



**Manitoba league of  
persons with disabilities**

**October, 2000**

***“Exploring Issues for Canadians with Disabilities”***

**Sponsored by the  
Council of Canadians with Disabilities**

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**for the  
MANITOBA LEAGUE OF PERSONS WITH DISABILITIES**

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## Executive Summary

The intent of the “**Do Not Resuscitate (DNR) Orders and Persons with Disabilities**” project was to create a research paper that explored the many aspects involved in the complicated process of discerning the appropriateness of placing DNR Orders on persons in Manitoba. Particularly emphasized is the threat perceived by many persons with disabilities regarding the value of their lives, and the vulnerability they feel with the law in Manitoba pertaining to the placement practices of DNR Orders as it stands now. The project objective included developing an understanding within the disability community in Manitoba of the legal, ethical and medical issues surrounding DNR Orders. It also involved developing an understanding within the medical community of the concerns of people with disabilities regarding DNR Orders. At the conclusion of the project these findings are presented to various voices representing Manitobans. These include:

- persons from the medical and medical ethics sectors;
- representatives from the various Regional Health Authorities (RHA's);
- persons involved in the legal aspects of DNR Order application; and,
- persons with disabilities who might be affected by any governance concerning DNR Orders and their applications.

Further research into the legal dimensions of DNR Order placement was conducted by Sherri Walsh, L.L.B., and is included separately as a part of this report.

The **first** chapter of this document contains a glossary of terms to help the reader navigate the sometimes difficult language associated with end-of-life issues. There is also a review of the history of DNR Order placements, the developments of various understandings regarding DNR Orders, and issues concerned with these understandings. This includes a description of

precedent setting legal cases, including those which occurred in Manitoba, namely *Lavallee v. CFS Manitoba* and *Sawatzky v. Riverview Health Centre*.

Other related cases across Canada are also reviewed.

Various cultural understandings of end-of-life issues are explored in the **second** chapter. Included in this section is the description of the first assisted suicide case brought to a Canadian court involving an Inuit community in 1963.

The lessons learned in exploring these cultural understandings provide a setting to examine the current context in which DNR Order applications exist. The **third** chapter looks at current discussions held by ethicists pertaining to DNR Orders. It also examines the positions taken by the Manitoba League of Persons with Disabilities, the Manitoba Medical Association, the College of Physicians and Surgeons, Manitoba Health and the law as it stands at the time this paper was written. Included in this section are the results of a survey of Manitoba physicians charting their opinions regarding such end-of-life issues as euthanasia and assisted suicide. This chapter also contains the results of a questionnaire sent to each Regional Health Authority in Manitoba and rural and urban hospitals, long-term care facilities, and health centres across the province. Following this is a summary of the Final Report of the Standing Senate Committee led by the Honourable Sharon Carstairs entitled, *“Quality End-of-Life Care and the Right of Every Canadian.”* The chapter concludes with discussions on what constitutes “quality of life,” including a description of material written by Francoise Baylis, Dick Sobsey, and a strong story of two physicians who underwent considerable transformations in their understandings of what “quality of life” meant to them.

The **fourth** chapter emphasizes the importance of hearing the voices of persons with disabilities in any discussion regarding DNR Order policies, DNR Order placements, and understandings of what constitutes “quality of life.” Current statistics regarding the representation of Manitobans with disabilities in various health policy decision-making bodies were gathered for this project and are reported in this chapter. Also found here are several written articles describing the perspectives of persons with disabilities and accounts of the experiences of Manitobans with disabilities encountering Do

Not Resuscitate Orders.

This paper concludes with recommendations for future actions. These recommendations have been divided into two sections: the first being recommendations for actions on the part of individuals so that persons can be as prepared as possible for any encounter with a DNR Order placement; and the second section being recommendations which encourage policymaking bodies such as the various structures of government and medical institutions, to re-examine the issues involved with DNR Orders, their placements, and the implications they have for all citizens of Manitoba.

The development of a protocol regarding the placement of DNR Orders using the knowledge gained from multiple sources, including the grassroots Manitoba citizenry provides an opportunity for those most likely affected by this practice will help answer the most basic of queries, namely – *WHO FITS THE CATEGORY OF HAVING A LIFE UNFIT FOR LIFE?*

## Scope and Outline of the Project

The Manitoba League of Persons with Disabilities (MLPD) was approached in the fall of 1998 with a request for support by Helene Sawatzky, who's husband Andrew was a resident of the Riverview Health Centre in Winnipeg. This need for support arose because the Sawatzky's were deeply concerned about a "Do Not Resuscitate" (DNR) Order which had been placed on Mr. Sawatzky's medical chart. This placement had occurred without the medical staff obtaining consent from either Andrew or Helene Sawatzky. They had to take the issue to court in order to have the DNR Order removed. The MLPD was sought out by them to assist as an advocate on behalf of this individual's rights; in doing so, the League played a role as intervener in the subsequent court case in support of the Sawatzky's.

This particular involvement served as an impetus for a research project conducted by the MLPD which examines the questions and issues arising out of this situation. The project objectives include the development of an understanding within the disability community in Manitoba of the legal, ethical and medical issues surrounding DNR Orders. It also involves developing an understanding within the medical community of the concerns of people with disabilities regarding DNR Orders. The project will conclude by bringing together various voices representing Manitobans - these would include:

- persons from the medical and medical ethics sectors;
- representatives from the various Regional Health Authorities (RHA's);
- persons involved in the legal aspects of DNR Order application; and,
- persons with disabilities who might be affected by any governance concerning DNR Orders and their applications.

The objective of this gathering is to put forward a model protocol that would

address the concerns surrounding the placement and removal of DNR Orders. Creating a “starting point” (such as a model protocol) for discussion regarding this sensitive and complicated topic could then be used for discussion purposes within the larger community. The development of a protocol regarding the placement of DNR Orders using the knowledge gained from multiple sources, including the grassroots Manitoba citizenry provides an opportunity for those most likely affected by this practice to influence decisions made in answering a very basic query - namely, *WHO FITS THE CATEGORY OF HAVING A LIFE UNFIT FOR LIFE?*

Research for this project was conducted as follows:

- the Chief Executive Officers and Chief Medical Officers of hospitals in Thompson, Flin Flon, The Pas, Dauphin, Brandon, Winkler, Beausejour and all hospitals in the Winnipeg area were contacted with a request to provide information regarding the practices they currently employ in their administration of DNR Orders, and the level of representation of persons with disabilities presently existing in those decision making bodies (i.e. ethics committees, policy making boards) which deal with the placement of DNR Orders.
- the Chief Executive Officers and Chief Medical Officers of all the Regional Health Authorities (RHA's) and Long Term Care Authorities throughout the province of Manitoba were contacted with a request to provide information regarding any protocols they have/have not established regarding the administration of DNR Orders in their catchment areas, and the level of representation of persons with disabilities presently existing in any decision making or feedback advisory bodies which deal with the placement of DNR Orders.
- examination of Manitoba government legislation and the Ministry of Health policies and responsibilities, as they pertain to the role of the Public Trustee and the Primary Care Mandate regarding DNR Orders.

- examination of such documents within Canadian legislation as;
  - ◆ the Special Senate Committee Report on Euthanasia/Assisted Suicide,
  - ◆ the Canadian Charter of Rights and Freedoms, and
  - ◆ the Canada Health Act.
- an overview of legal materials and Canadian judgements pertaining to disability rights, patients' rights, quality of life issues, euthanasia, assisted suicide, and unlawful death of vulnerable persons.
- a review of international decisions involving disability rights, patients' rights, and DNR Orders.
- obtaining the perspectives of members of the ethics and medical ethics community regarding current practices and possible future placement protocols for DNR Orders.
- an exploration of methods of establishing and implementing Living Wills and Advance Directives as they pertain to disability and patients' rights.
- interviews with individuals who have been directly affected by the placement of DNR Orders either on themselves or members of their families.
- the gathering of various disability perspectives on DNR Order experiences, quality of life judgements, and issues pertaining to assisted suicide and euthanasia.

Further research into the legal dimensions of DNR Order placement was conducted by Sherri Walsh, LLB, and is included separately as a part of this report.

## CLARIFICATION OF TERMS

### ***What do “CPR” and “DNR” mean?***

**CPR** (Cardiopulmonary Resuscitation) refers to the medical procedures used to revive a person’s heart and breathing when heart failure occurs. CPR may involve simple efforts such as mouth-to-mouth resuscitation and external chest compression. Advanced CPR may involve electric shock, insertion of a tube to open a person’s airway, injection of medication into the heart, and in extreme cases, open chest heart massage.

CPR, when successful, restores heartbeat and breathing and allows persons to resume their previous lifestyle. The success of CPR depends on a person’s overall medical condition.<sup>1</sup>

**DNR** (Do Not Resuscitate) **Orders** instruct medical professionals *not* to perform CPR. This means that doctors, nurses, emergency medical personnel, or other healthcare providers will not attempt emergency CPR if a person’s breathing or heartbeat stops.

DNR orders may be written for patients in a hospital or personal care home, or for persons at home. Hospital DNR Orders tell the medical staff not to revive the patient if cardiac arrest occurs. If a patient is in a personal care home or at home, a DNR Order tells the staff &/or medical emergency personnel not to perform emergency resuscitation and not to transfer the patient to a hospital for CPR.<sup>2</sup>

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<sup>1</sup>This definition is drawn from guidelines issued by the Canadian Medical Association (1995.)

<sup>2</sup>Ibid.

***What are some of the similarities and differences between the terms “DNR,” “Euthanasia,” and “Assisted Suicide?”<sup>3</sup>***

A **DNR Order** is a notation placed on a patient’s chart which states that if the patient should undergo respiratory or heart failure, no efforts should be made to resuscitate that individual. The placement of DNR Orders on patients’ charts in Manitoba can occur *without the consultation or consent of* the patient or someone acting on behalf of the patient’s best interests (sometimes known as a “patient surrogate,” a “proxy” or a “patient advocate.”) A distinction between DNR Orders and Euthanasia is that a death can occur because of a *lack* of action rather than the result of a deliberate action.

**Euthanasia** stems from the Greek term “*euthanatos*” which literally means “joyous” or “easy death.” Today’s euthanasia generally refers to mercy killing - the voluntary ending of the life of someone who is perceived as being terminally or “hopelessly” ill. Euthanasia has been defined in two ways:

- “**Active Euthanasia**” - whereby a healthcare provider takes a deliberate action that will induce death, such as administering morphine, insulin or barbiturates, followed by an injection of curare; and,
- “**Passive Euthanasia**” - which involves letting a patient die for lack of treatment or suspending treatment that has already begun. An example of this is the removal of a patient from a respirator or other life support system or stopping the food supply (usually intravenous feeding) to patients.

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<sup>3</sup>These definitions are drawn from a discourse regarding these definitions and their implications written by Anne Mullens in Timely Death: What We Can Expect And What We Need To Know. Toronto: Random House, 1997. See 25-26, 89-90, 94, 224-25.

Euthanasia is a deliberate action resulting in death that can occur without the patient's consent.

**Assisted Suicide** occurs when persons deemed as having terminal illness or a disability are aided in a deliberate act of ending their lives by physicians, loved ones or other care givers or acquaintances. The difference between euthanasia and assisted suicide occurs because the latter constitutes a joint action between the person wishing to die and another complying with those wishes.

These definitions show the distinctions between the terms DNR Order, euthanasia, and assisted suicide. Similarities exist because each of these terms deals with end of life issues, and, to a greater or lesser extent, undergoing the process of determining an individual's "quality of life." Currently in Canada it is illegal for someone to assist an individual in the act of suicide. However, there are many who support this action. (Derek Humphry's book "*Final Exit*," a guide for terminally ill people to commit suicide, became a bestseller in the United States in 1991.) Organizations such as the *Hemlock Society* offer encouragement and support for those who desire to take their own life with the help of others. Persons with disabilities have voiced repeatedly their concerns, expressing a sense of vulnerability because of a fear of not having the capacity to determine and/or have influence over a course of treatment. The devaluing of persons with disabilities which has existed historically and is still demonstrated in various situations today leaves persons with disabilities feeling more prone to such actions as the placement of DNR Orders without consent and the practice of euthanasia. It should be noted that many of the patients who's suicides were assisted by Dr. Jack Kevorkian, a well-known American advocate of this practice, were not diagnosed with terminal illnesses but had acquired a physical disability which led them to the conclusion that their lives were no longer worth living.<sup>4</sup>

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<sup>4</sup>There is extensive coverage in the [Detroit Free Press](#) of Dr. Kevorkian and his involvement in assisted suicide. References to the deaths of persons with disabilities can be found in the series "Suicide Machine." See the Detroit Free Press website for the entry Aug. 30, 1996.

There also exist organizations such as the American group “Not Dead Yet” who strongly oppose assisted suicide and have intervened in court cases where an appeal has been made to legalize assisted suicide.

### ***What are “Advance Directives” and “Living Wills?”<sup>5</sup>***

An **Advance Directive** (sometimes known as a “**Healthcare Directive**”) is a document which informs a doctor or other healthcare provider of the type of care a patient would like to have if he/she becomes unable to make medical decisions. Advance Directives can take many forms, and laws about advance directives vary from province to province.

A **Living Will** is one type of Advance Directive that usually only comes into effect when a person is deemed terminally ill. A Living Will is a legal document which states that the life of the person writing the will should not be prolonged under specified circumstances.

Currently in Manitoba, any requests within an Advance Directive for the cessation of treatment are honoured; however, if an Advance Directive states that there be the initiation or continuation of life-supporting treatment, this can be called into question by one’s attending physician or the hospital administration.

**It is important to note that while an Advance Directive and a Living Will allow patients to select someone to make decisions on their behalf in a surrogate or advocate capacity, it is recommended that this naming of a proxy occur through a “Power of Attorney.”**

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<sup>5</sup>Edmund D. Pellegrino, “Decisions to Withdraw Life-Sustaining Treatment: A Moral Algorithm.” Journal of American Medical Association. Vol. 283, No. 8, February 23, 2000. 1-7.

***What does “being competent” have to do with the placement of DNR Orders, and who determines if someone is competent?***

“**Competency**” is a term which describes one’s mental ability to perform a particular task or grasp a concept. When we are able to exercise judgement in making valid decisions in our day-to-day living, we are demonstrating our competency.<sup>6</sup>

Questions may arise in the course of health care as to a person’s capacity to make competent decisions, and if it is determined that a patient is no longer competent, the responsibility for making those decisions is placed with someone else. This transfer of decision making power can be made to a surrogate or proxy who is deemed as acting in the best interests of the patient, or to a medical facility itself.

Issues around competency have already risen with respect to the placements of DNR Orders in Manitoba. In cases such as the situation with the Sawatzkys, where patients have refused to consent to a DNR Order, the placement occurred against their wishes because they were deemed incompetent. When a family member objected to the placement of a DNR Order, she was deemed incompetent and the care of the patient was placed under the control of the Public Trustee. This decision was later reversed in the Manitoba Court of Appeal.

***What does it mean to be in a “persistent vegetative state?”  
When is one “permanently unconscious?” What does it mean to be “brain dead?”***

The American Academy of Neurology defines a **Persistent Vegetative State** as:

*“A form of eyes-open permanent unconsciousness in which the*

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<sup>6</sup>This definition is drawn from guidelines issued by the Canadian Medical Association (1995.)

*patient has periods of wakefulness and physiological sleep/wake cycles, but at no time is the patient aware of him or her self or the environment. Neurologically, being awake but unaware as the result of a functioning brainstem and the total loss of cerebral cortical functioning.*<sup>7</sup>

A Persistent Vegetative State (PVS) may be caused by a variety of injuries to the brain through accident or illness. Studies conducted on patients with PVS have led to the following conclusions:

*“All voluntary reactions or behavioral responses reflecting consciousness, volition or emotion at the cerebral cortex level are absent...there is no observable experience of pain or suffering...they remain permanently unaware.”*<sup>8</sup>

However, it is important to note that some of these same researchers state that although there is no observable experience of pain or suffering, they do not mean that there is nothing to observe.

*“The PVS patient may ‘react’ to painful stimuli, but does not ‘feel’ pain in the sense of conscious discomfort..”*<sup>9</sup>

**Permanent Unconsciousness** is a deep, prolonged unconsciousness in which a person cannot be aroused. This is usually a result of head injury, neurological disease, acute hydrocephaly, intoxication or metabolic derangement. Persons in this state *may be able to maintain respiratory functions*, but require maintenance of basic bodily functions.<sup>10</sup>

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<sup>7</sup>Daniel E. Deaton, “Questions Surrounding the Withdrawal of Artificial Hydration and Nutrition from Patients in a Persistent Vegetative State,” Journal of Biblical Ethics in Medicine, Summer 1992.

<sup>8</sup>K Mitchell, I Kerridge, & T Lovat, 1993, “Medical Futility, Treatment Withdrawal, and the Persistent Vegetative State,” Journal of Medical Ethics, 19, 71 - 76.

<sup>9</sup>Ibid

<sup>10</sup>This definition is taken from the “Medical-Links” web page created by the Pharmacy Association of Nova Scotia. Yarmouth: Electronic Publications.2000

**Brain Death** is a definition that carries much controversy with it.<sup>11</sup> No organism dies all at once. Major vital organs such as the brain, the heart, and the lungs can experience failure that can occur at different times from each other. Because of modern resuscitation techniques, failure of the heart or lungs does not necessarily mean the end of one's life. If, however, the heart or lungs cannot be revived and cease to operate, the brain will die of lack of oxygen. Conversely, if the brain dies, the heart and lungs will soon fail to function unless regulated by a respirator.

The failure of the heart or lungs is fairly easy to determine, but discerning brain death is more difficult, and is established by examining a combination of life signs. These include responses to stimulation; the ability to breathe; eye movement, swallowing or coughing; and evidence of electrical activity or blood flow in the brain. Negative responses to all of these indicate brain death, but no single sign is enough to warrant such an assumption.

### ***What does the term “futility of treatment” mean and how is it applied to DNR Order placement?***

When a person is deemed as no longer having the quality of life which would warrant treatment (in other words, any efforts made to prolong life would be seen as “futile,”) the application of a DNR Order has seemed, to some, to be ethical and reasonable. Often a determination is made by the physician in attendance or by hospital policy based on medical considerations. These considerations then establish the extent of the futility of treatment. If, in medical terms, there is no purpose for providing treatment, a DNR Order is applied.

“Futility of Treatment” is a term often used by medical practitioners when they assess that a patient would have no direct benefit from being

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<sup>11</sup>Further information regarding issues around medical understandings of brain death can be found in the abstracts of the 2<sup>nd</sup> INTERNATIONAL SYMPOSIUM ON BRAIN DEATH (Havana, Cuba, 1996), in particular the submission of Julius Korein entitled “Brain Ontogenesis, The Life and Death of the Human Being and Person.”

resuscitated or given intervening medical treatment because the patient's condition will not improve following intervention, and will only prolong an inevitable organ failure and death.

The objections to applying this term to a patient's medical chart stem from ethical and moral debates around the quality of life and the right to self-determination. The controversy over the concept of "futility of treatment" is based on several factors, namely:

- who makes the decision? Historically, patients and their families have been left out of this process and feel voiceless and powerless in determining the outcome;
- the decision to determine that treatment is futile and a DNR Order is appropriate has been argued to rest on a subjective evaluation of anticipated benefits and harms. Any outcomes are influenced by a number of probabilities; and,
- physicians have medical expertise, but are no more "moral agents" than many others in determining a direct course in the ending of a life.

## Review of Historical Precedents, Past Practices, and Analysis of Social Environments

***I came into this world  
without my consent  
and left in the same manner.***

- from a grave in  
Chattanooga, TN

“*Who should make life and death decisions about the terminally ill?*” was a question posed by Rex Murphy, host of the nationwide phone-in radio show “Cross Country Checkup,” a part of the programming of the Canadian Broadcasting Corporation.<sup>12</sup> Murphy introduced the topic of DNR Order placement practices in Canada by quoting Hamlet’s soliloquy, “to be or not to be, that is the question.”

Canadians voiced many opinions during that broadcast. It was noted that our life expectancy as a nation has increased by two decades for both women and men within the last century. In one generation, our understanding of death has been transformed by medical advances. Several persons commented on the role late twentieth century western medicine has played in expanding the arch under which the issues of life and death are discussed. Repeatedly, different listeners who joined in the discussion emphasized how medical science has protracted life. The borders between physical survival and clinical death are, in the words of Murphy, “extremely nuanced.”

It is important to take<sup>12</sup> note of the historical events which have shaped the thinking and the actions of Canadians and brought these kinds of concerns into public awareness and discussion. The following chapter will provide an

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<sup>12</sup> CBC Radio. November 15, 1998.

overview of historical decisions, legal precedents, medical practices, and various cultural understandings of illness, dying and assisted death in order for us to better understand the social environment from which much of our contemporary discussion springs.

Many Manitobans with disabilities have become increasingly concerned since the Manitoba Court of Appeal decided in December of 1997 that consent was not required in order for a physician to issue a non-resuscitation order for a patient. There were many extenuating circumstances which brought about this judgement, but the decision has continued to be of great concern because of its precedence.

The position of the MLPD and the Council of Canadians with Disabilities (CCD) regarding this issue is as follows:

***Our members and Provincial Council have the belief that patients (or their substitute decision makers) need to have some control over when and how DNR Orders are put on their files.<sup>13</sup>***

Self-determination, a concept which is integral to the basics of living independently and the impetus for the existence of the disability movement as a whole, is threatened at the most fundamental level by a decision such as the one which occurred in 1997.

A description and analysis of legal decisions concerning DNR Orders provides ways for us to understand the complexities of the legal aspects of this issue. This is done in greater detail in a legal study written by Sherri Walsh which serves as an attachment to this paper, but a brief sketch of some of the historical cases that have impact on legal decisions today are included here.

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<sup>13</sup>David Martin, "Self Determination Threatened by DNR Orders," CCD Latimer Watch. Winnipeg: Council of Canadians with Disabilities, 23 December, 1998.

## **Child and Family Services (CFS) v. R.L and S.H.L..**<sup>14</sup>

On November 4, 1997, a three member panel of judges made a decision in the Manitoba Court of Appeal in the case *Child and Family Services of Central Manitoba v. Raymond Lavallee and Susan Lorraine Hay*

This case was brought before the Court as a result of an assault upon an infant who, at the time of the trial, was eleven months old. The injuries inflicted upon this child resulted in what was testified by experts in the trial to be a persistent vegetative state. The issue before the court was: whether or not the physician could enter a DNR Order on the infant's chart over the objection of his parents. CFS had agreed with the doctor's recommendation to place a DNR Order on the child's file. However, when the parents refused to consent, CFS sought the approval of the courts. At the time, the police had not yet made an arrest in connection with this assault. Since a suspect could be charged with manslaughter<sup>15</sup> if the baby died within a year and a day of the assault, the judgement appeared to imply a question of good faith on the part of the parents around their objection to the placement of a DNR Order. This decision ruled that:

*The Court holds it is for the doctor to determine whether or not heroic measures are to be used to maintain the life of a patient in an irreversible condition. Neither consent nor a court order in lieu is required for a medical doctor to issue a non-resuscitation direction where, in his or her judgement, the patient is in an irreversible vegetative state. Whether or not such a direction should be issued is a judgement call for the doctor to make having regard to the patient's history and condition and the doctor's evaluation of the hopelessness of the case. The wishes of the patient's family or guardians should be taken into account, but neither their consent nor the approval of the court is required.*<sup>16</sup>

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<sup>14</sup>As cited in the Dominion Law Reports (1997), 154 D.L.R. (4<sup>th</sup>) 409.

<sup>15</sup>Assault causing death. See the Case Summary in the Health Law Journal Vol.7, 1999, 205 - 231, for further details

<sup>16</sup>"New Developments Regarding DNR Orders in Manitoba." Winnipeg: CCD Latimer

What is important to note here are the following implications:

- the Court **encouraged but did not order** physicians to take into account the wishes of the patient or patient's family;
- this Order enables physicians to have the "final say;"
- this is contrary to other current trends in the healthcare community where decisions regarding the initiating or foregoing of treatment require the consent of the patient or appropriate substitute decision maker;
- this is also contrary to another decision made in the Supreme Court in *Reibl v. Hughes* which emphasized the importance of a patient's participation in decisions regarding treatment and care. Some medical ethicists in Manitoba have addressed the outcome of that decision. Notable is the following comment made by George Webster and Pat Murphy, ethicists at the St. Boniface Hospital:

*Patients bear the burdens and consequences of these decisions. Therefore, the patient's interests must always be at the centre of the deliberations*<sup>17</sup>

Any action taken by our courts regarding the placement and/or removal of DNR Orders has a lasting effect on future decision making. Arnie Peltz of the Public Interest Law Centre in Manitoba made this comment with respect to the Manitoba Court of Appeal ruling on *Child and Family Services of Central Manitoba v Robert Lavalley and Susan Lorraine Hay*:

*As to the broader implications for persons with disabilities...there is a reason for concern. The case is about a situation of irreversible*

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Watch. Council of Canadians with Disabilities. 12 February, 1998

<sup>17</sup>Murphy, Pat and Webster, George. "A Question of Ethics." Winnipeg Free Press, January 3, 1998

*vegetative state, as illustrated by the tragic facts of the baby's condition. However, as noted by the counsel for the Agency...there is no clear, bright line between this situation and many other possible situations involving people with less severe permanent disabilities. The Court appears to be saying that these are matters for the exercise of physicians, and if the physicians turn out to be wrong afterwards, then an action for negligence can be taken, directing the physician or his insurer to pay money damages to the estate of the deceased.*<sup>18</sup>

This would seem to be cold comfort for those loved ones who survive this ordeal. Peltz also raises another concern, this one about the way in which the Court of Appeal made its decision. He states:

*Despite the fact that this is a matter of concern to a wide range of groups in society, the court made its decision without hearing from any of these. Even the parties directly involved in the case did not have an opportunity to make an informed comment on this issue.*<sup>19</sup>

Those who might be affected most by future implications of this decision were neither heard before the courts, nor, apparently, considered. It should also be noted that the Court refused to adjourn so that researched presentations could be shared on the matter of physician responsibility. A very important decision was made without any input from the community!

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<sup>18</sup>"New Developments Regarding Do Not Resuscitate Orders in Manitoba." CCD Latimer Watch. Winnipeg: Council of Canadians with Disabilities. 12 February, 1998

<sup>19</sup>Ibid

## Sawatzky v. Riverview Health Centre<sup>20</sup>

Andrew Sawatzky, a seventy-nine year old resident of the province of Manitoba, became the focus of a battle over the right to life-saving treatment. In 1998, while he was a patient at the Riverview Health Centre, a DNR Order was placed on his medical chart without the consent of Mr. Sawatzky or his wife. He was ruled by the Riverview medical staff as “mentally incompetent,” a decision challenged by his wife, who struggled to have the DNR Order removed. Because of her opposition to the decisions made by the Riverview Health Centre, the guardianship of Andrew Sawatzky was removed from his wife’s care and he was placed in the custody of the Public Trustee. Mrs. Sawatzky went to the Court of Queen’s Bench to have the DNR Order removed. The MLPD was granted full intervener status in this court case. Mrs. Sawatzky was successful, and the DNR Order was removed from her husband’s medical file.

What is important to note about this case are the following:

- Andrew Sawatzky had only intended to be at the Riverview Health Centre for a short term stay to receive therapy. This was never understood by the Sawatzkys as being a palliative care situation;
- until the Court of Queen’s Bench hearing, it was understood and accepted by a healthcare institution that a doctor was qualified to make both a “medical” and an “ethical” decision regarding the life of a patient, and neither the patient nor his family were consulted, nor their objections considered, in this decision making process.
- the involvement of the Office of the Public Trustee and the role it plays in protecting the rights of persons deemed as “incompetent” or “vulnerable.”

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<sup>20</sup>*Sawatzky and Riverview Health Centre, Inc.* Docket: C198-01-10245, [1998] M.J. No.506.

## **R.K. v London Health Sciences Centre**<sup>21</sup>

R.K. an eighty-three year old man was admitted to the London Health Sciences Centre in Ontario in 1997 as the result of an epileptic seizure and respiratory distress. While he was in Intensive Care, he was placed on a mechanical respirator. His medical record indicated he had high blood pressure and experienced several strokes prior to his admission. Approximately two weeks after he first came to the hospital, it was recorded by his attending physician that he was conscious, alert and able to communicate with signs or by mouthing words. He was unable to speak due to a tracheostomy. His breathing difficulties continued.

Shortly afterwards, R.K. was found in an unresponsive state. Repeated neurological exams indicated a lack of brainstem function. R.K did exhibit some capacity to breathe on his own, but this was described by his physician as “weak and feeble.” A CAT scan indicated severe injury and death of brain cells. R.K.’s physician informed the family that his patient was “one small step from death, “ and that any possibility of recovery was non-existent. However, R.K did not meet the generally accepted medical definition of death because of what was termed an “agonal breathing response,” on certain respiratory tests.<sup>22</sup> R.K continued to receive mechanical ventilation and tube feeding. His physician deemed that there was no medical justification for maintaining life support. The patient’s wife and son would not initially provide consent for a discontinuation of this treatment, although they had consented to the placement of a DNR Order. The London Health Sciences Centre went to the Ontario Court of Justice to obtain an order which would allow them to discontinue life support. The hospital wanted the court to grant them immunity from any criminal or civil prosecution if they should stop life-sustaining treatment for R.K.

The court dismissed this application, saying it had no jurisdiction to provide immunity to the Health Sciences Centre or R.K.’s doctors against criminal proceedings. Furthermore, the hospital and its physicians did not have a

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<sup>21</sup>For further details see [1997]O.J. No. 4128, DRS 98-00445

<sup>22</sup>Ibid

right to legal immunity from any kind of civil suit in this matter.

This was a complex situation, but what is worthy of the attention of those concerned with the rights of patients and their advocates is that *a distinction was made in the courts between consenting to a DNR Order, and consenting to the withdrawal of life-sustaining treatment.* The patient's family had agreed to not resuscitate R.K. if he should undergo cardiac arrest, but they were not willing to "pull the plug" on the machinery that was keeping him alive. The Ontario Court of Justice recognized this distinction and would not grant the hospital or the doctors immunity from any judicial procedures resulting as a consequence of removing R.K.'s respirator.

### **Coroner's Report: Herman Krausz (Montreal)**

Herman Krausz, a patient at the Jewish General Hospital in Montreal, died in 1998 after his respirator was removed. This withdrawing of life-sustaining treatment was done over the objections of his family.

The broader implications of an action such as this (removing life support against the patient's or family's wishes) can be seen when reading the recommendation of the coroner's report issued after Herman Krausz's death. The coroner stated that in circumstances such as these where families wish to continue life-sustaining measures while physicians and/or hospital administrations want to withdraw or withhold treatment, independent mediators should be appointed. The objective of this mediation process would be to facilitate *a struggle in good faith between families and doctors so that a true consensus be reached regarding difficult medical decisions.*<sup>23</sup>

There are many difficulties which might arise with regards to the implementation of a mediation process such as that proposed in the

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<sup>23</sup>For a more thorough discussion of the dynamics of this kind of mediation practice and the implications it might hold for persons with life-threatening illness, see Smith, Wesley, J. "Bio-ethics Stack the Deck Against 'Non-Persons.'" National Post. Toronto: February 25, 2000

coroner's report. Some of these challenges lie within the environment from which the concept of mediation itself arises. Mediators are, for the most part, trained in a mainstream of philosophy which does not necessarily take into account the perspectives of persons with disabilities who have traditionally been marginalized and whose perspectives have remained silent in our broader societies. Although the function of mediators is to remain neutral and to facilitate discussion between two dissenting parties, an unrecognized bias might exist because the mediators themselves would only perceive the situation from an "able-ist" standpoint. The Krausz situation can be seen as a case in point. According to Wesley J. Smith, an advocate for anti-euthanasia actions:

*It was the very value of Herman Krausz's life that the family and doctors disagreed about.*<sup>24</sup>

Clearly this was not simply a medical decision, but one that also involved ethics. The hinge of the physician's decisions was based on a determination of the "quality of life" of the patient, a topic that shall be discussed further in this paper.

## **Cultural Understandings of End-of-Life Issues**

The first case of assisted suicide tried in a court in Canada took place in 1963. The trial was located in a northern community where Kolitalik, a leader for forty years among the Inuit, asked members of his tribe to help him die. Kolitalik had contracted measles, and because the Inuit had little exposure to this disease, he was left, after some months, very weak and frail with no sense that he would recover. No court transcripts or records remain of the trial itself; what is known is what remains in the memories of members of that community.<sup>25</sup>

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<sup>24</sup>Ibid

<sup>25</sup>For more detail on this and other accounts of different cultural understandings of assisted death, see Mullen, Anne. Timely Death: What We Can Expect And What We Need To Know. Toronto: Random House, 1997. 53 ff.

“Assisted suicide,” is, admittedly, a modern term that is being applied to a much older practice. Helping elderly and sick persons in their wish to die was understood to be a noble and honourable act. Not only did this practice implement a release from a life that was no longer pleasurable, it was also deemed an essential and practical answer to the inevitable difficulties faced by the community in sustaining someone aged and dying within a very harsh environment.<sup>26</sup> Spiritually and culturally, this practice was perceived as a way of treating the elderly with dignity and respect. But it is important to keep in mind that for communities such as the one in which Kolitalik lived, bringing about the death of a weak, sick or old person is not longer a matter of corporate survival.

Anthropologists Charles Hughes and Alexander Leighton,<sup>27</sup> in their study of the Yuit Inuit of St. Lawrence Island near the Bering Strait in the 1940's, described the customs they observed concerning assisted suicide. They reported that when Inuit individuals decided they wanted to die, they made their request to the community three times. Traditionally, families would not consent to this wish after the first request, but would strongly dissuade the individual who wanted to die. Throughout this process, the community would make their value of that individual known and would grieve with them over the loss that would occur if the individual left them. Only after a third request would the community comply and assist in the individual's death. It should be noted that in the case of Kolitalik, it was only after he threatened to put a curse on the whole community that the three hunters agreed to assist him with his death.

The account of this Inuit practice and the trial which was the result of Kolitalik's death in particular does bring to our attention the probabilities of clashes between different cultures and their values. During the 1960's and 70's, the encroachment of the more dominant Judeo-Christian culture and the values it represents has infiltrated even the farthest reaching northern

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<sup>26</sup>It would be interesting to obtain the perspectives of those within these cultural settings who felt pressured into making a decision to end their lives. No research indicating such a position was located for this study, but that is not to say that such coercion did not exist.

<sup>27</sup>Ibid. 54

communities. This has led to a dramatic decrease in many traditional First Nations cultural practices. Advancements in technology have also changed the ways the Inuit and other cultures interact with their environment, making the practical aspects of assisted death less plausible. Since the death of Kolitalik there is no record of another Inuit assisted suicide.

The Inuit are one of many indigenous societies who have practiced assisted suicide. These include other North American First Nations groups, South American Indians, Sami (Laplanders), Siberian Native Peoples, African tribes, and South Pacific Islanders. Although, as with the Inuit, the practice of assisted death among these societies has diminished or disappeared from public scrutiny, it would be erroneous to assume that the basis for the beliefs which informed these practices have not left their influence on contemporary attitudes. It is also important to recognize that within the history of the dominant culture in Canada there are vestiges of earlier cultural versions of the practice of assisted suicide.

The custom of assisting someone to die was not only evident in tribal societies, but was also widely embraced in both Greek and Roman societies.<sup>28</sup> There is evidence of over seven hundred years of discussion regarding this topic<sup>29</sup>, beginning with Xenophon, who used *haireo thanaton*, a Greek term meaning, “to seize death.” Plato theorized about *hekonein haidon* (going voluntarily to Hades,) and the Stoics recorded the idea of *eulogos exagoge* (a happy or sensible removal.) There exist first and second century A.D. descriptions of *autocheira* (to act by one’s own hand,) *autoktonia* (self-killing,) and *mors voluntaria* (voluntary death.)

Perhaps it was in opposition to the beliefs of their Roman and Greek oppressors that followers of the Judeo-Christian religion developed a striking abhorrence for suicide. This repulsion was exhorted to the extent that, until recent times, the remains of those individuals who had taken their

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<sup>28</sup>*Ibid* p58.

<sup>29</sup>Anne Mullens makes direct reference to the writing of Paul Carrick, author of a dissertation on Medical Ethics in Antiquity. The historical overview presented in this paper is drawn mainly from Carrick and Mullens

own lives were not allowed to be buried in community church graveyards.

Other faiths proscribe, to a degree, self-willed death. In Islam, the bringing about of one's own demise to escape illness was and is viewed as overruling the will of the Divine.

Buddhist belief teaches that one of the Four Noble Truths is suffering, and one cannot avoid suffering by taking one's own life - it will only follow into the reincarnation of the next life by way of the individual's Karma.

Voluntary death was widely practiced for many centuries by the Hindus and Jains of India. According to Jainist belief, persons who were elderly, sick or disabled could announce their intention to be liberated through self-willed death, which was carried out through the practice of fasting. Members of their communities would assist these individuals to accomplish their goal. This was common until the eighteenth century, when the British Raj outlawed the practice.

Euthanasia, in its modern sense of a doctor assisting in the death of a patient, was first documented as a practice in the 1870's in Britain. The term itself was coined by Dr. S.D. Williams who stated, "*in cases of incurable and painful illness, doctors should be allowed, with the patient's consent, and taking all necessary safeguards, to administer so strong an anaesthetic as to render all future anaesthetics superfluous...a sort of legalized suicide by proxy.*"<sup>30</sup>

The following year, when concerns were voiced about potential abuses that could result if euthanasia were allowed, another doctor, L. Tollemache stated, "*if we rejected all reforms which might lead to contingent and remote evil, no reform would ever be passed.*"<sup>31</sup> Euthanasia was seen by many at that time as being a highly appropriate practice.

1901 brought about a more sinister development when a proposal was made to the Willesdon Medical Society of Britain that a committee of experts

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<sup>30</sup>Mullens, Anne. 60.

<sup>31</sup>Ibid. 60.

should decide the fate of any “*imbeciles and monstrosities*” who were deemed “*absolutely incapable of improvement.*”<sup>32</sup> Less than forty years later, the Nazis of Germany proposed much the same thing.

In 1935, the Euthanasia Society was established in Britain. This group attempted to usher in a Parliamentary Bill that would outline a set of regulations to oversee the practice of doctor assisted death. This was defeated a year later; one of its strongest opponents being Lord Dawson of Penn, the personal physician to King George V.<sup>33</sup>

Records of historical Canadian medical practices indicate that in the 1920's and 30's, any discussion regarding euthanasia was limited to reports of what was taking place in Britain. In the U.S.A., Reverend Charles Potter, representing a group of New York intellectuals, established the Euthanasia Society of America in 1938, but any attempts to legalize the practice were defeated in Congress. Following World War II, there was a world wide hiatus on any attempts to decriminalize assisted death in light of the revelations of monstrosities which occurred in the Third Reich's euthanasia programming. Nazi policies encouraged and implemented the extermination of thousands of individuals with disabilities or congenital illnesses because they were viewed as a “blight” on society that posed a threat to one of Hitler's goals, namely, the improvement of a more physically and mentally superior species of the human race.

Applying these historical lessons to our contemporary discussion helps us to identify the risks and abuse present in any practice involving deliberate death. Adhering to the rights of individual choice at all costs does not guarantee that depressed or ill individuals won't sense their own lack of value and place of belonging within society. For this reason alone, many

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<sup>32</sup>Ibid. 60

<sup>33</sup>Ironically, in 1994 it was revealed in Dawson's diary that fifty years prior, when summoned to the bedside of the King as he lay dying of respiratory failure, Dawson recorded that he decided to determine the time of the end of the King's life to occur late in the evening. He injected the King with a lethal dosage of morphine and cocaine. Dawson admitted he'd taken this action because he felt the announcement of the Monarch's death should first appear in “The Times,” early the next morning, rather than later, in the more lowly afternoon papers.

succumb to the idea of engineering their own premature death. At the other end of the spectrum, putting the perceived needs of a dominant society first before the needs of an individual orchestrates the potential for certain persons within that society being viewed as expendable and candidates for killing. It is for these reasons that determining any future legislation regarding how and when we die must be done with great care; any discussion preceding such decision making requires the representation and input from any and all members of our society who might be directly or indirectly affected by such laws. Key to this is the recognition that the voices of persons with disabilities are not being represented in the decision-making process.

## Current Discussions, Procedural Guidelines, and Developments

***“Thousands of ethicists and bio-ethicists professionally guide the unthinkable on its passage through the debatable on its way to becoming the justifiable until it is finally established as the unexceptional.”<sup>34</sup>***

This quote, in somewhat of a “tongue-in-cheek” fashion, distills the evolution of changes in our perceptions of what constitutes an action or idea as being “ethical.” It begs the question, **“HOW DO SOCIAL SHIFTS IN ETHICS OCCUR?”** Wesley J. Smith<sup>35</sup>, an anti-euthanasia activist and journalist, outlines the progression of the relaxation of medical ethical principles. He sees this relaxation occurring first among the experts in healthcare theory. This change then moves into the world of philosophers and other academics. The progression of the loosening of stringent values is then carried into the realm of physicians, who take it into institutions where it affects protocols and policies. By this time, the change in ethical standards will have reached the attention of some members of the public, and it is bantered about in debate between the conservative and liberal elements of the populace. A few legal test cases where “experts” give testimony take place (these experts rarely being persons who are directly affected by the loosening of these guidelines), and the result of these courtroom challenges is a legitimizing to the public via the media of this shift in ethical thinking. The media have a unique role to play in that often they provide very “in the moment,” sympathetic stories that involve the specifics of individual cases rather than presenting a projection of any long-term, larger implications of this shift in ethical standards.

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<sup>35</sup>Wesley J. Smith, Forced Exit: The Slippery Slope from Assisted Suicide to Legalized Murder. New York: Random House. 1997. 19. For a fuller explanation, the chapter “Creating a Caste of Disposable People” is invaluable.

Smith, like many others who monitor social policy and its impact on persons with disabilities, sees ethical changes as occurring in quiet and oblique ways, without a lot of drama which would draw public attention to the change in underlying morals involved in the alteration. Protecting human life, he states, has been viewed as the central purpose of organized society.<sup>34</sup> The issues around the placement of DNR Orders are only one part of a much larger discussion about the role of the state in preventing harm to the weak and the vulnerable. But even such a phrase as “the weak and the vulnerable” carries with it a tone of paternalism which is loathsome to those who want to be active in determining their own destiny as full citizens in a democratic society.

### **What are Manitobans saying about DNR Orders?**

What is the current public “radar” regarding the rights of persons with disabilities? What about the rights of patients? What if patients, (a group traditionally viewed as passive and helpless) disagree with the course set for them by physicians (who are supported by an institutional hierarchy)? What are those involved in the formal discourse of ethics at the academic and institutional level articulating about the practice of DNR Order placements?

**George Webster and Pat Murphy**, two medical ethicists on staff at the St. Boniface Hospital, responded to the Lavallee decision made in the Manitoba Court of Appeal by writing an article for the Winnipeg Free Press. They expressed a concern about the state of affairs in which the Court ruled that physicians need not seek the consent of patients or patient advocates in placing DNR Orders. According to Webster and Murphy, this decision flies in the face of current thinking and practice in healthcare decision making where medical decisions are made as a result of consultation by doctors with their patients. Furthermore, they stated:

*There is an essential reciprocity between care giver and patient that characterizes a healing relationship. The suggestion that physicians can act unilaterally has far-*

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<sup>34</sup>Ibid

*reaching and disturbing implications.*<sup>35</sup>

Murphy and Webster articulated a concern that has been voiced extensively in both the disability community and among bio-ethicists. This concerns the jurisdiction of expertise. Put more plainly, the problem lies in the decision to withhold or withdraw treatment based on “medical” expertise; however, the ending of a life is not simply a “medical” one, but also lies in the realm of the “ethical.” Doctors can make expert judgements about medical decisions, but decisions to not continue life communicate value preferences. Webster and Murphy describe these as “*moral choices, not just judgements of fact.*” The conclusions they draw lead them to state:

*“Questions about benefits of treatment, quality of life, and futile therapy are ethical decisions that touch on our understanding of life, life’s purpose, and societal obligations to those among us who are most vulnerable and in need of protection.”*<sup>36</sup>

**Barney Sneiderman**, a Professor of Law at the University of Manitoba, also wrote a response in the Health Law Journal to the recent court decisions made regarding DNR Orders.<sup>37</sup> In his opinion, the Manitoba Court of Appeal decision did not intend to restrict its judgement to the particular scenario presented in *C.F.S. v. Lavallee*. The legal basis of the ruling is grounded in the distinction between treatment and non treatment. Treatment (in other words, a physician touching the patient) requires consent. Non treatment (no contact with the patient’s body) , Sneiderman argues, is an action which can be decided unilaterally by the physician. Whether or not a patient is in a vegetative state such as the *Lavallee* baby is beside the point. It follows logically that if it is solely the physician’s

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<sup>35</sup>Ibid

<sup>36</sup>Ibid

<sup>37</sup>Barney Sneiderman. “A Do Not Resuscitate Order for an Infant Against Parental Wishes: A Comment on the *Case of Child and Family Services of Central Manitoba v. R.L. and S.L.H.*” Health Law Journal, Volume 7, 1999. 206-231.

prerogative to refrain from treating a patient, it matters not whether the patient (let alone a patient's surrogate) insists on treatment. Furthermore, Sneiderman states:

*"The only relevant concern is the reasonableness of the medical decision to forego life support measures, and that can be contested only after the fact."<sup>38</sup>*

Sneiderman cites the **Manitoba Medical Association's** position on futile therapy:

*"Patients have a legal right to refuse treatment, but they don't have a right to demand treatment."*

It is interesting to note that he cites the March 1998 Manitoba College of Physicians and Surgeons Guideline entitled, "**Do Not Resuscitate (DNR) and Supportive Treatment Orders.**" This document states the following:

*"Regardless of the expressed opinions of patient and family, physicians are not required to provide or continue interventions which could be considered futile."<sup>39</sup>*

The term "futile" is defined as *"treatment that offers no benefit and serves only to prolong the dying process."<sup>40</sup>* Sneiderman recognizes the vagueness of this definition and the questions it raises, such as "Benefit for whom? What would the time frame of the prolonging of a dying process be?" and so on.

Sneiderman also brings forth the argument about the allocation of resources. He asks:

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<sup>38</sup>Ibid. 208.

<sup>39</sup>Ibid.

<sup>40</sup>Ibid

*“If one must administer aggressive treatment to hundreds of patients in order to benefit but one, is that benefit outweighed by the expenditure of ineffective and burdensome treatment upon the other ninety nine? Does it represent a cost-effective application of scarce medical resources to devote so much time and effort with so little result?”<sup>41</sup>*

His own response is that for the one patient out of the hundred, the cost of prolonging treatment is, arguably, worth it. But financial considerations, as cold and pragmatic as they may seem, influence the scenario. Sneiderman states the following concern:

*“There is a fear, not totally unwarranted, that physicians on their own initiative or at the behest of health care administrators, will begin to make treatment recommendations and decisions based on the financial interests of the health care institution, rather than the best interests of the patient. The fact that this motivation may be unconscious does not make it any less pernicious; it may make it more dangerous because it is harder to detect.”<sup>42</sup>*

Sneiderman also acknowledges the difficulties with the concept of futility, which is far from “cut-and-dried.” Any decisions to withhold or withdraw treatment are not, he states, purely medical decisions; they implicate value judgements about when it is no longer worthwhile to keep a patient alive.

The law as it now stands in Manitoba states that physicians have the unilateral authority to make non treatment decisions. He advocates the use of review panels in those situations where patients and/or patient surrogates do not agree with a doctor’s decision to withdraw or withhold treatment. This panel, he suggests, should have within its representation certain non medical members such as hospital chaplains and patient advocates. He sees this as a kind of remedy to help alleviate public anxiety that patients’ interests are not at the forefront of medical decision making at the end of

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<sup>41</sup>Ibid. 209.

<sup>42</sup>Ibid. 227.

life.<sup>43</sup>

**Arthur Schafer**, a professor in the Faculty of Philosophy at the University of Manitoba, has offered his own comments regarding end-of-life decisions for patients in hospitals. His statements appear to grow from the opposite end of the spectrum from many in the disability movement. He argues from the viewpoint of those who have decided to end their own medical treatment, and in so doing, determine the end of their own lives. Despite the fact that Schafer does not address the perspective of those who wish, against the judgement of their physicians, to remain alive, his comments are included in order to provide a more comprehensive picture of the widespread views held by ethicists in terms of end-of-life issues and the roles doctors and hospitals play in confronting these issues.

Schafer states:

*“There is virtually universal consensus on withholding and withdrawing treatment. No one says that a competent individual should be forcibly kept alive on a respirator or kidney dialysis machine against his or her will, that life is a supreme value and that physicians should always protect life.. What was controversial fifteen years ago is now understood as a fundamental human right.”<sup>44</sup>*

He speaks of euthanasia as being, in some circumstances, a socially acceptable action.

*“Our society, even if we are reluctant to admit it, has accepted another category of justifiable homicide in the death of an individual, besides that of self-defense and war. When a physician allows a patient to die, either by withholding an anti-biotic that permits pneumonia to kill the patient, or by taking them off a respirator, as a society we have recognized that under certain conditions it can be justified to be an*

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<sup>43</sup>Ibid. 229.

<sup>44</sup>Mullens. 251.

*agent in bringing about the death of another person, even if it is in an indirect way.”<sup>45</sup>*

Schafer does not define the difficulties in assessing what is the most appropriate course of action in determining the continuance or stoppage of treatment. He does, however, make a distinction between euthanasia (the act of ending a life as decided by the attending physician<sup>46</sup>) and contemplating the request of a patient to withhold treatment. He poses several questions for this dilemma:

*“How do we know it is not the illness speaking? How do we know they [the patients] are genuinely competent? How do we know they have not been coerced by family or doctors?”<sup>47</sup>*

Here Schafer flags the potential pressures patients could feel to end their own lives in order to relieve the burden they think they are imposing on others by not dying. The problems of patient-doctor communication, and the complicated dynamics often found in family life present concerns that many in the disability community have raised as well.<sup>48</sup> Schafer, however, argues from an opposite perspective of that heard among persons with disabilities. Rather than seeing this issue of coercion on the part of families and doctors as one that might prevent consent for the patient to die, Schafer describes the potential for patients to linger unnecessarily because doctors aren't straightforward enough with families responsible for making the decision to end a patient's life.

*“It is often the way the doctors phrase the questions that lead to families asking for continued treatment when the clinical*

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<sup>45</sup>Ibid. 251.

<sup>46</sup>It should be noted that the definition of euthanasia is not offered by Schafer. He makes the distinction by stating that the stoppage of treatment on the behest of a patient is a “different problem” from that of euthanasia. Ibid. 254-5.

<sup>47</sup>Ibid.254-5.

<sup>48</sup>This concern will be discussed further in Part D of this paper - THE VOICES OF PERSONS WITH DISABILITIES.

*outlook is dim. Rather than ask if the family wants to remove treatment, doctors should present the realities of the case (i.e. the patient will never gain consciousness) and ask if the patient would have wanted to remain living. This removes the burden from the family.*<sup>49</sup>

Given all this, Schafer believes that in the last fifteen years of debate over this struggle, the rights of patients have increased, and patients do have more opportunities to determine their own courses of treatment. He states:

*“Respect for the patient has increased. The humanity of our hospitals has increased. They are more sensitive..to wishes of patients. Patients feel more secure, more in control.”*<sup>50</sup>

## **Futility of Treatment Discussions**

The issue of medical futility has taken on progressively greater importance in medical treatment as health care costs have spiraled and new modes of therapy have been developed. Physician and ethicists Daniel Eisenberg notes an interesting development apparent in futility of treatment discussions. He states:

*When therapeutic options were the limiting factor in medical treatment, the fact that a treatment was felt to be “futile” had little significance, since economics allowed trying “everything” for every patient. Today, when there are almost limitless therapeutic options, but limited economic resources, society may not be willing to provide “useless” therapies to patients who will not benefit.*<sup>51</sup>

There is certainly the potential for the possibility of a dichotomy to occur between expanding therapeutic options and economic limitations!

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<sup>49</sup>Ibid. 272.

<sup>50</sup>Ibid. 279-80.

<sup>51</sup>Daniel Eisenberg, M.D. “Futility of Treatment.” Institute for Jewish Medical Ethics: San Francisco. February 15, 2000. 1.

# DNR Order Policies in Manitoba

## Manitoba Health

Bill 73, the **Health Care Directives Act**, was proclaimed in force July 26, 1993. This Act gives Manitobans the right to accept or refuse medical treatment at any time. Competent persons *may* express their wishes regarding the amount and type of health care and treatment they wish to receive in the event they are unable to speak for themselves. The Act also gives the right to appoint another person with the power to make medical decisions on their behalf if they are unable to speak for themselves.

The following information was issued from the Minister of Health's Office in January 2000 upon an inquiry about the Ministry's position on DNR Orders.

*"A DNR Order, a decision to forego CPR, does not limit in any way the implementation of any other medically appropriate treatments or procedures. The patient's physician writes DNR Orders on a patient's medical chart. An order to reverse a DNR Order must also be written on the patient's medical chart by the patient's physician."*

The Minister's Office also acknowledged the discussion which took place at a national level regarding DNR Orders and their placement practices. A joint statement was formulated by the **Canadian Medical Association** (CMA) Board of Directors, the **Canadian Healthcare Association**, the **Canadian Nurses Association** and the **Catholic Health Association of Canada**, and was developed in conjunction with the **Canadian Bar Association**. This statement encouraged medical facilities to have interdisciplinary committees which could develop policies, programs for policy implementation and conflict resolution mechanisms pertaining to DNR

Orders. It should be noted that according to the statement issued from the Minister's Office, "*all major facilities in Manitoba have such policies in place.*"<sup>52</sup>

Also of note in the Joint Statement is a recommendation for institutions to have reviews of DNR Orders at regular intervals. The conditions for the implementation of these reviews include the request of patients or patient proxies. This review could occur if there is a substantial improvement in a patient's condition and if the patient is to undergo a surgical procedure or is transferred to intensive care.<sup>53</sup>

### **College of Physicians and Surgeons of Manitoba**

The following is the text of a document published by the College of Physicians and Surgeons of Manitoba in February 1998. This statement was made following the decision rendered by the Manitoba Court of Appeal regarding DNR Orders in 1997.

*"The decision to resuscitate must comply with the accepted standard of the medical profession. The physician must determine and document the relevant criteria accepted by the profession for the decision not to implement or discontinue therapy. The responsibility to consider the family in issues relative to patient care becomes more relevant when the patient cannot contribute. In a situation involving withdrawal or non-provision of treatment, clear communication becomes very important, even though the issue of consent is not relevant"*<sup>54</sup>

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<sup>52</sup>Statement issued from the Minister of Health's Office, January 2000.

<sup>53</sup>These conditions, it is assumed, would be determined by the attending physician or healthcare team. Absent from the Joint Statement is any mention of a DNR Order review that would be the result of a conflict between a physician and a patient/patient surrogate.

<sup>54</sup>"Consent to DNR Orders." From the College. Vol. 34, No. 1. Winnipeg: College of Physicians and Surgeons of Manitoba. February 1998. 1.

The College recommends the following in its Guidelines<sup>55</sup>:

*“All facilities are expected to have policies regarding DNR and supportive treatment orders. Policy makers should determine how controversial concepts applied to CPR should be interpreted into the policy, in light of the facility’s mission, the values of the community it serves, and ethical and legal developments. All members of the medical staff should be familiar with the policy.”*<sup>56</sup>

The College recommends that if the person for whom resuscitation is being considered is deemed incompetent, decisions made on his/her behalf are based on the following principles:

- *the treatment decisions must be based on the wishes of the person if they are known;*
- *when the person’s wishes are not known, treatment decisions must be based on the person’s best interests determined by*
  - 1) the diagnosis/prognosis;
  - 2) discussions with the partners and close family members;
  - 3) the person’s known values and preferences;
  - 4) aspects of the person’s culture/religion that would impact on a treatment decision.<sup>57</sup>

It is important to note that although informed consent from the patient or patient surrogate should be clearly understood and communicated, it is not mandatory. The expressed opinions of the patient, family and other care givers regarding DNR Orders are to be considered; **but this is only a**

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<sup>55</sup>It should be noted that the College defines a “guideline” as a practice generally recommended. Nowhere does it state that there is a legal obligation or mandatory order to follow these directives.

<sup>56</sup>“Do Not Resuscitate’ and Supportive Treatment Orders.” Guidelines. The College of Physicians and Surgeons in Manitoba. I - G97.

<sup>57</sup>Ibid.

**recommendation and not a prerequisite** established by the College.

## **Survey of Manitoba Physicians**

Several recent studies have charted physicians' opinions regarding such end-of-life issues as euthanasia and assisted suicide. Although these two practices are not what theoretically constitutes a DNR Order, they do indicate how doctors feel they should exercise their discretion during these very difficult yet similar issues. Reported in the Health Law Review are the survey results of such a study of Manitoba physicians in 1996.<sup>58</sup> A summary of some of the results of that study indicate that from a sample of 122 physicians:

- 52% indicated that they did not discern an ethical difference between not starting a life-support measure and stopping a life-support measure once it had begun.
- 12% of physicians surveyed reported that they saw no ethical difference between stopping treatment and assisting suicide.
- **6%** would assist a suicide or practice euthanasia.
- 71% agreed that some patients must be reduced to an unconscious state in order to combat pain or suffering.
- 91% agreed that pain and suffering endured by some people while they continue to receive nutrition and hydration can outweigh the benefits of prolonging life.
- 95% agreed that a patient can be given any dose of pain medication so long as it is medically necessitated, even when the patient's death may be hastened by this action.

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<sup>58</sup>Neil Searles. "Silence Doesn't Obliterate the Truth: A Manitoba Survey on Physician Assisted Suicide and Euthanasia." Health Law Review, No. 3, 1996. Health Law Institute, University of Alberta. 9 - 16.

- 83% of physicians agree that the provision of pain medication is not made less appropriate when it will certainly lead to death.
- 60% believed euthanasia should be legalized where a patient has an incurable disease that causes great suffering.
- 62% believed that a doctor who hastens the death of a terminally ill patient should not be subjected to criminal prosecution.
- 62% also believed they would be less likely to pursue palliative care options if euthanasia were to be legalized.
- 80% said they would not participate in assisted suicide or euthanasia while these acts remain illegal. If these acts were decriminalized, just over 50% of physicians indicated they would never assist a suicide or participate in euthanasia.
- However, 72% believe active euthanasia is performed by fellow practitioners.
- 18% of the physicians surveyed indicated they had received requests from terminally ill patients for assisted suicide or euthanasia, and of these, one in seven had facilitated these requests. In practical terms, this means *a significant number of physicians in Manitoba reaching into the hundreds have violated the law*. If their actions were uncovered, they could be charged with offences that carry sentences as severe as life-imprisonment.<sup>59</sup>

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<sup>59</sup>Ibid. 5.

## **The Role of the Public Trustee**

*What medical decisions, if any, does the Public Trustee get involved with as a policy position?*

“The Public Trustee is making itself available where a physician wishes to consult with respect to resuscitation. The Trustee is seeking to clarify this position with the medical profession through the College [of Physicians and Surgeons].”

*The answer to this question was provided by then Attorney General Victor Toews in an article written in the College of Physicians and Surgeon newsletter From the College, January 4, 1999.*

*Does a physician, when caring for a patient who is also a client of the Public Trustee, have any obligation to involve the Public Trustee in a decision to place a DNR Order on the patient?*

“If a person is a client of the Public Trustee, the physician should consult with the Public Trustee around the question of placing an order on a client’s chart. If the Public Trustee disagrees with the position of the physician, then [the College of Physicians and Surgeons] will take the steps considered necessary to resolve the issue, such as obtaining a second opinion or referring the issue to an ethics committee.”

*From the College, May, 1999*

## **POLICIES OF REGIONAL HEALTH AUTHORITIES (RHA's) AND HOSPITALS IN MANITOBA**

Each of the Regional Health Authorities in Manitoba and a sampling of 26 rural and urban hospitals and long-term care facilities throughout the province were approached during this research project and requested to provide information regarding the policies these authorities and institutions hold concerning DNR Orders.

The specific questions directed to them were the following:

7. What are the current DNR Order placement protocols for your RHA catchment area and/or hospital or care facility?
8. Is it mandatory that the patient or patient advocate/surrogate have knowledge of the placement of a DNR Order?
9. Is it mandatory that the patient or patient advocate/surrogate give consent to the placement of a DNR Order?
10. Does your RHA catchment area/hospital/care facility have an ethics board or similar body which is consulted in decision-making regarding DNR Orders?
11. If such an ethics board exists, is there any community representation on that board?
12. What protocols exist for DNR Order placement when a doctor and a patient or patient advocate/surrogate disagree about that placement?
13. Would your organization support the idea of having persons with disabilities involved in establishing guidelines regarding DNR Orders in medical facilities? If so, how would that involvement occur?

Responses to these questions are recorded are as follows:

## **REGIONAL HEALTH AUTHORITIES**

### 1. Re: Current DNR Order Policies

- one region stated the patient had the final say in determining DNR Order placement
- one region stated their DNR policy was based on a prior Advance Health Care Directive or determined by the physician in consultation with patient or patient proxy
- one region stated competent patients had the final say
- one region had no policy
- the remainder of regions reported they had policy development underway.

### 2. Re: Patient/Proxy Knowledge of DNR Order Placement

- 3 regions reported that patient/proxy knowledge is *mandatory*
- 1 region reported that the practice of informing patients/proxies of DNR Order placement is *encouraged*
- 1 region reported that patient/proxy knowledge is not required, and that the decision to inform them is made by individual facilities within the region
- the remainder reported that policy development is underway

3. Re: Patient/Proxy Consent of DNR Order Placement

- 3 regions reported that patient/proxy consent is *mandatory*
- 1 region reported that the practice of obtaining consent from patients/proxies of DNR Order placement is *encouraged*
- 1 region reported that patient/proxy consent is not required, and that the decision to inform them is made by individual facilities within the RHA
- the remainder reported that policy development is underway

4. Re: the Existence of an Ethics Board **or Similar Body Consulted on Ethical Issues**

- 3 regions reported they had no ethics board or similar body
- 2 regions reported they had an ethics board
- 1 region reported they had no ethics board but consulted with the Health Sciences Centre ethics committee as required
- the remainder reported that development of this concept was underway

5. Re: Community Representation on the Ethics Board

- 2 regions reported that they had community representation on their Ethics Board
- 2 regions reported they had no community representation on their Ethics Board
- 1 region reported that this information was not available

- 1 region reported that community representation on an ethics board was not applicable to an RHA
6. Re: Policies Concerning a Disagreement Between a Patient/Proxy and a Physician Regarding a DNR Order Placement
- 1 region reported that a 2<sup>nd</sup> consult can be requested, but that the patient/proxy has the final say
  - 1 region reported that the patient/proxy has the final say
  - 1 region reported that a *competent* patient has the final say
  - the remainder of the regions had no policies in place, 1 of these stated that this policy was in development
7. Re: Representation of Persons with Disabilities in Establishing Guidelines Concerning DNR Order Placement
- 1 region reported that they had identified people in the community to provide feedback regarding DNR Order policies
  - the remainder of the regions did not have any representation of persons with disabilities in establishing guidelines. Out of this group, 1 reported that there was support for the idea of input through focus groups or committee representation, and 1 was open to input from the Manitoba League of Persons with Disabilities.

**POLICIES BY REGION**

**BURNTWOOD REGION**

<b>ORGANIZATION ?</b>	Burntwood RHA	Thompson General Hospital
<b>POLICIES ?</b>	-----	-----
<b><i>Current DNR Order Placement Policies</i></b>	patient has final say	competent patients have rights to determine course of treatment
<b><i>Patient/Proxy Knowledge of DNR Order Placement</i></b>	patient/proxy knowledge mandatory	required
<b><i>Patient/Proxy Consent of DNR Order Placement</i></b>	patient/proxy consent mandatory	required
<b><i>Ethics Board</i></b>	none - consultation with Health Sciences Centre Ethics Committee as required	n/a
<b><i>Community Representation on Ethics Board</i></b>	n/a	n/a

<b><i>Disagreement between patient - doctor</i></b>	consult can be requested; patient has the final say	patient has final say
<b><i>Representation of persons with disabilities in establishing guidelines</i></b>	identified people in community to provide feedback	n/a

**BRANDON REGION**

<b>ORGANIZATION ?</b>	<b>Brandon RHA</b>	<b>Brandon General Hospital</b>
<b>POLICIES ?</b>	-----	-----
<b><i>Current DNR Order Placement Policy</i></b>	as per a prior Advance Health Care directive of patient or determined by doctor in consultation with patient/proxy	patient/proxy must agree to placement of DNR Order
<b><i>Patient/Proxy Knowledge of DNR Order Placement</i></b>	mandatory	mandatory
<b><i>Patient/Proxy Consent of DNR Order Placement</i></b>	mandatory	mandatory
<b><i>Ethics Board</i></b>	yes	yes
<b><i>Community Representation on Ethics Board</i></b>	yes	yes
<b><i>Disagreement between patient-doctor</i></b>	patient has final say	patient/proxy has final say

<b><i>Representation of persons with disabilities in establishing guidelines</i></b>	no - open to input from MLPD	no - open to input from MLPD
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**CENTRAL REGION**

<b>ORGANIZATION ?</b>	<b>Central RHA</b>	<b>Winkler Bethel Hospital</b>	<b>Gilbert Plains Health Centre</b>
<b>POLICIES ?</b>	-----	-----	-----
<b><i>Current DNR Order Placement Policies</i></b>	development underway	development underway	resuscitate only in exceptional cases
<b><i>Patient/Proxy Knowledge of DNR Order Placement</i></b>	development underway	development underway	policy made known at time of admission
<b><i>Patient/Proxy Consent of DNR Order Placement</i></b>	development underway	development underway	no; decision made by individual facilities
<b><i>Ethics Board</i></b>	concept currently in discussion	n/a	policy made known at time of admission
<b><i>Community Representation on Ethics Board</i></b>	not applicable to RHA	n/a	n/a

<b><i>disagreement between patient - doctor</i></b>	no policies in place	no policies in place	patient must express a desire to be resuscitated
<b><i>Representation of persons with disabilities in establishing guidelines</i></b>	none	n/a	n/a

**DAUPHIN REGION**

<b>ORGANIZATION ?</b>	<b>Dauphin Regional Health Centre</b>	<b>Dauphin General Hospital</b>	<b>Dauphin Personal Care Home</b>	<b>St. Paul's Home</b>
<b>POLICIES ?</b>	-----	-----	-----	-----
<b><i>Current DNR Order Placement Policies</i></b>	competent patient has final say	determined by doctor	resuscitate only in exceptional cases	resuscitate only in exceptional cases
<b><i>Patient/Proxy Knowledge of DNR Order Placement</i></b>	mandatory	yes	policy made known at time of admission	policy made known at time of admission
<b><i>Patient/Proxy Consent of DNR Order Placement</i></b>	mandatory	yes	policy made known at time of admission	policy made known at time of admission
<b><i>Ethics Board</i></b>	no	no	no	n/a
<b><i>Community Representation on Ethics Board</i></b>	no	no	no	n/a

<b><i>Disagreement between patient-doctor</i></b>	Competent patient has final say	Competent patient has final say	discussion with patient/proxy	dealt with on case-by-case basis
<b><i>Representation of persons with disabilities in establishing guidelines</i></b>	supports the idea but not in place now	no, supportive of input thru focus groups or committee representation	no, but supports idea for RHA	n/a

**PARKLAND REGION**

<b>ORGANIZATION ?</b>	<b>Parkland RHA</b>	<b>Winnipegosis General Hospital</b>	<b>Grandview Personal Care Home</b>	<b>Roblin District Health Centre</b>	<b>Winnipegosis Mossey River Personal Care Home</b>
<b>POLICIES?</b>	-----	-----	-----	-----	----- -----
<b><i>Current DNR Order Placemnt Policies</i></b>	none	determined by doctor	determined by doctor with patient/proxy input if possible	determined by doctor	determined by doctor
<b><i>Patient/Proxy Knowledge of DNR Order Placement</i></b>	no, decision made by individual facilities	doctor requested to speak to patient/proxy	if possible	mandatory	doctor requested to speak to patient/proxy
<b><i>Patient/proxy consent of DNR Order Placement</i></b>	no, decision made by individual facilities	verbal consent required	if possible	mandatory	verbal consent required

<b><i>Ethics Board</i></b>	none	none	n/a	no, follow guidelines of College of Physicians & Surgeons	none
<b><i>Community Representation on Ethics Board</i></b>	none	none	n/a	n/a	none
<b><i>Disagreement between patient-doctor</i></b>	no, decision made by individual facilities	patient/proxy has final say	dealt with on case-by-case basis	patient has final say	patient/proxy has final say
<b><i>Representation of persons with disabilities in establishing guidelines</i></b>	none	yes - is seen as necessary to set protocol for DNR Orders for persons with disabilities	n/a	supports idea through survey & project team input	n/a

**WINNIPEG (RHA and Chronic Care Institutions)**

<b>ORGANIZATION ?</b>	<b>Winnipeg RHA</b>	<b>Riverview Health Centre</b>	<b>Concordia Personal Care Home</b>	<b>Deer Lodge Centre</b>
<b>POLICIES ?</b>	-----	-----	-----	-----
<b><i>Current DNR Order Placement Policy</i></b>	in process	“no CPR” placed upon admission	doctor decides in consultation with patient/proxy - resuscitation under patient’s Advance Directive	n/a
<b><i>Patient/Proxy Knowledge of DNR Order Placement</i></b>	practice is encouraged	policy information available at time of admission	consultation expected	n/a
<b><i>Patient/Proxy Consent of DNR Order Placement</i></b>	practice is encouraged	no	consultation expected	n/a
<b><i>Ethics Board</i></b>	yes	yes	ad hoc committee formed for specific situations	n/a

<b><i>Community Representation on Ethics Board</i></b>	yes, through hospital board members	yes, through board members	n/a	n/a
<b><i>Disagreement between patient - doctor</i></b>	n/a	order can be withdrawn by doctor	opinion of 2 <sup>nd</sup> doctor sought	n/a
<b><i>Representation of persons with disabilities in establishing guidelines</i></b>	n/a	policies are forwarded to Residents' Committee for comment	n/a	n/a

**Winnipeg Acute Care Hospitals**

<b>ORGANIZATION ?</b>	<b>Concordia</b>	<b>Health Sciences Centre</b>	<b>Seven Oaks</b>	<b>St. Boniface</b>	<b>Victoria</b>
<b>POLICIES?</b>	-----	-----	-----	-----	-----
<b><i>Current DNR Order Placement Policy</i></b>	doctor decides in consultation with patient /proxy - resuscitate under advance directive	must have patient/ proxy consent	DNR determined by doctor; can be rescinded by patient/ proxy	patient primary decision maker	under review
<b><i>Patient/Proxy Knowledge of DNR Placement</i></b>	consultation expected	mandatory	recommended with some exceptions	yes	consultation expected
<b><i>Patient/Proxy Consent of DNR Placement</i></b>	consultation expected	mandatory	recommended with some exceptions	yes	consultation occurs

<b><i>Ethics Board</i></b>	<b>ad hoc committee for specific situations</b>	<b>yes</b>	<b>yes</b>	<b>yes</b>	<b>Bioethics Committee</b>
<b><i>Community Representation on Ethics Board</i></b>	<b>n/a</b>	<b>yes, thru board members</b>	<b>yes</b>	<b>yes</b>	<b>Committee representation</b>
<b><i>Disagreement between doctor-patient</i></b>	<b>opinion of 2<sup>nd</sup> doctor sought</b>	<b>patient has final say</b>	<b>competent patient has final say</b>	<b>opinion of 2<sup>nd</sup> doctor, then mediation by Ethics Board</b>	<b>Staff &amp; Bioethics committee assist in resolution</b>
<b><i>Representation of people with disabilities in establishing guidelines</i></b>	<b>n/a</b>	<b>no - open to input from MLPD</b>	<b>no - open to input from MLPD</b>	<b>no - open to input from people with disabilities</b>	<b>no - open to input from MLPD</b>

## National and International Related Issues

- \* Doctors in Alberta will be allowed to euthanize seriously malformed fetuses in the womb before they are aborted, according to new rules under consideration by the Alberta College of Physicians and Surgeons. If this policy is approved, doctors will be able to inject the heart of the fetus with a fatal dose of sodium chloride so when it is induced it will not be born live. This procedure, known as “feticide,” will be performed “in order to reduce suffering,” according to the College policy. The College recognizes “this will be a difficult decision for patient, physician and other members of the health-care team and it may be unacceptable. “In that case there must be careful consideration and documentation of a **Do Not Resuscitate Order in anticipation of a possible live birth**” the policy document states. The College is responsible for setting standards of medical care across the province.<sup>60</sup>
  
- \* The charity group “Age Concern” reports that doctors in some British hospitals are allowing elderly patients to die as pressures build up on the National Health Service to make beds available for new patients. Some doctors ignore national guidelines on the resuscitation of older people which state that such decisions should be based on “clinical need and the express wishes of the patient.” Some elderly patients have found “**not for resuscitation**” written on their medical notes without their knowledge “The evidence we have received points to a disregard of the national guidelines,” states Sally Greencross, director of Age Concern of England. At the end of March, 2000, leading British doctors described the lack of funding for long-term care of the elderly as a national disgrace and said it was causing untold hardships and anxiety. In a letter to The British Journal, the president of the Royal College of Physicians and the chief of the British Geriatric Society have called for a public debate on the issue of funding for the National Health Service.<sup>61</sup>

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<sup>60</sup>Robert Walker. “Fatal Injections OK’d for Malformed Fetuses,” The Calgary Herald. Tue 06 June 2000.

<sup>61</sup>Reuters, London, April 13, 2000. Reported in DAN (Disabled People’s Direct Action Network [UK]).

# **QUALITY END-OF-LIFE CARE: THE RIGHT OF EVERY CANADIAN**

A current development for Canadians is the recent findings of a report prepared by the Standing Senate Committee on Social Affairs, Science and Technology. Led by the Honourable Sharon Carstairs, the task of this committee was to examine the quality of end-of-life care in Canada. The following contains a summary of the Final Report.

## **FINAL REPORT**

### **the Standing Senate Committee on Social Affairs, Science and Technology**

**Chair: The Honourable Sharon Carstairs**

**Deputy Chair: The Honourable Gérald A. Beaudoin**

**June 2000**

- As set out in the 1960 Canadian Bill of Rights, Canada is founded upon the dignity and worth of the human person. That dignity and worth compels the provision of excellent end-of-life care at a time when each person is at his/her most vulnerable.
- Quality end-of-life care must become an entrenched core value of Canada's health care system. Each person is entitled to die in relative comfort, as free as possible from physical, emotional psycho-social, and spiritual distress. Each Canadian is entitled to access skilled, compassionate, and respectful care at the end of life.
- Calls for a more compassionate and comprehensive approach to end-of-life seems to be assigned a low priority in the existing health care system. Despite statistical evidence indicating an increase in the number of deaths, disease patterns, and health care institutions, there has not yet been the required shift of resources to end-of-life care.
- The Subcommittee believes that appropriate quality end-of-life care will not happen unless the federal government takes a leadership role in developing a national end-of-life strategy.

## Recommendations

1. The federal government, in collaboration with the provinces, develop a national strategy for end-of-life care.
2. The federal government, in collaboration with the provinces, establish a 5 year plan for implementing this national strategy.
3. The federal government prepare an annual progress report on implementing this national strategy.

## Summary

- The focus of the Senate Subcommittee report is the promotion and implementation of Hospice/Palliative Care standards throughout Canada.
- The report urges the guarantee of greater support for programs and training through funding of community resources, education of professional care providers, and the initiation of programs that enable people to care for their chronically ill and dying family members.
- The Subcommittee does not promote a “compassionate homicide” provision in the criminal code due to the possible influence on the Supreme Court of Canada’s review of Robert Latimer’s sentence in his second degree murder conviction for killing his daughter Tracy. Such a criminal code provision might lead to less protection in law and possibly more cases of abuse and murder of disabled, elderly, chronically ill and other vulnerable people.

## UNDERSTANDINGS OF “QUALITY OF LIFE”

“Twenty years ago I recruited Lance for our medical internship program. Lance was a charming 26 year old man who loved learning medicine and loved the outdoors. He was a stunt pilot and during his years with us in the training program he learned to play the viola in his spare time, <sup>62</sup> recollects Neil Abramson, a medical doctor who authored the article, “*Quality of Life: Who Can Make the Judgement?*”. Abramson goes on to describe how, in his 3<sup>d</sup> year of medical training Lance began experiencing intermittent numbness and weaknesses of various extremities which led to the diagnosis of amyotrophic lateral sclerosis (ALS). As his condition worsened, Lance’s motor strength waned. He became, in Abramson’s words, “wheelchair-ridden”; he lost the ability to speak clearly, to eat or take care of his personal hygiene, and he anticipated suffering from all the complications of severe respiratory muscle dysfunction. Most of the health care professionals and friends around him recognized the disorder as being incurable and untreatable. Abramson describes Lance’s recognition of his life being one full of quality in the past, but his future might simply be a burden to others. This was expressed in his wish, “*Never let them tube me. I wouldn’t want to live restricted in any way.*”

A near fatal lung failure changed Lance’s mind, and, because of a fear of suffocation, he started using a respirator. Although most of the people involved in his care and his life felt heroic measures were not in his best interest, Lance and his wife used any methods available to keep him alive.

**Nine years later**, Abramson reports, Lance and Abramson met again. Lance was propped up in a wheelchair, his arms were strapped to his sides, and a ventilator supplied oxygen to him via a tracheotomy. A fistula was embedded on the side of his neck, he was unable to greet people with a handshake, a smile, or even the nod of his head. His speaking was un-interpretable to Abramson until it was translated by Lance’s wife. This is what Abramson expected. But what astonished him was Lance’s explanation that his life was rich. He explained that although he had lost the use of his muscles, his brain

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<sup>62</sup>Neil Abramson, M.D. “*Quality of Life: Who Can Make the Judgement?*” The Journal of Medical Ethics. San Francisco: Institute for Jewish Medical Ethics of the Hebrew Academy. January, 2000.

functioned perfectly. Furthermore, **Lance worked almost full time as an emergency room physician.** He was able to process patient histories and physical examinations and provide therapies through the assistance of nurse practitioners. He avidly researched current medical literature assisted by equipment which turned pages. He was in the process of opening a clinic to provide medical care and lifestyle transition skill-building to other ALS patients. He had also learned to fly a plane all over again using technology which took direction for its operations via Lance's eye movements.

This is not a Manitoba story, nor does it directly involve the placement of a "Do Not Resuscitate" Order. It is, however, an account of not one, but two medical doctors, Abramson and Lance, who undergo a dramatic change in their understandings about what constitutes "quality of life." Abramson expresses this succinctly in his comment:

*In our current healthcare climate, issues of quality of life, euthanasia, doctor-assisted suicide, cost benefit considerations, and the use of scarce resources for individuals with incurable diseases are common themes. Nevertheless, our medical ethics and individual morals commit us to focus on the patient as an individual. Had I been asked to be the one responsible for starting the respirator in order to extend Lance's life, especially given the serious debilitation he had already suffered, I would have been negatively affected by the quality of life that I had pictured at that time based on my values. Never could I have envisioned the exceptional quality of life that Lance discovered; a creativity of life with richness and fullness.<sup>63</sup>*

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<sup>63</sup>Ibid. 4.

## “Deciding for Others,” and “The Futility Debate” (Baylis)<sup>64</sup>

Françoise Baylis, Associate Professor of Bioethics Education and Research in the faculties of Medicine and Philosophy at Dalhousie University, prepared two reports for the Sawatzky v. Riverview Health Centre court case in 1999, namely, “*Deciding for Others: The Established Ethical Framework for Treatment Decisions*,” and “*The ‘Futility’ Debate*.” Both of these reports deal with issues around understanding the quality of life. This work is grounded in the ethical principle of respect for persons, which, to Baylis, gives patients the right to accept or refuse treatment, and deems the health care provider to be obligated to respect and promote the autonomy of the patient. Advance directives, within this context, are to be morally binding.

Baylis describes the need among practicing physicians for a change in approach from one that is *paternalistic towards* the patient to an attitude of *interaction with* the patient. Today, states Baylis, it is widely understood that good clinical decisions are made with and not for patients. Decisions that need to be made by patients who are unable to participate in the process due to incompetence should be made by the surrogate who acts in the best interest of the patient, and not by medical staff whose actions may be devoid of those interests.

The whole matter of futility adds another dynamic to the complex issues around DNR Order application or the alternative life-saving measures. In Canada, states Baylis there is no moral obligation to provide futile treatment. This claim is not typically based on cardio-pulmonary resuscitation being completely ineffective, but rather that resuscitation is not in the patient’s (or society’s) best interest.

Baylis applied this premise directly to the Sawatzky case. When the Chief Medical Officer (CMO) of the Riverview Health Centre stated in her affidavit that “*treatment [for Mr. Sawatzky] is totally futile*,”<sup>65</sup> Baylis contended that the

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<sup>64</sup>Françoise Baylis, PhD. Deciding for Others: The Established Ethical Framework for Treatment Decisions and The Futility Debate. Dalhousie University: 1999.

<sup>65</sup>Ibid. 2.

term “totally futile” remained undefined and was used as an appeal to “*the moral weight that attaches to the claim that treatment will not work.*”<sup>66</sup>

Furthermore, when the Riverview CMO stated that if resuscitation for Mr. Sawatzky did work, it would not be in the patient’s best interests because “*very likely he would be left with additional brain damage and in a persistent vegetative state,*”. Baylis points out the inconsistency, at a philosophical level, of this argument, which can be summed up as follows -

Does “futile” mean:

- the treatment will not work medically? Or,
- the treatment is not worth doing ethically?

These are two different futility arguments which have the potential to contradict each other!

This debate leads to the question “who has the authority to make these decisions?” Baylis suggests two ways of processing this question:

1. The decision can be based on medical considerations by persons with relevant expertise, but this should still involve consultation with the patient or patient surrogate.
2. The decision rests on the subjective (in other words, personal and idiosyncratic) evaluation of the anticipated benefits and/or harms with particular attention to the magnitude and the probability of the outcome.

Clearly, with this second option, there is no objective standard to refer or appeal to in terms of making the decision.

Who, then, decides what is the quality of life of the patient? Do we see physicians as moral agents? Do they have the expertise to make these clearly value-laden decisions? Do they have the moral authority derived from a broad

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<sup>66</sup>Ibid. 2.

and just social consensus to do so?

Baylis puts forward a “Course of Treatment” Argument by contrasting the following:

*Premise One*

**PHYSICIAN SOLE DECISION MAKER  
?  
HAS NO OBLIGATION TO DISCUSS WITH PATIENT/SURROGATE  
?  
THEREFORE UNILATERAL DECISION MADE**

*Premise Two*

**PHYSICIAN SOLE DECISION MAKER  
?  
HAS AN OBLIGATION TO CONSULT PATIENT/SURROGATE  
?  
POSSIBLE RE-CONSIDERATION OF DECISION**

*Premise Three*

**PATIENT/SURROGATE & PHYSICIAN DECIDE  
?  
CO-DETERMINATION OF COURSE OF TREATMENT  
?  
PHYSICIAN’S UNILATERAL DECISION BECOMES A  
VIOLATION OF PATIENT’S RIGHTS AND VALUES**

Making these decisions, according to Baylis, is further complicated when we pose the question, What is the goal of treatment?<sup>67</sup> Is treatment futile if it cannot achieve:

- the postponement of death?
  - the prolonging of life?
  - the improvement, maintenance or restoration of quality of life?
  - an improved prognosis?
  - an improvement of patient comfort?
  - the reversal of an underlying condition?
  - restoration of consciousness?
  - restoring function?
  - the ability for the patient to leave the hospital?
  - achieving short term survival?
  - achieving long term survival?
- Or
- achieving the patient's goals?

Obviously, Baylis states, this is far too complex to be amenable to a resolution, but posing these questions does bring into sharper focus the various agenda at work in such a scenario and the possibilities for a conflict between end goals. All the components of this argument, however, become moot until the primary conclusion of determining who has the authority to make which decision is settled.

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<sup>67</sup>Ibid. 5.

## Additional Comments

Dick Sobsey, professor of Educational Psychology, University of Alberta, also makes several comments regarding quality of life issues in his paper, *Disability, Discrimination and the Law.*<sup>68</sup> He makes the following observation:

*“:The quality of life argument says that for someone with a severe disability, particularly a severe mental handicap, the potential quality of life is very poor. By keeping them alive we are condemning them to a life of suffering. What’s interesting about the quality of life argument is that it makes an assumption that we can objectively measure the quality of somebody’s life. The truth is that if there is such a thing as quality of life, it exists only as a subjective phenomenon. People can only rate **themselves** with any kind of meaning. When we talk about quality of life in terms of severely handicapped newborns, we are talking about our view of their potential IQ. Can we correlate IQ with quality of life? Most of us would disagree.”*<sup>69</sup>

Sobsey substantiates his comments with a description of a most interesting study done recently at the University of New Jersey.<sup>70</sup> It involved caregivers and their ventilator-assisted patients. The caregivers were asked to rate their own quality of life on a scale from 1 - 8. They were then asked to use the same scale to rate the quality of life of the people for whom they provided care. At the same time, the people who were ventilator-assisted were asked to rate their own quality of life using an identical scale.

The results of how the care-givers and the ventilator-assisted people rated their own lives were virtually identical - one group was 5.30 and the other was 5.36. However, when the care-givers rated the lives of the others, the

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<sup>68</sup>Dick Sobsey. “*Disability, Discrimination and the Law,*” *Health Law Review* (1993) 2 Health L. Rev. No. 1, 6 - 10.

<sup>69</sup>Ibid. 3 - 4. (Emphasis mine)

<sup>70</sup>Ibid.4.

rating was remarkably lower, 2.5. Sobsey remarks on his assessment of this study by saying:

*“This quality of life measurement is only the particular view that we impose upon people with disabilities. For people with disabilities, there is an initial period of adjustment, but their lives, in terms of thier own quality of life ratings, are neither better nor worse than anyone else’s.”*

Sobsey goes on to state another problem with the “potential quality of life” argument, stating it can be made about many facets of the population, not just persons with disabilities.

*“If you had a child who was born into a Jewish family in Germany in 1938 or 1939, how would you rate its potential quality of life? In our present society, if we look at children who come from poor families versus those who come from rich families, who has the better potential quality of life? Or children who are born into families with chronic abuse problems? If we can identify many children who, at the time of their birth, have a potential for a very poor quality of life, are we prepared to propose killing all those children as a reasonable solution to their particular problem?”<sup>71</sup>*

Sobsey concludes by asking - if we are not prepared to let all these other people die, why should we apply that rationale to persons with disabilities?

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<sup>71</sup>Ibid. 5.

## **THE VOICES OF PERSONS WITH DISABILITIES**

It is a sad comment on our society as Canadians that in those situations which can so profoundly affect persons with disabilities, it is exactly these people who are excluded from the discussion. The following section of this report looks at the current representation of persons with disabilities in the discussion around DNR Orders and their placement; it provides some perspectives of persons with disabilities that have been written in various disability advocacy publications; and we hear the voices of some Manitobans for whom this issue was critical and life-changing.

### **CURRENT STATISTICS REGARDING REPRESENTATION OF PERSONS WITH DISABILITIES**

Earlier in this paper, results of a survey conducted with the provincial Regional Health Authorities (RHA's), and various hospitals, health care centres and long term care facilities across the province were presented. One of the questions included in that survey asked whether there was representation of persons with disabilities within the decision making bodies when ethical guidelines were being established.

To review those statistics:

#### **By Region**

- **One** region has identified persons with disabilities within the community to provide feedback when guidelines are being established;
- **One** states that although there is no representation of persons with disabilities at this time, they would be open to input from the Manitoba League of Persons with Disabilities in exploring this further;
- **One** supports the idea but nothing is in place presently;

- **One** did not have an answer available; and,
- the **remainder** of regions had no representation of persons with disabilities when making ethical medical decisions.

### **Hospitals, Health Care Centres, & Long Term Care Facilities**

- **One** (Winnipegosis General Hospital) of these institutions reported that representation of persons with disabilities in establishing guidelines was seen as necessary in setting protocols of DNR Order applications for persons with disabilities;
- **Five** (Brandon General Hospital, Winnipeg Health Sciences Centre, Seven Oaks General Hospital, St. Boniface Hospital and Victoria General Hospital) reported they were open to input from MLPD in exploring this further;
- **One** (Riverview Health Centre) forwarded a copy of policies made to their Residents' Committee for comment;
- **One** (Roblin District Health Centre) supports the idea of representation of persons with disabilities in establishing guidelines through survey and project team input;
- **One** (Dauphin General Hospital) states that although representation of persons with disabilities is not occurring now, they do support community input through focus groups;
- **One** (Dauphin Personal Care Home) reported that although there is nothing in place now, they would support this concept for the Dauphin Regional Health Authority
- the remaining **ten** respondents did not have an answer available for this question.

## Written Articles - Perspectives of Persons with Disabilities

### ***“Attitudes About Disability Prove Almost Lethal” - Laura Hershey<sup>72</sup>***

Laura Hershey describes the trauma of discovering the application of a DNR Order on a hospitalized friend with a disability very similar to her own. The onset of pneumonia had brought about the need for a tracheotomy; subsequent to this came questions from medical staff regarding this individual's competence, prognosis and quality of life.

Hershey powerfully articulates the questions surrounding the presuppositions often employed in examining patient competence, prognosis and quality of life.

All three concepts, all subjective but wrapped in objective, clinical language, that are often only seen from a medical point of view. Furthermore, decisions regarding these concepts are often based on assumptions and stereotypes the medical profession holds regarding persons with disabilities. Hershey illustrates this by replaying a conversation between her friend, her friend's physician, and herself. The doctor had not informed the patient of the DNR Order application. When asked about this, he posed the question, “Would you *want* to be put on a respirator?” Laura, recognizing the vulnerability of her friend, quickly rephrased the question by asking, “If you couldn't breathe on your own, would you want them to use a respirator to save your life, rather than letting you die?”<sup>73</sup> The patient insisted on the use of a respirator if that would provide her the means to continue living, and the doctor removed the DNR Order.

However, the account does not end there. The patient's family - and it is not indicated whether or not they had prior knowledge of the DNR Order application - felt it was not the patient's, but the family's decision to remove the DNR Order. It took an arduous process for them to overcome their own perception of what constitutes “quality of life” and to support their daughter.

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<sup>72</sup>Taken from the web page

[ourworld.compuserve.com/homepages/LauraHers.../cc110299](http://ourworld.compuserve.com/homepages/LauraHers.../cc110299). November 2, 1999

<sup>73</sup>Ibid. 2.

Hershey's article brings to light the perspective of someone who could be in a very similar situation to her friend - they both had significant disabilities. Furthermore, Hershey identifies the pressure that is sometimes felt by persons with disabilities who sense they should just give up and die because they are not able to live the quality of life prescribed by others. Within that is also the perception that they are a burden to family, the health care system, and even to friends. *It is assumed, she states, that people go into a hospital to get well; but non-disabled people suffering from acute illness are not so strenuously urged to have a DNR Order in place. People with disabilities too often get the subtle or not-so-subtle message that they'd be better off dead. There's a double standard that equals discrimination.*<sup>74</sup>

Hershey concludes by stating that although the attitudes displayed by medical staff and even family members are rarely rancorous, they do reflect the feelings many have towards persons with disabilities, namely pity, sorrow, discomfort, and a little dread.

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<sup>74</sup>Ibid. 3.

## ***“Suicide: Political or Personal?” - Julie Reiskin<sup>75</sup>***

Reiskin writes from an interesting perspective because she is a person with Multiple Sclerosis, a condition shared by some of the patients who were assisted in their deaths by Dr. Jack Kevorkian.

Reiskin addresses a broad range of ideas around death and disability, including assisted suicide, suicide, the right to die, and the right to live. Valuable to the discussion about DNR Order applications and persons with disabilities is Reiskin's comments on living with a severe disability and dealing with life and death issues. She writes:

*“Our bodies are not as capable, and cannot weather as much trauma or interference as can the bodies of non-disabled people. Many crips [sic] have their line. The line (just so you non-disabled readers will know...) Is the level of disability at which you believe you could not continue living. Three years ago my line lay at not being able to run. Then it moved to: not being able to climb the stairs. It moved again to: not being able to walk, then to: not being able to drive. Seeing as how I am writing this and I can no longer do any of those things, it's clear I've changed my line again.”<sup>76</sup>*

What is crucial to Reiskin, and very relevant to this discussion, is the perceptions people hold about their own quality of life. This changes as adjustments to disabilities occur, but if end of life decisions are rushed by medical or other persons involved because of pre-determined perceptions regarding that “line,” as Reiskin puts it, persons with disabilities might feel some urgency to end their lives without waiting to make those adjustments.

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<sup>75</sup>Julie Reiskin, “Suicide: Political or Personal?” The Disability Rag, March/April 1991. 19 - 22.

<sup>76</sup>Ibid. 20.

Reiskin reflects on this further:

*“We’re not dealing with the need to come up with some sort of [standardized] value statement on our lives. Nor are we really grappling with what I would do if I were in so-and-so’s shoes - or chair. This is about the individual. Where am I in my life? Do I have options? Have I done my job in life?”<sup>77</sup>*

She concludes this portion of her writing with a question very relevant to the DNR Order discussion - should, or can, anyone else answer those questions for us? Clearly, these answers cannot be imposed on persons with disabilities if they are seen to have equal access, rights and privileges as those non-disabled members of society.

***“Any Choice You Want: As Long As It’s Death” - Alice Mailhot<sup>78</sup>***

Mailhot draws on the experience of another person who was almost denied life-saving treatment based on his disabilities. She states that when this individual made it clear he wanted to be admitted to hospital and to receive medical treatment, he was referred for a psychiatric consultation. His problem? He wasn’t accepting death.

She outlines her concern about the collusion of ethics and cost-effectiveness. Although Mailhot writes from an American perspective, the issues she addresses can certainly be seen as transnational. She poses the question, *“How do we decide who gets to receive a scarce health resource? How long may they receive it?”<sup>79</sup>* This, of course, is not an answerable question because no across-the-board policy exists in Canada or the United States. These questions are dealt with on a case-by-case basis, often at the sole discretion of an attending physician. Mailhot poses a frightening scenario with this question:

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<sup>77</sup>Ibid. 21.

<sup>78</sup>Alice Mailhot. “Any Choice You Want” As Long As It’s Death” The Disability Rag & ReSource. January/February 1995. 8 - 13.

<sup>79</sup>Ibid. 8.

*“‘What is the value of human life?’ is becoming, ‘What does your life cost us?’ and ‘What could we do with the money that we would value more than we do you?’”<sup>80</sup>*

Mailhot’s chief concern is that an elite group of health managers will debate those who live, who die, and who gets what health care. A debate, she notes, is not an exercise in exploring the depths of a topic, but rather it offers wordsmiths an opportunity to be clever and to present the best argument. Her worry is that the assumptions are preset, the most obvious assumption being that the first step in designing a health care system is to decide whodies to fund it.<sup>81</sup>

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<sup>80</sup>Ibid. 9.

<sup>81</sup>Ibid. 12.

## ***“The Right to Live and Be Different” - Disabled Peoples International***

This past February, 130 disabled people representing 27 countries in Europe, Africa, Australia, and North America met in Solihull, UK, to discuss bioethics and human rights. This was the first occasion of its kind, and from it grew the declaration, *The Right to Live and Be Different.*” Segments of that document are highlighted here as a way of providing further insight into the global perspectives of persons with disabilities and the right to life.

*Up until now most of us have been excluded from debates on bioethical issues. These debates have had prejudiced and negative views of our quality of life. They have denied our right to equality and have therefore denied our human rights.*

*We must be the people who decide on our quality of life and life experience.*

*Particular support must be given to empower the voice of mental health survivors, people with learning difficulties, people who cannot advocate for themselves and disabled children in this debate.*

*We are full human beings. We believe that a society without disabled people would be a lesser society. Our unique individual and collective experiences are an important contribution to a rich, human society.*

*We must strive for alliances with scientists, the medical professions, ethicists, policy-makers, human rights advocates, the media and the general public.*

*Human rights are the responsibility of the state as well as the individual. Disabled people, our organizations, families and allies must work to ensure that international, regional and national legal instruments must ensure the implementation of rights through all scientific advances and medical practices concerning assessments of quality of life, therapeutic measures,*

*and alleviation of “pain and suffering.”*

*In particular we demand the provision of full and accessible (i.e. jargon-free, easy to read and in alternate information from which people can make informed decisions.*

*Biotechnology presents particular risks for disabled people. The fundamental rights of disabled people, particularly the right to life, must be protected.*

## **Experiences of Manitobans Encountering Do Not Resuscitate Orders**

Five Manitobans who had direct experiences with DNR Order placement, either for themselves or someone in their immediate family circle, were interviewed for this project. Some of these persons have requested they remain anonymous. It is for this reason that no sources are named.

### ***The Circumstances***

The circumstances around the application of a DNR Order varied from:

- having a DNR Order placed on a spouse’s chart without the surrogate’s knowledge;
- having a DNR Order placed on a spouse’s chart without the surrogate’s consent;
- being included in part of a decision-making process to withdraw medical treatment which led to a loved one’s death. This occurred with 2 interviewees;
- being asked to consider placement of a DNR Order on their own medical chart at a time of critical illness.

## ***Knowledge of DNR Order Application***

Awareness that a DNR Order had been placed or was a consideration occurred as follows:

- the medical wristband indicator was spotted by someone else who then inquired as to its purpose to medical staff. The DNR Order had already been placed and it was not rescinded at the request of the patient or the surrogate;
- a non-medical staff member felt compelled to tell the family that a DNR Order had been placed on the patient's chart. The attending physician had not informed or consulted with them regarding the placement. It was not rescinded at the family's request and is still in existence at the time this report was written;
- information was provided to the family regarding the medical prognosis of a critically ill patient undergoing ever-worsening medical trauma. The family and doctor agreed together to cease treatment and the patient died. This occurred in the cases of 2 interviewees;
- the patient was informed and consulted regarding the possibility of DNR Order placement. The patient refused, but underwent considerable pressure to reconsider. Within the space of several hours 6 different medical personnel approached the patient to review the decision.

## ***Participation in Decision-Making***

When asked if they felt their input was a valued part of the decision-making process by medical personnel, the interviewees responded as follows:

- After repeated attempts to have a DNR Order removed, the patient surrogate felt "blacklisted" by the hospital, felt subjected to a media smear campaign fueled by the hospital, and had their own sanity and capabilities questioned publicly in an attempt to have the

complaint withdrawn.

- After repeated attempts to have a DNR Order removed, the patient surrogate was excluded from all other decision making regarding aspects of patient care. The patient surrogate was informed that there would be a meeting between themselves and the Chief Medical Officer, but upon arrival discovered the staff psychologist was there instead to conduct a psychiatric assessment of the surrogate (a non-patient.)
- The doctor strongly stated his preference in terms of the withdrawal of care and the family agreed.
- There was a joint decision between family and health care providers regarding the cessation of treatment.
- The patient felt a distinct prejudice due to their disability which influenced the medical staff's perception of quality of life. When the patient refused the DNR Order placement, a very grim projection of life was presented, including the inevitability of institutionalization, and unendurable pain and suffering. The patient felt hospital staff did not have a strong enough knowledge base of options available for persons with disabilities to live in the community, and also was not ready to accept the medical prognosis. This was met with some resistance, and the patient was asked repeatedly to "be realistic." The patient now lives in the community and has not experienced the physical hardships nearly to the extent that they were described.

## **CONCLUSION**

Phil Bereano, a member of the National Board of the American Civil Liberties Union, talks about the progression beyond an analysis of rights as “atomized individualism.” Human rights are social rights, creating the texture of a desirable society which recognizes that the diminution of “someone else’s” rights actually diminishes the rights of every member of that society.<sup>82</sup>

This recognition is echoed by many Canadians who are gravely concerned about what happens to the rights of individuals when faced with decisions concerning life and death. Persons with disabilities face a myriad of social stigma. It is not easy for mainstream society to understand that “disability” is not merely a medical condition, but also a consequence of societal prejudice, exclusion and environmental structures. The fundamental values Canadians have endorsed through the Charter of Rights and Freedoms declare we believe in the security of the person, and that all citizens have equal benefit and protection under the law. The circumstances under which we are (or are not) protected reflect who we are as a society.

It is for this reason that the **Manitoba League of Persons with Disabilities** has undertaken the task to create this report on DNR Order placement and practices and the implications they have on persons with disabilities. The objective of bringing this information to light is to create a starting point for discussion between members of the health care, legal, policy-making, and disabled communities which will facilitate the development of a province wide policy regarding DNR Orders. This policy should reflect the equal rights of all Manitoba citizens to access the health care needed to sustain meaningful life - as determined by those who act in the best interest of the patient.

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<sup>82</sup>This was stated by Bereano as a response to a discussion re: the CRG’s Genetic Bill Of Rights. Bioethics Listserv. Bioethics@onelist.com. March 30, 2000.

## RECOMMENDATIONS FOR FURTHER ACTION

Recommendations drawn from the research for this report are as follows:

### *For Individuals*

3. Advance Health Care Directives - creating a “living will” or advance directive, although not absolutely and certainly in all cases, does provide physicians and surrogate decision makers with indicators as to the direction a patient would want his/her health care to occur, should the patient be unable to express this. An advance health care directive takes considerable pressure off the surrogates and physicians who would otherwise have to “guess” what the patient’s wishes would be.
4. Prior Knowledge of Hospital/Health Care Facility Policy - provides information which may be critical as a patient considers which institution will be optimal in terms of receiving the kind of care desired. Discussions with personal physicians could include making this information known so if a sudden hospitalization is required, this preference is considered.
5. Awareness of the Devaluing of Persons with Disabilities - there is a devalued social role of persons with disabilities, and it is important to recognize how this attitude has permeated institutions and decision-making bodies. Persons with disabilities should be vigilant in their expectations of equal care, and be aware of their rights as citizens to expect appropriate medical care.
6. Awareness of A Full Range of Options - persons with disabilities are often not informed of the services and options available to them. Living a healthy, productive life within the community is achievable even for persons with severe physical limitations. Limited knowledge of these options and restrained staff hours often prevents health care providers from being able to give persons who are undergoing considerable lifestyle changes. An example of this is the predilection to paint being dependent on a respirator as a very grim existence. Another example is the view that if one requires considerable personal care this means living

in an institution. Speaking with organizations that advocate for persons with disabilities might provide considerably more information in terms of options.

### ***For the Community***

1. Development of a Uniform Province Wide Policy that Advocates Patient/Surrogate Knowledge and Consent Prior to DNR Order Placement. The individual's wishes would govern the course of treatment. This would be reviewed regularly and would involve broad public discussion.
2. Representation of Persons with Disabilities on Ethics Boards or other Bodies that Make Ethical Decisions Regarding Medical Treatment.
3. Development of Nation Wide Template for Advance Health Care Directives to ensure consistency from one health care institution to another and from province to province.