

EUTHANASIA

Principles and Observations from a Christian Perspective

*This paper was submitted to **The Special Senate Committee On Euthanasia and Assisted Suicide**. It was written by Dr. Sheila Rutledge Harding and Dr. John Patrick, on behalf of the **Christian Medical and Dental Society of Canada**.*

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Euthanasia, Mercy Killing and Assisted Suicide.

Preamble: Christian Presuppositions

The Christian Medical and Dental Society represents over 1000 practitioners in Canada. The essential premises of their position on euthanasia are these six beliefs:

1. We are all created by God and are not to be understood solely as the products of random processes.
2. We are therefore responsible to God for our actions.
3. The time of the giving of life and the termination of life should be God's prerogative and not ours.

4. Death is not the end because we have eternal souls.
5. Suffering should always evoke compassionate care and euthanasia should not be used as a way out.
6. Those who suffer are important members of society who should be affirmed. We believe that the courageous bearing of suffering has the utmost moral and social benefit to society and the recognition by society of that contribution affirms the individual. (Recall the impact of Terry Fox on Canadian life.)

We do not propose to *prove* these statements since proof is always futile in matters so general. Instead we endorse them because of the conception of human life they uphold.

Listen to how Dietrich Bonhoeffer puts it, a man who saw more suffering than most of us will ever see:

"In the sight of God there is no life that is not valued, that is not worth living; for life itself is valued by God. The beggar, Lazarus, a leper, lay by the rich man's gate and the dogs licked his sores; he was devoid of any social usefulness; yet God held him to be worthy of eternal life. And where, if not in God, should lie the criterion for the ultimate value of a life?"

*We cannot ignore the fact that the supposedly worthless life of the incurable evokes from the healthy the very highest measure of self sacrifice and even genuine heroism; this devoted service which is rendered by sound life to sick life has given rise to real values which are of the highest utility to the community."*¹

We accept that these statements are all beliefs which are open to neither proof nor disproof, but we respectfully assert that the contrary positions are also beliefs, acts of faith, that can neither be proved nor disproved. Each of the beliefs listed in this preamble is not opposed by a neutral, rational position but by an alternative faith statement. For example, in the first instance, the alternative belief is that we are not created by God but are the product of some unknown processes that can only be described in terms of chance. Neither statement is open to incontrovertible proof. Nobody has a monopoly on rationality in this debate.

1 Bonhoeffer d. Ethics SCM Press, London, pp 138-9

The Abuse of Language

"Words mean what I choose them to mean." (Humpty Dumpty)

Although euthanasia is commonly understood to be the epitome of mercy and the logical extension of "death with dignity", the legalization of euthanasia should be expected to lead to forms of killing which have no necessary connection with either mercy or dignity. Would euthanasia, once legalized, remain the rare event it has been up to the present? We think not. Consider what has happened with abortion. The fundamental act described blankly by the word abortion has been obscured by arguments about rights and freedoms. Legalization of abortion was also originally proposed to be merely the process of legalizing what was already happening; i.e., abortion for the rare pregnancies arising from rape and the occasional situation in which there was judged to be a real risk to the mother's health. It has become the most frequent medical procedure in Canada. The numerical result of legalization of abortion world-wide is 50 million procedures a year.

In discussions of euthanasia, the term "death with dignity" is particularly unfortunate because it creates a false dichotomy which appears to be intended to persuade rather than to inform. The alternative to death with dignity through mercy killing or assisted suicide, is not, as implied, death with indignity. The vast majority of deaths fit in neither category; they are dignified, often courageous and without any involvement in killing by caregivers. The obfuscation of language in this debate is one of the most pernicious aspects of the whole process. Only if the proponents of euthanasia and their antagonists agree to use language to communicate truthfully and to call things by their proper names, can the debate be honest.

The Tradition of Medicine

"Honour your profession and its traditions." (The Canadian Medical Association Code of Ethics)

The beliefs which we have set out have united Christians through the centuries. They are not fringe positions but, on the contrary, they have formed the ethos in which what we now know as medicine first took root. Medicine began with compassion, not with effective treatment. Doctors have traditionally taken, as the first duties of medicine, to do no harm and not to kill. This was true of Hippocrates as well as Christian physicians. The famous French aphorism, to cure sometimes, to relieve often and to comfort always, is still a description that most patients would approve. It is a denial of the noble tradition of medicine for doctors to become the bringers of death.

"The anthropologist Margaret Mead recognized this. For the first time in our tradition there was a complete separation between killing and curing. Throughout the primitive world the doctor and the sorcerer tended to be the same person. He with power to kill had power to cure, including specially the undoing of his own killing activities. . . . With the Greeks, the distinction was made clear. One profession, the followers of Asclepius, were to be dedicated completely to life under all circumstances, regardless of rank, age, or intellect □ the life of a slave, the life of the Emperor, the life of a foreign man, the life of a defective child. . . [T]his is a priceless possession which we cannot afford to tarnish, but society always is attempting to make the physician into a killer - to kill the defective

child at birth, to leave the sleeping pills beside the bed of the cancer patient. . . . [I]t is the duty of society to protect the physician from such requests." 1

The fact that doctors have, on occasion, been guilty of prolonging dying rather than promoting life is not justification for euthanasia but reason to amend the errors of meddling medicine. The hospice movement commenced by Dr. Cicely Saunders (a member of our sister organization in England) is precisely aimed at more appropriate and compassionate care. It is worth noting that it is not physicians with long experience of palliative care who are leading the movement to allow mercy killing and assisted suicide, but rather pathologists and physicians from the technological end of the medical profession. These physicians are the most vulnerable to the danger of treating a person as an object.

All physicians accept that patients have the right to refuse treatment, a right which has been established in Canadian law since 1935. Better communication of these rights, with clearer descriptions of the likely outcome of treatment to enable informed decision-making, would undoubtedly defuse much of the public's fear of meddling medicine. The current wide and naive acceptance of the proposition - either you die in writhing agony or you vote for euthanasia - is in our view a failure of communication. The first motive of the doctor should be to comfort and relieve. It is extremely rare for it to be impossible to treat pain and comfort the patient. Mercy killing and assisted suicide are not the appropriate responses to painful deaths; better and more accessible palliative care is.

Euthanasia as Departure from the Tradition of Medicine

We submit that within the tradition of medicine it is unethical to give or withhold treatment solely for the purpose of causing death. If euthanasia is legalized there will be immediate pressure for doctors to be the agents of euthanasia when it is requested, be it directly or in the form of a living will. It should be noted that the Dutch Minister of Health has already said that she would like to revoke the licence of any physician who refuses to kill a patient when asked. Subsequently, there will be pressure to perform euthanasia without rigorous requirements for repeated requests, second opinions, terminal illnesses, and so on. The covenantal relationship between patients and physicians - to be with them in affirming life - which is at the heart of medicine would be destroyed. It is essential that the physician's responsibility be only to the patient, as an individual, within a life-affirming covenant.

When Hippocrates first started to practise medicine under the commitment to the oath which bears his name, he represented a small fringe group who were considered foolish because they were giving up an important source of income. Nevertheless, the public soon recognized that theirs was a better way and they forced the rest of the profession to follow suit.

2 Mead M. quoted in Marker R et al. Euthanasia: a historical overview. Maryland J Contemporary Legal Issues. 1991;2:257-298.

Earlier Death as a Consequence of the Treatment of Pain

Death as a side effect of treatment is not euthanasia. There is a valid, non-casuistic distinction between death occurring earlier as a consequence of drugs given for the relief of pain and death caused by those same drugs given in lethal doses with the intention to kill. The critical self-assessment required of the physician is to answer the question, "If I had another drug which would relieve the pain and not shorten the life, would I use it?"

The arguments which seek to blur this distinction should be resisted purely on the grounds of intellectual honesty. The law has a long and honourable record of careful interpretation of language. This honourable record will be destroyed if the verbal sleight of language is allowed which falsely equates euthanasia with a primary commitment to comfort. Motive has always been an important consideration in our legal system.

Responses to the Consequences of the Technological Capabilities of Modern Medicine

The ethical dilemmas posed by our increasing technological capacity to prolong life in the face of imminent death should not be solved by the legalization of killing. To prolong the dying process is usually unethical and this certainly needs more emphasis. Patients do need help to formulate their beliefs and to work out what they should do in navigating the complexities of modern medicine. When a treatment extends life from two months to three months at the cost of two months in hospital, many patients would take the two months at home, if the options were appropriately explained. Such a choice is quite ethical. Much more research is needed on how patients receive information and make decisions. Hospitals are not ideal learning environments and rules of informed consent do not adequately serve patients at present. We need to learn more about which choices bring about the best outcomes for which patients, and for those they love. Medical students need much more instruction in this area.

We, as a society, need desperately to come to terms with our own mortality so that we can make appropriate choices about how we will die. It is now a common medical practice to manage death so that it creeps up, almost unnoticed, rather than confronting us with the questions it poses about the meaning of our lives. Once these fundamental questions of meaning are addressed we can expect a change in the way we end our lives and in the way we honour lives which were lived well up to their natural exit. The dying process can be the most important and poignant period of life, the time when everything begins to make sense. To take away this consummation during the initial periods of anger and disbelief is a real disservice to both the dying person and those who remain.

In particular, decisions about the treatment of the terminal phase of life for patients no longer able to make their own decisions requires the involvement of other people, usually the patient's family. Any government appointed representative is not likely to be sufficiently sensitive to the implications of the patient's world view (vide infra). Legalization of assisted suicide could allow a physician to neglect the whole tenor of the patient's previous life, without any fear of legal consequences. The administrative pressures to quickly ease patients out of life will be immense.

Respect for Autonomy,

Over the past three decades, there has been a steadily increasing emphasis on the autonomy of the patient as a guiding ethical principle for the practice of medicine. Autonomy is understood as self-determination, the concept is of rights, in particular the right implicit in the well-known saying, "Whose life is it, anyway?" As Christians, we are content with the language of autonomy in so far as it reflects the unique individuality of each human being, created in the image of God, and ultimately accountable to Him.

But we find it perplexing that patient autonomy should be one of the main arguments advanced in favour of voluntary euthanasia. Autonomy is not just about choice, but about choice that is fully-informed, rational, and freely made. Could a sick and frightened patient near the end of life truly be in a position to make such a choice? Depression, confusion, unrelieved physical symptoms, a sense of being a burden, and conscious or unconscious pressures from family, friends, caregivers or society could all invalidate the choice as being autonomous. We are convinced that one or more of these factors would be operating in the vast majority of requests for euthanasia. Our respect for autonomy means that we therefore oppose euthanasia.

Unlike suicide, euthanasia is not a private act. For the patient's autonomy to be exercised, another's autonomy must be affected. It is argued that conscience clauses would protect doctors with objections, but the evidence from The Netherlands suggests otherwise. We are concerned that permissive legislation might drive from certain specialties the very doctors who otherwise ought to be there, as permissive abortion legislation has done in Obstetrics and Gynecology. We are also concerned about the effect on the character of the healer who becomes, however rarely and with whatever good intentions, the killer.

Despite these objections, we accept that there would be a very small percentage of requests for euthanasia which were deliberated choices, which did genuinely reflect autonomy. Why should the law not be changed to accommodate these people? The answer lies in the nature of our inter-relationships in society. For the law to be changed to permit Mr. A. to exercise his carefully deliberated right to be killed, society would have to move away from a situation of absolute protection of all patients into the uncertain area of value judgements, which are relative in nature. These would inevitably be arbitrary and inherently unjust to some. Mr. A.'s responsibility to society, then, would be to forgo his right to euthanasia.

The evidence from The Netherlands makes it clear that where voluntary euthanasia is tolerated, euthanasia which is not voluntary will follow. This is clearly not an illustration of respect for autonomy, but the worst possible example of paternalism, where the physician decides that someone else's life is not worth living. Hence, we believe that respect for autonomy is an argument against euthanasia.

3 Submission from the Christian Medical Fellowship to the Select Committee of the House of Lords on Medical Ethics. Journal of the Christian Medical Fellowship. 1994;40:52-64. (Adapted with permission.)

Palliative Care

Good palliative care can relieve most suffering. It also provides people with assured support in their final illness. It is often fear of being alone which is overwhelming in the face of imminent death. The laments that are part of the vocabulary of the dying should not be taken as requests for assisted suicide or mercy killing. They are more often requests by the dying for affirmation of the value of their lives from those they love, who are suffering with them. In the past, the greatest fear of death was dying unshriven, without a final confession of one's sins. Even today, it is clear that a slower death that allows time for reconciliation and leave-taking is demonstrably better for those left behind. Thus, we should expect that, as clinical experience with euthanasia grows, there will emerge late untoward effects amongst those who will have to live with the memory of their part in the premature deaths of others. It should be noted that the descriptions of dying from ALS which have appeared in the press in relation to the Rodriguez case were not those of a "normal" ALS death and said nothing about the normal poignancy of natural death.

Palliative care also addresses the much discussed high cost of dying, because most of that cost is due to high technology attempts at definitive treatment which palliative care avoids.

The Effects of World View

I. Multiculturalism and Pluralism

The consequences for our dying of our general understanding of the meaning and purpose of life are insufficiently understood in Canada. We are so used to the idea that we are part of a multicultural and pluralist society that we do not define what this can and cannot mean. We are rightly proud of the way we have accepted into Canada people from many ethnic and cultural backgrounds. Tolerance of diversity, of difference, of varieties of insight is important for the success of the Canadian experiment. However, this cannot mean □ as so many seem to believe □ that all views about good and evil are equally valid. Some are contradictory. Only a moment's consideration is necessary to realize that we could not accept the Ayatollah Khomeini's understanding of how a state should be run as equally valid with the western tradition that forms the foundation of Canada. Our concept of individual freedom and his are irreconcilable. Some views are incompatible with who we are. Neither is it possible to be neutral in these issues. To take a modern example, we do not allow female circumcision in Canada despite the cultural importance of this rite to some immigrants. In practice, we simply say our way is right.

Multiculturalism and pluralism, then, refer to the acceptance, in terms of private belief, of other ways of understanding the world. They do not allow any public credibility to moral judgements that conflict with traditional western liberalism. But over the last few centuries the idea of liberalism has changed; the initial idea of rights as "blameless liberties" has been subtly refashioned to a rampant promotion of individual liberty regardless of others. Many political choices □ abortion on demand until birth, public funding of abortion, "homosexual rights", capital punishment □ do not have public majority mandates. The legislature must not treat the public with contempt. In these important moral issues, of which euthanasia is the current example, it is necessary to consider the cultural state of Canada if we are to

be worthy of the adjective democratic.

The current cultural ethos of Canada is well set out by the 1992 census data from Statistics Canada (see Appendix 2). The people providing this data almost certainly did so by default; that is, they decided what they were not, and found themselves by default in the Catholic, Protestant or No Belief categories. None of the other categories is more than two percent. What these data indicate is the cultural story which will be evoked by fundamental moral questions and which must be the context to any legislation if the law is to regain respect.

2. Cultural Echoes in Canada Relevant to the Discussion of Euthanasia.

To see fulfillment in the mere satisfaction of basically animal desires for food, sex, and physical comfort for oneself or one's family is unworthy of the story of Canada. We have a long tradition of fulfillment of unwritten obligations to society. We have always recognized that suffering nobly borne civilizes our society. We have only to look at the way service clubs and people generally are lifted above their usual levels of altruism by the needs of suffering children to be convinced of this.

For the Christian ethos, which is still the dominant informative story in Canada, self-sacrificing love is the central motif. Nothing should be done for our personal comfort that even potentially threatens the lives of others. The rights desired by those who want to legalize euthanasia would soon become unwanted duties for many others, whose very lives would be at risk in a society that has accepted the attitude that there is such a thing as a life not worthy to be lived.

The Limitations of Legal Constraints

The most common response to the scenario we have envisaged is that we are scare mongering. There is ample evidence that this is not the case. The Dutch experience has shown that the law is not enforceable. Dr. Karl Gunning was able to show that within a few months of their formal adoption, the guidelines were being systematically breached with impunity. It is readily apparent that prosecution of those doctors who breach the guidelines would simply lead their colleagues to stop reporting cases of euthanasia deaths. These guidelines □ that the patient must be suffering from a terminal illness, that the request must be free and explicit, that the request must be durable, that a second opinion must be sought □ have all been broken. Tacit permission has thus been given to kill disabled infants, to include the demented by proxy, to euthanize the depressed, and to kill someone with metastatic cancer without consent. Under these circumstances, are we going to be insufferably arrogant and maintain that we will do better than the Dutch who, after all once resisted Hitler so courageously?

Conclusion

Sadly, we live in a fractured society that no longer possesses an agreed moral consensus. For those who believe that they cease to exist at death, life and suffering are ultimately absurd, and asserting even derisory power over death offers some sense of power. Dylan Thomas expressed the sentiment well:

*Do not go gentle into that good night,
Old age should burn and rave at the close of day,
Rage, rage against the dying of the light.* ¹

In contrast, those who share the convictions of St. Paul,

"I know whom I have believed, and am convinced that he is able to guard what I have entrusted to him for that day." ⁴

will certainly wish to trust God in their final exit from this life. They do not believe that life is ultimately absurd and that suffering has no function. There can be no easy intellectual rapprochement between these two views.

If victory were to go against those who share the view expressed in this paper, it seems certain to us that certain logical but ethically abhorrent consequences would inevitably impose themselves on the old, the helpless, the disabled, as is already happening in Holland. It would be naive to deny this. It would also be naive not to recognize the pressures that will bear down on physicians, surgeons, nurses and administrators should euthanasia become a right enshrined in law. Let no-one imagine that it will be applied with clinical detachment; history, at least, teaches us that. This is no route to a kinder, gentler Canada. The recent reports from Holland ⁵ indicate that, with increasing acceptance of mercy killing and assisted suicide, attention to and treatment of pain are diminishing, and up to 25 percent of people dying by mercy killing do so without giving consent. Although the right to end their lives at will is logical for those who believe there is no God, our plea must be that the fulfillment of such requests has no place within medicine.

4 The Bible. 2 Timothy 1:12.

5 Gunning KF. Lancet, Nov 2, 1991 and to the Special Senate Committee on Mercy killing and Assisted Suicide.

We would like to conclude with the words of Albert Camus, not because he shared the general philosophical position espoused in this paper, but because, as a non-Christian, he clearly saw the value of a Christian ethical constraint upon some of the more problematical impulses of modernity. He wrote:

"The world expects of Christians that they will raise their voices so loudly and clearly and so formulate their protest that not even the simplest man can have the slightest doubt about what they are saying. Further, the world expects of Christians that they themselves will eschew all fuzzy abstractions and plant themselves firmly in front of the bloody face of history. We stand in need of folk who have determined to speak directly and unmistakably and come what may, to stand by what they have said."

Camus also said in his Nobel Prize acceptance speech that he wanted "...to fashion an art of living in times of catastrophe, to be reborn by openly fighting against the death instinct at work in our society." ⁶

It is our hope that we have gone some way towards being the kind of Christians that Camus said the world needs, at least in the sense of leaving nobody with the slightest doubt about what we mean. If euthanasia is legalized and made a responsibility of physicians, Canada will be on the way to being a country where physicians of integrity, who represent the direct descendents of the honourable story of medicine, will have to struggle to maintain their right to practice and where patients will have to ask for care to avoid death.

APPENDIX I:

ILLUSTRATIVE STORIES FROM THE PRACTICE OF DR. SHEILA RUTLEDGE HARDING.

These cases are true stories of real people who have confronted life-threatening illnesses. They have been chosen to illustrate how vulnerable such people may be, and how complex the issues and interpersonal interactions may be in these circumstances. The first three have been in my care. The fourth taught me what care really means. The fifth continues to be in my care.

⁶ Camus A. Nobel Prize Acceptance Speech.

I. Mrs. S. T.

Mrs. T. was a woman in her sixties, married, with three grown children. She had multiple myeloma and had been in the care of one of my colleagues for several months. She had been in hospital frequently with complications of her disease and its treatment. She had bone lesions, but her pain was well controlled with oral narcotic.

I became involved in Mrs. T's story while my colleague was away. She was admitted to hospital with pneumonia. She was recovering uneventfully and looking forward to going home, when her discharge was delayed by a severe nosebleed, requiring blood transfusion support and a very uncomfortable posterior nasal pack to control the bleeding. This relatively minor event was the "last straw" for Mrs. T. She announced that she wanted no further treatment, that she wanted the pack removed immediately, and that she was going home "come what may."

Mrs. T. and I had our first of several long talks that day. I promised that I would do all I could to get her home safely and soon. She agreed to leave the pack in for 24 hours. Over the next two days, she was able to clarify what she did and did not want for herself. A meeting was arranged with the patient, her family and the palliative care team. Agreement was reached on the details of palliative home care with guidelines for symptom management without more aggressive interventions. A discharge date was set. Mrs. T. was at ease and apparently content with the decisions she had made, was looking forward to getting home, and was planning to stay at home "come what may."

As the meeting adjourned and the patient was assisted back to her room, I was approached by Mrs. T.'s daughters. Her husband was with them, but a few steps back and silent during the subsequent conversation. The daughters said, "Mom has had enough. She has suffered enough. She doesn't want active treatment. She's ready to die. Let's get it over with. She's already getting high doses of morphine. Surely you could do her the favour of making it a big enough dose to ensure that she sleeps soundly and comfortably, and doesn't wake up to the troubles of this world again. Please?" I explained as gently as I could that I would not intentionally cause the death of this woman. I agreed that the situation was hard on everybody, and I postulated that they feared her return home more than she did. I suggested that perhaps it was the family, rather than the patient, who had had enough. I encouraged them to take advantage of the support and expertise of the palliative care team members. I promised that I would try very hard to respect the patient's instructions for her own ongoing care.

The patient was discharged as planned, my colleague returned to town, and I heard nothing further about Mrs. T. for about 6 months. One day, in the hospital parking lot, one of her daughters called out and ran over to intercept me. She expressed her gratitude that I had denied their request to "get it over with". She said that her mom had had a peaceful, contented few months at home, that the palliative care team had been very helpful, that the family had appreciated the time spent with mom at home, and that much healing had taken place in the family relationships. The patient died peacefully and without "assistance".

This is the only time I have been asked to kill a patient. I've never had a patient make the request directly. Is it because I'm not approachable? Is it because they know what the answer would be, so they don't ask? Or is it because they trust me to continue to care for them through their dying?

2. Mrs. L. P.

L. was a 32 year old married woman with two young children. She was being treated for acute myeloid leukemia. Complete remission had been attained following one course of chemotherapy. The first course of consolidation chemotherapy had been relatively uneventful. The second and final course of chemotherapy was given. Three weeks later, just as bone marrow recovery was anticipated, she became infected and developed adult respiratory distress syndrome, requiring ventilator support.

Over the next two weeks, the staff of the Intensive Care Unit predicted imminent death on a daily basis, based on published predictors of survival in such situations. Mr. P. was angered by this and eventually refused to speak directly with ICU physicians, choosing to communicate through me instead: "When you tell me it's time to quit, I'll believe it." Mr. P. and I recalled for each other the discussion I'd had with L. and him about the rationale for consolidation chemotherapy and the associated risks, including a ten percent risk of death from chemotherapy complications. L.'s response had been, "I want you to do whatever it takes to beat this thing, and I'll do whatever it takes to get through it."

Over the next two weeks, L. remained ventilator-dependent with multi-organ dysfunction. She was on five antibiotics and numerous other drugs, including sedatives and narcotics. Her bone marrow had recovered and her blood counts were adequate. Whenever sedation was withheld, L. tried to remove her endotracheal tube. She wrote strong pleas onto a notepad, asking that the ventilator support be stopped, that she be left alone and allowed to die.

Mr. P. and I agreed between ourselves that her original decision should take precedence over requests made in the midst of such circumstances. I communicated this on his behalf to the ICU staff. Several physicians, nurses and one social worker accused me of supporting Mr. P. in his denial of reality and spoke heatedly of L.'s right to autonomy and refusal of treatment. They then approached Mr. P. directly and tried to persuade him that they should accede to her requests. He refused. I supported his refusal and, thankfully, they left it at that. From that point on, however, Mr. P. questioned every change in management, to be sure that it was not withdrawal of support in disguise.

L. was successfully weaned from ventilation 28 days after her initial intubation. She left the ICU five days later and has not returned. Almost five years later, she remains in remission. She has no clear memory of her time in ICU and does not recall her repeated requests to have the endotracheal tube removed or to be allowed to die. She is shocked to think that anyone might have acted on those requests, rather than recognizing them as expressions of fear and frustration.

I believe that had either Mr. P. or I been less than dogmatic that all efforts be made to support her, L. would have died in the ICU. The death certificate would have stated the cause of death as complications of acute leukemia. "Self-fulfilling prophecy" would have been equally true.

3. Mr. K. R.

K. was a 27 year old married man with one young daughter. Mrs. R. was quiet and quite shy. Mr. R. Sr. was a loud and intimidating man. The first time Mr. R. Sr. called me for information, I explained that I would ask K.'s permission to talk about him with his father. K. said that he did not want me to discuss his situation with any family members other than K. himself, or his wife. He asked that I refer any family questions back to him.

K. had come into my care because of amegakaryocytic thrombocytopenia. It had been refractory to all available treatments, but he hadn't had any life-threatening bleeding episodes. Two years later, he developed new symptoms and signs, leading to a diagnosis of Hodgkin's Disease. His marrow worsened to full-blown aplastic anemia. The only reasonable treatment for both disorders was bone marrow transplant, and that was done.

K. had persistent marrow failure post-transplant. He was transfusion dependent and often septic. Many conventional therapeutic approaches were tried. All failed. We discussed some experimental therapies that had been suggested by the Transplant Centre, and K. was considering whether he wanted to give them a try.

Several weeks after K.'s return from the Transplant Centre, Mr. R. Sr. and K.'s brother came to my office and demanded to see me, angry that I would not provide medical information concerning K. directly to them. They were not willing to approach Mr. and Mrs. R. Jr. directly. They told me that I was being too aggressive, that I was being dishonest with K. and giving him false hope, that I should withdraw supportive treatment and "let him go in peace."

Although we had talked about such things often, I again approached K., made sure he understood that we had only long-shot options left, with little chance of success. He said that he knew I was being pressured by his family to back off, that he knew they were ready to throw in the towel. "If they knew for sure when I was going to kick it, then they could plan their lives. This is all very inconvenient for them." He then said that he himself wasn't ready to quit, because his wife hadn't yet come to grips with things, and he didn't want her to be left thinking that he had chosen to "bail out on her." He added that any time spent with his daughter, even in a hospital room, was time well spent. He acknowledged that, should ICU care be necessary for his survival, he didn't want it and his wife had accepted that. When I suggested it might be helpful to sit down with the extended family to try to help them understand K.'s point of view, he declined. He commented, "Dad has never been too concerned to see things from my point of view."

Active treatment was continued on the ward. K. died of sepsis a short time later. His wife expressed her gratitude for my efforts on their behalf. She is currently a student in an affiliated faculty, and she continues to greet me openly and courteously.

Mr. R. Sr. and K.'s brother were not so grateful. They wrote scathing letters of complaint to the hospital administration concerning the care I had provided for this man. It was a situation in which it would have been much easier for me had I adhered to the family's wishes rather than the patient's wishes. It's already hard enough to protect the patient's interests on occasion, without the legalization of euthanasia.

4. Dr. Stuart Rutledge

Dr. Rutledge was my father. He died in 1990 at the age of 67 of breast cancer. For several weeks before he died, he was completely bedridden and suffering, by anyone's definition, from the myriad manifestations of widespread malignancy. I lamented to a close friend, "I don't understand why he's still here! He's ready to die, Mom's ready to let go, I've sure had enough. Where is the meaning in this? Where is God in this? What's the point?"

My friend is wise. She comforted me, then gently suggested that I widen my field of view a bit. She said, "Look for the other people in the picture. Look to see what God might be doing in their lives, through your Dad's life. You might be surprised." She was right. The following is a brief inventory of some important things that happened during the last month of Dad's life. Who's to say what other important things took place that I know nothing about?:

- × My oldest brother, the son who had always gone his own way, was able finally to sit with Dad, to say and to hear many of the things that had been left unsaid or unheard over the years.
- × Dad's sister, also battling breast cancer, had been unable to bring herself to visit him because she feared seeing a glimpse of what was to come. In that last month, she was able to overcome her own fears, and they spent many contented hours together.
- × Mom, a nurse who for many months had felt unable to help this man who had been so dear to her for over 60 years, found opportunity to use her skills for his benefit in a way that validated her and comforted him.
- × Mrs. G. is one of Mom's neighbours. Mom had helped her to care for Mr. G. when he was dying. During Dad's last few weeks, Mrs. G. was able to help Mom in return. In so doing, the two women forged a bond of friendship that has continued to be an important support for both of them.
- × Dad's grandchildren had enough time to really understand how sick their Bampa was, and to recognize that he wasn't going to get better. When he died, their grief was tempered by the reassurance that he was now relieved of his suffering

Dad had an easier way out. His disease had caused pituitary failure. Had he refused his steroid supplements, death would have come quickly and quietly. Because he chose to live until death came to him, many other lives were strengthened and enriched.

5. Ross Harding

Ross is my 8 year old son. He has Menkes' Disease, an inborn error of copper metabolism. The books still describe it as a disorder "uniformly fatal in infancy." However, the first successfully treated boy with this disease is currently 18 years old. We understand that there may now be as many as a dozen survivors world-wide. The treatment, a daily subcutaneous injection of copper histidinate, prevents the neurologic toxicity that usually kills these boys in infancy. They continue to have problems related to defective connective tissues. The long-term prognosis is unknown.

Ross has been in hospital more than twenty times. He has had ten surgical procedures. The most recent was the emergency reconstruction of his bladder after the rupture of a diverticulum through the peritoneal membrane into the peritoneum, filling it with infected urine and precipitating septic shock. He knows about severe, acute pain. He also knows about chronic pain due to lax ligaments and recurring joint dislocations.

Ross was three weeks old when the diagnosis was recognized. There were many who advised us to refuse treatment, to let nature take its course. On many occasions we have been asked if we wanted a particular complication treated at all. At least three times we have overheard a new pediatric trainee, who has read about Menkes' Disease but is unfamiliar with Ross, questioning the appropriateness of aggressive treatment of a child "who is going to be dead soon anyway."

Although in many respects Ross is a child with disability, he is also bright and verbal, with a keen sense of humour. That is his protection in this world that often denies the value of a life made difficult by disability, particularly if communication is difficult. However, when very sick, Ross has been known to say such things as, "I'm really going to like living in heaven!" It scares us to think how such a statement might be interpreted and acted upon by a well-meaning but misguided person in a medical milieu that tolerates death by choice.

The details of Tracy Latimer's death have been repeated many times in the news recently. Ross has been paying very careful attention. He knows that he is perceived as disabled, and doesn't hesitate to acknowledge his limitations. He has been talking about what he and Tracy had in common, and about what he is able to do that she could not. One of the most significant differences is that Ross can communicate clearly. At breakfast recently, with the news in the background recounting Tracy's story yet again, Ross said, "You know, Mom, the next time I get sick, no matter how much it hurts, you don't have to kill me, OK? Because I can handle it." We reassured him that, no matter what, we would not kill him. It makes me suddenly sad for every person with disability who has been listening to the details of this case and cannot, for whatever reason, receive the same reassurance.