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CENTER NOTES

"When my time comes, I want to die with some degree of dignity, in peace and with purpose."
Robert E. Kavanagh

This year marks the tenth anniversary of the decision by the New Jersey Supreme Court in the case of Karen Ann Quinlan. In this landmark case the court approved the removal of life supports from Ms. Quinlan, who was irreversibly brain-damaged but not brain dead. Those who are interested in medical ethics issues are in Karen Quinlan's debt for raising public consciousness of the issues of medical ethics.

Ten years later, a similar case arose, and it received a great deal of publicity. This case concerned Paul Brophy, a 49-year-old former firefighter, who was in a vegetative state for several years, after suffering irreversible brain damage from a cerebral hemorrhage. He was incapable of any communication, verbal or nonverbal, and had to be fed by tube.

Mr. Brophy's wife and family requested that his G-tube be withdrawn and that he be allowed to die, but the attending physician and hospital did not agree. So the case went to court. On September 18, the Massachusetts Supreme Court ruled in favor of Mrs. Brophy.

This important legal case dealt with an important ethical question: whether artificial feeding can be discontinued in the case of someone who is hopelessly ill – if not terminally ill.

Paul Brophy died October 23, after 3½ years in a vegetative state. The Brophy case itself has come to a close, but its effect on law and medical ethics continues.

Myra Christopher
Executive Director

The Law

by David L. Wing

AIDS
and Handicap Discrimination Laws

As persons with AIDS, AIDS-related complex (ARC), and persons who test positive for the AIDS virus antibody perceive that they have been discriminated against, some of them will look to the legal system for redress of their grievances, and they may look to federal and state handicap discriminations laws to support those claims. While claims under these laws are slowly winding their ways through governmental agencies and trial courts, it is likely to be many months and possibly years before courts have issued definitive opinions concerning AIDS and handicap discrimination. Thus, employers and others who are potentially liable under the statutes must assess their risks based upon the information that is now available.

The starting point for any analysis of handicap discrimination laws is Section 504 of the Rehabilitation Act of 1973 (1). This section imposes upon employers who are recipients of federal assistance a duty not to discriminate against "handicapped" persons. Similarly, Section 503 of the Act imposes the same duty upon federal contractors. The definition of handicapped is broad and includes a physical or mental impairment which substantially limits one or more of the person's major life activities; it also covers persons merely regarded as having an impairment (2).

The federal government recently interpreted Section 504 of the Act in an unexpected way. In response to an inquiry from the Department of Health and Human Services the Department of Justice, which enforces this Act, issued an interpretation on June 20, 1986 concerning the application of Section 504 to persons with AIDS, ARC, or AIDS virus antibody positivity. (3)

The Department maintains that a person suffering form the disabling effect of AIDS or ARC (or a person who is perceived to be suffering from those effects) can be considered handicapped because such a person has a mental or physical impairment which substantially limits one or more major life activities, or is regarded as having such an impairment.(4) However, the Department further contends that the mere ability to transmit a disease or merely being regarded as able to transmit a disease is not such an impairment. Thus, the Department concludes that any employment deci-

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AIDS and Handicap Discrimination Laws

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sion made on the basis of fear of contagion (rather than because of a person's impairment) is **not** discriminatory, whether or not the person has AIDS, ARC, antibody positivity, or is merely perceived to have such conditions.(5)

One surprising aspect of the DOJ interpretation is that it defines handicap in such a way as to exclude the otherwise healthy carrier of a virus. This DOJ AIDS memo contends that an otherwise healthy carrier does not have a mental or physical impairment substantially limiting one or more major life activities. The Department refuses to recognize the ability to transmit the virus of the increased potential for developing AIDS as an impairment. For instance, the memo does not address the fact that any carrier of a virus such as AIDS must substantially limit sexual conduct, a major life activity, if he or she has any sense of personal or social responsibility.

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Theodore M. Knapp

require insurance reimbursement for treatment of AIDS can receive, as policy holders, some of the pool reserved for sick people. Can we not, as citizens, join with insurers and employers in acknowledging that we have social and ethical obligations as well as economic boundaries? At best, out of our uncertainties and fears can emerge understanding and compassion to create a country in which we can be proud to live, and to die.

(1) formerly HTLV-III/LAV

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The second surprise in the DOJ memo is the recognition of fear of contagion of AIDS, no matter how

> "... the interpretation appears to be completely at odds with the medical evidence..."

unreasonable, as a legitimate basis for any employment decision. Without doubt, this interpretation appears at first blush to be protective of employers and very detrimental for employees with AIDS, ARC, antibody positivity, or anyone who might regarded as having any of the above conditions. However, the Department's analysis is sure to be challenged when it is eventually raised in court proceedings. Most importantly, the interpretation appears to be completely at odds with the medical evidence and the guidelines of other federal agencies that the AIDS virus is not transmissible by casual contact in the workplace. Using an unreasonable fear of contagion as a basis for decisions, one could justify any number of bizarre employment decisions. For instance, an employer could refuse to employe an otherwise qualified person with cancer or with sickle cell anemia because of an alleged belief that these conditions are contagious. It is very difficult to believe any court would give even slight attention to such arguments.

One effect of the Department's interpretation may be to encourage employers to discharge all persons who are feared to be capable of transmitting the AIDS virus. If the employer waits until the employee is suffering from disabling effect of AIDS, a dispute could arise concerning whether the reason for the discharge was the disability, which is protected, or the fear of contagion, which is not protected. If an employer discharged only an employee with the disabling effects of AIDS allegedly because of a fear of contagion, the discharged employee could focus on the failure of the employer to discharge antibody positive employees without symptoms as evidence that the employer's alleged fear of contagion was a pretext, and the true reason for discharge was the protected physical disability of the individual.

At this point, no one can tell whether the Department's interpretation will be accepted. The courts are not bound to follow the Department's analysis or result. Because an affected person can file a private cause of action against an employer under Section 504, the Department many not even be directly involved in the litigation that will resolve this issue.

Additionally, almost all states have handicap discrimination laws and these laws are not subject to the Department's interpretation. One state case interpreting the Massachusetts handicap discrimination law agreed with the Justice Department's opinion that the disabling effects of AIDS would qualify as a handicap(6). However, the Massachusetts court expanded the definition of handicap from the

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Department of Justice memo somewhat and noted that it is the potential to contract other illnesses that constitutes the handicap. Thus, a person with AIDS who dose not presently suffer from any adverse physical effects of AIDS would still be considered handicapped. Moreover, the

Massachusetts court expressly refused to adopt the Department's position on fear of contagion. The court noted that a person with AIDS "may also qualify as a protected handicapped person based solely on an employer's erroneous perception of him as someone who is contagious to co-workers."

Aggressive employers covered by the Act who have no fear of litigation may decide to focus on the fear of contagion in discharging employees, relying on the Department's interpretation. Other covered employees may choose to take a more conservative approach and treat even an asymptomatic person who might be capable of transmitting the AIDS virus as possibly protected by the Act. This latter approach is consistent with the mainstream of legal opinion from attorneys who have been most closely following the development of AIDS legal issues. The supposed fear of contagion defense for employers is not considered a safe harbor. Certainly, any employer who is contemplating discharging an employee, relying on the Department's fear of contagion defense should discuss the action with legal counsel knowledgeable in this area.

(1) 29 U.S.C. S 794 (1985).
(2) 29 U.S.C. S 706(7)(B) (1985); 41 CFR S 60-741.2 (1985).
(3) Memorandum from Charles J. Cooper, Department of Justice, to Ronald E. Robertson, Department of Health and Human Services, June 20, 1986.
(4) Id. at 1, 22-29.
(5) Id. at 29-36.
(6) *Cronan v. New England Telephone Co.*, CA No. 80332 (Mass. Sup. Ct., Suffolk County).

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The Killing Will

Ernest W. Johnson

Our spring 1986 issue concerning living will laws was generally in favor of them. This author presents another view.

A fashionable, widely practiced notion is the execution (double entendre) of a "living will." This document projects an exodus from a terminal sickness or injury...permission given ahead of time to relatives or physicians to detach or otherwise disable life-extending devices.

In other words, it suggests that spouse or physician murder someone. It prescribes a planned suicide with or without assistance from family, friends or health professionals. Witness the controversial recent book, *Last Wish,* in which Betty Rollin describes how she helped her 76-year-old mother with cancer to die prematurely.

The term "living will" is an oxymoron–an intrinsic contradiction akin to calling the MX missile a "peacekeeper." Perhaps it is appropriate to label it a euphemism–like "revenue enhancement" for "taxes."

My inclination as a physician is to approach these situations with flexibility and tolerance. Technology is changing our practice but we shouldn't be stampeded into supporting legal solutions for defining death. Judges can't practice medicine.

Brain death is human death. Determination of brain death is more accurate now but we still should exercise caution in shutting off the life support systems. Examples abound, even today, of individuals existing in "irreversible" coma for several months who then recover to have useful lives.

A recent TV segment presented an elderly man with ALS (Lou Gehrig's disease) and a tracheostomy and ventilator. His wife wanted to end his (her?) suffering. As the video interview continued, it seemed clear to many of the viewers that he didn't want to die in spite of his previous "living will."

We have ways of breathing (without compromising communication) for patients who need ventilation assistance. A ventilator is *NOT* an extraordinary means of survival. Ask the thousands of post-polio people who have been on ventilators for 30 years or more.

Only our brain makes us human, and technologies to keep the brain viable and thinking *ARE* rational and appropriate! If we need to use kidney dialysis, a heart pacemaker, a ventilator–hats off to technology. All of these life extenders are, in principle, no different than giving insulin to a diabetic or penicillin for pneumonia.

The Living Will is a license for murder or suicide. Or, more accurately, it can be described as a technique to minimize the suffering of the *relatives* and *health professionals* caring for the patient. William Osler, our honored forebear, reportedly philosophized that the most uncomfortable people in a terminal situation were the relatives, physicians and nurses–NOT the patients. Intractable and unbearable pain is almost always in the eyes of the beholder–either the health professional or the family member.

A "living will" is–as we used to say in the Army–"anticipating the command."Our will to live is strong and over-riding; "don't hasten death" is sound advice in most situations. A "living will," on the other hand, is permission for killing.

Reactive depression at these difficult times clouds clear thinking, fosters irrationality and may result in a wrong decision about giving permission to die prematurely. Whether passive or active measures terminate the life is irrelevant and only distracts from the crucial decision of killing someone. Programming death is murder if done by others, or suicide if unassisted.

Life is priceless and should not be "willed away." As Yogi Berra so inaptly phrased it: "It's not over 'til it's over."

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