



# Rehabilitation Gazette

Gazette International Networking Institute (G.I.N.I.)

June 1991 Vol. 31, Number 2

The Saturday morning session of the Fifth International Polio and Independent Living Conference featured presentations on ethical issues, including the "right-to-die." This **Rehabilitation Gazette** features four gentlemen who presented:

**福** the evolution of the notion of the "right-to die;" .....Page 1

**福** the experience of a physiatrist involved in such a case; .....Page 5

**福** two reactions from individuals with a disability.....Page 7

In addition, we have included:

**福** an article defining "basic care" and .....Page 9

**福** an essay on the unfinished business in the Cruzan case, plus information for ordering *Advance Directive or Future Health Care Decisions: A Christian Perspective*. .....Page 10

## Evolution of the Idea of the Right-to-Die

Daniel Wikler, M.D., Ph.D., Professor, Department of Philosophy, Medical School, Program of Medical Ethics, University of Wisconsin, 1300 University Avenue, Madison, WI 53706 USA.

This morning I want to speak about the evolution of the idea of the right-to-die. It has undergone some changes in recent years, maybe without our noticing it. The idea of the right-to-die is still evolving, and I think it is important to keep track of these changes because we are uncertain where they are leading us. Unless we clarify where the idea comes from and where we are now, it is unlikely that we can chart our future course wisely.

The right-to-die is very important for fairly obvious reasons and is enormously confusing. There are several different ideas that are mixed together to produce this concept. Let me begin by summarizing four sources of our present thinking so we can trace the evolution.

The idea of the right-to-die arose in part because of changes in medical technique. Physicians were able to keep people alive longer. In so doing, they also became more intrusive. In their last days and weeks, people found that they were given a certain amount of hope but at the cost of losing control of their lives and by having health professionals perform invasive procedures.

The second source is one of the many continuing results of the cultural revolution of the 1960's in the United States. The rights of individuals were championed and the authority and status of professionals was deeply questioned. This occurred across the board from judges to politicians to

doctors. In the past, doctors made the decisions about what would happen to you. A patients' rights movement arose in which people said that these decisions are the business of the person whose life it is. Physicians should primarily be advisors and facilitators and not the ones invested with the authority to make decisions. Taken together, the result is an assertion by patients that they, and not the physician, should decide what to do with all these new medical powers.

At the same time, two background factors screen the movement toward the right-to-die. Both of them are very important for the present and for the future.

We have a continuing taboo on taking life. When I say taboo, I do not mean to ridicule. What I mean is that it is a moral principle that is not treated as soft-headed or as something to think about on a rainy day. Most of us feel very deep in our bones that it is fundamentally wrong to take another person's life. Only in the rarest circumstances such as all out war or capital punishment (because someone has committed the most terrible of crimes), do we imagine permitting, in fact, endorsing the taking of another person's life.

Secondly, we are still living in the shadow of the Nazi era, which began its career toward mass murder with an euthanasia program. In the middle 30's, before the mass murders that

(continued on page 2)

## Evolution of the Idea of the Right-to-Die

(continued from page 1)

occurred during World War II, the Nazis sent emissaries to institutions housing the mentally disabled. After a very short period of transition, they took on a policy of systematically murdering the most disabled residents of these institutes. Insult was added to injury by sending the parents a bill for the extermination process. This was done without consent, of course, and with a good deal of lying.

Prior to this, Germany had been considered one of the great centers of the civilized world. It happened there, and we are not so sure it could not happen here. So, all of our thinking of our right-to-die and about the collaboration in taking life has to consider this historical precedent.

Let me state my thesis about our right-to-die. There has been a systematic demedicalization of the concept and the term means just what it suggests. Namely that whereas before it had been a concept that was firmly imbedded in a medical context, today that is less and less true. My guess is that in the future the idea of the right-to-die may be thought of having to do with health care.

Let me state my argument for such an evolution. First, the decision about the right-to-die is being brought up with respect to conditions that are less and less serious medically. The earliest cases involved such catastrophic conditions as brain death in which the patient was permanently unconscious. If the patients were not brain dead, they were in the last stages of a terminal disease. If you look at the recent court cases which grab the headlines and are referred to in subsequent judicial decisions, you see the introduction of cases in which the patient is not about to die. Some are not even terribly sick, but they are somewhat demented and confused and perhaps, ill. We also have cases in which the patient is not terminally ill, in which they are quite stable and not demented, but rather conscious and competent to make decisions. There has been an evolution away from very, very sick patients in which we raise the question of their right-to-die toward patients who are less and less sick.

Now, what happens when this goes on is that the question of whether life can be terminated turns out to depend less on a medical judgment about the condition of the patient, but instead, on a subjective judgment

on the patient's part as to whether that patient's life is worth living. This is what I mean by demedicalization. Previously, the main testimony the judge would want to listen to was the doctor. Now that is less important. Today testimony is more concerned with what the patient says, and it has less and less to do with medical care.

Secondly, there has been a demedicalization, in my view, of the kinds and means of life support whose removal is considered in the context of the right-to-die. In the early days when the right-to-die was invoked, the medical means in question were highly intrusive. They were called extraordinary, and in fact, they were the ones that were used at the very moment of crisis. The most typical case would be a do not resuscitate order. As the doctrine of the right-to-die has evolved, the types of patients that would invoke the doctrine have also changed from more serious to less serious and the means have become more and more prosaic. Instead of imagining the all out assault of the Intensive Care Unit, we are speaking about the removal of life support from someone living at home and for whom the means are only marginally medical.

### Gazette International Networking Institute (G.I.N.I.)



4502 Maryland Avenue  
Saint Louis, Missouri 63108 U.S.A.  
Telephone: 314/361-0475

*Written by individuals with a disability, Rehabilitation Gazette (formerly Toomey j Gazette) has been published since 1958. Its aim is to reach, to inform, and to dignify individuals with disabilities throughout the world.*

**EDITOR:** Joan Headley

*Special thanks to:* Joseph B. Leone

#### **PUBLISHER:**

Gazette International Networking Institute  
(G.I.N.I.)  
4502 Maryland Avenue  
Saint Louis, Missouri 63108 U.S.A.  
314/361-0475

#### **ANNUAL SUBSCRIPTION:**

U.S.A.: Individual \$10; Health Professional \$15; Institution \$25

CANADA/MEXICO & OVERSEAS (Surface):  
Individual \$12; Health Professional \$17;  
Institution \$27

OVERSEAS (Air): Individual \$15.25; Health Professional \$20.25; Institution \$30.25

**June 1991  
Volume 31, Number 2**

**ISSUED IN JANUARY  
AND JUNE**

Copyright ©1991 by  
Gazette International Networking Institute  
4502 Maryland Avenue  
Saint Louis, Missouri 63108 U.S.A.

Permission to reprint portions must be  
obtained from the Editor.

ISSN 0361-4166

The current controversy in medical ethics has to do with the removal of food and water. Food and water is fed into the patient through a conduit. To call the feeding tubes, medical, is stretching the point. In fact, some patients who are in a persistent vegetative state could actually be fed with a spoon because the swallowing reflex survives the loss of consciousness. Patients are fed through tubes because it is more convenient. For some reason we prefer to call withdrawing food and water medical technology. I think it is because of the past evolution of the concept and to treat the removal of devices as a medical event. But pretty plainly, that is not what is really going on.

Finally, I think there has been a demedicalization of the right-to-die. At one time the right was a right invoked by people in the role as patients against doctors. Why were doctors the villains of the peace? They had inherited an activist tradition in medicine which says it is a mark of disgrace and shame to lose a patient. Also, doctors were afraid of liability and frequently got conservative advice from their lawyers who said that the way to avoid trouble is to keep the patient alive.

In those days and under those conditions, the patient felt helpless and needed allies to do battle against the doctor. But this is less and less true partly because the legal battles have been won already and partly because the doctors have been converted. (Sometimes now when I teach my medical students, I have to hold them back. They are too interested in helping the patient "get through it all.") The situation has transformed itself completely, and now it is the doctor who will often be on the side of the patient invoking the patient's right to commit suicide with medical help. And the two of them are fighting that battle against society, which may be threatening to crack down on them with

the full force of the law. Now it is a right not on behalf of people in the role of patients, but just as people. And it is not against doctors, but if it is against anybody, it is against society as a whole.

So, I think that there has been an important change in the character of the right-to-die away from being a purely medical idea to being a less medical idea and,

---

***Sometimes now when I teach my medical students, I have to hold them back. They are too interested in helping the patient "get through it all."***

---

in my mind, this has affected our thinking on two underlying concepts.

First, the right-to-die has been based squarely on the notion of patient autonomy, which means very simply that when you become a patient, you do not lose your freedoms and you retain the right to chart your course. In the past, patient autonomy has been literally that. It is in your role as patient that you have autonomy. You can decide what kind of medical care you want and you can decide to stop medical care.

As the right-to-die has become demedicalized, we can invoke patient autonomy as a basis for the right-to-die only at a certain cost. And the cost is that we are no longer talking about autonomy in medical affairs, but in general. And so, the right-to-die in the form of the right to refuse medical care now shifts and it becomes the right to commit suicide. Whereas, there had been a social consensus growing over the years in favor of the right to refuse medical care, there is much less social consensus over a right

to commit suicide. In fact, there are still many people who think that it is an immoral thing for a person to do and certainly for another person to help that person do it. The underlying notion that patient autonomy, which once lent a lot of support to the right-to-die, now may not be lending so much support. And if it does, it will certainly involve a shift in some fundamental attitudes of Americans.

The second thing has to do with the taboo on killing which is an important factor in our thinking about the right-to-die. The American ethic has drawn a very sharp line between killing a patient, which is taboo, and letting a patient die, which is thought to be perfectly okay. What is the difference between these two kinds of actions? In the case of someone whose death is imminent no matter what you do, it is fairly clear. The patient is going to die within days and the only issue is whether you are going to try to prolong that agony or to just let it occur with less agony. To let that patient die is to decide not to intervene in the course of events.

But it is less clear what the distinction means with a stable patient. In a stable patient, death is not inevitable and a decision to let this patient die is a decision to change the course of events. It is a decision to make something happen which otherwise would not happen.

Does this decision to so-called "let die" or allow to die constitute a killing or not? One thing that is usually said by people who insist on drawing that distinction very sharply is that when you let a patient die you have an omission. It is not an act. You are deciding not to intervene and that is not an incidence of killing. There is confusion because it is perfectly possible to kill somebody by omission.

A colleague of mine, Dan Brock,

(continued on page 4)

## Evolution of the Idea of the Right-to-Die

(continued from page 3)

tells a very simple story. Suppose that you have a nasty young man who is named in his uncle's will and the will, for some obscure legal reason, becomes null and void as of midnight. The nephew is very concerned that his uncle die on that day, but the uncle is stable and on a ventilator. So, the nasty nephew steals into the hospital, turns off the ventilator and his uncle dies. Certainly this is a case in which the nephew killed his uncle. Undoubtedly, he would be accused of murder in any court of law. Then why would it be different if, for entirely different reasons, a doctor had wandered over to that ventilator and turned it off? Does the fact that the doctor had the MD after his name and a white coat on his body mean that turning off the ventilator did not constitute killing? Why would it be "letting die" when the doctor does it, where it is "killing" when the nephew does it?

Consideration of a range of cases like that has led some of my colleagues, and sometimes myself, to believe that the distinction between killing and letting die in the case of stable patients is a lot blurrier than is often thought. What this suggests is that when the right-to-die becomes demedicalized and begins to be turned on stable patients, this underlying absolute, the taboo on killing, becomes threatened. The things that we would do to patients as patients, which are seen as relatively unproblematic at the present, suddenly become very troubling. This leaves us in quite a fix in my view. It is very hard to tell which principles we should insist on as absolutes and which ones, in fact, we are violating every day. For some people, there is one absolute which we have to keep, and that is to not cross the line between passive and active. What we have done so far with

passive euthanasia, or allowing patients to die, is okay because it is really another form of recognizing the autonomy of patients. But if we cross the line into active euthanasia, or turning off machines, we would have taken quite a wrong turn.

Here, I would like to introduce a foreign point of view. At the University of Wisconsin, we were recently visited by a Dutch anesthesiologist who assists his patients in dying. Five thousand patients die each year in Holland from active euthanasia. He has written many articles in support

---

### ***Does the fact that the doctor had the MD after his name and a white coat on his body mean that turning off the ventilator did not constitute killing?***

---

of this practice. What I want to do is to present his verdict on the situation in America, because it is a very different and challenging view. He sweeps away the objection that in Holland they cross an important line by going from passive to active euthanasia. He thinks that the distinction, especially with respect to stable patients, is a difference that does not make a difference. It is a way of fooling ourselves so that we can do something that he regards as an out and out killing of patients, mainly withdrawing life supports, and yet tell ourselves that we are still obeying our taboo against killing and involves no change in our fundamental morals. He thinks that is all a lot of hogwash.

In his view, and what they have done in Holland is to recognize that the distinction in question

is a very unsubstantial one. It makes no real difference. There is a distinction that does make a difference, he thinks, and that is the difference between voluntary and involuntary dying. In his view the United States is the country that has crossed that divide, because what we have done here in a series of judicial decisions and in the change of practice in clinics across the country is to practice passive euthanasia on patients who have not requested it. The line of reasoning used in court decisions, following the theory involved in *Roe vs. Wade* on abortion, is that the right-to-die is a right which follows from a right of privacy which is okay. Privacy here means autonomy or the right to do as you please. But it has now been invoked with respect to patients who never were competent. The courts have insisted that someone profoundly retarded from birth has a right of autonomy just like everybody else. That right of autonomy justifies withholding of care so the patient actually dies. (This did occur in a case in Massachusetts.) From his point of view, this is also a lot of nonsense. This patient has no autonomy to begin with, never was competent, is not competent, and never asked to die. Yet, we are taking steps which lead to that patient's death, and in his view, these are equivalent to actually killing a patient.

According to him, in the United States, we have already crossed the boundary between exceeding to patient wishes to die and simply killing them, even though they have not asked to die. And that, he thinks, is very troubling. Whereas what is going on in Holland is simply what you do when you try to be moral and at the same time not deceive yourself.

To summarize, we are at a crossroads, I believe, in trying to figure out where this evolving concept of the right-to-die is going to lead. It is changing; it is not the same

right that we were invoking even in or fifteen years ago. And it is also clear that it is going to change more. How it should evolve and in which direction it should evolve is something which only time will tell. Some have held that we should keep the Nazi precedent firmly in mind and that we should be very clear that what happened there does not happen here.

For some people that means we have to retreat from where we already are. And others take comfort in the fact that in the Nazi era, the killing was done in the context in which the state had all of the rights, whereas, here it is done in the name of individual rights. And for some people, what has happened before need not deter us. Relying on data collected by some of the Dutch anesthesiologist's opponents in Holland, the problem appears to be that once the public gets used to the idea of killing patients for one reason, it is not so clear that they might not accept the idea of killing patients for other reasons. Some recent polls in Holland have found that the policy of killing patients at their request is very popular. Some 67% of the Dutch public supports this idea. Polls have also found a growing consensus in favor of killing patients for other reasons such as saving money. The problem, of course, is that the general public does not consist of philosophy professors or members of the high court, and these careful distinctions that people make between killing for a good reason and killing for a bad reason may get blurred in the public policy process.

The conclusion of all of this is, I am afraid, rather muddled. I hope that I have showed that our thinking about the right-to-die is a lot less clear than many of us think it is. It is up to us to clarify it and depending on what we do, we will just have to live with it and we will also have to die with it.

## A Physiatrist's Experience

Frederick Maynard, M.D., University of Michigan Medical Center, Model Spinal Cord Injury Care System, Department of Physical Medicine and Rehabilitation, N1-2A09-0491, 300 North Ingalls Building, Ann Arbor, MI 48109-0491 USA.

Of all the topics I have had the opportunity to address at a G.I.N.I. conference, this is the most difficult. I am certainly not an expert on the right-to-die but in the course of taking care of people with high level spinal cord injuries, I have been involved with ten people who have requested, and sometimes demanded to have ventilators removed. Most of my experience has been with competent people, although some were not. Each case has been quite different. I would like to share one case.

A seventeen-year-old gentleman was at a high school party when he took a running, flying leap to catch a frisbee in about two and a half feet of water. He missed the frisbee but at the last split-second decided to dive into the water. He broke his neck and was brought immediately to the hospital. At that time he showed a C-5 level of quadriplegia, so he had a little movement left in his arms and was able to breathe.

Unfortunately, a few days later he began losing the movement in his arms and lost his ability to breathe. An exploratory surgery found no cause for his worsening paralysis. He remained permanently paralyzed at a C-1 level, which essentially means he had sensation of the face only. He could not move his neck either way. He was able to move his tongue and mouth, although they were weak, and he had to re-learn to swallow.

His condition required twenty-four hour ventilator use and positive pressure ventilation by tracheostomy was used. Several months later he and his family elected a feeding gastrostomy tube on a permanent basis because swallowing was so slow and labored. They worried about his

ability to take medicine and sufficient fluid. They knew that the tube could always be removed if he was ever consistently successful with adequate fluid and food intake by mouth. A suprapubic catheter was chosen for urinary drainage and he had a bowel program. He required constant turning and repositioning to avoid bed sores. He required medication for severe spasms in his extremities and for persistent and severe neck pain.

He participated in a comprehensive rehabilitation program and was able to achieve a several-hour sitting tolerance in an electric wheelchair which he controlled with his tongue. Perhaps because of pharyngeal muscle weakness, cuff deflation for speaking could not be used because of inadequate ventilation. A talking tracheostomy (with a cuff) was done with a second, small air source that produced a soft whispered voice enabling him to speak on a telephone. Using a "sip-and-puff" type of control switch, he learned to operate a computer, an environmental control unit, and other devices.

One or the other of this young man's parents was with him twenty-four hours a day during the eight months of his initial hospitalization. Nevertheless, they continued their jobs and began working on discharge plans earlier than most families facing a similar situation. An excellent catastrophic insurance policy covered his need for home care. During the several months' hospitalization, a totally accessible addition was built onto the home which included a carport, an extra room for nurses, and a large area for visiting and for working with computers. Within

(continued on page 6)

## A Physiatrist's Experience

(continued from page 5)

eight months of injury he was able to go home.

Following his discharge, he participated in a local community college program. He went to rock concerts with friends and had a reasonable number of visitors, although for the most part he felt alienated from his high school friends. Unfortunately, he developed a deep belief that his life was not worth living any longer. He composed several interesting paragraphs using his computer that explained his logic and reasons for wanting the right-to-die. He argued for the supremacy of patient autonomy. Boredom was a very difficult feeling for him. He also expressed resentment about the lack of privacy that resulted from being constantly surrounded by nurses and other people.

His desire to be removed from life supports was never discussed with the medical staff during hospitalization. I learned after his discharge that he had made this request to his parents about the second month after injury. Their initial response was, of course, negative. They eventually decided to bargain with him and asked him to try life out for at least a year. They promised to help him pursue his right-to-die if he continued to feel the same way after he gave it (life using a wheelchair and ventilator) a chance.

Because he was a compliant patient and did not discuss his profound hopelessness with staff during the hospitalization, we felt he did not require a great deal of psychological services. During the last few months, we recognized his withdrawal and distancing, and confidential counseling was provided. His whole family was perceived to need a great deal of privacy. They were very competent people and did not readily

ask for help. Although little emotional support was obtained from hospital personnel, they had a large network of supportive friends, extended family, and personal contacts in the community.

By one year after discharge, he had not changed his mind. His parents sought help from a local attorney who reviewed pertinent laws and previous legal decisions. It was decided to petition the local court for a declaratory

---

### *He argued for the supremacy of patient autonomy.*

---

judgment that would establish the young man's competence (he was age 18 by then) and his right to direct caretakers to do as he requested. The attorney decided his client's autonomy or right to have control over his own life and body was the only argument that he was willing to put before the court. If the petition was granted, it was implied that the young man had the right to ask his caretakers to disconnect his ventilator and that the person disconnecting it would be immune from legal prosecution.

The judge who heard the case was distressed by the implications of granting the petition but found the argument persuasive. Two psychiatrists and a psychologist interviewed the patient. I was also interviewed concerning my opinions about his mental condition. It was considered crucial to the legal decision that the young man was not unduly depressed and was fully aware of the implications of his decision. It was interesting to me that he always had an amazing sense of humor and did not have a depressed affect. He was able to form relationships with people and engage in activities. Therefore, he had no difficulty in conveying that

impression to the court appointed psychologists.

The petition was eventually heard in open court. One of the family's major concerns was keeping the story out of the newspapers since they did not want a lot of public attention. I am sure they were concerned about other people's opinions and their concern was conveyed to the judge. However, the judge felt that the proper procedure was to hear the case in open court, but he scheduled it at three o'clock on a Friday afternoon, when it was least likely that observers would be present. The story was never covered by the press.

The parents later said that after the court granted his petition, he chose to live for a few weeks. He appeared to be much happier at that time, because he felt like each day that he was living was his own choice rather than feeling as though he was trapped. He eventually chose to arrange a time with his family for the ventilator removal. On an afternoon when the nursing staff was dismissed (a not unusual occurrence), the family reminisced with him and said their good-byes. The father stayed with the young man and removed the ventilator. He was reported to die peacefully in about five minutes.

Several months after his death the parents offered to assist me and their attorney with documenting their son's story for medical professionals through a journal article "The Choice to End Life as a Ventilator-Dependent Quadriplegic," *Archives of Physical Medicine and Rehabilitation*, December 1987, Volume 68. They also offered to speak to other people or groups about their experience.

Discussing the circumstances that surround a request for ventilator removal will contribute to a greater understanding and compassion for those directly affected by these difficult decisions.



## Reaction

August Rüggeberg, Ph.D., Hirschgartenallee 37, 8000 Munich 19, Germany.

Dear friends of life, I am not going to do what some may expect of me, namely to comment on what has been said as a member of the scientific community. I am consciously stepping out of this framework and am going to comment as a person and as a result of my own concern.

My personal impression is that we have been talking about the so-called "right-to-die" in an almost easy-minded way. Easy-minded because we have not taken into account what the public will say if we concentrate only on methods of committing suicide in the case of very disabled people. The reason for discussing this matter seems to be what I might call an inadequate under-estimation of the capability of even severely disabled people to commit suicide. I frankly do not believe that there is any disabled person who, with respect to the severity of his or her disability, should not be able to end her or his life if she or he really wishes to do so. It is a myth or over-simplification to think that a severely disabled person would need assistance to end his or her life. Can any of you come up with a concrete case of a severely disabled person who cannot put his decision to commit suicide into practice?

I think that behind this purely ideological discussion lies one of the modern views of our western world, namely, that people should not only become comforted by money making services or companies during their lifetime, but also they should be comforted to death. As you know, there are associations in the United States, as well as Germany, that advertise for an easy and comfortable death, which reminds me of advertising a new hamburger! I condemn person-

ally the cynical business of making death easier than it is.

The decision to die is, indeed, a very difficult decision. If we honestly believe that people should be responsible for their decisions, including disabled people, we should not approve of an assistive service which makes suicide easier for disabled people than for non-disabled people. If we are not clear and outspoken as to this point, we are going to foster the public prejudice that disability is the worst thing in the world, even justifying suicide services. As a German, I might call them "SS"!

For most disabled people, who now and then may be in the situation of considering suicide, the reason does not lie in the disability as such, but in the same life problems or crises that also

woman or a couple after careful consideration to have a baby that they honestly do not want. This must also apply if the reason lies in a possible disability of the baby.

On the other hand, many disabled people recognize the future of genetic screening for possible disabled fetuses. They feel extremely frightened if they hear their friends or neighbors or non-disabled spouses say they would not want a disabled baby. We must take this into account as friends of disabled people, especially as the vast majority of society already does hold this notion. If we allow these ideas to become generally accepted standards, at least to begin with in those cases of very severe disability, we will one day not be able to stop the inflation of social values demanding and irresponsibly pretending the possibility to abolish any kind of suffering. In my opinion suffering will never-

---

***If we honestly believe that people should be responsible for their decisions, including disabled people, we should not approve of an assistive service which makes suicide easier for disabled people than for non-disabled people.***

---

drive non-disabled people to consider suicide from time to time. As we all know, these crises tend to be of limited duration. After a crisis, many people put the idea of suicide far apart from themselves. This is especially true if we honestly offer our personal friendship and partnership instead of depressing isolation; if we would grant support for living instead of easy comfort in dying.

Now, some words about other ethical issues which should concern us. First, I am convinced that it is not right to force a

theless remain an inevitable and also positive constituent of living. To begin with, abortions of very severely disabled babies will be looked upon positively and in the end, people like me will not be allowed to be born. This perspective frightens me, especially when I look back on the German history between 1920 and 1945.

Germany will shortly have new legislation which allows for the sterilization of people with severe mental disabilities. As I see it, it is a point of shame for the legislature that they have to confess

(continued on page 8)

## Reaction (continued from page 7)

that severely disabled women will be the unnecessary victims of this regulation. Birth control methods would suit them just the same as they do non-disabled women. I want to point out the thinking behind this regulation to show the moral standards carried with the practical arguments. These standards are that it is obviously acceptable to have sex with mentally disabled females who are judged unable to decide about their own sterilization, but, it is not worthwhile to think about loving these disabled people.

I would like to additionally remind you that such regulations were the starting point of mass sterilization under the Nazi regime which included, not only Jews, but also people in wheelchairs or people who were blind.

Scientists, which are greater in number than the number of all scientists in the whole history of human thinking, are now about to make the genetic code readable and writeable. That means the handwriting of scientists and physicians may, technically speaking, be found in the faces, bodies and brains of at least our grandchildren.

The great American researcher in genetics, Jeremy M. Rifkin, has outlined these visions in his excellent book, *Genesis II*. There are reputable scientists today who say that mankind should refrain from further research in this area, and I personally agree. The reason for this extreme position which can, perhaps, not be put into scientific or political practice is that mankind does not show the slightest sign of being morally grown up enough to handle those technical instruments which will enable us to reform the total variety of God's Genesis. The illusion created with these possibilities comes to the point that we could create the perfect human beings, vegetables, animals, or

even, a perfect ecological system. Reality, however, proves the opposite if we look at our environment and how it is threatened by these experiments which are mostly guided by highly capitalist interests.

I will not talk about the irrevocable threat to the whole ecological system and of mankind's part in this, but I would like to emphasize the values that would arise in such a future bio high-tech society. I imagine that the lives of the people with disabilities among us, viewed from such a perfectionist angle would seem so old fashioned, so imperfect, so stupid, that it would only be a natural step to eradicate all those medieval appearances of living with a disability. And yet, this future bio high-tech society would not naturally be as perfect as it promises to be. We can be sure that the prevention of the disabilities or chronic diseases we know today could easily create new disabilities or chronic diseases. How would these modern disabilities be looked upon by a society that has learned to believe in perfection? Would not discrimination and devaluation of living with a disability increase vastly in such a society?

Friends of life, please let me urge that all these future perspectives be discussed. Let me urge that we all increase our endeavors to show people that are living with a disability, living with weakness, and even living in the face of death, is worthwhile. Who could better bring these matters to the attention of the public and show society and the international disability community, that we feel our lives to be worthwhile, not requiring biotechnological repair or pseudo-betterment of God's Genesis.

福

## Reaction

Holger Kallehauge, High Court Judge, President, National Society of Polio and Accident Victims, Tuborgvej 5, DK-2900, Hellerup, Denmark.

As I listened to Dr. Wickler and Dr. Maynard, I wondered if they, as physicians, always would remember to use sound judgment in assisting their patients.

It is a question of accepting what is given to all of us. We shall die. Why do we hurry so much, and why do we interfere? The decision should be left to the head person, the person whose life is at stake.

In my opinion, physicians have been trapped into taking upon their shoulders the responsibility of alleviating us of the end. They shall alleviate us of pain, they shall minimize our sufferings, but they shall not relieve us of the end of our lives. We can do that ourselves. I believe, just as August Rüggeberg said, that it is impossible to find individuals with a severe disability unable to end their own life. One can always stop eating or drinking, and if one does that, one will eventually die.

I do not ask that physicians give us a pill. Instead, I ask that they put a switch on the ventilator and allow the person who wants to die to press the button. We, then, would not have all these complicated discussions about what the physician should do.

Again, in my opinion, the physician should not kill. I want to be assured that when I meet a physician, he is not a person representing a death patrol.

Perhaps the current concept comes from the patronizing attitude of physicians. They feel so much responsibility for us, that they are taking upon their shoulders a burden which is not theirs.



## The Basis of Basic Care\*

Frederick R. Abrams, M.D., Associate Director, The Center for Health Ethics and Policy, University of Colorado at Denver, 1445 Market Street, Denver, CO 80204 USA.

Fifty years ago, my friend and teammate "Joey" became sick. When he came back to school, Joey could not play shortstop any more because he did not walk — he lurched. I saw metal braces fastened to the tops of his ugly brown shoes. Polio became terribly real. I was 10 years old and afraid of summer.

The Fox Movietone newsreels showed people in iron lungs, which to us looked like the sarcophagi we learned about in history class, except they were open at one end. A head stuck out, and a person standing behind could talk to a reflection in a mirror. They were heroes, the people in the iron lungs. They survived. More than that, one lady took a paintbrush in her mouth and made beautiful pictures. We wondered how she went to the bathroom. All the newsreels showed how cheerful and courageous polio victims were. Sometimes the lights in the movies came up, and boxes were passed across the rows so we could contribute to the March of Dimes to buy iron lungs or braces. Then our idol, President Franklin Delano Roosevelt, came on. He also was a hero.

No one considered for a moment that the victims in iron lungs were using resources which could be used better by some other people who were sick, or by some other part of the economy that needed bolstering.

Our national schizophrenia inefficiently pours most of its public funds into rescue medicine and little into prevention. It is a system that the public, by a large majority, wants broadened, but fewer appear willing to be taxed to support it. It pressures physicians to be gatekeepers, on guard lest patients find their way in the health-care maze and deplete

resources, it yet exalts the high-tech medicine which use the resources.

### WHAT IS SCARCE?

"The allocation of scarce resources" is a phrase which rings in our ears daily. It leaves so much open to interpretation that it cannot go unqualified. Some things are genuinely scarce. Currently, organs for transplant are in this category. We may, through education, increase the supply, but it is quite possible that we always may have a shortage. The challenge becomes one of true distributive justice, a principle on which most bioethics texts and many papers have dwelt exhaustively, if not conclusively.

Other resources, however, are scarce by choice — political choice. I seriously question that choice. We are beginning to define Dr. Charles Fried's "basic decent minimum" and the presidential commission's "Adequate Level of Care Without Excessive Burdens" at a level which the public has stated, in poll after poll, is insufficient. No one, the public says, who wants care should be denied critical or lifesaving care because of inability to pay.

### WHAT IS BASIC?

What could be more basic than saving the life of someone who finds the resulting quality of life, albeit diminished, nevertheless acceptable? When we talk about decent minimum, are we led to think this means minimum cost? When we talk about "basic", are we led to think this means inexpensive?

Not long ago, I attended a conference concerning persons with high quadriplegic injuries for whom respiratory assistance was

needed around the clock. These people could not breathe without pneumobelts, phrenic pacers or portable respirators. Only a few decades ago, they would not have lived long enough after a high spinal injury to reach the hospital. Technology has created another class of patients to add to those who are alive because of dialysis or intravenous feedings. The average first-year cost for a high-quadruplegic is \$300,000 and annual maintenance averages \$100,000. Here comes the heresy: I maintain that this is "basic care."

We speak much of ideals and virtues. Not all of us would choose to survive an injury which left us paralyzed and dependent on a respirator. But for those who

---

***Before we decide to provide "basic care" for all, we must decide what "basic" means.***

---

choose to respond to this challenge, ought we not recognize such persons as prime examples of the indomitable human will, the very essence of the spiritual possibilities for humankind? Without glorifying the spiritual at the expense of the sensual, ought we not cherish them as symbols, as examples of the values which remain to be experienced in our culture which has leaned so heavily toward the materialistic?

One of these remarkable persons whom I met has transcended the injury she sustained at age 16, has completed law school and now practices law. She needs attendance virtually 24 hours per day for her needs, yet after a few minutes of conversation, her wheelchair "disappears." The bobbing motion she uses to activate the respirator knob with

(continued on page 10)

## The Basis of Basic Care

(continued from page 9)

her chin becomes as natural as breathing. It is only later, during reflection, that one realizes how significantly such persons help the nondisabled around them.

### CHOICES WE SHOULD NOT MAKE

For those who say we must choose between worthwhile preventive measures such as immunizations and prenatal care or high-tech rescue interventions such as transplants and high-quad respirator, I say no. We must not. Certainly we need to maintain our country's infrastructure, education and defense, but for whom do we maintain them? We do not maintain them only for the healthy or those who can buy high-tech interventions and maintenance. But who uses the bridges and roads, the colleges and the factories? As we all pass beyond the fantasy or immortality and invulnerability of youth, we fear over and over again how health is at the top of the necessities list. Given a defined sum to spend on health care, we certainly will have to set priorities. How high shall we set the defined sum? We clearly are showing in our Medicaid programs that we are not allocating sufficient funds now or making them accessible to all those in need.

Let's cut waste, inefficiency, supplication — the legendary "fat" of health systems. Let us not force care on anyone who does not desire it. Let patients choose or refuse care based on their own assessment of life's quality.

Let us face the fact that medicine's technical success, more than greed and waste, shares the blame for our dilemma. Like any expensive but desirable product, the society which demands it must pay for it by sacrificing other goods. The people have declared repeatedly how high a

## Ethical Issues in Health Care: Unfinished Business in the Cruzan Case

Rev. Kevin O'Rourke, OP, St. Louis University Medical Center, Center for Health Care Ethics, 1402 S. Grand Blvd., St. Louis, MO 63104 USA.

In November of 1990, Charles Teel, Judge of the circuit court of Jasper County in the State of Missouri, heard once again the petition of Joe and Joyce Cruzan to remove life support from their daughter Nancy Beth, who survived an automobile accident in 1983 but existed in a persistent vegetative state (PVS). Discerning that there was "clear and convincing" evidence of her previously expressed wishes, on December 14 Judge Tell declared that artificial hydration and nutrition could be withdrawn from Nancy Beth. Nancy Beth died of natural causes on December 26, 1990.

Unlike his response to a similar decision of Judge Tell in 1988, William Webster, the Attorney General of Missouri, did not appeal the decision of 1990. He maintained that "The state is no longer interested in the Cruzan case." But allowing Nancy Beth Cruzan to die of natural causes was not the final curtain for the Cruzan case. There is some

unfinished business. Namely, revoking the ethical reasoning the Supreme Court of Missouri expressed when reversing the original decision of Judge Teel. Otherwise, many other families will experience the same anguish and suffering as did the Cruzans and future legislation of Missouri in regard to removing life support will be flawed.

Clearly, decisions of courts are based more upon legal precedent than upon ethical reasoning. But some reliance upon ethical reasoning is required in order to formulate equitable court decisions. As the Missouri Supreme Court stated in the Cruzan case: "We remain true to our role only if our decision is firmly founded on legal principle *and reasoned analysis*." Reasoned analysis is another term for ethical reasoning. What was the ethical reasoning underlying the Missouri Supreme Court decision in the Cruzan case?

### THREE ASSUMPTIONS

Three assumptions underlie the efforts of the Court at ethical reasoning. All three assumptions seem deficient when examined in the light of ethical norms for removing life support from people who suffer from a fatal pathology. First of all the Court assumes that allowing a person to die because therapy is ineffective is the same as killing the person. The Court stated: "This is not a case in which we are asked to let someone die ... This is a case in which we are asked to allow the medical profession to make Nancy die by starvation and dehydration." "Making someone die," or "causing the

priority they give health care. If they are informed and if they participate in structuring the tax burdens and the distribution of health benefits, I believe they will be willing to pay for that which they appear to value highly if they perceive they have been treated fairly. A nation which spends four billion dollars annually on potato chips can provide its citizens with a high level of medical care.

*\*Reprinted with permission from Frontlines (Vol 7, No. 2), October 1990. Frontlines is published by the Center for Health Ethics and Policy, The University of Colorado at Denver, 1445 Market Street, Denver, CO 80204 USA.*

death" of another person means that the agent of the action intends the death of the other person, and by placing or omitting actions brings about death. When a person will not benefit from medical care however, the intention of people removing the care is not to bring about death, but rather to admit that the illness or pathology threatening death cannot be treated in a manner that is beneficial for the patient. When life support is removed from a patient because it is not beneficial, we are simply admitting the limits of human ingenuity and medical science. How many times do people express their intentions when support is removed from loved ones, uttering such phrases as: "We cannot help Mom anymore;" or "Dad would not want to live in this condition." While the distinction between intending death and admitting human limitations is a fine one, it is realistic. Good ethical distinctions are thin as silk and strong as steel. In the case of persons in persistent vegetative state or in other conditions in which therapy is either ineffective or would impose a grave burden, removing life support does not *cause* death. Rather, removing life support allows death to occur as the result of a natural pathology which is not beneficial to resist. There is no moral imperative to prevent people from dying if they are in PVS or suffer from other severely debilitating conditions from which they will not recover.

Moreover, the Court's statement that Nancy Beth would die of starvation and dehydration if life support were removed is inaccurate as well as inflammatory. This language brings to mind a vision of a conscious and healthy person dying an excruciating death because she is deprived of beneficial care. Reference to "starvation and dehydration" of PVS patients has little relation to reality. People in PVS die because of injury to their cerebral cortex.

Just as they can no longer chew or swallow, so they do not feel pain. (*Neurology* 1/89; p. 125ff)

The second assumption underlying the decision of the Missouri Supreme Court in the Cruzan case is that persons suffering from fatal pathologies must be kept alive as long as possible. The Court expresses this assumption by consistently referring to the fact that Nancy "is not terminally ill" and for this reason would not allow removal of life support. Others repeated this error by stating: "Nancy is not dying."

---

***First of all the Court assumes that allowing a person to die because therapy is ineffective is the same as killing the person.***

---

But both statements imply that Nancy's fatal pathology would be assessed ethically only after life support has been utilized. To be "terminally ill" in the mind of the Missouri Supreme Court means that a person will die *even if* life support has been applied. According to this assumption respirators, dialysis, and especially artificial hydration and nutrition should not be removed unless they fail to prolong life. But when assessing whether or not to use or continue life support, the essential question is not *if* life can be prolonged, but rather *whether* life should be prolonged. Will the person benefit if life is prolonged? In ethical reasoning the questions "will the life support impose a grave burden, and will the life support be effective" are asked before life support is utilized. The Illinois Supreme Court recently presented a more accurate interpretation of terminal illness. It stated: "If the very delay caused by the procedures were allowed to govern the assessment of imminence, the definition of a terminal illness would be rendered circular and meaningless and make it impossible for compassionate care for people unable to

benefit from therapy. *Imminence must be judged as if the death delaying procedures were absent*" (Greenspan Case; 7/90). Hopefully, this insight in regard to "terminal illness," which is more in accord with ethical reasoning will become accepted across the country. If so, much of the misunderstanding and contention which surrounds the removal of life support should be obviated.

The third assumption underlying the Court's decision was that "The state's interest is not in the

quality of life. The state's interest is an unqualified interest in life." If quality of life implies impaired function due to serious pathology, and if the state has no interest in quality of life, then every means possible must be utilized in order to prolong the life of every person suffering from any impaired function whatsoever. How severely impaired the person might be would not matter, as long as the person could be kept alive. According to this thinking, we should consider kidney transplants for people in PVS who have end stage renal disease and heart transplants for people in PVS who have chronic cardio-myopathy. These conclusions are ludicrous but in accord with the Court's reasoning. All other state courts which have rendered decisions in PVS cases have admitted a reasonable limit to state interest in the face of seriously impaired function. As Judge Blackmar pointed out in his dissent to the majority opinion in the Cruzan case, if Missouri has an unqualified interest in preserving life, how explain the existence of capital punishment and the Living Will law in Missouri.

## Ethical Issues in Health Care

(continued from page 11)

### CONCLUSION

The "reasoned analysis" of the Missouri Supreme Court in the Cruzan Case should be analyzed and improved in the light of basic ethical principles. Until it is,

---

***The family forum is public; not only family members but physicians, nurses, clergy and others are involved in the ultimate decision.***

---

there is unfinished business in the Cruzan Case. But in a certain sense, the decisions of the Court and the supporting argumentation are beside the point. More important is the question: Is the court the place to decide questions which concern prolonging life for persons severely debilitated as the result of fatal pathologies? Questions of this nature have been settled in the family forum for years. Does the court do a better job than the family? The family forum is public; not only family members but physicians, nurses, clergy and others are involved in the ultimate decision. Moreover, the family forum has a more humane and compassionate motivation than the legal forum. Rather than being mainly concerned with state interest and legal precedent, the family forum is concerned with doing what is best for the patient.

Please send both your old and new addresses to:

**Gazette International  
Networking Institute (G.I.N.I.),**  
4502 Maryland Avenue, St. Louis, MO  
63108 when you move.

*Rehabilitation Gazette* will no longer be forwarded by your post office.

## Advance Directive Booklet Available

The Patient Self Determination Act will go into effect on December 1, 1991. As a result of this USA Federal Legislation, Advance Directives will become more important in the provision of health care.

Kevin O'Rourke, O.P., and the staff of the Center for Health Care Ethics at St. Louis University Medical Center, have written a unique booklet which helps people execute a legally valid Advance Directive in light of the Christian faith.

Virginia Publishing Corporation, 232 N. Kingshighway, Suite 205, St. Louis, MO 63108, USA (314/367-6612 FAX 314/367-0727), publisher of "Advance Directive for Health Care Decisions: A Christian Perspective," is targeting hospitals

and nursing homes. It feels the booklet will:

- Enable them to present a clear and comprehensive Advance Directive to present and future patients.
- Insure that the requests made by patients and their proxies will be in accord with their pastoral mission.

Contact Virginia Publishing Corporation by mail, phone, or FAX for:

1. A free review copy.
2. Five inspection copies (enclose \$25.00).
3. A price list for bulk copies which can include hospital name on cover.

Individuals may order a copy for \$5.00 (postpaid).

# Potpourri

福

## INFORMATION FOR VENTILATOR USERS

### Directory of Sources for Ventilator Face Masks

Bud Blitzer, ventilator user, compiled this 16-page directory which is available for \$2.50 postpaid. Please send a check (no cash) made out to G.I.N.I., 4502 Maryland Ave., St. Louis, MO 63108 USA. If you know of other sources for future listings, write to Bud Blitzer, 400 S. Saltair, Los Angeles, CA 90049 USA.

### Ventilator User Survey

The Spring, 1991 (Vol. 5, No. 1) of *I.V.U.N. News* contained a four-page ventilator user survey. If you did not receive this issue, and are a ventilator user, please request it from G.I.N.I., 4502 Maryland Ave., St. Louis, MO 63108. Your participation is important and will be appreciated.

## INTERNATIONAL EXCHANGE OF EXPERTS AND INFORMATION IN REHABILITATION

The International Exchange of Experts and Information in Rehabilitation (IEEIR) is actively seeking fellowship applications from the disability community for brief overseas study-visits to take place in countries in Asia (all-inclusive), the Pacific region, and/or Africa.

The project, funded by the National Institute of Disability and Rehabilitation Research (NIDRR), has monies for ten 3-5 week study-visit fellowships per year.

One of the priority areas in this current project which runs until September 30, 1993 is to increase involvement in disability advocacy issues. Several countries

have expressed an interest and/or some kind of need to have recognized rehabilitation professionals with disabilities from the West who are tuned in to cultural differences visit their countries.

Although the main objective of the IEEIR is to "import" to the U.S. information about exemplary programs in other countries, we feel it is important to arrange exchanges where both sides will benefit from the U.S. fellow's study-visit. If you have an idea and wish to pursue it, please contact: Diane E. Woods, Project Director IEEIR, International Exchange of Experts and Information in Rehabilitation, University of New Hampshire, Institute on Disability, 6 Hood House, Durham, NH USA 03284-3577 (603/862-4767).

### **NINDS SEEKS APPLICATIONS TO STUDY STROKE**

The National Institute of Neurological Disorders and Stroke invites investigators to submit research applications concerning stroke.

Stroke remains a leading cause of death and a prime cause of disability in the United States, with nearly half a million Americans suffering an acute stroke annually. Grant applications are being sought for basic, applied, and clinical studies related, in the broadest sense, to the etiology, prevention, early diagnosis, and treatment of stroke as these may relate to blacks, other minorities, and women.

For more information, potential applicants should contact: Dr. Patricia Grady, NINDS, Federal Building, Room 8A-13, Bethesda, MD 20892 USA (301/496-4226).

福

### **ANTHOLOGY ON REPRODUCTIVE AND SEXUAL RIGHTS AND DISABILITY**

We are seeking submissions for an anthology which will explore the sexual, reproductive, and family-life rights of people with disabilities. We welcome work by both professionals and non-professionals. The anthology will include fiction and poetry as well as articles. Our goal is to include a wide variety of approaches to legal, personal, and political issues.

The deadline for abstracts or outlines (either in print or on tape) is September 1, 1991. Include your resume or a brief biographical note with your submission to: Barbara Faye Waxman, P.O. Box 127, 8863 Pico Blvd., Los Angeles, CA 90035 USA or Anne Finger at Department of English, Wayne State University, Detroit, MI 48202 USA. For additional information, please contact Ms. Waxman.

This project is funded by a grant from the Norman Foundation to All The People, a not-for-profit organization which develops disability-related media.

### **SEARCH FOR COMPUTING TO ASSIST PERSONS WITH DISABILITIES**

A national search for computer based application to help persons with physical or learning disabilities is being conducted by The Johns Hopkins University with grants from the National Science Foundation and MCI Communications Corporation.

A grant prize of \$10,000 and more than 100 other prizes will be awarded for the best ideas, systems, devices and computer programs developed by professionals, amateurs, and students. Entry deadline in August 23, 1991. For an entry blank write to: Computing to Assist Persons with

Disabilities, P.O. Box 1200, Laurel, MD 20723 USA.

### **HOLOCAUST MEMORIAL MUSEUM REQUEST**

The United States Holocaust Memorial Museum which will open its doors to the public in April, 1993, is seeking information for its Identity Card Project. The United States Holocaust Memorial Museum's ID Card Project will use personal narratives of actual Holocaust victims and survivors to lead each visitor through the years of the Nazi regime.

Upon entering the museum, each visitor will receive an identification card of an actual Holocaust victim, who will be of the same gender and approximate age as the visitor.

At specific locations, the visitor will insert his or her card into a computer which will print an updated segment correlated to the exhibition. Therefore, the visitor will get a glimpse into the life of the victim at different stages of the Holocaust.

Anyone who has information that would be useful for the project, such as diaries, journals, letters, or narratives detailing their experiences during the Third Reich, should contact: ID Card Project, The United States Holocaust Memorial Museum, 2000 L Street, NW, Suite 717, Washington, DC 20036 USA (202/822-6464).

### **FREE RESOURCE GUIDES AVAILABLE FROM NARIC**

Resource guides on traumatic brain injury and spinal cord injury are currently available free-of-charge by calling or writing NARIC (National Rehabilitation Information Center), 8455 Colesville Road, Suite 935, Silver Spring, MD 20910-3319 USA (800/346-2742 or 301/588-9284 — both voice/TDD).



# FRIENDS AROUND THE WORLD

Each year the International Polio Network works to promote awareness of polio and its late effects. This year's effort prompted the following response from Louis S. Sullivan, M.D., the Secretary of Health and Human Services:

## THE SECRETARY OF HEALTH AND HUMAN SERVICES

WASHINGTON, DC 20201

May 28, 1991

Ms. Joan Headley, Executive Director  
International Polio Network  
4502 Maryland Avenue  
St. Louis, Missouri 63108

Dear Ms. Headley:

I am pleased to recognize the week of June 1 through June 7, 1991 to promote awareness of polio and its late effects and to offer my support to those brave polio survivors across the country.

Today there are an estimated 650,000 paralytic polio survivors in the United States. Many of them suffer from post-polio syndrome, a recurrence of polio's symptoms decades after the original illness, even though no polio virus is present in the body. In addition to pain, fatigue, and muscle weakness, symptoms can include difficulty in sleeping, breathing and swallowing, and rarely, respiratory problems. Having overcome polio once, post-polio patients often experience intense emotions such as denial, anger, frustration, and hopelessness as they must once more learn to accept and cope with new limitations.

No cure exists for post-polio syndrome, but it can be treated with a regular exercise program, physical therapy, weight loss, and drug therapy, such as anti-inflammatory drugs. Most patients can adapt and improve the quality of their lives if they rest when tired, exercise moderately, control their weight, and avoid smoking and drinking alcoholic beverages.

Scientists cannot explain what causes polio's symptoms to recur nor why the syndrome targets some people and not others. Thanks to dedicated investigators supported by such Federal agencies at the National Institute of Neurological Disorders and Stroke, we continue to learn more and more about polio and its late effects.

Much remains to be done, however. The Decade of the Brain provides exciting new opportunities to discover the answers to the mysteries of polio and its late effects — knowledge critical to the development of new treatments — and ultimately, to our ability to conquer polio once and for all. Working with the National Institute of Neurological Disorders and Stroke are voluntary health organizations such as the International Polio Network. I commend your efforts to wage a three-pronged attack on polio through support of research, patient support, and public education. Your enthusiasm and accomplishments are fundamental to our ability to help understand and meet the challenges created by this complex disorder.

My thoughts are with you and you have my very best wishes for continued success.

Sincerely, Louis W. Sullivan, M.D.

## UPDATE ON THE LATE EFFECTS OF POLIOMYELITIS IN FRANCE

For the last two years, the quarterly review *Le Point Carre*, mainly intended for people paralyzed by an accident, has published a post-polio section for both professionals and survivors. We are now ready to accept contributions which we can translate into French. Contributions should be sent to: Club des Loisirs et d'Entraide de l'Hopital Raymond Poincare 11, rue Claude Laird, 92380 Garches, France.

Thanks to an agreement with **Gazette International Networking Institute (G.I.N.I.)**, the Association des Paralyses de France (A.P.F.), 17, boulevard Auguste Blanqui, 75013 Paris, France, is publishing (summer, 1991) the "*Manuel des effets a long terme de la poliomyelite, pour les medecins et les post-polios.*" This book includes:

- The *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors*, edited by Gini Laurie, et al (1984) translated into French;
- An additional chapter devoted to updating the bibliography (1990) by four French polio survivors including an M.D.;
- A note on the nomenclature of the late effects of poliomyelitis (1990) by a French specialist;
- A medical-social chapter which includes centers and associated physicians who have agreed to be officially listed for medical follow-up. They are also listed in International Polio Networks's *Post Polio Directory-1991*.

The Association d'Entraide des Polios et Handicapes (ADEP), 194, rue d'Alesia, 75014 Paris, France, is in charge of gathering books,



publications, theses, etc. This collection is available to physicians, other professionals, and to polio survivors.

Questionnaires were sent in early 1991 to French post-polio individuals. The project is supported by the Societe Francaise de Medecine de Reeduction et de Readaptation and the Institut National de la Sante et de la Recherche Medicale.

One of our goals is to obtain better support of post-polio patients for their medical-social problems from all concerned parties.

The creation of a specific association for polio survivors does not appear useful in France. We, instead, encourage polio survivors to join the existing multi-disability associations. Collaboration between these associations is also actively encouraged as is the collaboration with professionals and survivor circles abroad.

*Polio Network News* and *International Polio Network* are essential as a link to that part of our activity. **Henri Charcosset**, 22, avenue Condorcet, 69100 Villeurbanne, France; **Dr. Catherine Cousergue**, 27, chemin des Maraichers — Bat C, 31400 Toulouse, France and **Nicole et Gerard Richier**, 63, route de Delbex, 15000 Aurillac, France.

## POST-POLIO SUPPORT GROUP OF SOUTH AUSTRALIA, INC.

"I must admit that when I came back from the Fifth International Polio and Independent Living Conference in St. Louis I felt that I was coming to a setting where the interest in polio-related issues by health professionals was non-existent. We had a lot of patients asking to be referred to a doctor who was interested in post-polio and no one who was prepared.

"In South Australia we now have two specialists, one a physician and one a rehabilitation specialist, who are prepared to set up

polio clinics. Western Australia has a clinic run mainly by voluntary health professionals, and New South Wales has an ongoing polio facility in one of their public hospitals.

"Considering the size of the problem, all this was really not enough. We have published two booklets by Charlotte Leboeuf: *The Late Effects of Polio: Information for the Care Providers* and *A Practical Approach to the Late Effects of Polio*. These booklets (approximately 40 pages) are available to Australians for \$2.00 handling and postage. We are receiving requests for the booklets from general practitioners each day, so I am hoping that we will soon have a pool of health professionals who are interested in and informed about post-polio.

"At present I am working with several other health professionals on developing a major research project to establish what the treatment needs are in South Australia, and we will use the results to obtain funding for adequate treatment facilities.

"We are planning a national conference on post-polio the 13th and 14th of March, 1992. The theme will be the same as the booklet "Managing the Late Effects of Polio" and will give an overview of management.

"Dr. Roy Lee, who is our rehabilitation specialist, will be visiting Ranchos Los Amigos, Downey, CA, later on this year." **Heather Trenorden**, Post-Polio Support Group of S.A. Inc., Neurological Resource Centre of S.A., Inc., 37 Woodville Road, Woodville, South Australia, 5011 (08/268-6222).

## THE SEARCH FOR ANSWERS

"Although I have never experienced a bout of polio I find a great deal of personal support on the pages of *Polio Network News* and *Rehabilitation Gazette*. The reason is that for the last eight

years I have had Chronic Fatigue Syndrome (CFS), and many of my ongoing symptoms are surprisingly like those of post-polio syndrome. (Difficulty with swallowing was the first symptom that sent me to a doctor, who was baffled and intimated that I might have a psychosomatic disorder!) The similarities between CFS and post-polio syndrome — however tenuous — have prompted me to educate myself about the life-altering effects of polio.

"Physicians seem to be non-plussed by a new range of baffling symptoms, and research funding for serious studies seems not to exist. Individuals have trouble finding information that is consistent or helpful, and some medical advice has even proven to be injurious to their self esteem.

"I realize that medical research has not yet produced a definitive diagnostic test for CFS or fibromyalgia or post-polio syndrome, but I want to make an honest inquiry: I wonder if any of your readers suspect a correlation among these "new" syndromes? Is anyone aware of studies which have explored this possibility?

It may seem far-fetched to link these three syndromes.

"With an open mind, I continue my own search for accurate, responsible information trying to winnow out the misleading or inappropriate material and will be interested to learn what others may know about possible post-polio syndrome/CFS/fibromyalgia links and successful schemes for dealing with the symptoms of each." **Carol Greentree**, 8720 Villa La Jolla Drive, Suite 109, La Jolla, CA 92037 USA.

We welcome items or articles for the  
**Rehabilitation Gazette.**

Please send them to:  
Joan Headley,  
4502 Maryland Avenue,  
Saint Louis, MO 63108 USA.

## UPCOMING EVENTS

**Fifth Annual Post-Polio Conference**, Pine Tree Camp for Handicapped Children & Adults, **Bath**, ME USA, July 20, 1991. Contact: Rick Meade (207/443-3341).

**Ohio Polio Network Post-Polio Conference**, Holiday Inn on the Lane, **Columbus**, OH USA, August 24, 1991. Contact: Betty Sugarman, Ohio Easter Seal Society, 2204 S. Hamilton Road, Columbus, OH 43232-0462 USA (614/868-9126).

**Second Colorado Post-Polio Educational Conference**, Westin, **Denver**, CO USA, September 13-14, 1991. Contact: Alison Kron (303/233-1666).

**Mississippi Polio Survivors Association Quarterly Meeting**, Busey Auditorium, Baptist Medical Center, **Jackson**, MS USA, September 14, 1991. Contact: Benton Kane (601/355-0545) or Robert Thayer (601/924-9284).

**The Second Texas-Oklahoma Post-Polio Symposium**, Wichita Falls Ramada Inn, September

21-22, 1991. Contact: Barbara Miller, 4503 Allison, **Wichita Falls**, TX 76308 USA (817/691-3497).

**Third Provincial Conference on Post-Polio — The Late Effects**, Holiday Inn South, 1330 Pembina Highway, Winnipeg, Manitoba, Canada, September 27-28, 1991. Contact: Post-Polio Network (Manitoba), Inc., c/o Canadian Paraplegic Association, Inc., 825 Sherbrook St., **Winnipeg**, Manitoba, R3A 1M5, Canada.

**Greater New York Post-Polio Conference**, Marriott Hotel, **Uniondale (Nassau County)**, New York USA, Sunday, October 13, 1991. Contact: Mike Kossove, Touro College (516/351-8888).

**Independence 92, International Congress & Exposition on Disability**, Vancouver Trade & Convention Centre, British Columbia, Canada, April 22-25, 1992. Contact: Independence 92, Suite 200, 1190 Melville Street, **Vancouver**, B.C. V6E 3W1 Canada (604/689-5084).

福

## THE GINI LAURIE ENDOWMENT

"I prefer to think of the movement as an interdependent living movement rather than as an independent living movement."

Gini Laurie, September 18, 1988,  
Springfield, Illinois

The Board of Directors and the staff of Gazette International Networking Institute (G.I.N.I.) are diligently working to continue Gini Laurie's lifelong work. On the second anniversary of her death, we seek your continued support by asking you to contribute to The Gini Laurie Endowment, G.I.N.I., 4502 Maryland Avenue, St. Louis, MO 63108 USA. Because G.I.N.I. is a nonprofit 501(c)(3) organization, your contribution is tax-deductible.

Please add my enclosed contribution of \$\_\_\_\_\_ to The Gini Laurie Endowment.

Name \_\_\_\_\_

Address \_\_\_\_\_

☐ Use \$25.00 for my annual subscription fee to *Rehabilitation Gazette*, *Polio Network News*, and *I.V.U.N. News*, and the *Post-Polio Directory*.