person's position. We refrain from caricaturing positions with which we disagree. It also means that we assume that the other person believes or acts as they do from the best possible motives. As both the report and proposed pastoral guideline affirm, people on both sides of the debates concerning euthanasia and assisted suicide share many values in common. What they disagree about is often not the key values, but what the implications of those values are for persons making decisions at the end of their lives and in painful and difficult circumstances. At times we will have to agree to disagree. To reach this point is not a failure if we understand each other better, and better appreciate the reasons for each other's positions. If you reach this point, acknowledge it and move on to the next step in your group discussion.

## **Study Session 1**

### **Definitions**

#### *Opening Prayer:*

The following or other suitable prayers and readings may be used.

#### *Scripture*

Psalm 23 or Psalm 31:1-5

#### *Prayers*

Preserve us O Lord, in all our doings with thy most gracious favour and further us with thy continual help: that in all our works begun, continued, and ended in thee, we may glorify thy holy name, and finally by thy mercy obtain everlasting life; through Jesus Christ our Lord. Amen.

(Collect from the Ordinal: BCP)

Eternal God, you create us by your power, and redeem us by your love. Guide and strengthen us by your Spirit, that we may give ourselves in love and service to one another and to you; through Jesus Christ our Lord. Amen.

(Collect for Morning: BAS)

#### *Introduction:*

Take some time to share around the group. Introduce each other and share the experiences and stories of which you have some knowledge, and which have shaped your interest in the subject of euthanasia and physician assisted suicide. Be careful to distinguish your own experiences from experiences that have been reported to you.

What made the situations you have described particularly difficult for those concerned? Could these difficulties have been overcome had the situation been dealt with differently?

#### *Definitions:*

Look at the definitions. You might want to read the section of the report to get more clarity. We have included only a summary of the definitions here for ease of reference. Notice that the definitions speak of the type of act (termination of treatment, euthanasia, physician assisted suicide, etc.), and also the degree of consent achieved (voluntary, involuntary, non-voluntary).

1. *Brain Death and removal of "life support"*: Although often confused with so called "passive euthanasia", the term brain death relates to the clinical criteria developed to determine that death had occurred in patients on life support. Such patients are dead, and the removal of "life support" simply acknowledges this.
2. *Termination of Treatment*: This refers to those situations where medical treatment is no longer indicated and all treatment except palliation (food, hydration, pain relief, etc.) is withdrawn. The intention is not to cause death, but rather to recognize that it can no longer be effectively resisted. The results intended by the provision of certain therapies can no longer be attained, so the treatment is deemed useless and withdrawn.
3. *Passive Euthanasia*: occurs where the *intention* is to allow the patient to die. Perhaps the best example of this would be the decision not to treat a duodenal atresia, the blockage of the digestive tract that sometimes occurs in a Down's Infant. In such cases we are not dealing with the recognition that death cannot be effectively resisted, nor are we addressing a situation where treatment has been declined by a competent adult. Instead, death is sought by a decision not to act to effectively correct the condition that, untreated, will result in death.
4. *Physician Assisted Suicide*: This refers to the provision by a physician of the means by which a patient ends his or her own life, or the provision of information which a patient may use to obtain effective means to end their own life.
5. *Euthanasia*: This differs from physician assisted suicide in that the physician does not merely advise or provide the means for suicide but intervenes directly to bring about the death of the patient. Thus, the provision of sufficient barbiturates for suicide to a patient who is known to intend to use them for that purpose is a physician assisted suicide. To inject a patient with a lethal dose of morphine at their request would constitute active euthanasia.

There are three levels of voluntariness to be considered with regard to euthanasia:

1. *Voluntary Euthanasia*, the act is carried out according to the wishes of an informed and competent patient who without coercion requests that his or her life be ended.

2. *Involuntary Euthanasia* takes place when a person who is competent to consent, but has not requested euthanasia, is killed. It would include cases where consent is not sought because it is not deemed relevant, and situations where euthanasia is carried out because a care giver or family member is moved by the suffering of a patient and acts to alleviate pain and suffering without seeking or obtaining permission.
3. *Non-voluntary euthanasia* refers to a situation in which the patient does not have the capacity to consent either through age or immaturity, unconsciousness, mental illness, or incompetence. Examples of such non-voluntary euthanasia might include appeal to substituted consent, where the consent of a parent, guardian, or legal proxy is obtained prior to euthanasia but where there was no supporting evidence of the wishes of the patient. It might also include situations where consent is presumed. In such a case the use of this category presumes that there are reasons for believing that the patient would have consented had they been able to do so.

In terms of these definitions what sorts of actions do you think are appropriate / inappropriate? To help reflect back on the experiences you discussed earlier, write up your results on newsprint.

### *Case Studies*

Read the following case outlines: These are summaries of high profile cases taken from the Canadian context. Each of these cases has ended up before the courts and is quite well known. Feel free to draw on your own knowledge of these cases as they were reported in the press. If your group is large enough you may want to divide into smaller groups and tackle one case per group.

#### **The Case of Nancy B.**

For most of her life, Nancy B. had been a healthy, active woman. In her early twenties, however, she acquired an extremely severe form of Guillain-Barre syndrome, which required her hospitalization for two and a half years. Her illness rendered her incapable of movement, and she was completely bed-ridden. She was reliant on others to provide for every aspect of her physical needs. She was also dependent on a ventilator to assist her to breathe. Her mind, however, remained unaffected by this terrible disease.

In 1991, Nancy B. expressed to her physician her desire to have her ventilator turned off so that she could be allowed to die. She continued to express this wish over the next year. Unsure of how to



proceed, her physician sought the support of the Quebec Supreme Court to remove Nancy B. from the ventilator. The Supreme Court ruled that stopping the ventilator was legally permissible: "What Nancy B. is seeking, relying on the principle of autonomy and her right to self-determination, is that the respiratory support treatment being given her cease so that nature may take its course; that she be freed from slavery to a machine as her life depends on it". (Nancy B. v. Hotel-Dieu de Quebec et al. (1992), 86 D.L.R. (4th) 385-95 (Q.S.C.)). Since Nancy B. was unable to move, the removal of her ventilator would require the assistance of her physician. The court permitted this act on the basis that such an act constituted the termination of a treatment refused by the patient. Further, the court argued that its effect was to allow the underlying disease to take its natural course, and did not constitute assisted suicide.

### **Paul Mills**

Mr. Mills, a 65 year old patient suffering from throat cancer was in the intensive care unit at the Victoria General Hospital, part of the Queen Elizabeth II Health Sciences Center in Halifax Nova Scotia. He was in the final stages of his illness but had been transferred from a hospital in Moncton, New Brunswick, in the hope that the more advanced treatment facilities available at the Halifax hospital would help. Instead his situation rapidly deteriorated. Earlier surgical interventions had not eased, but rather complicated Mr. Mill's condition. On November 9<sup>th</sup> it was agreed that no more surgery be done and that only palliative care be provided. The following day the breathing tube and ventilator were removed. Although Mr. Mill could only communicate by blinking his eyes, his wife said that he never said that he wanted to die. However, since there was very little that could be done it was agreed to gradually wean him from life support devices. In his son's words, the point, "was to let nature take its course."

The course which nature took was brutal. According to the nurse caring for Mr. Mill's, he "writhed in agony," gasping for breath. He received potentially lethal doses of the narcotic pain killer Dilaudid, but this appeared to have little effect on his condition. A respirologist was called in who administered nitroglycerine to lower Mr. Mill's blood pressure to attempt to relieve his symptoms. It still had no effect. Finally she administered potassium chloride, a compound that will stop the heart unless it is highly diluted. A few minutes later Mr. Mills died.

The doctor was disciplined by the hospital for her actions which suspended her from the intensive care ward for three months with pay. She later resigned from the intensive care unit, citing the very high stress levels associated with the intensive care ward, although she continued to work at the hospital. Some physicians at the hospital, unhappy with the hospital's handling of the case reported her to the police who arrested her in May of the following year. The case was, however, dismissed. It turned out that the catheter into which the narcotics were being administered, and into which the potassium chloride was injected, was incorrectly inserted and the drugs were entering Mr. Mill's body cavity rather than the vein. It could not be shown therefore that the injection administered by the doctor was the cause of her patient's death.

### **The Case of Sue Rodriguez**

At age forty-two, Sue Rodriguez was terminally ill with advanced Amyotrophic Lateral Sclerosis (ALS or Lou Gehrig's Disease), a severe degenerative disease. Despite the physical deterioration she was experiencing, her mind remained alert. She requested the legal right to seek the assistance of her physician to end her life when she could no longer do so on her own. She was aware that the course of her illness was such that a time would come when she could no longer swallow or breathe on her own, and would need to rely on others to provide for all of her needs. She wanted peace of mind to know that, when her life had become intolerable for her, her physician would assist her to end her life.

The Supreme Court of Canada denied her request in a split 5-4 decision. The judges ruling against her argued on various grounds that the denial of such assistance did not contravene her Charter rights. They argued that there was no right to die enshrined in the charter, that the state had a compelling interest in upholding the principle of the sanctity of life that would over-ride some restrictions of charter rights. However, the Justices also concluded that a refusal to assist Sue Rodriguez to commit suicide did not compromise her right to equal treatment under the law, because it was the illness that limited her freedom, not an arbitrary decision of a doctor, and because the removal of legal sanction against suicide was not the same thing as granting a right to commit suicide.

Shortly after the decision of the Supreme Court was released, Sue Rodriguez died with the assistance of a physician in the presence of the MP Svend Robinson.

### **The Case of Robert Latimer**

Tracy Latimer had cerebral palsy, which rendered her unable to walk, talk, or feed herself. She had had this condition from birth, most likely the result of an injury to her brain during the pregnancy or at birth. Throughout her childhood, she had undergone many surgical operations to alleviate her pain that stemmed from her inability to move her muscles. A further operation was proposed to try to help Tracy's pain. On October 24, 1993, while his family attended church, Robert Latimer placed twelve year old Tracy in his half-ton Chevy pickup, and filled it with carbon monoxide fumes. He stood in the snow and watched through the window for seven minutes until she died. He then returned Tracy to her bed. When the family returned from church Tracy's mother went up to her room and found her dead. They called the police who were initially told that Tracy had died in her sleep. However, the autopsy made clear that Tracy had died of carbon monoxide poisoning and Robert Latimer was arrested and after a confession in which he showed the police how he had ended Tracy's life, he was arrested and charged. This led to an intense and emotional public debate about the ethical issue of mercy-killing.

Because the killing of Tracy had been premeditated the prosecutors had to bring a charge of murder which carries a mandatory life sentence with no chance of parole before ten years. Many in Canada thought this sentence inappropriate given the motivation and circumstances of Robert Latimer's actions. At his second trial, Latimer received a constitutional exemption based on the Charter of Rights and Freedoms with a sentence of two years less a day - half to be served in a provincial jail, the other half on his farm.

The Judge wrote that “the evidence establishes Mr. Latimer was motivated solely by his love and compassion for Tracy and the need - at least in his mind - that she should not suffer any more pain”. Latimer’s defense team argued that Tracy’s pain could not be controlled by the medication available, given the side-effects she experienced. Only death, they argued, could ease her pain. Groups representing people with disabilities rushed to condemn the judge’s decision on the grounds that such a decision undermined the value of the life of a disabled person, and posed a danger to anyone who is vulnerable and unable to speak for themselves. The sentence is currently under appeal.

Now try and apply the definitions to each of the cases. Try to work out which of the definitions best describes the situation being described. What sort of action was contemplated? Was it voluntary or not? If not, was it involuntary or non-voluntary? Write up your results on newsprint.

You should now have a summary of each case in terms of the definition. Discuss your reactions to the cases in terms of where they come on the spectrum described by the definitions. What are the points where you believe that we begin to pass from appropriate to inappropriate actions? On a sheet of newsprint list the definitions and draw a line across the list representing this point for each member of the group. Does the line come in the same place for everyone? You might want to talk about the differences you observe and why?

Was your reaction to each case the same before and after working with the definitions? If it changed, you might want to talk about how the definitions helped to clarify your thinking.

## **Study Session 2**

### **The Proposed Pastoral Guideline**

#### *Opening Prayer:*

The following or other suitable prayers and readings may be used.

Psalm 139:1-17

O God our heavenly Father, in whom we live and move and have our being: Grant to thy servants grace to desire only thy most holy will; that whether living or dying, they may be thine; for his sake who loved us and gave himself for us, Jesus Christ our Lord. Amen  
(Adapted from the Ministry to the Sick, BCP Canada)

Remember us, gracious God, when we are lonely and depressed, and support us in the dark night of grief and despair, for your love is faithful, and you do not forget your broken ones. We ask this in the name of Jesus Christ the Lord.

(Psalm prayer, Ps.40, BAS)

#### *Introduction:*

If this is the only study session you have done, take some time to share around the group. Introduce each other and share the experiences and stories of which you have some knowledge, and which have shaped your interest in the subject of euthanasia and physician assisted suicide. Be careful to distinguish your own experiences from experiences that have been reported to you. What made the situations you have described particularly difficult for those concerned? Could these difficulties have been overcome had the situation been dealt with differently?

If you have already done the study session on the definitions give people time to talk about their thoughts since the last meeting.

The main part of this study session is in two parts. In the first part we will look at the proposed guideline as a whole. In the second part we will examine the guideline in

more detail, dividing it into three sections for the purposes of this study; *Foundations in Faith, Shared Values, and Living as Community*.

### *Overview of the Proposed Pastoral Guideline*

Read the proposed pastoral guideline together from the front of the book. Ask each person in the group to read a paragraph at a time. What is your general impression of this brief guideline? What do you like? What concerns do you have about what is written here?

How, in general does it relate to the experiences you have shared together?

### *Part 1: Foundations in Faith*

The first two paragraphs of the guideline suggest some of the concerns that motivate us as Christians. The first paragraph focuses on the notion of life as gift. The second on the importance of community and the experience of interdependence which Paul suggests is central to the life of Christians.

Christian thought through the ages has been guided by the principle that human persons are made in the image and likeness of God (Genesis 1:26-27) and our life is to be seen as a gift entrusted to us by God. Life is thus seen as something larger than any individual person's "ownership" of it, and is not simply ours to discard.

In Romans 14:7 St. Paul says that we do not live to ourselves and we do not die to ourselves. We are members of Christ's body, each member being an integral part of that body. While we recognize there is a diversity of opinion, both within the church and in society at large, this vision of human dignity and community gives rise to some profound misgivings with current proposals to legalize euthanasia in the form of physician assisted suicide.

It is important to remember that these are insights that we all share, even when we come to different conclusions about the appropriateness or otherwise of euthanasia and assisted suicide. It is important also to notice that these insights are rather different from the images of the body as property and the centrality of individual autonomy that are dominant in our culture. Spend some time talking together about the different ways we understand and experience our lives as gift to be lived in community with each other.

How do we relate these images to the more widely held approaches that suggest my body is my property and that an individual's personal decision is always the primary criterion for deciding how we should act?

The section of the report, *Care in Dying* that discusses the notion of life as gift draws attention to the fact that this image is a very ancient one in the life of the Church (page 23), but the image can be used in several ways. Do you think that the notion of gift means that we have to hold onto life at all costs? (See the discussion of life as gift on page 28-29, and the discussion of withdrawal of treatment, pages 26-28)

One of the most important images that the bible uses to speak of the Christian community is that of "the body of Christ." Read 1 Corinthians 12:12-26. What are the qualities of the type of community that Paul is describing? Can we really aspire to be that sort of community today? What would it mean for the church to be such a community?

With these questions in mind you might want to read Case Study II from the case studies at the end of this section. What does it mean in this situation to think of life as a gift? What does the community of the church have to offer the people involved in this situation that will support them in their decision-making?

What are the dangers of talking about community in this sort of way? How can communities guard against these dangers?

### *Part II: Shared Values*

As Anglicans we are members of a community that has a long history of concern for and involvement in issues of health care. Our shared history reflects our shared values. Spend some time talking about those values that we share in common, and how they motivate our actions (See the comments from the report of the Episcopal Diocese of Washington reported on pages 17-18).

The Anglican Church of Canada shares with other Christian communities in a long history of providing many forms of health care, healing, and support of the suffering and dying. Churches have actively supported the development of palliative care facilities and practices, including pain management. This commitment is expressed in the central role they have played in the development of hospices and palliative care institutions in many parts of the world. In Canada these programs involve health care professionals and volunteers from the church community in the attempt to alleviate pain and maintain

dignity of life even at the moment of death. Christians are called by God to take part in caring communities which make God's love real for those who are suffering or facing death. It is through these communities that we bear witness to the possibility that human life can have dignity and meaning even in the context of the realities of pain, suffering, and death.

We believe we share with other members of society, on both sides of this issue, a concern for the protection of human persons and respect for their dignity and life. However, there are reasons to believe that the legalization of euthanasia could present special risks for those in our society who are already vulnerable. Social and familial coercion, elder abuse, widespread undiagnosed depression, the pressures of materialism and greed, as well as medical convenience are all realities to be considered and which increase the vulnerability of the elderly and the disabled. We would further urge that the attempt to change law and practice at a time when health services are being cut back and costs downloaded onto patients and their families is inappropriate. We believe that physician assisted suicide should only be discussed within the wider context of changes to the Canadian health care system.

Although the report recognizes that we share certain common values across our differences it nonetheless takes a position on the issue of assisted suicide and euthanasia. The report does this because it chooses to look at our community from the bottom up, from the perspective of those it understands to be most vulnerable. Do you think that those it identifies as vulnerable need particular protection? Do you think that it is possible to protect them while allowing euthanasia in very restricted circumstances? How possible do you think it would be to keep those circumstances restricted? (See the discussion of the Dutch experience on pages 13-16.)

In talking about shared values we need to speak not only about what we oppose, but what we support. How has the guideline done this? Has it done it adequately?

The key theme here is that of care. How do we live as caring communities? What constitutes care in the context of terminal illness? In the report the notion of care functions in two ways. In the discussion of the obligations of physicians the need to care is contrasted with the desire to cure? In the discussion of the withdrawal of therapy it is suggested that this might be an expression of care in a way that killing a person, for whatever motive, is not.

What are your views about the way the task group have used the notion of care? Do you find the distinctions they have made helpful?

Look at Case Study III from the end of this section. What are the ways care might be expressed here?

*Part III: Call to Community.*

The church needs to be a caring community. It is not enough to issue pastoral guidelines if we are not prepared to be involved in the lives of the people those guidelines are addressed to, seeking to address their needs, and providing realistic alternatives.

In the light of these considerations, we believe that respect for persons would not be well served by a change in law and practice to enable a physician, family member, or any private citizen to take the life of another, or assist in their suicide. Both the request for assistance in committing suicide, and the provision of such assistance must be taken seriously as a failure of human community. The Christian response is always one of hope. From this hope there arises the commitment to give all members of society, especially the most vulnerable, the assurance that they will be supported in all circumstances of their lives, that they will not have dehumanizing medical interventions forced upon them, and that they will not be abandoned in their suffering.

Good medical practice sustains the commitment to care even when it is no longer possible to cure. Such care may involve the removal of therapies that are ineffective and / or intolerably burdensome, in favour of palliative measures. We do not support the idea that care can include an act or omission whose *primary* intention is to end a person's life. Our underlying commitment is that health care delivery as a whole should reflect the desire of Canadians to be a community which sustains the dignity and worth of all its members.

In the discussion of the Latimer Case the task group commented on the lack of support that the Latimers believed to be available to them (page 13). Even if more support was available, the Latimers were unaware of it, or unable to take advantage of it.

How can the church function as a more supportive community for those involved in end of life decisions? What sorts of changes in Canadian Health Care policy, and law would provide more support, and more alternatives to those facing end of life decisions?

Do you think that we would still need to legalize euthanasia in some circumstances, even in the presence of such changes?

Read Case Study I from the case studies at the end of this section. What are your views about the alternatives available? Is the doctor right to say there are no good



alternatives at this point? Do you agree that withdrawing artificial nutrition and hydration is an act of care? How would this compare with a decision not to treat pneumonia?

## Case Study I

She had been so full of life, and the love of life. A musician, she was creative and willful. Younger than usual, she was well qualified to begin at the conservatory and it just did not seem right to hold her back. We used to laugh at her absent mindedness. Still, she was mature, and although we anticipated the inevitable little crises when she forgot something, or locked herself out of her apartment, we never thought of this.

The year end recital that evening had been a triumph. Her voice in perfect form she had worked her way through a difficult recital program without a hitch. She was so excited that she never even saw the car coming as she stepped off the sidewalk and into the nightmare we were all going through.

At the hospital they rushed her into surgery. There were internal injuries, and they couldn't say too much until she came out of the operating theater. They would just have to see, they said. The doctors were so kind to us. When they spoke to us afterwards they told us that it was their worst nightmare. They had stabilized the patient only to find out that there was nothing they could do. She never regained consciousness, and now six months after the accident we sat in the office of the consultant neurologist. He was grave, and clearly not happy to have to deliver the news he gave us.

"The simple fact of the matter is that the longer she is in a coma like this, the less likely it is that she will ever come out of it. I said that to you before, but now it's been six months and at this point the chances of her ever recovering consciousness are minimal. In any case, if she does come round, at this point there will probably be a great deal of permanent brain damage. She will never be able to live a normal and independent life. However, I'm sorry, but I have to say that I doubt she will ever come out of the coma."

We looked at each before replying. "So, what do you suggest we do, doctor?"

Leaning back in his chair he played with his pen as he spoke. "We have two options at the moment. We could carry on as we are, but I wonder how fair that is either to you or to her."

My wife and I spoke almost instantaneously, "We agree."

"I can't believe that Elizabeth would have wanted to live like this," said Janice, "She was so full of life. This isn't her. It isn't even a shadow of her."

"The alternative, is that we could remove the tube through which we are feeding her."

"What?" We looked at him appalled. Obviously, he thought we had not understood him and began to explain. "The Naso-Gastral tube, it's how we..."

"I understood what you said," I interrupted, "but..."

“You would starve her to death.” Janice finished.

The doctor shifted position uncomfortably as he spoke. “I don’t think that is a very helpful way of describing what we are proposing to do...”

But Janice interrupted again. “□ We are proposing. □ Do you mean that you have already discussed this here in the hospital before you have spoken with us?”

“I’m only saying that...”

This time I was the one who interrupted and the edge of anger must have been clear in my voice as I spoke. “You wouldn’t call it starving her to death, well what would you call it when you remove her food?”

“If she has got to die surely there is a more humane way” said Janice as she leaned forward. “I mean she is really already dead, she isn’t there. Elizabeth isn’t there. Isn’t there a better way to do this, can’t you give her an injection or something.”

“Euthanasia is illegal.”

“But it isn’t illegal to starve her to death.” Now there was no masking the anger and bitterness.

The doctor leaned forward and paused as he put his hands together on the desk. Taking time to collect his thoughts, he looked up at us. “You have to understand that she can’t feel anything in a coma of the type that she is in. Even if we thought she might feel anything we can hydrate. We carry on giving her water. Death by starvation, if you want to call it that, is only painful because people become dehydrated and we can prevent that. In addition if we believed that there was any residual possibility of her feeling pain, we could use morphine.”

“But not enough to end it.” I said shaking my head. Try as I might this did not seem to make much sense to me. “Do you think this is kind? Is this what you would want?”

The doctor shrugged his shoulders, not unkindly, but resigned to the need to cope with our anger and grief. “I think that this is a cruel situation. It really isn’t what any of us would want, and in situations like this it is hard to know how to be kind. We have discussed the situation in the team that is caring for Elizabeth, of course. We talk about what is best for our patients regularly. What we are suggesting now is that it might be time to remove a medical treatment from her that isn’t really helping. We can remove the tube and end the feeding that is preventing her from dying, and once the tube is gone, we can care for her while she dies. Isn’t that what we want to do for Elizabeth now, care for her?”

Still he did not seem to be hearing what it felt like to me. “I don’t see how that’s care and the other isn’t.” I said. But Janice put her hand on my arm.

“We need to talk about it,” she said, “Can we talk alone.”

“Take your time. Would you like anyone else to help?”

“Thanks Doctor,” said Janice, “but she was our daughter. I think our family needs the time to think this one out together.”

## Case Study II

It wasn't what she would have chosen. Then again, few of us would have chosen to end up on a geriatric chronic care ward. Try as we might, the conditions were far from ideal. The funding is tight. This isn't an area of medicine that politicians seem to find attractive to support. There always seems to be extra money for a ward for kids, but old people have a harder time of it in the health system. Of course, the patients who can afford it move into the private nursing homes as soon as they are well enough, but there was no chance of that for Theresa. There wasn't even a house that could be sold to help with the financing. That was the route that most of them went. But Theresa's little home had gone a long time ago, shortly after her husband died. She had a small apartment before coming here. Theresa enjoyed her independence there and had stayed as long as possible. After the first stroke she had home care and regular visits from meals on wheels, and these met most of her needs. At that stage her daughter Christina lived pretty close by, and she was constantly in and out. They were, I think, very close. But then Christina's husband was transferred across the country. It was a move that, like many, he had to accept if he hoped to keep his job. So the family moved, and with them a big part of Theresa's support. Then after the second stroke it was clear that she was not going to be able to go home. There was really nowhere else for her. Once she was on the ward she would stay here until a suitable alternative was found, but the chances of that were minimal. Her son Daniel was still in town but there was no way he could cope with her. He visited as much as he could, almost every day at first. But then three months ago he was transferred onto permanent nights. From that point onwards it became more difficult for Daniel to visit every day. Two or three times a week was all he could manage now.

I guess, looking back, that it was about then that Theresa seemed to become less and less responsive. She began to eat less, and became irritable. Some of the nurses would avoid her, especially after one of her daughter's rare trips back. Both Christina and Daniel tried their best, but Theresa was difficult to deal with and the visits became harder and more frustrating. A few weeks ago she stopped going to bingo, but the biggest surprise was when she decided she wasn't well enough to go to the mass that patients were taken to each week. I'd never known her miss mass, even on her worst days, and now she hadn't been for two weeks. Given that, I should have noticed when she returned her trays untouched two days ago, but it was only yesterday that I finally noticed that it was a pattern, not just the odd meal. I spoke to the doctor first, but he really didn't seem convinced that it was anything to worry about. He had said that old people often go off their food for a couple of days. I nearly said, not Theresa, you must be joking!

Then today Daniel came in while I was on the ward. I hadn't planned to speak to him, but when I saw him I called him into one of the consulting rooms. I wasn't sure what to say, but I felt that someone had to tell him what was going on. I gave him an outline of what I had seen. "And now she hasn't eaten for two days." I finished.

"Hasn't someone tried to make her eat?"

"Of course," I said defensively, "but she won't try and she sends back every tray untouched."

"Then make her eat," Daniel said rather abruptly.

"Would you like to try?" I asked. "She is an adult you know and short of force feeding there isn't much we can do"

"You are supposed to be looking after her" Said Daniel, his anxiety making him seem belligerent.

"And we are," I replied, "but she won't eat. Why don't you have a talk with her? She might listen to you."

"What will you do if she doesn't?"

"We will have to discuss that when it comes."

"What is there to discuss?" He said, the anxiety resurfacing. "If she won't eat you must make her. She's depressed that's all. She will be better when she is eating properly again."

I wanted to agree with him, but instead I found myself thinking aloud. "I'm not so sure. She was eating fine until a few days ago. She stopped eating quite suddenly, but she has been turning her back on things for some time now. She doesn't go to bingo any longer. She doesn't even go to mass. Fr. Allen has spoken with her, but with no success. It's more like she is slowly switching off. She might be depressed, but she might be sending us a message that she simply doesn't want to live like this any longer."

"So what has caused this?"

"I don't know, but I think it would help if you talk with her about it. Then maybe we can think about what the options might be."

### Case Study III

I realized on that day that I'd been living in a dream world for the last eleven years. It's amazing how it hits you and you know that you have got to do something. You understand that things just can't carry on as they have been doing; that the status quo just won't do anymore. Of course, nothing had changed really. I'd lived with the AIDS virus for eleven years. Eleven years of knowing that one day it would all start up. My immune system would fold, and I would die. I knew all that in my head, but after the first panicked realization that I was infected, you learn to live with it. You learn to forget. At least, while you can never really forget, you learn to push it to the back of your mind. I was one of the lucky ones. I'd been able to handle most of the drugs, although the last cocktail had been too much and had left me so sick and so weak that we decided that we would have to go back to my earlier treatment. That should have been the warning bell, but once I was back on my old medication I was feeling well and I blocked it out. Refused to think about it. You can't refuse to think about pneumonia though. I tried to tell myself that everyone gets pneumonia. Its common, I said to myself, it doesn't mean anything. However, not everyone ends up in hospital with it. There is a lot of pneumonia about. But PCP is rare, unless you have HIV.

John sat reading through the file. It was the first time we had met since I had come out of the hospital. He was a good family doctor and I'd been with him since Gordon and I met. In fact it was Gordon who suggested his name to me. John had a lot of patients in the gay community, and that meant he had seen a lot of patients with AIDS. I wanted to believe he would understand, but part of me said, how could he? Did he know what it was like to live with this thing, to have to tell your partner that you have this thing, to wonder what is going to happen next. Gordon and I never spoke about how I became infected. It was like some unwritten rule. We somehow both sensed it would make things harder, and anyway, what was the point. It was too late now. Both Gordon and John had been great when I was first diagnosed. At that time I had felt an overwhelming wave of panic. It seemed as if my life was over and I just wanted to lie down with my face to the wall. Gordon and I had met the year previously, and quickly realized that this wasn't just going to be one of those brief volatile relationships that would end all too quickly. I felt as if my life were taking on a new shape that I really liked. Then came the diagnosis. For days afterwards I would lie there wondering if I would see my next birthday, whether I would get to make the trip I had planned. What would happen to my career? Could I complete my work? The first couple of weeks I felt numb. But gradually it passed. The sun still came up every morning. With encouragement from Gordon, I carried on working. We still went out to eat and to movies, and

slowly I realized that I could cope. I started to enjoy life again. And as the years went by it began to seem like a bad nightmare and occasionally I'd find myself wondering if I'd dreamed it after all. Then would come time for my check up, and I knew I hadn't.

"Pardon?" I said, as I realized that John had been speaking.

"I said the blood count doesn't look too good. We are going to have to think again about medication. I see they've suggested..."

"What's the point?"

"Sorry?"

"It's OK. I'm sorry. Of course I want to stay healthy as long as I can. I don't want to go through that again."

"I understand"

"No you don't." Somehow I sounded more forceful than I'd intended. I regretted it. John was a good friend and I would need his support through my illness, and for what I wanted to do. "Look, I'm sorry. I know you care, but I don't see how you can understand. I don't see how anyone can understand who doesn't live with this day after day."

Folding his hands on the desk in front of him he hesitated before saying, "Does Gordon understand?"

I was silent. "Of course," continued John, "In a sense he does live with this every day doesn't he?"

"Its not the same." I said.

"No," said John firmly, "but is it easier or harder or just difficult in a different way?"

"He's not going to die."

Again John hesitated, as if choosing his words carefully. "He's not infected," he said, "but he still cares for you. He knows that he'll probably loose you, and the knows that before that he will have to care for you."

"I won't need caring for. I don't want to be cared for, not like that."

John raised his eyebrows and waited for me to carry on.

"I don't want to wait 'till I am that sick. You know what they say," I said with a ghastly attempt at humour, "Live fast, die young, and leave a good looking corpse."

John just waited. Obviously he could see that I had things to say and decided to give me the time to say whatever I needed to. I felt uncomfortable, but at least he wasn't moralizing.

"I don't want to waste away. I've seen what this disease does to you. You know as well as I do what it's like. I don't intend to end up dependent on everyone around me, not even able to control my own bowels. What a joke! Gordon always calls me retentive. Well I'd like to stay that



way, if you don't mind." After hesitating I decided to go on. "Look, I need your help." John shrugged and looked at me waiting for me to carry on. "I don't want to end up a vegetable. I need to be able to end it when it's clear that I'm just getting too sick. Suicide is legal. You know that. I would just like to have enough of something that I could take when I need to; when I need not to wake up again. Do you understand?"

"Do you?" he asked. "Suicide may be legal, but assisting it isn't, is it? You see the point isn't just your suicide, if that's what you choose to do. It's how you involve and implicate everyone else around you."

"What do you mean?"

Again he hesitated before replying. "How do you think Gordon would feel knowing that you would rather die than be cared for by him?"

Here it comes, I thought, here comes the moral big stick. "So your saying that I shouldn't do what I think is right for myself because it might hurt other people. You're saying that it is fine to stay alive, in excruciating pain, to waste away, so long as I don't hurt anybody. Am I supposed to suffer so I don't hurt your feelings?"

"No, it's your relationships I don't want to hurt. After all what else can you leave behind." He paused before continuing. "What I'm saying is that I don't think you've thought this through. I think you are in shock because your illness has entered a new phase, and you need time and support to come to terms with that like you needed time and support when you found you had HIV."

"But what you think is not what I have to live with."

"Of course, your point of view has to be the most important one in this situation, but it doesn't have to be the only one. What about Gordon? What about what he thinks? Do you understand the implications of what you are asking; for me? But most importantly for Gordon? Whatever you say he has lived with this too you know. Doesn't he deserve some input here?"

"I just don't want to become dependent."

"That's one way of looking at this. Maybe Gordon would see it as an opportunity to show he cares, however sick you become."

I wasn't convinced and I imagine it showed.

"Look," he said, "all I am trying to say at the moment is that you need to take time to think and to talk it over with him. If you decide to overdose, what will it feel like for him? And if you don't he will be your primary caregiver through this, and whatever you do he'll be your primary mourner."

"I feel trapped." I said as much to myself as to John.

“I’m sorry. Life is pretty messy sometimes. When life gets messy we all want to find ways to try and stay in control somehow. I think I understand that. But death with dignity isn’t just about control. Its about being supported by our friends and surrounded by those we care for and being able to sustain the relationships that really matter to us. Even if you do decide to end your life at your own time there are still things you are going to need to say in the end to those who care about you. Why don’t you think about including them while you make your decisions at the beginning?”

