REPORT OF THE WRHA

WORKING GROUP ON WITHHOLDING AND WITHDRAWING LIFE-SUSTAINING TREATMENT

A. PURPOSE

Withholding and withdrawing life-sustaining treatment is widely acknowledged to be one of the most emotionally charged issues in health care. In 2008, the WRHA Board of Directors requested a review of the organization’s approach to withholding and withdrawing life-sustaining treatment. Life-sustaining treatment is defined as any treatment that is undertaken for the purpose of prolonging a patient’s life, and is not intended to reverse an underlying medical condition.

In response to the Board’s request, WRHA Senior Management formed a Working Group on Withholding and Withdrawing Life-Sustaining Treatment to review current WRHA policies and practices, review relevant professional standards and legal precedents, solicit input from those involved in a recent challenging case involving the provision of life-sustaining treatment and make recommendations. Members of the Working Group were selected from within the WRHA for their expertise and diversity of opinion (Appendix 1).

B. BACKGROUND INFORMATION

The Working Group reviewed a number of documents and reports including:

a) recommendations developed by Dr. Barakat for the Working Group, based on interviews in the fall of 2008 with staff involved in the recent case – December 10, 2008 (Appendix 2);

b) a compilation of relevant legal cases prepared for the Working Group by Ms. Catherine Tolton, WRHA General Counsel – fall 2008 (available on request);

c) Environmental Scan and Literature Review prepared for the Working Group by Ms. Sheila Toews, Regional Director, Ethics Services – January 2010 (Appendix 3);

d) Report of the VP Net: End-of-Life Ethics & Decision-Making conference in Winnipeg, Manitoba – June 9, 2008 (available on request);

e) draft journal article regarding the College of Physicians and Surgeons of Manitoba (CPSM) Position Statement on Withholding and Withdrawing Life-Sustaining Treatment authored by Jocelyn Downie and Karen McEwen (2010);
f) minutes of past WRHA Board Ethics Committee meetings where withholding and withdrawing life-sustaining treatment issues were discussed (2008).

The Working Group was also informed by a special sub-committee of the WRHA Board of Directors, chaired by Mr. Bob Minaker, which provided feedback and advice to the Working Group (Appendix 4).

At the outset, it is very important to note that the overwhelming majority of patients (or their proxies or representatives) are able to reach agreement with their care providers related to withholding and withdrawing life-sustaining treatment decisions. However, in the small number of cases where consensus is not achieved, the anguish experienced by both patients/families and those providing care can be enormous. The focus of this paper is to consider what more can be done to better manage and prevent these situations.

C. DISCUSSION

To ensure an approach to withholding and withdrawing life-sustaining treatment that is considerate of the needs and wishes of patients and their families, and supportive of staff, it is important to understand the complexity of this issue from multiple perspectives.

On June 9, 2008 a conference was held in Winnipeg by VP-NET (Vulnerable Persons and End-of-Life New Emerging Team) that was focused on end-of-life ethics and decision-making. The proceedings of the conference were published and provide important insights and opinions from prominent local and national persons with a strong interest in this issue. Excerpts from this conference are used below to describe the different perspectives.

1) Why does this issue evoke strong emotional reactions?

In situations where a patient’s family wants to continue therapy, or initiate new therapy, and the physician does not agree, the family will assert that the physician has no right to withhold or withdraw life-sustaining therapy. They may do so because they believe that is what the patient would have wanted, or they may have strongly held religious convictions, or they may believe that the system is denying care due to limited resources, or that the physician is biased. Physicians, by contrast, do not believe they are obligated to provide treatment that they believe is causing suffering to the patient and delaying the dying process. The quotes below from those involved with persons with disabilities, and from an Intensive Care Unit (ICU) physician, give a sense of the strongly held views.

Wiebe, Kaufert and Neufeld in their overview of the June 9th conference provide an important perspective from the disabilities community:

"Part of the narrative of many people with disabilities... is the perception that their quality of life is significantly devalued within their wider socio-cultural environments. This social devaluation occurs at personal, familial, community and systemic levels, including..."
professional settings that involve health care decision-making. It also occurs in news media, literature, film and television. Such persons are portrayed as one-dimensional characters that lose dignity and autonomy as a result of disability, and these losses culminate in decisions that can involve either the choice for them to end their own lives, or the choice on the part of someone else to end their lives for them.

The pervasiveness of social conditioning through media and cultural exposure provides little accountability or scrutiny of possible discrimination, and the disability community has vocalized its concerns that health care professionals, including those that make end-of-life decisions &/or those who develop policies that direct such decisions, do not adequately take into consideration how they are influenced by the social devaluation of people with disabilities. ... People with disabilities and others facing vulnerability demand full participation in decisions about their own health care. People want the opportunity to participate fully in treatment decisions, including those involving end-of-life deliberations, by situating these decisions within the context of their own life experience.”

Jim Derksen, advocate for the disabled, at this same conference commented:

“... many people with disabilities rely on life-sustaining treatment on a daily basis. As a result, we are in a situation naturally threatened by any policy that extends the authority to withdraw these technologies and treatments from us because that would certainly and quickly end our lives. That's one very simple reason we have a very deep interest in this area.”

Dr. Bruce Light, Intensivist, at this same conference commented:

“Certainly there are jurisdictions in the world where ... you need warehouses to keep ... permanently comatose people on life support with no prospect of getting better ... although ninety-five percent of people who are dying don't want to face that kind of future, one in twenty does ...”

“... My experience is it's never about the patient, it's about power, it's about some religious belief; it's about guilt. Guilt I would say is the most common one that's driving these sad situations ... about eighty percent of all patients who die, in fact die as a result of a decision to withhold treatment. Less than twenty percent actually die despite everything we can do, so this is a very common situation ... with the technologies we have today we can keep some of these people going for years. Personally, I mean if we do that, if we go down that road in society, I won't be working in these units anymore; that's for sure.”
"... the very last thing to go in consciousness is the ability to suffer, the mind is gone long before ... I mean the definition of a deep coma is unresponsive to deep pain. So before you're in a deep coma you can still suffer at least, even if you can't think about it. So most of us, if asked day after day to do that to a patient for what we perceive as no good purpose ... are resigning over this, because of moral distress".

The Working Group acknowledges that there are very strong and divergent views on this issue held by many thoughtful and caring individuals. As such, it is not possible to develop an approach to withholding and withdrawing life-sustaining treatment that will fully satisfy all parties. The Working Group strived to develop an approach focused on the best interests of patients and the needs of their families, while respecting the views and needs of caregivers.

2) What have other health care jurisdictions done to guide patients and care providers?

The environmental scan and literature review conducted by Sheila Toews suggests that what is happening in the rest of Canada provides limited guidance for us in Manitoba. A review of selected hospital and health region policies found that all emphasised respectful engagement with patients and their representatives, inclusion of patient beliefs and values where possible, congruence with professional standards of practice, and guidance regarding second opinions and conflict resolution. Only one health authority, Capital Health Region in Nova Scotia, included fairness in the allocation of health resources as one of its guiding principles.

3) What guidance have the Courts provided?

The cases that have gone to the Courts in Canada have provided limited guidance. The first such case dealing with a unilateral withholding treatment issue was the 1997 Manitoba case of Child and Family Services v. R.L. (the R.L. case”). In this case a physician placed a Do Not Resuscitate (“DNR”) order on the chart of a child, based on an assessment that resuscitation was not in the best interests of the child, and the parents objected. The judge supported the DNR order and the case was appealed. The Court of Appeal then ruled that physicians have the unilateral authority to place DNR orders on the charts of patients in a persistent vegetative state. Justice Twaddle stated:

"The only fear a doctor need have in denying heroic measures to a patient is the fear of liability for negligence in circumstances where qualified practitioners generally would have thought intervention warranted. The conclusion that neither consent nor court order in lieu is required for a medical doctor to issue a non-resuscitation directive when in his or her judgment the patient is in an irreversible vegetative state is the situation. 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 a court is required."

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The next case in Manitoba was Sawatzky v. Riverview Health Centre in 1998 in which a physician, without informing the patient’s wife, placed a DNR order on the chart of an elderly man with advanced Parkinson’s disease. The Judge granted an injunction against the order and ruled that the issue of unilateral decision-making authority by physicians had not been settled by the R.L. case.

The most recent court case in Manitoba was Golubchuk v. Salvation Army Grace General Hospital in 2008 in which physicians wanted to withhold and withdraw potentially life-sustaining treatment and the family objected. The judge issued an injunction holding that the law on unilateral withholding and withdrawing was not settled and needed to be addressed through a full trial. Mr. Golubchuk died before the case could go to trial.

Other cases in Canada that have gone to Courts during this period have not provided any further clarity on the issue of physician’s rights to unilaterally withhold and withdraw life-sustaining therapy.

4) What guidance have nurses been provided by their professional bodies?

The Canadian Nurses Association 2008 Code of Ethics includes the following statements:

- **Nurses advocate for persons in their care if they believe that the health of those persons is being compromised by factors beyond their control, including the decision-making of others.**

- **Nurses question and intervene to address unsafe, non-compassionate, unethical or incompetent practice or conditions that interfere with their ability to provide safe, compassionate, competent and ethical care to those to whom they are providing care, and they support those who do the same.**

- **If nursing care is requested that is in conflict with the nurse’s moral beliefs and values but in keeping with professional practice, the nurse provides safe, compassionate, competent and ethical care until alternative care arrangements are in place to meet the person’s needs or desires. If nurses can anticipate a conflict with their conscience, they have an obligation to notify their employers or, if the nurse is self-employed, persons receiving care in advance so that alternative arrangements can be made.**

It is important to note that ICU physicians and nurses on the Working Group believe that more often than not it is the nurses in the units, not the physicians, that first come to the conclusion that for a particular patient treatment is futile and should be withheld or withdrawn.
5) What guidance has the CPSM provided physicians in Manitoba?

In 2007 the CPSM issued Statement Number 1602 that applies to all physicians in Manitoba. The Statement applies to physicians only because the CPSM’s jurisdiction does not extend to other health care providers. All physicians are required to practice in accordance with this Statement.

The Statement asserts that patients have no legal right to demand life-sustaining treatment and physicians have no legal right to impose life-sustaining treatment on a competent patient. With respect to the former, the authority to withhold or withdraw treatment without the consent of a patient or family is subject to certain general and specific requirements. The Statement asserts that “a physician cannot be compelled by a patient, proxy, representative or member of the patient’s family to provide treatment that is not in accordance with the current standard of care.” Conversely, “in accordance with the current standard of care” means that physicians cannot deny heroic measures to a patient in circumstances in which qualified practitioners generally would have thought intervention warranted. The Statement is further supported by the CPSM Code of Conduct that states “treatments that offer no benefit and serve only to prolong the dying process should not be employed.”

The Statement describes different patient scenarios and the general and specific physician requirements that apply in each scenario. The scenarios are constructed around the concept of a “Minimum Goal of Life-Sustaining Treatment” which is defined by the CPSM as the “maintenance of or recovery to a level of cerebral function that enables the patient to achieve awareness of self ... and environment ... and experience his/her own existence”. It must be noted, however, that the minimum goal does not comment on the quality of the patient’s experience; rather it states that the patient must simply experience his/her own existence.

The Statement describes several scenarios that include the following:

1) Patient, proxy or representative agrees with physician treatment plan (therefore no conflict);

2) Physician offers treatment and patient or proxy declines (physician then abides by patient or proxy wishes) or representative declines (physician then decides based on accepted standard of care);

3) Minimal Goal is not achievable, but patient, proxy or representative does not agree or demands life-sustaining treatment (patient not treated or patient transferred to a physician who will treat, if available);

4) Minimum Goal is achieved or achievable, but physician supports withdrawing or withholding treatment based on concerns about quality of life and patient, proxy or
representative does not agree (options: time-limited trial of care; additional mediation; another physician identified; or 96 hours notice of intent to withdraw treatment given by the physician).

While the Working Group acknowledges that many people take exception to certain aspects of the College Statement, it would be very difficult for our medical staff if the WRHA were to develop policies that conflicted with the College’s expectations of physicians.

6) Why is the Minimal Goal proposed by the CPSM controversial?

The Minimum Goal is controversial in part because physicians through their College have stated that a patient in a state of permanent unconsciousness should not have their life prolonged by medical interventions. Others believe that consciousness should have no bearing on the decision to withdraw or withhold life-sustaining therapies. Some believe that the minimum goal is about ability and disability as opposed to physicians who interpret the minimum goal to be about consciousness and unconsciousness. The following excerpts illustrate the controversial nature of the Minimum Goal proposed by the CPSM.

Jocelyn Downie at the June 9th conference commented:

“First, I believe the College should be given enormous credit for providing guidance with respect to physician’s obligations. I take strong exception, however, to the College defining the minimum goal of life-sustaining treatment. This is not something to be clinically defined. It is a moral and not a medical judgement and, as such, does not belong to the physicians but rather to society.”

... 

“I have concerns about the role of autonomy in the Statement. ... We need to return to core values of the Charter of Rights and Freedoms ... autonomy can only be limited in certain ways.”

George Webster, Ethicist at SBGH, at the conference commented:

“... it is unthinkable that such a wobbly concept as “the minimum goal of life-sustaining treatment” would serve as the foundation for critically important and potentially life altering end-of-life decisions with patients and families.”

Jim Derksen at the conference commented:

“... the minimal goal of treatment as defined in the College Statement requires “cerebral function that enables (someone) to achieve or the potential to achieve.” This is really talking about ability and disability, and that definition, if one can understand it in any practical way as useable (since these elements of awareness and experience are very difficult to discern in any case and are largely philosophical), but if one can discern them
as useable, they would disqualify from life-sustaining treatment a certain sector of persons with disabilities in our population."

... 

"We believe the decision to define the minimum goal of life-sustaining treatment in terms of disabilities is fundamentally wrong. This definition as it occurs in the Statement creates a sub-class of people with disabilities for whom it may be decided by others that life-sustaining treatment should be withheld or withdrawn."

Dr. Bruce Light at the conference commented:

"I would say two-thirds of the patients who are in an ICU are disabled in some fairly major way ... so we're very accustomed with dealing with people ... who are not entirely able-bodied and whose goals of treatment are different than what an able-bodied person's might be. When we're talking, at least for myself, about withdrawing or withholding therapy, it's usually after a trial of therapy has been demonstrated not to be working, where not only can we not meet the minimum goal of a person who's at least awake and not dependent on life support, what we're doing when we get to that point, we are making a judgement that we are not saving a person's life to put them back on their life track, what we are doing is dragging out their death."

... 

"An awake patient, who has the capacity to be conscious ... and we see them every day in the hospital ... who have been in hospital a long time with a bad disease, they've exhausted all treatment options and they've been slowly dying for weeks, and then at the point of death, the ICU gets called, because a decision not to proceed, not to resuscitate has not been made. So we get called to the scene (of) a patient who has been dying for weeks and (are) asked to intervene to bring the person back to the day before they were dying. What we would like to see in the minimal goals is that there is some possibility of a reversible illness, if there was a reversible illness it will take the person out of the ICU at some point where the goal is to get them on track in their life."

Dr. Bill Pope, Registrar of the CPSM, at the conference commented:

"Physicians are required to practice medicine in accordance with the law and appropriate standards of care, not based on an individual's cultural, personal, and religious beliefs. By requiring that physicians base their decision about life-sustaining treatment on clinical criteria it will mean that the decisions they make will not be influenced by age, gender, race, religion or culture."
In response to concerns at the conference that the Minimal Goal was too broad, Dr. Pope responded by saying:

"What we tried to do is to give a general clinical indication rather than defining what would be a specific identified issue."

Dr. Light commented:

"... the College's minimum goal refers to absences of consciousness basically. And whether you start out able-bodied or disabled, if you can't meet the minimum goal it's the same. ... there are a variety of neurologic conditions that can underlie ... absence of consciousness, but again for our practical purposes, I find that a not unreasonable definition."

Questions were raised in discussions between the WRHA Board sub-committee and the Working Group about whether physicians should be required to apply objective tests, such as EEG, when determining whether patients have achieved the Minimal Goal, or may achieve the Minimal Goal. However, critical care physicians have stated that there is no one test that should be mandatory for all clinical situations. The EEG may be an absolute necessity for some patients but in other clinical situations it will not add anything to the assessment. Currently, physicians must perform a complex assessment based on the diagnostic tools available, selecting the appropriate tests based on patient factors.

The Working Group is aware of the differing opinions and concerns about the Minimum Goal as defined by the CPSM. However, given that it is central to the College Statement that governs physicians in Manitoba, the Working Group believes it cannot be ignored.

7) Who has legal authority to speak on behalf of a patient?

The College Statement takes the position that "No one, including the patient's next of kin, has the legal authority to consent to or refuse medical treatment, including life-sustaining treatment, on behalf of an adult patient, unless that person has been granted that authority by the patient in a valid health care proxy or by Court appointment or pursuant to legislation." The College defines a "Proxy" as the person who is legally authorized to make health care decisions on behalf of a patient, whereas a "Representative" is someone who represents the patient and/or patient's family in discussions about the patient's health care, but lacks the legal capacity to make health care decisions.

George Webster at the September 9, 2008 conference commented:

"... most people have not formally appointed a proxy or substitute decision-maker. Most people assume that their spouse, or partner, or loved ones would be able to speak for them in a time of crisis."
“I want you to read here with me now what the College Statement provides for with respect to the representative who is not in agreement with a decision to withhold or withdraw treatment ... and this is a startling thing because of the emphasis in the College Statement on communication, on respect, on being engaged, on involving third parties, on mediation and appropriate conflict resolution: “... the physician should exercise his/her discretion as to what, if any, notice should be provided to the representative before treatment is withdrawn.””

The Working Group understands that from a legal perspective, the CPSM is correct with regard to how a “Proxy” is defined. However, the Group believes that every effort should be made to communicate effectively with “Representatives” as well and try to incorporate their views in the treatment plan.

D. RECOMMENDATIONS

Following lengthy deliberations involving active discussion and thoughtful consideration of the divergent perspectives, and consultation with the WRHA Board sub-committee, the Working Group submits the following recommendations for consideration by the WRHA Senior Management and Board of Directors. Many of these recommendations were informed by discussions Dr. Barakat had with staff who were involved in the recent case.

1. **Aim:** That our approach to withholding and withdrawing life-sustaining treatments be first and foremost focused on the best interests of patients, while at the same time respecting and supporting their loved ones during this difficult time.

2. **Advance Care Planning:** That priority be given to reducing the likelihood of conflict related to end-of-life decision-making by strongly promoting Health Care Directives and Advance Care Planning both within the WRHA and publically through:

   a) completing revisions and approving a new WRHA Advance Care Planning Policy (current policy approved in 2003);

   b) asking patients at the time of admission if they have a Health Care Directive or Goals of Care document;

   c) encouraging providers and patients to update Advance Care Plans as circumstances change;

   d) providing health care provider teams with access to education and training materials relevant to Advance Care Planning;

   e) encouraging providers most familiar with their patients to complete Advance Care Planning prior to transfer to an acute care facility;
f) educating the public about the importance of Health Care Directives and Advance Care Plans.

The WRHA Board Ethics Committee suggested that “Advance Care Planning and Health Care Directives should be maximized to minimize conflict”. The Working Group agreed that discussions between an experienced health care provider and patient/family regarding Advance Care Planning, in advance of an acute episode, could reduce conflicts.

The Working Group met with those responsible for revisions to the WRHA Advance Care Planning policy and strongly supported the approach recommended and the new Goals of Care form. The Group expressed concern that health care providers faced with these difficult patient discussions often lack experience. Therefore, the Group recommends that relevant staff receive appropriate education and training.

3. Communication: That communications be improved by:

a) communicating regularly with patients and families and actively seeking their input;

b) ensuring that members of a patient’s care team are giving patients/family consistent messages;

c) sending facilities identifying for the receiving facilities any extraordinary family expectations or issues;

d) care teams being given as much advance notice as possible of any extraordinary service that they will need to provide (such as dialysis);

e) facility and regional leadership being informed early of any significant end-of-life disputes;

f) regional and site leadership communicating regularly with direct care providers and other stakeholders, as appropriate.

The WRHA Board Ethics Committee suggested that “emphasis must be on good communication and processes in end-of-life decision-making”. Dr. Barakat’s interviews with those involved in the care of the patient in the recent case revealed opportunities to improve communications within sites and regionally. While communication regarding this case did occur at all levels in the organization, and with other stakeholders, it is believed that such communications could be improved, if such a situation were to occur again.
4. Long-stay ICU Patients: That for long-stay patients in ICUs:

   a) the multidisciplinary team meet weekly to review the patient’s status;

   b) a care plan be developed that is modified only after discussion with the multidisciplinary team and patient, family or proxy;

   c) continuity of physician care be enhanced by having the Unit Medical Director, or other appropriate physician, kept informed of the patient’s progress;

   d) one member of the multidisciplinary care team be responsible for following the patient throughout his/her stay and ensuring that messaging by staff is accurate and consistent;

   e) a member of the multidisciplinary team be identified to oversee interactions with a long-stay patient/family.

Each ICU in Winnipeg has a single attending physician that is responsible for all patients on the unit. The physicians change over on a weekly basis. For long-stay patients it is important that there be good communication among providers to ensure continuity of care, and consistent and quality communications with the family.

5. Mediation and Ethics Support: That staff at all levels have timely access to mediation/facilitation and ethics support services, and staff be encouraged to use such services when managing difficult end-of-life situations.

A growing body of literature on organizational ethics in health care calls for multi-faceted, integrative ethics strategies to address the range of ethics challenges confronting our health care systems. In recent years, there has been a strong movement across North America away from isolated ethics committee structures and towards the integration of ethics throughout health care organizations. Integrated ethics initiatives rely for their success on a number of key factors:

- Board and Senior Management commitment, support and engagement
- Staff engagement at all levels of the organization and in all contexts
- Dedicated staffing
- Strategic planning to address key ethics priorities
- Networking and communication
- Awareness of advancements in ethics nationally and internationally

The Accreditation Canada Qmentum Program contains many standards that support integrative ethics. For example, Effective Organization Standard 5.0: “The organization’s leaders deliver services and make decisions according to the organization’s values and ethics.
The organization’s leaders develop and implement an ethics framework which is adopted by the governing body, where applicable. The ethical framework defines formal processes for managing ethics-related issues and concerns."

The CPSM Statement encourages physicians to use available mediation and ethics supports when dealing with disputes regarding end-of-life decisions. It is the Working Group’s recommendation that WRHA sites, programs and services should enhance the availability of such supports and ensure physicians and staff know how and where to access these supports.

6. **Multidisciplinary Team**: That the Physician of Record actively solicit and carefully consider the input and opinions of other members of the multidisciplinary care team when making life-sustaining treatment withholding or withdrawing decisions.

   The WRHA Board Ethics Committee observed that “with ultimate authority vested in the physicians, decision-making will be polarized and it will appear arbitrary”.

   The Working Group strongly believes that input from other members of the multidisciplinary care team into end-of-life decision-making must be actively sought, wherever possible.

7. **Staff Support**: That staff involved in the care of such patients be supported through:

   a) regular communication and visits from senior site and regional leadership;

   b) education and training on Advance Care Planning, including communication strategies with families that have extraordinary expectations, and understanding the religious or cultural context for certain care requests;

   c) access to skilled social work and psychology support;

   d) relief for staff who need a break from the situation or feel they cannot continue due to moral/ethical concerns;

   e) leadership providing ongoing positive reinforcement to direct care staff.

   Staff involved in the recent case believe they could have been better supported by their site and the region. There was a strong sense that the health care leadership, government and the public did not fully appreciate how difficult the situation had really become. Closer attention to the needs of staff is recommended, if a case like this should arise again in the future.
8. **ICU Visitors:** That visiting hours in the ICUs should continue to be as flexible as possible for families and friends; however, voice recording, photography or videotaping of care providers, without their consent, should be strictly prohibited.

The Working Group did not believe that visiting hours should be restricted, particularly during morning rounds, as some staff have suggested. However, the Group does believe that videotaping of care providers, without their consent, should be strictly prohibited.

Videotaping, pictures or voice taping may compromise the privacy of other patients and result in PHIA breaches. As well, the Working Group noted the chilling effect of such activity on staff morale and working conditions. However, the Group appreciates that for some families the end of life is an opportunity to record memories of importance to family members. So, where the purpose is to record memories rather than monitor staff, some recording activity could be permitted. Ultimately, however, staff need to be assured that it is their right not to be photographed or taped.

9. **Long-Term Care:** That long-term care facilities (Personal Care Homes) establish better access to medical specialty consultancy support, so that some transfers to acute care facilities may be avoided.

The Working Group recognizes that efforts have been made to improve family physician coverage in long-term care facilities. However, access to medical specialists in personal care homes is limited. If this could be enhanced, then fewer personal care home residents may need to be transferred to an acute care hospital for assessment.

10. **Specialty Consultants:** That specialty consultants continue to provide their expert opinions and then support, where possible, the requests of a physician of record who is practicing under the auspices of a Court order.

In the recent case, some staff were critical of specialty consultants who agreed to provide specialty services, against their better judgement, when the physician of record was obligated under a Court order to provide life-sustaining therapies. However, physicians are legally obligated to follow Court orders.

11. **CPSM Statement:** That the WRHA recognize the College of Physicians and Surgeons of Manitoba (CPSM) Statement 1602 on Withholding and Withdrawing Life-Sustaining Treatment as applying to physicians only; and that WRHA policies and procedures that go beyond the CPSM Statement, and apply to all WRHA staff, not be in conflict with the CPSM Statement.
12. Treatment Withdrawal Notification: That in any patient scenario, the physician of record, where possible, will advise the patient, proxy or representative of the specified location, date and time that treatment will be withdrawn; and that discussions with the patient, proxy or representative about treatment withdrawal will occur before a patient is transferred to another setting (e.g., discharge from an ICU to a ward).

The WRHA Board Ethics Committee noted that with the exception of the 96-hour requirement defined in one particular scenario, the CSPM Statement is otherwise silent with regard to the obligation of physicians to provide advance notice of treatment withdrawal.

The Working Group believes that such advanced notice is appropriate in situations of clinical stability. Imposing additional time requirements in other scenarios assumes clinical stability which often does not exist, especially for patients who cannot achieve the minimum goal or who are about to experience a cardiac arrest. The Working Group believes that most physicians currently do provide, where possible, such advance notice to patients, proxies or representatives. The Working Group does not support additional mandatory notice periods, other than those currently in the CPSM Statement.

13. Minimal Goal: That the WRHA provide further clarity to the definition of “minimum goal of life-sustaining treatment” by stating that the minimal goal is not achieved when a patient is determined clinically to be in irreversible coma, irreversible (persistent) vegetative state, or will die without regaining consciousness.

The Working Group concluded that the minimum goal as defined by the CPSM (whether the patient will have enough cerebral function to be aware of self, environment and experience his/her own existence) is intended to be a clinical determination. The quality of the patient’s experience is not part of the definition nor does it factor into the assessment of the minimum goal.

Common clinical examples in which the minimum goal is not achieved are irreversible coma and irreversible vegetative state. In these conditions the patient is irreversibly unconscious. In contrast, a patient who develops “locked in syndrome” achieves the minimum goal. It is not possible to list all medical conditions that would prevent a patient from achieving the minimum goal.

Underlying the CPSM Statement is the assumption that physicians, with their clinical knowledge and experience, are most appropriate to determine if the minimal goal is achievable for a particular patient.

The group acknowledged that the CPSM Statement does not apply to legally defined “cardiac death” or “brain death”. In these circumstances the patient is legally dead and no treatment is indicated, with the exception of maintenance of circulation, respiration and other body functions for the purpose of organ donation.
14. Alternatives: A) That WRHA encourage Government to establish a review panel that has authority under legislation to adjudicate disputes between care providers and patients, proxies or their representatives related to withholding or withdrawing life-sustaining treatment. B) That if a legislated review panel cannot be established in a timely manner, then a review panel process without status in law be developed by WRHA.

The WRHA Board Ethics Committee raised concerns that “there is a greater likelihood of cases going to court, now that the 96-hour rule is in effect”.

The Working Group believes that the Courts have not proven to be an effective venue for resolving withholding and withdrawing life support disputes. In those few cases in which agreement cannot be reached, a review panel with knowledgeable representatives and authority under law would be a better alternative. Such legislated review panels have been established in jurisdictions such as Texas.

However, if this is not possible, the Working Group believes that WRHA should proceed to establish its own review committee process, recognizing that this does not preclude individuals from seeking a court injunction. A structured review committee could increase patient, family and public confidence in our approach to end-of-life decision-making, thereby reducing the likelihood of families going to Court. For those cases that do go to Court, it may allow the Courts to focus more on whether or not the WRHA process was followed, rather than the Courts having to deliberate on complex medical issues.

The review committee would consider input from both the care providers in the multidisciplinary team and the patient, proxy or representatives. The review committee could also solicit input from experts in the relevant fields. The composition of the review committee would be broad, but membership would need to be adjusted to reflect the time available from a clinical perspective for decision-making. Under certain clinical circumstances, convening a review committee may not be possible due to time constraints.

If a review committee supports the care plan of the existing care team, then the existing care plan would be followed. Patient, proxies or representatives may still seek a Court injunction, but it is also possible that the review committee process may have addressed their concerns sufficiently.

If the review committee opposes the existing care team’s plan, then ideally a physician member of the review committee would be prepared to assume responsibility for the care of the patient. If not, administration would have to try and identify a physician who would be willing to assume ongoing care.
CONCLUSION

If WRHA Senior Management and Board support the recommendations described above, then responsibility could be assigned to appropriate individuals or groups to develop and initiate implementation plans.

The Working Group thanks the WRHA Board and Senior Management for the opportunity to review this important issue and offer recommendations.

Submitted by Dr. Brock Wright, Chair
Appendix 1

**Working Group on Withdrawing and Withholding Life-Sustaining Treatment**

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<th>Member</th>
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<tr>
<td>Dr. Brock Wright - Chair</td>
<td>Sr. VP Clinical Services, Chief Medical Officer</td>
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<tr>
<td>Dr. Brian Postl</td>
<td>CEO and President WRHA</td>
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<tr>
<td>Ms Catherine Tolton</td>
<td>General Counsel</td>
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<tr>
<td>Ms Sheila Toews</td>
<td>Regional Director, Ethics Services</td>
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<tr>
<td>Dr. Perry Gray</td>
<td>Physician (CMO)</td>
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<tr>
<td>Dr. Samia Barakat</td>
<td>Clinical Director</td>
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<tr>
<td>Dr. Patrick McDonald</td>
<td>Peds Neurosurgeon</td>
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<td>Ms Barb Bunko</td>
<td>Patient Safety Officer, HSC</td>
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<td>Dr. Aviva Goldberg</td>
<td>Ethics Representative</td>
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<td>Ms Betty Lou Rock</td>
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<td>Dr. Bruce Light</td>
<td>Medical Director Critical Care</td>
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<td>Dr. Clare Ramsey</td>
<td>Attending in Critical Care</td>
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<td>Ms Kaaren Neufeld</td>
<td>Chief Quality Officer</td>
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<tr>
<td>Dr. Jamie Boyd</td>
<td>Dept. Head, Program Director, Family Med.</td>
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<tr>
<td>Dr. Michel Tetreault</td>
<td>CEO, St. Boniface Hospital</td>
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<tr>
<td>Dr. Murray Kesselman</td>
<td>Attending on PICU</td>
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<tr>
<td>Dr. Kenneth VanAmeyde</td>
<td>Attending on Medicine Units</td>
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[name deleted] Review
Recommendations

Submitted by Dr. Samia Barakat

December 10, 2008
Introduction

At the request of Dr. Brian Postl, a series of interviews were conducted to gain insight on what can be learned from the [name deleted] case. The interviews were moderated by Dr. Samia Barakat, Associate Dean, Professionalism and Professor, Department of Psychiatry, University of Manitoba. Special thanks to Ms Lorri Dahl for her valuable assistance.

Interviews were held with:

- Grace CMO
- Clinical Manager, Grace Hospital ICU
- Grace Hospital ICU Attendings and HMOs
- Grace Hospital ICU Nursing Staff:
  - Medical Director, Surgical ICU HSC
  - Medical Director, WRHA Critical Care Program
  - Administrative Director, WRHA Critical Care & Emergency Program
- HSC Nephrologists
- Salvation Army Ethics Consultant
- Deer Lodge Centre, Resident Care Manager, L6
- Program Director, WRHA Critical Care Program
- Grace CN0
- WRHA Regional Director, Ethic Services
- WRHA Legal Counsel
- WRHA Senior VP, Clinical Services and CMO
- Head, St. Boniface General Hospital CICU
- Medical Director, WRHA Medicine Program
Theme: Advanced Care Plan/Health Care Directive

Recommendation #1: All individuals be required to present an Advance Care Plan/Health Care Directive upon admission, just as you need a MB Health card upon admission to Emergency, hospital or long term care setting.

Recommendation #2: All ACPs be updated on a regular basis to avoid situations where the current wishes of incapacitated individuals are not represented.

Recommendation #3: Relevant dialogue, in terms of what can be done medically and what cannot be done at end of life, occur between the family and/or patient and an experienced health care provider who is skilled in providing compassionate and factual information.

Recommendation #4: Develop a process to ensure that the ACP has been agreed upon between the family/patient and health care provider, prior to transferring the patient to an acute care setting.

Theme: Care Plans

Recommendation #1: Ensure the care plan articulates any risk management issues, (eg., medical, social, psychosocial, family issues, personality disorder, etc.) that are then carried forward with each transfer of the patient.

Theme: Communication

Recommendation #1: One individual (physician, CRN, clinical manager) be designated as the only point of contact between the family/patient and the unit staff and physicians.

Recommendation #2: Establish a solid communication process between the sending and receiving sites in terms of relaying extraordinary family expectations/issues before a patient is transferred (see also recommendation #1 Care Plans).

Recommendation #3: Teams be advised in advance that they will be asked to perform extraordinary mechanisms (i.e., providing dialysis at a non-dialysis site). This would allow time for team members to consult with their professional bodies and/or legal counsel.

Recommendation #4: That meetings held between the region and site be productive and facilitated with a pre-determined agenda.

Recommendation #5: That site senior management provide ongoing, direct support and status reports to the staff directly affected by the case.
Recommendation #6 That the responsibilities of the ICU Clinical Manager be reviewed in terms of strengthening their role in providing communication and support to the ICU staff.

Recommendation #7 Develop a mechanism whereby the entire ICU team (physicians, nurses, clinical managers) meets on a regular basis to review and discuss all aspects (medical, psychosocial and family) of long-stay patients in the ICU.

Recommendation #8 That site leaders raise risk issues with regional leaders at the early stages of the event and those regional leaders, in turn, raise the urgency of these cases early on with Government to advocate for a timely resolution on matters.

<table>
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<tr>
<th>Theme: Education/Training</th>
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<tr>
<td><strong>Recommendation #1:</strong> Train physicians and staff on how to have meaningful end-of-life dialogue with patients and their families in a compassionate and factual manner <em>(see also recommendation #3 - Advanced Care Plan/Health Care Directive).</em></td>
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<td><strong>Recommendation #2:</strong> Train physicians and staff on how to work with and cope with families that consistently present with extraordinary expectations that have a negative affect on morale.</td>
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<td><strong>Recommendation #3:</strong> Provide education to physicians and staff on the religious aspects of family/patient requests to help staff understand the reasons behind the requests.</td>
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<th>Theme: ICU Visiting Hours</th>
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<tr>
<td><strong>Recommendation #1:</strong> Visiting hours in the ICU be established that will not allow for visiting before noon so that physicians and staff may conduct consultations with their patients in privacy.</td>
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<th>Theme: Legal Counsel</th>
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<td><strong>Recommendation #1:</strong> WRHA Legal Counsel must be actively involved from the onset of extraordinary cases and have the opportunity to prepare a strong case before the courts.</td>
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Theme: Management of Families with Extraordinary Expectations

Recommendation #1: Social Workers are involved with cases where families present with extraordinary expectations.

Recommendation #2: Families should be fully engaged with physicians and nurses who are skilled in difficult, compassionate dialogues. The dialogue should focus on clear expectations of what can be provided and what can’t be provided in terms of care.

Theme: Management of Patients and Long-Stay Patients in the ICU

Recommendation #1: One attending physician is assigned to long-stay patients for the duration of their stay in ICU, to allow for continuity of care.

Recommendation #2: One individual (physician, CRN, clinical manager) be designated as the only point of contact between the family/patient and the unit staff and physicians. (see also recommendation #1 – Communication).

Recommendation #3: Establish criteria/mission statement for the ICU in terms of what level of care will be admitted to ICU and what levels will not.

Recommendation #4: Develop a trigger point where an automatic review is undertaken on patients who have been in ICU for a particular length of time.

Theme: Media Relations

Recommendation #1: The region investigates how [name deleted] obtained the specifics of the medical information that was contained in the letter to [name deleted] and deal with that leak appropriately.

Recommendation #2: The WRHA media team meet with all parties affected by the situation and provide an orientation/training on how to deal with the media.

Recommendation #3: The WRHA media team directly contact those named in the media to advise not to speak with the media.

Recommendation #4: The region aggressively responds to media reports where non-factual information has been reported.
Theme: Physician Consults

Recommendation #1: Long-term care sites develop a system to allow for a timely consultation at the site, in terms of respiratory, nephrology, internal medicine and diagnostics, to avoid transfers to the ER.

Recommendation #2: Revisit the expectations/roles of consultants in terms of whether or not it is an appropriate expectation for consultants to make a decision on withholding or withdrawing life sustaining care.

Recommendation #3: Patients that are transferred from a long-term care setting to an acute setting should be transferred directly to an internist, by-passing the ER.

Recommendation #4: Develop a mechanism for obtaining timely senior physician consults at the early stages of the case and articulate which senior physicians should be consulted.

Theme: Regionalization

Recommendation #1: Programs and sites work together as a region and not as individual programs and sites that have the choice of whether or not to accept a patient.

Theme: Support for Nurses and Physicians

Recommendation #1: Regional and site leaders make regular, personal visits to staff affected throughout the duration of the event.

Recommendation #2: Social workers/psychologists provide regular, on-going, on-site sessions for staff and physicians throughout the duration of the event.

Recommendation #3: Develop support structures for staff who are ‘trapped’ and mechanisms for temporarily relieving them of their duties if they believe it’s morally unethical for them to continue.

Recommendation #4: That site and regional leadership acknowledge positive reinforcement with staff, not just when staff has ‘done something wrong’.
### Theme: Tribunal/Mediation/Facilitation

**Recommendation #1:** Early intervention/mediation with families should occur when red flags have been raised in terms of extraordinary expectations. Establish a system where mediation services are available 24/7.

**Recommendation #2:** The process for ‘mediation’ is replaced by a process for ‘facilitation’ through an inter-disciplinary expert, who can facilitate the dialogue with the family according to the uniqueness of each case and individual. A ‘mediator’ is trained to mediate in a “one-size fits all” template which would not be of benefit considering each case presents with unique challenges.

**Recommendation #3:** A legislated tribunal consisting of a layperson, physician, lawyer, clergy or ethicist be established to provide a timely decision (within 3 days) on cases where mediation has not resolved the situation. Families may then appeal the tribunal’s decision to a legal body. The tribunal would mirror that of the Ontario Consent and Capacity Board.

### Theme: Physicians’ Ability to Resign

**Recommendation #1:** Physicians be employed by the WRHA under contract.

### Theme: Videotaping/Taping Medical Care and Staff

**Recommendation #1:** A policy is established to restrict visitors from videotaping, photographing and taping conversations of medical staff and medical care.

**Recommendation #2:** Staff be made aware they have the right to say “no” when families videotape them.
WRHA WITHHOLDING & WITHDRAWING TREATMENT WORKING GROUP

ENVIRONMENTAL SCAN & LITERATURE REVIEW

January 2010

CONTENTS
1. Background
2. Environmental Scan
   o Hospitals & Health Regions
   o Professional Colleges and Associations
   o Provincial Agencies
   o Other Canadian Initiatives
   o The Continued Public Debate
3. Literature Review
4. Ethical Considerations
5. References
At the December 2009 Board meeting, members reviewed the Draft Report of the WRHA Working Group on Withholding and Withdrawing Life-sustaining Treatment. The Board asked that the Withholding and Withdrawing Life-sustaining Treatment Working Group conduct an environmental scan to identify any legislation or policies specific to this issue as developed by other Canadian health care contexts. The Board also asked to meet with the Working Group at its January 2010 meeting.

In response to the Board’s request, the Working Group embarked on an environmental scan of withholding and withdrawing life-sustaining treatment legislation or policy in other Canadian health care contexts. Concurrently, the Working Group asked the WRHA librarian to conduct a literature search. Results were used to prepare a review of current literature on withholding and withdrawing treatment.

The findings are as follows.

**ENVIRONMENTAL SCAN**

The Working Group contacted legal departments, ethics services, and policy writers across Canada and checked many Canadian websites (December 2009-January 2010). For the purposes of this report, the environmental scan was limited to policies or legislation specific to withholding and withdrawing treatment or containing significant sections on this aspect of end-of-life care.

**HOSPITALS & HEALTH REGIONS**

The three policies identified below share many common elements about respectful engagement with patients, their substitute decision-makers and families; respect and inclusion of patient beliefs and values wherever possible; congruence with professional standards of practice; and guidance regarding second opinions or conflict resolution processes in cases of disagreement.

Only the policy from Capital Health Region, Nova Scotia, includes fairness in the allocation of health resources as one of its guiding principles.
CAPITAL HEALTH REGION, NOVA SCOTIA
Policy: Decision Making about Potentially Life-sustaining Treatment (2009)

- This policy is grounded in 8 guiding principles: 1) commit to patient-centered decision making; 2) encourage and enable patients to make fully informed decisions about their care and treatment; 3) respect and, where possible, act in accordance with the values, beliefs and interests of patients (including, but not limited to, their cultural and spiritual/religious beliefs; 4) value the professional judgment of our health care providers and support their engagement in clinical decision making; 5) support the goal of shared decision making in the making of decisions about the use of potentially life-sustaining treatments/interventions; 6) offer and provide, as appropriate, emotional and social support to patients, substitute decision makers, 'families' and health care providers; 7) communicate honestly and openly with patients, substitute decision makers, 'families' and other health care providers; 8) support policy development that takes into account the fair allocation of limited, publicly funded health resources.

- The policy requires that all decisions with respect to the use of Potentially Life-Sustaining Treatment will be made within the framework of the principles, values and procedures in the document.

- The policy is to assist health care providers in "appropriate and sensitive management of their patients' end-of-life circumstances, which are often complex.

- Decision making support provided to all involved includes patient representatives, clinical ethics consultation, spiritual care and legal services.

JEWISH GENERAL HOSPITAL, MONTREAL
Policy: Levels of Intervention for Resuscitation and Other Critical Interventions (2007)

- This policy is grounded in 8 guiding ethical principles: 1) Quality Care; 2) Compassion, Dignity and Respect; 3) Teamwork; 4) Professional Integrity; 5) Respect for Autonomy; 6) Promotion of Patient Well-being (Beneficence); 7) Minimize Harm to the Patient (Nonmaleficence); 8) Access to Care.

- The policy outlines five levels of intervention that are determined in discussion with a physician upon admission to the hospital and revisited as appropriate. Healthcare team roles are defined and the procedure for documenting discussions and decisions is described. Guidelines are presented for discussion of critical interventions and for conflict reconciliation.

- Step 4b of the policy addresses withholding or withdrawing treatment directly. Healthcare teams are not obligated to provide a requested intervention that is "clearly ineffective and falls outside the professional standard of care". However,
the policy requires that every effort be made to continue discussion to attempt to resolve conflicts. Patients or their surrogates should be informed of a decision to withhold or withdraw an intervention and the rationale for that decision.

- This section of the policy also indicates that "when the patient indicates a preference to follow Jewish Religious law, the distinction between "withholding" and "withdrawal" of an intervention should be respected whenever possible". Similar consideration is to be shown to other patients with cultural/religious preferences.

**PROVIDENCE HEALTH CARE, ONTARIO**

Policy: Artificial Nutrition and Hydration – Provision, Withholding and Withdrawal (Last revised August 2008)

- The hospital’s philosophy, mission and values are founded on “respect for the dignity of the person and the sacredness of human life”.
- The purpose of the policy is to assist the healthcare team and patients/substitute decision makers with "ethical reflection and decision making" about whether or not to withhold or withdraw artificial nutrition and hydration.
- The care team is required to consult with the clinical ethicist whenever withdrawal of artificial nutrition and hydration is being considered for a patient “who is unable to receive adequate nourishment by mouth”.
- Throughout the decision-making process, the emphasis is on the patient’s dignity and comfort; and social, emotional and spiritual supports, education, counseling and ethics consultation, are provided as required to those involved.
- Lack of consensus by equal ranking substitute decision-makers will result in referral of the decision to the Ontario Public Guardian Treatment Decisions Unit (OPGT).
- A conflict resolution process exists to assist when there is conflict between the patient/substitute decision-makers and the health care providers.

**WINNIPEG REGIONAL HEALTH AUTHORITY**

From the Board to direct care, our health region works extensively to address end-of-life issues in the context of applicable Manitoba and Canadian legislation; e.g.,

- WRHA responses to the College of Physicians and Surgeons of Manitoba Draft Statement on Withholding and Withdrawing of Life-Sustaining Medical Treatment (2006-2008)
- WRHA Withholding and Withdrawing Life-sustaining Treatment Working Group.
• Initiatives by WRHA Clinical Programs and Services.
• Related services & departments such as WRHA Ethics Services and WRHA Legal.
• Agenda items and educational initiatives at all levels of the organization.

PROFESSIONAL COLLEGES AND ASSOCIATIONS
A number of Professional Colleges and Associations have addressed withholding and withdrawing treatment either in the form of specific position papers or, more frequently, as sections of end-of-life documents. Common elements include the need to act in the best interests and benefit of the patient; the importance of dialogue with the patient and family; and the reality that conflict can and does occur and therefore conflict mediation processes are necessary.

BIOETHICS COMMITTEE, CANADIAN PAEDIATRIC SOCIETY
The Society’s publication and resource section includes a position statement on “Treatment Decisions Regarding Infants, Children and Adolescents” (revision in progress)\(^1\) The statement includes a section on withholding and withdrawing treatment. The section states that “These difficult and often controversial decisions should not be made in isolation, and should include members of the interdisciplinary team and, when possible and desired, an ethics committee or consultant. All discussions and decisions to withhold or withdraw treatment should be well documented and reviewed after the child or adolescent’s death”. It further states that the “religious, spiritual, cultural and moral background of families should be recognized in these situations because they frequently influence families and their decisions”.

COLLEGE OF PHYSICIANS AND SURGEONS OF MANITOBA
Information on The CPSM Statement: Withholding and Withdrawing of Life-sustaining Medical Treatment (2008) has not been summarized here as WRHA discussions of the Statement - both in draft and final format - are documented elsewhere.

COLLEGE DES MÉDECINS DU QUÉBEC
The College’s ALDO-Québec “Legal, Ethical and Organizational Aspects of Medical Practice in Québec, Section C: End-of-Life Issues” (2009)\(^2\) uses a case based approach to illustrate issues in cessation of treatment. In the conclusion to Section C, it the observation is made that death is often a “taboo” subject which has many implications in the physician-patient relationship and in society. The College calls on

\(^{1}\) [http://www.cps.ca/english/publications/Bioethics.htm](http://www.cps.ca/english/publications/Bioethics.htm)

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physicians to “provide supportive care and information to the patient and his family at the end of life and, in so doing, help patient and family go through the final stages of life with dignity”. The College also states that physicians must be part of the “increasingly frequent public discussions on these questions”.

**COLLEGE OF PHYSICIANS AND SURGEONS OF ONTARIO**
The purpose of the “CPSO Policy Statement – Decision-Making for the End of Life” is to “assist physicians in providing medically and ethically appropriate care to patients at the end of life; specifically, care that aims to reduce suffering, respects the wishes and needs of patients and their families, and lessens conflict and distress”. Part 3.2 addresses life-sustaining treatments and outlines criteria to guide decision-making. CPSO calls for physicians to initiate “timely discussions” about treatment choices, assessment of benefits and preferences with patients, substitute decision-makers and families. Physicians should refrain from initiating treatment that will not benefit or may harm the patient. Conflict resolution measures outlined in Part 4.1 emphasize the need for continued efforts to resolve any disputes that may include relevant legislative processes (e.g., the Health Care Consent Act). Conflicts related to Power of Attorney for Personal Care can be addressed to the Consent and Capacity Board or to the courts.

**CANADIAN ASSOCIATION OF CRITICAL CARE NURSES**
CACCN issued a “Withholding and Withdrawing of Life Support” position statement in 2001. It is grounded in patient-focused ethical beliefs and principles. It states CACCN’s belief that “critical care nurses play an integral part in how the decision making processes regarding withholding or withdrawing of life support occur for the critically ill. The Association believes that every person is autonomous and has the right to withhold or withdraw treatment when an underlying condition will cause their ultimate death”. It calls on healthcare institutions and provincial associations to direct the process of withdrawing or withholding life support treatments. Policies should include a) educational opportunities for critical care nurses that include content on palliative care, communication with the dying patient and the family, and information about available resources to provide comfort and dignity; b) mechanisms to relieve critical care nurses from duties that may breach

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3  
http://www.cpso.on.ca/uploadedFiles/policies/policies/policyitems/End%20of%20Life.pdf
personal beliefs; c) conflict resolution processes; d) on-site debriefings or counseling to support critical care nurses when difficult situations are encountered.⁴

**PROVINCIAL AGENCIES**

The governments of Manitoba and Ontario have taken the following approaches to the issues inherent in decisions about withholding and withdrawing life-sustaining treatment.

**CONSENT AND CAPACITY BOARD, ONTARIO**

Ontario’s Consent and Capacity Board is an independent provincial tribunal. Its mission is “the fair and accessible adjudication of consent and capacity issues, balancing the rights of vulnerable individuals with public safety”. It adjudicates on matters of capacity, consent, civil committal and substitute decision-making. The Board is authorized to deal with the Health Care Consent Act, the Mental Health Act, the Personal Health Information Protection Act, the Substitute Decisions Act (review of statutory guardianship for property), and the Mandatory Blood Testing Act.

**MANITOBA LAW REFORM COMMISSION**

Information on the Manitoba Law Reform Commission Document on Withholding or Withdrawing Life Sustaining Treatment (2003) has not been summarized here as WRHA discussions of the document- both in draft and final format – are documented elsewhere.

**OTHER CANADIAN INITIATIVES**

Common issues about withholding and withdrawing life-sustaining treatment shared in the following include 1) concerns about unilateral decision-making by physicians; and 2) the concern that negative bias and misconceptions about the quality of life of persons with disabilities will unduly influence decision-making about the withholding or withdrawal of life-sustaining treatment.

**MANITOBA LEAGUE OF PERSONS WITH DISABILITIES, INC.**

The MLPD exists as a voice of citizens with disabilities in Manitoba. In a response to the Manitoba Law Reform Commission’s discussion paper on Withholding or Withdrawing Life Sustaining Treatment (2002)⁵, MLPD raised a number of concerns related to a) Trust and the Doctor / Patient Relationship; b) Vague Terminology; c) Non-specificity of DNR; d) Therapeutic Privilege; e) The Fallibility of Medical

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Judgement; f) Negative Bias; g) Euthanasia; h) Purpose of Guidelines; i) Intentions; j) Futility and “Scarce Resources”

THE END-OF-LIFE PROJECT
The Dalhousie Health Law Institute End of Life Project is designed “to facilitate public policy debate regarding the provision of potentially life-shortening palliative treatment and the withholding and withdrawal of potentially life-sustaining treatments”. Its resources include a brochure “What you need to know about Withholding and Withdrawing of Potentially Life-sustaining Treatment”.

VP-NET
The Vulnerable Persons and End of Life New Emerging Team (VP-NET) is a five-year CIHR funded research project that brings together a team of investigators to explore the availability and accessibility of end of life care for specific populations of vulnerable people. In 2008, VP-NET partnered with St. Boniface General Hospital Health Care Ethics Service to host a one-day forum on End-of-Life Ethics and Decision-Making Forum: Current Policy Debates About Withholding and Withdrawing Life-Sustaining Treatment. During the Forum, Heidi Janz, Visiting Scholar, John Dossetor Health Ethics Centre, University of Alberta, emphasized the importance of taking a well-considered approach to the quality of life of people with disabilities, “understanding that some people with disabilities need help and sometimes equipment to eat, breathe and live. But needing this help and equipment does not mean these people have a bad quality of life”.

THE CONTINUED PUBLIC DEBATE
A retrospective review of newspaper articles, TV stories, or web searches related to withholding and withdrawing life-sustaining treatment generate widely divergent viewpoints and responses. This is to be expected. As this report was written, the case of baby Isaiah May was being debated in the Alberta courts. Isaiah’s story powerfully illustrates the complexities, moral distress and deep emotions inherent in decision-making about withholding and withdrawing life-sustaining treatment.

LITERATURE REVIEW
The Environmental Scan resulted in the identification of common themes in Canadian policies, guidelines and position statements. Many were also evident in the literature. As the end-of-life literature is extensive and the time frame to research

6 http://as01.ucis.dal.ca/dhli/cmp_about/default.cfm?fuseaction=shwAbout2
7 http://www.umanitoba.ca/outreach/vpnet/

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this report was one month, the decision was to focus on articles closely concerned with withholding and withdrawing life sustaining treatment. However, this did not unduly limit the effectiveness of the review as the composite knowledge and experience of the Working Group membership made it possible for findings to be considered in the broader context.

In his 2009 reflection "Withdrawal of Care", Alberta neurosurgeon J. Max Findlay tells the story of a "much-loved mother and grandmother" and the withdrawal of her care (8). Despite its brevity, this narrative succeeds in capturing many of the themes found in the literature on the withholding or withdrawing of treatment.

Findlay's narrative describes how he and the team endeavored to build relationship with the family. Cook et al. (2006) share four reasons why this may be more difficult in the tertiary ICU than in other settings: 1) dialogue with family rather than the patient; 2) recidivism is rare in terms of repeat visits; 3) new relationships; 4) mortality [may be] imminent (4). At the same time, family meetings in the ICU can be very difficult (4).

As Findlay illustrates in his narrative, family meetings need to be approached with sensitivity. A family that is experiencing "anguish, guilt, fear, disbelief, distrust - a symphony of emotions" is also trying to comprehend the complexities of life sustaining treatment. Cook et al. (2006) would agree: "Life support withdrawal has explicit social, ethical, and esthetic meaning. Decisions about whether to, and how to, withdraw technology are certainly influenced by attitudes; this decision is socially negotiated and individualized to orchestrate "the best death" possible from the perspectives of clinicians and families on behalf of patients" (4). The need for supportive engagement and dialogue with the family is paramount (4) (8) (18) (24).

Williams et al. (2009) conducted a qualitative research study to develop and pretest a questionnaire to assess the practice of life-sustaining treatment in the NICU on the basis of the experiences of bereaved parents. Their issues of importance were grouped into 6 domains: communication, quality of care, quality of life, shared decision-making, the withdrawal of life sustaining treatment process, and bereavement care. The top ranked domain was communication: "encourage parents to ask questions; allow parents time to digest the details of the diagnosis and prognosis; adequately explain the likely outcomes in words that parents understand" (24).

Marcoux et al. (2007) would argue that whether or not the explanation is understood should also be explored, based on the findings of a 2002 Quebec public opinion poll. Respondents were asked to distinguish between euthanasia and other
end-of-life scenarios in hypothetical scenarios. "66% identified treatment withdrawal as euthanasia, 49% thought the double effect of providing pain medication which may accelerate death was euthanasia and 38% identified withholding treatment as euthanasia" (15). This invites reflection on the medical terminology used in relation to this issue. A brochure designed with good intent to inform and clarify could be misconstrued. For example, “Withholding of life-sustaining treatment means not starting treatment that has the potential to sustain the life of a patient.... Withdrawing of life-sustaining treatment means stopping treatment that has the potential to sustain the life of a patient“ (23).

In Findlay's narrative he decides, in this particular case, to introduce the idea of withdrawal of care early in his engagement with the family. But first they help him learn more about this elderly woman who is so central to their lives. Then he embarks on the difficult task of helping them to understand that she could not recover and “return to who she was”. He explains withdrawal of care as “a medical decision, something they must understand and accept before we proceed, but not something they are responsible for”. In this scenario, the family agrees to withdrawal of treatment the following day.

The physician and family in the Findlay narrative were able to reach consensus, but what if the story had evolved differently? There are some interesting observations in the literature in terms of the physician-patient/family relationship. Garland and Connors (2007) collected prospective, observational data for three years in the adult medical ICU. They found that “physicians exert significant influence over decisions to limit life support”, though recommend further study, given that their research findings were based on an assessment of nine physicians in one ICU (9). There may be some explanation for this in the work of Heyland et al. (2002) who conducted a Canadian study of 789 family members of ICU patients. “Of respondents, 15% preferred that the physician primarily make the decision, 24% preferred that the physician make the final decision after considering their opinion, 39% preferred that the physician shared responsibility to make the decision, 22% preferred to make the final decision after considering the physician’s opinion, and 1% preferred to make the treatment decision alone.“ (cited in 4).

It is well recognized that the complexities inherent in the ICU context and life-sustaining treatment, coupled with the reality that health care teams must continually form new relationships with families in crisis, can easily lead to conflict. Consequently, the need for supportive decision-making processes and conflict resolution mechanisms is emphasized in the literature and many examples are shared. (7) (11) (19)
ETHICAL CONSIDERATIONS

- As stated earlier, our society holds widely divergent views on the issue of withholding and withdrawing life-sustaining treatment. It is therefore not surprising that ethics is frequently mentioned when difficult and distressing cases are reported in the media.
- Ethics is concerned with the value dynamics in human relationships. It’s an “endeavour....It’s about discernment, knowledge and self reflection. It’s sustained through seeking, clarifying and translating.” (Weiss Roberts, 2002).
- A broad range of ethics theories, principles and considerations provide us with multiple lenses on the issues we encounter in clinical and organizational decision-making on a daily basis. For example,
  - Ethics theories, for example
    - virtue ethics
    - consequentialism & utilitarianism
    - deontology
    - feminist ethics
    - disability ethics
    - relational ethics
  - Bioethics principles
    - autonomy
    - beneficence
    - non maleficence
    - justice
  - Moral rules
    - veracity & fidelity
    - privacy and confidentiality
  - Contextualism
    - history
    - politics
    - culture
- Multiple ethical lenses are evident in the public and professional debate on the difficult issue of withholding or withdrawing life-sustaining treatment. Viewed positively, there is scope and potential in this debate. Complex issues cannot be addressed with simplistic solutions. When multiple perspectives are shared constructively and with good intent, effective policies and decision-making processes generally result.
REFERENCES


WRHA Withholding & Withdrawing Treatment Working Group
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WRHA Withholding & Withdrawing Treatment Working Group

Environmental Scan and Literature Review – January 2010
WRHA Board - Working Group on Withdrawing and Withholding Life-Sustaining Treatment

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