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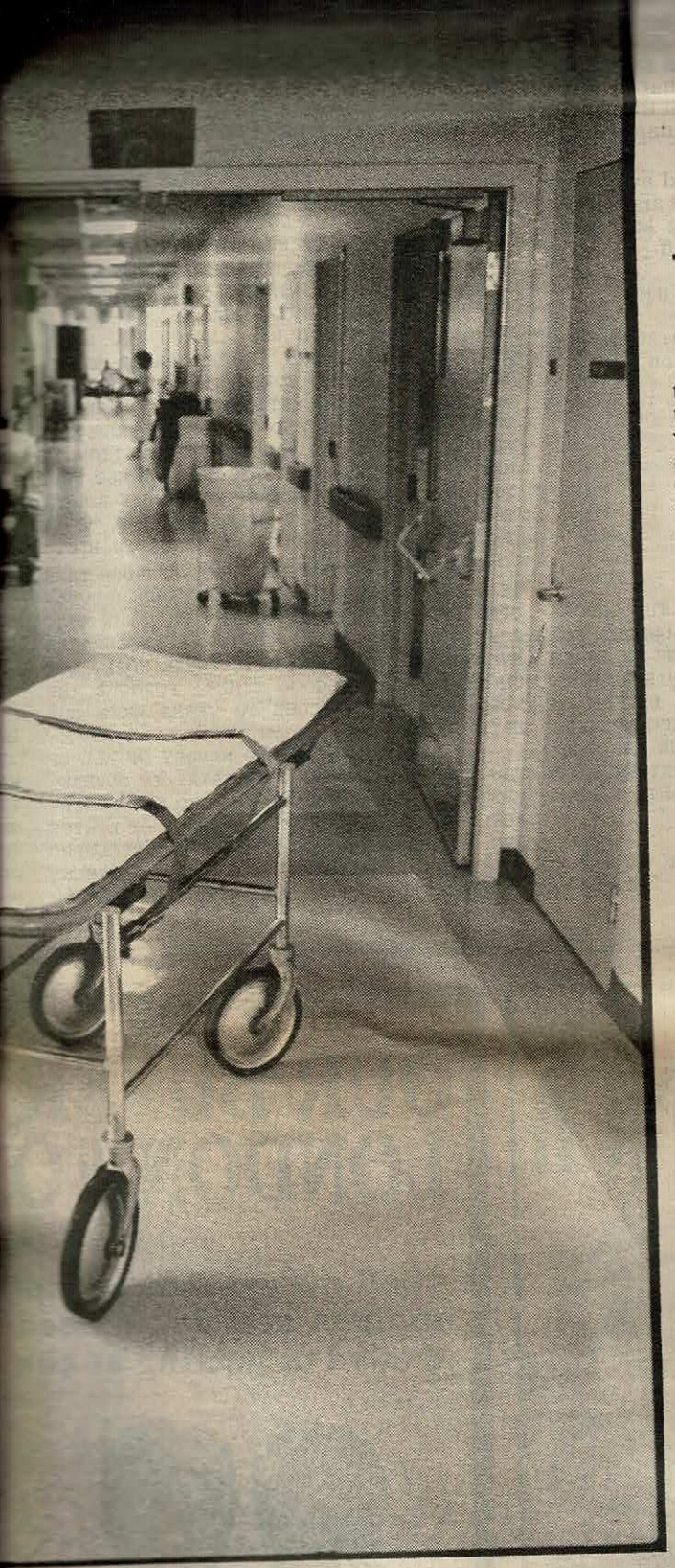
15 YEARS

Monday

MAGAZINE

END OF THE ROAD

Life is our most precious gift. But some people, in desperate medical condition, would prefer to die. Should they have that right?



of the major moral and medical issues of the decade.

By JOHN HOFSESS

FIFTY-ONE years ago in Vancouver, a cheerfully confident groom vowed to his bride: "I, Charles Le Moir, take thee, Margaret, to be my wife...to honour and cherish..in sickness and in health...till death do us part." He was 38; originally a Maritimer of French descent. She was 31; their wedding day in May marked her birthday as well. Together they were transformed through a ritual in which he was not merely a fireman, nor she just a secretary, but a mythic man and woman enjoying the smiles of a summer night, the dance of life, and later, the purblind oblivion of flesh cleaving to flesh.

There is no commemorative photograph of Charles and Margaret on their *last* night together, 50 years later in Victoria; only smudged details of a long dark night of the soul. Sometime after midnight on Dec. 13, 1990, they bound themselves to one another with a belt around their chests, she sitting in his lap, and fell backwards through a window from the 14th floor of Charter House, a James Bay apartment building and their residence for 20 years. They died as they had lived: intertwined, together. Presumably because she could not help herself, Margaret screamed on the way down. The belt had slipped—noose-like around their necks.

Love story? Tragedy? Moral offence?

The judgment of many residents in the building was harsh and unforgiving. Charles had been respected by his neighbours (having served for 35 years with the Vancouver Fire Department); well-liked for his energetic charm. Their deaths however brought disgrace to the building according to other tenants. "We all felt we had been betrayed," said one. (The well-planned act included borrowing another tenant's apartment for the evening, because the Le Moirs' own apartment on the seventh floor was not considered high enough.) Only three people showed up at the Le Moir's Memorial Service.

"I'm sure it was Margaret who planned it," said one of their friends. "She was terrified of being alone." Charles had been operated on for cancer of the bladder. He had had heart bypass surgery. Now his eyes were failing and he suffered from debilitating headaches that eluded diagnosis. He was having severe problems with a malfunctioning ileostomic-device for the passing of urine (following the removal of his bladder) and —at 87—was facing another serious operation. Margaret, meanwhile, suffered intensely from osteoporosis. (My mother who had the same condition for 15 years said it was the worst pain she had ever experienced—as the vertebrae in her spine literally crumbled.) Neighbours said that Margaret was more reserved than Charles; "a real lady" always impeccably dressed and well-mannered. But "once she developed her back problem, Margaret became a different person," said one friend. "She rarely spoke to anyone." Moreover, at 80, she dwelt in the creeping darkness of narrow-angle glaucoma and feared the day she might be blind.

Once the Le Moirs had been a couple with wide-ranging interests; they took early retirement and toured the U.S. for four years in a mobile home. But now health problems became the focus of their existence. They were well off but money was of little consolation. They had no children. On one occasion when Margaret discussed with a friend the prospects of going into a certain Victoria nursing home that caters to a posh clientele, she said: "I'd rather die."

Clearly, Charles and Margaret Le Moir believed that life—for them—had run its course, not right down to the last excruciating

7 STEPS TO HEALTH

1. Choose to be a non-smoker.
2. Eat a well-balanced diet, low in fat and high in fibre that helps you maintain your ideal weight.
3. Have regular medical and dental check-ups.
4. Find out about any lump or sore that does not heal or any change in your normal state of health.
5. Protect yourself against too

Charter House, the Le Moirs last home: 'I'm sure it was Margaret who planned it'

minute but beyond anything they cared to endure. Given their assessment of their condition, who could they turn to? What kind of understanding could they expect from the society in which they had long been productive and responsible citizens? More and more Canadians are asking such questions. Approval of legalized euthanasia has risen in public opinion polls from 45% in 1968 to 78% in 1990. However, society's medical, legal and political leaders continue to treat death and dying like dirty secrets, best passed over in silence.

THE Criminal Code of Canada, as adopted in 1892, specifically prohibits any person from aiding the suicide of another; even giving advice about methods of suicide can result in up to 14 years' imprisonment. Moreover, by the current code's definition, euthanasia is indistinguishable from murder since anyone who clearly intends to take the life of another and does so is guilty of culpable homicide. The means does not matter, the motive does not matter—even a request to die written or otherwise recorded by the deceased, is not admissible as a mitigating factor in judging or sentencing an accused under present law.

In the U.S., the determination of whether euthanasia should be legal or illegal is up to each state legislature to decide (see accompanying article Last Exit to Seattle) but in Canada, it would require an act of Parliament to amend the Criminal Code. So far, none of the major political parties has expressed any interest in legalizing euthanasia. One of the few rays of hope for federal action is embodied in MP Svend Robinson (NDP Justice Critic from 1981-83, and from 1984-89) who, for the purpose of this article, confirmed that he personally favors the decriminalization of assisted suicide and the legalization of euthanasia. Unfortunately political polls indicate the likely result of a fractious and fractured Canada in the next election and no party may be able to advance euthanasia legislation in such a political climate.

Officially, federal parties say they are waiting to hear the recommendations of the Canadian Medical Association (even though the current government ignored the recommendations of the CMA in drafting their abortion bill.) A report headed *Proposal For Advanced Directives* drafted by the CMA's Committee on Ethics is due to be presented this August in Toronto, at the CMA's annual assembly. Eike Kluge, the CMA's director of ethics and legal affairs (formerly a philosophy professor at UVIC), says that the report is the result of a two-year study covering such matters as living wills and durable power of attorney authorized by patients; an interim report on another study currently under way dealing specifically with euthanasia can be expected in August as well.

In addition, all three federal political parties justify inaction on euthanasia by saying they are waiting for the next round of recommendations from the Law Reform Commission of Canada—which has been mulling over the subject for some 15 years. In its last published report (1983) the commission recommended that no changes be made in the Criminal Code (concerning euthanasia or assisting suicide.) The Commission doubted that "there is...strong social pressure in Canadian society today for the legalization of euthanasia." In essence, the report concluded: We see no need to reform the law.

Well-known Victoria physician Dr. Scott Wallace (now retired) says the commission's report is a legal exercise in inertia. Wallace, a former Conservative MLA, is often described as an "outspoken member of the medical profession" on the subject of euthanasia. But he only appears to be outspoken because so many other doctors are silent on the issue. "I would oppose legislation which allows a patient and doctor in private consultation to decide

whether euthanasia was justified," he says. "There's great potential for abuse in such a situation. Rather I envision a system whereby a patient would have to consult a minimum of two doctors—since in matters of life and death one should always have a second opinion—and then together with other immediate members of the family or loved ones, plus a family advisor—who might be a lawyer or a minister—an agreement would be signed authorizing euthanasia for the person requesting it." (Dr. Wallace's views on euthanasia closely correspond to the system adopted in Holland—available only to Dutch residents. For a report on Holland's euthanasia experiment see *Scientific American*, March, 1991.)

LAWRENCE McLAGAN

Dr. Scott Wallace describes 'a terrible crisis for thousands of people'

Responsibility for the legalization of "living wills" lies within provincial jurisdiction. This month, Ontario became the third province—following enactment of similar legislation in Nova Scotia (1988) and Quebec (1989)—to advance a "Natural Death Act." The bill presented by PC MPP Norm Sterling authorizes patients to determine for themselves—through living wills—the degree of medical intervention they wish to receive in emergency situations; it has the support of a majority of NDP government members (a final vote is expected before June.)

HERE in British Columbia, under former Premier Bill Vander Zalm the Socred Party's legislative priorities when dealing with moral issues were to persuade the current government under Premier Rita ("that was then, this is now") Johnston to place a Natural Death Act on a referendum in the upcoming election. The New Democrats' Health Critic, Dr. Tom Perry, responded on this subject by making three main points: (a) that if the NDP forms the next provincial government in B. C. he would immediately press for a commission to study the issue—principally to determine the extent to which legislation on living wills would be useful. In the interim, he welcomes any comments from seniors and others on the subject of living wills, euthanasia, or any other aspect of medical care in B. C. which they find problematic. (b) Dr. Perry cited the example of a woman who wrote to him recently outlining an instance where her 78-year old father was given an inadequate dosage of painkiller during his last week of life. In addition, her father was moved out of one Vancouver hospital (because the head nurse said she had to "free up some beds,") into another three days before he died. Whereupon the new hospital mislaid her father's medical records and he once again received insufficient morphine; he died in convulsive agony. The woman suggested to Dr. Perry that instead of spending frustrating hours trying to cut through bureaucratic red tape, every hospital have a patient's Crisis Line to quickly address problems of this kind. Perry says: "This suggestion deserves implementation. It's appalling that people who are dying should be so mistreated." As official [illegible]

that Living Wills offer much protection in emergency situations; that in at least five or six instances where he has diagnosed a probable death the patients have recovered; and finally, if legalized euthanasia does become available in the United States, he would have "no problem" with expanding the B. C. Medical Plan's provisions to cover out-of-province consultations for euthanasia.

With Canada's medical profession treading water on the topic of euthanasia and Canada's politicians and legal profession upholding ambered tradition for the lack of any better ideas, who else can one turn to for leadership?

Ellen Campbell, executive director of the Canadian Unitarian Council, says: "the church affirms the role of 'individual conscience' in deciding such intensely personal issues as the 'right to die.' The drawback to such an approach however, is that it renders the church (and any other group that takes refuge in ambiguity) *politically* ineffectual on the issue of euthanasia." The Anglican Church of Canada has issued no statements or resolutions on euthanasia or death and dying since 1980 but the *Anglican Journal*'s newly-appointed editor Carolyn Purden reports that the church's doctrine and worship committee has been asked to study the issue of death and dying and develop theological guidelines which can be used by the state, by medical professionals and by families. The United Church of Canada has no policy on euthanasia but is in the process of considering a new report on reproductive technologies which according to *The Observer*'s Mary Frances Denis will include many of the same ethical issues raised by euthanasia.

The Roman Catholic Church aggressively follows a different course of opposing euthanasia. The Catholic church has long found deathbed desperation a rich source for the harvesting of souls; its leaders are unlikely to support euthanasia since the suffering of the corporeal body is a matter of relatively little concern to those so otherworldly oriented. But it should be remembered that one of the most eloquent defenses of euthanasia ever written appears in Sir Thomas More's Utopia (1516; translated into English from More's scholarly Latin in 1551.) More is the highly-principled Catholic Archbishop and theologian whom we have come to know as "a man for all seasons"—tried for treason, executed and later canonized (1935.) He wrote in part: "If, besides being incurable, a disease also causes constant excruciating pain, [illegible] priests and government officials visit the person concerned and say...'Since your life's a misery to you, why hesitate to die?...We'll arrange for your release.' [illegible] patient finds these suggestions convincing, [illegible]

LAWRENCE McLAGAN

Thousands of elderly people grapple with the right to die or roll the dice and take what fate sends them

to contemporary Catholics than those of Thomas Aquinas—the chief philosophical opponent of euthanasia in church history. In any event, there is no shortage of distinguished moral philosophers throughout the centuries who have defended the "right to die"—ranging from Socrates to Bertrand Russell. Yet if we ask again who could the Le Moirs turn to in their time of despair, the answer is not encouraging: The pillars of Canadian society have hearts of stone.

* * *

FACED with the fact that what they want is illegal, the Le Moirs would be forced to consult the social underground. Here there is some help. They could turn to The Hemlock Society (see accompanying article, The Right to Know...) where they would first be counselled on how not to commit suicide. "No one should commit suicide in such a way as to inflict trauma upon others," says Hemlock's Executive Director Derek Humphry. "Death

est to form a Victoria chapter of the national organization, drew a capacity crowd of nearly 300 at the Unitarian Church on Superior Street. On that occasion they heard DWD executive director Marilynne Seguin outline the long and winding road ahead before Canadians could be assured of death with dignity. For many in the room this was a discouraging message; they desperately wanted help now. What they did not realize is that under the rubric of DWD's respectability they will find more radical members who do not speak or act on the organization's behalf and who will go far beyond DWD's official mandate in providing help. These senescent rebels-with-a-cause are as well-informed about euthanasics as a Colombian druglord is about his contraband stock-in-trade. Finding such people is simply a matter of discreet inquiry.

In another day and age, not so long ago, Charles and Margaret Le Moir would not have faced the

The leading cause of death was pneumonia (sometimes dubbed "the old man's friend") which generally killed a person within eight to 10 days, most of the time spent in feverish semiconsciousness. As medical science made advances, however—conquering a number of common illnesses with relatively benign symptoms—aging human beings began falling prey to an array of rare and previously unknown diseases and disabilities, some of which deprive a person of meaningful identity. (There are an estimated 10,000 people designated as comatose in U.S. hospitals—each one costing around $125,000 per year to keep technically alive. In Canada, the Dying With Dignity Society estimates we have 1,000 such patients and many thousands more who are chronically ill and have minimal cognitive ability. The late Victor Copps, for example, father of Liberal MP Sheila Copps and once mayor of Hamilton, suffered a heart attack in 1976 that caused substantial brain damage. He stayed at home under constant medical care for 12 years until he died at age 69.) The race to stretch human life to its uttermost limits still goes on.

"We can't turn back the clock," says Dr. Scott Wallace. "I have absolutely no doubt that we are better off today than ever before, but without an euthanasia policy we are creating a terrible crisis for thousands of people who are living in protracted misery." The problem for many (including the Le Moirs) is that they don't have a "terminal illness" but rather multiple disabilities, each of which might be tolerable in itself but not in their totality. I received a letter recently from British writer Quentin Crisp, well-known for his autobiography *The Naked Civil Servant* (made into an even more renowned Granada television film of the same name in 1980 starring John Hurt) but interwoven into my life as the co-author of our book *Manners From Heaven* (Harper & Row, 1984.) He's 82 now and lives on New York's Lower East Side. Having endured all that a smug and intolerant English society could dish out to him (which was plenty) while he was primping in his prime, Crisp now finds the "ravages of time" to be life's most onerous burden. He suffers from a particularly virulent form of excema—which no doctor has been able to relieve: *"The itching sores cover most of my body and make me want to tear my skin off."* he writes. *"Frankly I long for death. Everyday I saunter forth, up the Bowery, past the crack houses, through the street gangs—hoping that someone will oblige me with a good bop on the head. But nothing ever happens. Contrary to New York's image abroad, the truth is you can never find a criminal when you want one."*

one 87-year-old told me: "My days are filled with nothing but funerals."

TAKE a moment to dream about an alternative: In an enlightened society, euthanasia could be a far more imaginative and variegated service than merely the cessation of life. Research could be conducted into developing euthanasics of varying characteristics: there might be a single pill or injection (to replace the 60 or more barbituates that one currently has to swallow) for those who want to die instantly; there might be a timed-release capsule or a dilute intervenous formula developed which gradually produces a peaceful sleep over the period of, say, one hour or 90 minutes—while one listens to Chopin's Nocturnes, Mahler's Second Symphony ("The Resurrection") or whatever piece of music seems most transcendent to one's ears. Perhaps it would be the quiet buzz of a summer's day in a country garden that would make the most pleasant setting. *Why shouldn't death be pleasant?* There could be men and women trained in various compassionate therapies to assist us—through dialogue, massage, tender embraces, cooking one last splendid meal for us, or exploring who we are in pre-euthanasia counselling and helping us come to terms with whatever we have been: What we most cherish in our memories, what we most regret; so that our leavetaking of life would be as richly satisfying as humanly possible. For those who are more gregarious, perhaps a last hurrah—a "farewell party" of friends would be in order. (It could be that some would choose through this life-reconciling therapy to postpone the act of euthanasia.) Moreover a policy of planned death could greatly reduce an elderly person's financial worries; instead of eking out a long, dwindling existence on a meagre pension, the person choosing euthanasia would be eligible to receive a lump sum payment from Canada Pension and other plans so that they could enjoy themselves prior to dying; in that way, anyone could afford a pleasant pre-death period and euthanasia service. We have the means of making human death enriching and beautiful; but at present we are told we have no option but to "roll the dice" and with luck, experience cardiac arrest or, with increasing probability, suffer whatever form of disability and agonizing death that inhuman nature may inflict upon us, while doctors and nurses ritualistically stand guard

LAWRENCE McLAGAN

There may be a long road ahead before Canadians are assured of death with dignity, says Marilynne Seguin

Last exit to Seattle

NOTHING depresses Canadians who are seeking the respite of euthanasia more than to be told that legalized euthanasia may be 10 to 15 years away and that it will only come about as the result of a long, drawn-out grassroots struggle.

The truth is—although the Canadian media has never re-

to die" bills over the years but Washington or Oregon would be the first to actually legalize euthanasia.

In Washington, Initiative 119 will be put to the state's voters in a special election on Nov. 5. (If the initiative receives 51% of the vote it will automatically become law.) In January, a Gallup poll showed that 66% of Washington's residents support Initiative 119, which allows a person with

to Hemlock Society's Derek Humphry, an eligible Canadian would simply consult doctors (possibly from a Hemlock-recommended list) in the state of Washington and would quickly be processed. Right to Life groups are currently engaged in a nationwide fundraising campaign with the avowed aim of defeating Initiative 119; no one —on either side of the issue— has any illusions about the his-

and likely to die within six months to consult a panel of three doctors in that state for the express purpose of obtaining aid-in-dying. In California, petitions are currently underway to have a "right to die" law placed on the ballot (as an initiative) during the November, 1992 election. It appears that in the United States euthanasia is an idea whose time has come, and that for many ill people, mired in

and wring their hands.

To make matters worse, there is the spectre of long-term and intensive-care wards literally becoming battlegrounds: so-called "prolife" activists in the U.S. have made it clear that the terminally ill and the dying will be given no respite as far as they're concerned. In one recent instance, in Mount Vernon, Mo., a group of 25 protesters tried to gain access to the hospital room of Nancy Cruzan, following a United States Supreme Court decision granting Cruzan's parents the right to disconnect her feeding tubes. Cruzan was in a coma for seven years—and it cost her parents over $200,000 to win the three-year legal battle. When the "pro-lifers" could not succeed in reconnecting Miss Curzon's feeding apparatus they held a "religious protest" by blocking a fire-exit stairwell in the hospital, culminating in the arrest of 19 of their number. Presumably we can expect the contagion of far-righteous gangsterism to spread to Canada—as activists turn a vigilante eye on those who want to die, forcing the frail and the helpless to suffer even more as victims of someone else's politico-religious agenda.

The leading U.S. medical ethicist, Daniel Callahan, author of the bestseller *Setting Limits: Medical Goals in an Aging Society* (Simon and Schuster, 1987) fears that "prolife intransigence" will only increase public support for active euthanasia. He envisions that many people will opt for euthanasia at an earlier point of ill-health rather than get caught in the quandary posed by Physicians for Life and other ideological groups who vow to override the provisions of living wills. Yet for all his sympathy for the plight of the terminally ill, Callahan rejects the Hemlock Society solution: "Euthanasia...would be a way of legitimizing the view that old age is a special time of lost hopes, empty futures and personal pointlessness."

Callahan's "never say die" philosophy is essentially that which motivates the hospice movement in North America, England and Europe. But Marilynne Seguin points out that hospices tend to specialize in patients with cancer (or people with AIDS, such as Casey House in Toronto, founded by writer June Callwood) and can accommodate only a small fraction of people who apply. Some patients find that the heavier staffing ratios of a hospice offer a higher quality and more personalized form of palliative care, but even so, large numbers of people who are chronically ill, terminally ill, or what B. C's civil rights specialist John Dixon calls the "catastrophically ill" do not want to die a lingering death even in a hospice.

The right to die is not age-specific but condition-specific; no one in good health, of good fortune and good spirits, of any age is going to choose to end their life; however, having made such a decision, there ought to be a humane means available of bringing suffering to an end. Each of us should vow in our hearts: "No more Le Moirs!" •

Research assistance by Gillian Fosdick

(Next week, in Part 2 of End of the Road, *John Hofsess relates what he learned from giving "round-the-clock" care to his ailing 81-year-old mother.)*

The right to know about the right to die

IN a Gallup poll conducted last year, 78% of Canadians supported the view that a terminally ill individual has a "right to die" at a place and time of the individual's own choosing. Here are some of the principal organizations and publications which are recommended for further information and assistance.

Dying With Dignity,
175 St. Clair Avenue West,
Toronto M4V 1P7
(416) 921-2329

For information about activities of the Victoria Chapter, contact: Bertha Schmidt 478-2653 or Clement Finney 477-4003.

For an annual membership fee of $30 (or $40 per family), the association provides a quarterly newsletter and a variety of documents (living will, durable power of attorney for health care and voluntary euthanasia declaration) which may be of assistance in directing an individual's health care. (The caveat is that such documents are not legally recognized in B.C. at present.) Note: Those who cannot afford the requested fee will not be denied membership. Contact DWD

This is the leading North American source of information about voluntary euthanasia. Founded in 1980 by Derek Humphry and Ann Wickett, The Hemlock Society is a nonprofit organization with over 40,000 members. (Note: You do not have to be a member to purchase Hemlock's wide range of publications.) Its most important books are:

Let Me Die Before I Wake (1991 revised edition, $10). This best-selling book (dubbed by CBS's 60 Minutes as "the Bible of euthanasia") was first issued in 1981. It's a well-written account by former British journalist, Derek Humphry, of how and why mature adults who are suffering unbearably choose the option of ending their life. The new edition has large easy-to-read type and 74 more pages than the original.

Final Exit by Derek Humphry (Forword by Betty Rollin.) This is Hemlock's boldest and most salient book (just published, $16.95 hardcover); a clear and detailed guide to ensuring successful acts of "self-deliverance"

Other books (at your local bookseller):

I Don't Know What To Say: How to help and support someone who is dying by Dr. Robert Bucknar (Key Porter Books, $12.95).

Bucknar is a Toronto doctor well known for his use of "humour" in treating cancer patients. Like Norman Cousins (author of *Anatomy of an Illness* and *The Biology of Hope*), Buckner emphasizes the realistic role of the human spirit in coping with biological illness. This book is specifically designed for those friends and family members who are caring for someone who is terminally ill.

On Death and Dying by Elisabeth Kubler-Ross (1969, Macmillan, $8.50)

No writer in the 20 century has been more influential in exposing "the conspiracy of silence" about death than this wise and compassionate psychiatrist and thanatologist. *On Death and Dying* is one of her most justly famous books in its plain-speaking analysis of the emotional "stages" people go