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WHO CAN YOU TRUST WITH YOUR MOST IMPORTANT END-OF-LIFE DECISIONS? A MEDICAL PERSPECTIVE FOLLOWING A RULING FROM ONTARIO'S SUPERIOR COURT OF JUSTICE

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I. INTRODUCTION

Although physicians will often say, "I want to be left alone to practice medicine, which is my profession and why I studied medicine", the reality of current medical practice is that medicallegal concerns and the interface of ethics and law cannot be relegated to others. Physicians must be cognizant of the rules, regulations and law and be advocates for their patients, not only in the realm of medical treatments, but in protecting their interests and wishes should they not be able to express them. It is almost a given that older individuals appoint their children to be their substitute decision-makers ("SDM") when they make a Power of Attorney for personal care, whether or not it includes an advance care directive, known colloquially as a "living will". The understandable assumption is that who better can you trust to fulfil your most important decisions about end-of-life care than your most cherished family members? Sometimes, unfortunately a parent may never have communicated their wishes to their children; it is different problem if after your deep-felt wishes to your children are expressed through a living will, the children choose to reinterpret or ignore your instructions for personal reasons or values.

1. What One Might Expect from Family Substitute Decision-Makers?

All lawyers and physicians understand the concept of what is often referred to as "dysfunctional families" by family therapists. There is a wide spectrum of actions which might fall into such a

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 [&]quot;Health Care Consent & Advance Care Planning – Frequently Asked Questions" (Toronto, Advocacy Centre for the Elderly), online: http://www.advocacycentreelderly.org/advance_care_planning_-_frequently_asked_questions.php.

category which appears to have existed from time immemorial. Varying degrees of family strife and conflict are not uncommon. It is generally believed that, with what would appear to be fully functional and ostensibly loving and respectful families, when important decisions have to be made, such formally or informally expressed wishes and values would be respected and heeded. It therefore often comes as a surprise when apparently loving and devoted family members, acting as SDMs, dissociate themselves from those they are meant to represent and couch their decisions in terms of moral distress and personal psychological conflict. This concept of "moral distress" is more commonly used to describe conflicts that occur when health care professionals find that they are fulfilling a patient's decision that conflicts deeply with their professional and personal values and are powerless to intervene other than in a supportive manner rather than one that might alter the decision.

(a) Case Example

There are numerous cases in the legal literature in which the expressed wishes of the older patient are over-ridden or ignored by apparently loving and devoted children. One of the more commonly repeated scenarios is when an older person has executed a living will with the assistance of a responsible legal advisor and has consistently indicated a mentally competent wish to not have a feeding tube inserted on a permanent basis. In the cases that make it into the legal literature, it is because the children request that such a tube be inserted even in the face of the apparently contrary instructions. This occurs most commonly in the face of late-stage dementia or other brain diseases in which the level of mental interaction will never return to any semblance of function known to be acceptable to the person executing the living will. The results often involve physicians who become "caught in the middle" on the one hand trying to best represent their patient's interests while at the same time providing support to the caring family in the face of what appears to be a decision that is inherently not what the patient wanted or indicated.

(b) Case Study

In a recent Ontario ruling² by the Consent and Capacity Board ("CCB"), released on June 14, 2012, it was held that the Power of

^{2.} F. (F.), Re, 2012 CarswellOnt 8663 (Ont. Cons. & Capacity Bd.).

Attorney for Personal Care signed by the patient in question almost 10 years prior to the 2012 hearing should be respected by the SDMs. The judgment indicated that the claim by the children who challenged the validity of the advance care directive, that their mother was not capable of understanding and appreciating the document that she signed in the presence of her lawyer, was not compelling. In the intervening years, the individual, known in the CCB hearing as "FF" (hearing TO-12-0289 and TO-0290), gradually developed dementia and required assistance in all of her activities of daily living. Tragically while in Florida for the winter with her personal support worker, she accidentally inhaled some food and by the time emergency help arrived and assisted in expelling the bolus of food, she had experienced significant brain anoxia. She did not recover significant consciousness and the Florida hospital medical staff inserted a feeding tube to provide nutritional support as well as a tracheostomy to assist in maintaining her airway. Her children acting as her SDMs consented to the treatment.

She eventually was transferred to Toronto's Baycrest Hospital. As stated in the CCB ruling, soon after admission the family produced an advance care directive dated approximately 10 years previously which they claim they had not been aware of previously. The document included among other expressions of wishes the following instructions, "I hereby instruct that if there is no reasonable expectation of my recovery from physical or mental disability, I be allowed to die and not be kept alive by artificial or heroic measures. I do, however instruct that medication be mercifully administered to me to alleviate suffering even though this may shorten my remaining life." 3

During the CCB hearing, witnesses, including rabbis, were brought forth by the family attesting to her orthodox life practices and the expectations in Jewish Orthodoxy that artificial nutrition and hydration are not heroic measures. Rather than being conceptually artificial in the sense of a medical intrusion, such feeding methods would have to be considered part of normal and compassionate care; discontinuing such nutritional support would be contrary to the tenets of Judaism. The family contended that such a framework of decision-making would have been important to her and was one which she embodied previously in all aspects of her life. Lawyers for her children suggested reasons as to why she might not have understood the questions at the time she gave

^{3.} F. (F.), Re, supra, footnote 2.

instructions. The lawyer who drafted her advance care directive testified that her "normal" practice was to explain the details and implication of all instructions and despite the inability to recall the exact words used, the absence of any provisos indicated to her that the client FF (now the patient in question) understood what was written and what she signed; her religious beliefs did not seem to be a factor in her decision-making at the time of execution.

The CCB came down in favour of the request by the attending physician on behalf of Baycrest Hospital to be allowed to discontinue the treatments in the medically most humane manner possible. The family appealed the ruling which meant that for a number of months treatment as prior to the CCB decision continued.

The Ontario Superior Court of Justice handed down its decision on April 3, 2013.⁴ After hearing the evidence from both sides and reviewing the rationale expressed in the CCB's decision the judge ruled that the CCB had erred in a number of its assumptions and interpretations including the following:

- The patient in question may not have truly understood all the implications of what she signed due to language issues;
- The lawyer who presided over the creating and signing of the Power of Attorney for Personal Care ("PAPC") could not definitely document what was discussed specifically with FF and, therefore, her "normal" practice may not have captured important and subtle nuances that may have affected the decision to sign the document without, for example, discussing details of potential religious implications nor the true meaning in contemporary and at the time of terms such as "heroic" and "artificial".
- The issue of the patient's lifelong adherence to her Orthodox Judaism was accepted as an important factor that was not sufficiently taken into account by the CCB because it was not mentioned specifically in her PAPC. It was thought that the claim by the family of her religious characteristics for her whole life could not be ignored and, in a sense, dismissed because it was not specifically noted in the document. A life of historical consistency seemed to have important sway on the court's decision.

^{4.} Friedberg v. Korn, 2013 ONSC 960, [2013] O.J. No. 6135 (Ont. S.C.J.).

• The other issue focused on the meaning and implications of terms such as "heroic" and "artificial"; it was agreed by the physician that at the time of the procedures being undertaken one might have classified them in those terms. It was argued that the "heroic" aspect of maintaining the tubes in place was likely long passed as they were causing no particular discomfort or harm. As for understanding the word "artificial", the argument returned to the very well-known tension between those, primarily from the religious world, who see nutrition as part of the normal obligations to a patient to provide them with lifesustaining nourishment and fluids, and those from the secular and medical world who see nutrition provided by a feeding tube as an artificial intervention like any other mechanically-based medical treatment. The importance of how the physician framed her response to the questions may have swayed the court in one direction or another. As a matter of conjecture, if the physician is inherently sympathetic to the family's concerns for example for her personal reasons, she may or may not focus as strongly on the issue of the patient's autonomy as indicated through her living will.

In the end, the court ruled in favour of the children and relied on the evidence of the solicitor and therefore against the physician and institution and overturned the ruling of the CCB. At the time of the hearing, the patient continued to receive nourishment through a feeding tube, had a tracheostomy to facilitate the patency of her airway and received treatment for inter-current illness such as infection with antibiotics. She continued to be in a minimally aware or alert state. If, as a physician, one were to compare what she appeared to mean through her living will done while she was capable and the life she is now leading, it would be a real challenge to believe from a clinical perspective that she would have agreed to be kept in her current state; the advance care directive appeared to be pretty clear and quite explicit in it goals.⁵

2. Discussion and Implications for Future Advance Care Directives and the Health Care Consent Act

A great deal of effort, support and encouragement has accompanied the creation of Ontario's Health Care Consent Act,

 [&]quot;Law Review: Cases and Other Legal Reviews: Friedberg et al v. Korn, 2013 ONSC 960, Court File No.: 03-58/12, 20130403" (April 2013), 3:1 Whaley Estate Litigation Newsletter.

1996 and the jurisprudence that governs issues of consent to medically treat in other provinces and jurisdictions. The underlying ethical principle for this major piece of health-related legislation is the foundational principle of autonomy as originally outlined, described and virtually embedded into the practice and values of North American ethics since the release of the first edition of Beauchamp and Childress' classic text *Principles of Medical Ethics* in 1979, with the latest 6th edition having been released in 2008.⁷ The reason that this book had such a profound effect on the medical and subsequently on the ethics and legal communities is that for the first time since ethics entered into the practice of medicine, the classical and traditional primary ethical foundational principles of non-maleficence and beneficence, which in essence were held closely in the hands and culture of the medical professionals, were transferred to the patient with the creation of the ethical principle of autonomy. Any physician old enough can remember the process by which medical decisions were made which was in essence physician-centred. It would have been considered very abnormal for a physician to defer serious decision-making to a patient, much less to a family member. At the time there was little in the way of jurisprudence that defined the role of an SDM in medical decision-making.

By formally allowing for and in essence requiring patients to provide consent to all medical interventions, the dominant role of the physician was modified to a more collaborative and supporting role than in the previous centuries of medical practice. It changed forever the way decisions about medical care would be made in the future. It has been a slow evolutionary process. In contemporary North America there is virtually no health care practitioner who would undertake any clinical activity without first obtaining a proper informed consent to treatment with the exception being emergency situations for which there are provisos for extenuating clinical circumstances.

Consent to treatment is the natural consequence and legal translation of the ethical principle of autonomy. It is the way in which an individual can manifest their personal values, choices,

 Tom L. Beauchamp and James F. Childress, Principles of Biomedical Ethics (New York, Oxford University Press, 2008).

^{6.} S.O. 1996, c. 2, Sch. A.

Charles E. Gessert, "The Problem with Autonomy: An overemphasis on patient autonomy results in patients feeling abandoned and physicians feeling frustrated" (2008), 4 Minn. Medicine, online: http://www.minne-sotamedicine.com/CurrentIssue/CommentaryApril2008/tabid/2509/Defaul-t.aspx.

characters, belief systems and other aspects that impact on why people make the decisions they do. Prior to the world of consent, it was physicians, and through them, other professionals, who determined what treatments would occur due to their *superior* knowledge and beneficent nature but also by dint of their professional standing and respect. The law in general almost always sided with a physician's *best, considered, and professional opinion*: ⁹ any physician old enough to recall practice in the era prior to the autonomy movement or from jurisdictions where this is not well developed will understand the power of the physician's opinion in patients' decision-making. Even if "consent" may have been required, the actual process of getting it fell far short of what discussion and explanations are now expected to occur.

3. The Development of the Advance Care Directive Concept

Once informed consent was established as a requirement for treatment and became universally practiced, and as an outcome of advances in medical technology, some formulae had to be developed to assure that necessary and potentially life-saving treatments could take place even if the patient was unable to personally provide it. This is where the doctrine of necessity always has and still does apply. As well, the age-old informal practice of turning to family members or close friends to provide substituted consent was merely an extension of the ancient practices that parents would have over their children and in many jurisdictions that husbands would have over their wives. With formal consent becoming integrated into care decisions, the concept of substituted consent was required for those for whom decisional-capacity was not possible because of medical conditions such a loss of consciousness or mental disease and dementia.

With the advent of Cardio-Pulmonary Resuscitation ("CPR") in the early 1960s, it took only a few years before it became not only almost universally available in North America but began to be considered part of the obligatory standard of care especially in the acute hospital setting. Many clinicians began to observe that a technique that seemed to be a life-rescuing intervention under very defined and special circumstances had virtually morphed into what many believed was an end-of-life ritual that was hard to decline for what were deemed to be ethical, clinical or medico-legal reasons.

Edmund D. Pellegrino and David C. Thomasma, For The Patient's Own Good: The Restoration of Beneficence in Health Care (New York, Oxford University Press, 1988).

The idea of "letting someone die", if that person could be potentially saved, became almost anathema in the acute care setting. The media responded with depictions of CPR with an over-dramatized presentation and highly inflated success rate which the public began to believe was accurate. Front-line health care practitioners know that many individuals of all ages and stages in life experience suffering from medical conditions which will result in death. Quite often these people were subjected to CPR as their last medical rite of passage, rather than being allowed to die peacefully. It became such a well-recognized issue that a hidden practice of the "slow-code" developed, fulfilling the appearances of CPR without actually exposing the dying patient to the true indignities of the CPR chest-pounding and often rib-breaking quasi-assaultive process. 10

Eventually through a combination of lobbying by enlightened medical practitioners, lawyers and legislators, the first advance care directive, the DNR order, came into being. Many hospitals developed their own individual policies about its implementation but once the law allowed for it, discussions about DNR orders began to be part of the conversations between very ill individuals and their treating doctors. Safety valves existed so that people who might potentially benefit from CPR were not deprived of it because the conversation did not take place, but a new psychology was developing in North America; asking the patient before performing a medical act if that was acceptable to them, asking a patient at risk of a cardiac arrest if they wanted CPR should it occur and allowing individuals in each situation to refuse the medical intervention for whatever reason they had as long as they were deemed capable of making such a profound decision. 11

4. The Role of the Attorney for Personal Care or Proxy for Personal Care

With the need for consent for most medical undertakings and the major advances in medical technology, it became abundantly clear

Michael Gordon, "Assault as Treatment: Mythology of CPR in End-of-Life Dementia Care" (2011), 19(5) Annals of Long-Term Care: Clinical Care and Aging 31, online: HMP Communication LLC http://www.annalsoflong-termcare.com/article/assault-treatment-mythology-cpr-end-life-dementia-care.

Mark Handelman, "Consent to Life Support: What the Supreme Court Said in Cuthbertson and Rubenfeld v. Rasouli" online: Whaley Estate Litigation http://whaleyestatelitigation.com/resources/WEL_What_the_Supreme_-Court_Said_In_Cuthbertson_and_Rubenfeld_v_Rasouli.pdf.

that there would always be individuals from whom consent should be obtained who were not able to provide it in a timely fashion. In emergencies, physicians were allowed to act according to common law established precedents and the new legislative initiatives. But in the face of the inability to give consent, the need developed for a robust system of determining who could give or refuse consent on behalf of another person based on established criteria. The duties of the attorney for personal care, proxy or SDM became defined more clearly and in Ontario for example became embedded into law with the *Health Care Consent Act*, 1996.

In this Act, the criteria for action are defined in detail outlining most of the possible circumstances with some degree of flexibility to assure that all decisions that have to be made can be made. The Act allows the SDM to follow advance care directive instructions provided by an individual as long as the instructions reflected a capable decision at the time that they were given. Thus was generated the concept of the advance care directive through which an individual, by appointing an SDM, could have their wishes fulfilled sometime in the future by the person appointed by them, carrying out the instructions or values expressed in an advance care directive. ¹²

5. Formulation of Advance Care Directives

An advance care directive is merely a tool that should be part of what is often called "advance care planning." With the complexities of new medical technologies, the increased growth of the aging population, and an increase in the prevalence of cognitive impairment and dementia, it is becoming clear that some level of discussion, planning and documentation might decrease the likelihood that someone will receive treatments that they would prefer to forgo. The Ontario Health Care Consent Act, 1996 attempts to assure those involved in their advance care planning that such wishes should be considered when treatment decisions are being made. It is often recommended that an advance care directive be in writing, even though it is not required by law. The main problem with the lack of a written document that outlines one's wishes is that verbal instructions might be challenged if those responsible for making medical care decisions are in disagreement

^{12.} Arthur Schafer, "Right-to-die ruling: Win for families, loss for common decency", *The Globe and Mail* (October 18, 2013), online: *The Globe and Mail* .

about what was said or intended by the verbal advance care request. Without some evidence of intentions, unless there has been good communication and congruence and acceptance by those charged to act as SDMs, there might be problems should conflicts exist. For physicians, getting caught in the middle of what might in essence be a continuation of a long-standing family conflict does not lead to optimal medical outcomes.

The other important factor that is often forgotten in the advance care planning process is that the advance care plan is merely the communication of the person's preferences which are then to be interpreted and in essence translated into an actual care plan based on the clinical circumstances at the moment that the decision for treatment has to be made. The advance care directive is not a substitute for consent to treatment or refusal, but rather a statement of wishes to the person(s) responsible for consenting to or forgoing an individual treatment undertaking.

Advance care directives cannot "demand" a treatment that is not part of the protocol of valid clinical options in a given therapeutic situation. It can instruct the SDM to refuse a treatment even when the particular treatment has a substantial likelihood of success in the same way that a competent person can make that choice of refusal by not consenting to the treatment.

For example, one commonly hears family members and health care professionals use the phrase, "Mrs. X is a full code." That implies that one is obligated to perform CPR on the person at the time they are found without vital signs. This is, in fact, not the case. A person can request a DNR order — that is, a refusal of potentially offered or provided treatment. A full code (which is a medical treatment) should only be provided if it is deemed to be potentially beneficial, which, in many circumstances, it is not. Only after the treating physician has assessed the circumstances and determined the medical likelihood of beneficial CPR should the intervention be provided. The "R" in CPR does not stand for "resurrection". 13 Even though, for many families, CPR might appear to be a pre-requisite before accepting that someone has died, failure of CPR should not become the sine que non for confirming that death has occurred.

^{13.} Michael Gordon, "In long-term care, the 'R' in CPR is not for resurrection" (2001), 34 Ann. R. Coll. Physicians Surg. Can. 441.

6. Relevance of the CCB and Superior Court Rulings in the FF Case

The advance care document that was provided to the health care staff "after the fact" gave instructions to all of FF's three children as her SDMs. Legally, they would have to agree together on the decisions related to treatment. If a decision could not be reached it might have been necessary to refer to the Public Guardian and Trustee. This was not the case, as the children agreed with their decision to continue with the tube-feed, contrary to the apparent instructions in their mother's living will. It is known that sometimes children claim, even in the face of very clear instructions about not wishing permanent artificial nutrition and hydration (feeding tube) in a well-documented living will, that they "cannot bring themselves to make that decision" or that they "could not live with themselves in making such a decision." Such cases may end up being referred to the legal tribunal that adjudicates such situations. Sometimes, as in the Friedberg case, 14 even in the face of a decision that upholds the living will instructions by the CCB, the family may pursues other legal means to allow them not to carry out the wishes of their parent — and these presumably are from families that espouse love and devotion as the reason for their failure to follow the instructions.

What is the solution, short of designating a non-family member who is not intimately involved emotionally in the necessary decisions that one can trust as one's substitute decision-maker? It is at minimum to discuss with one's loved ones the wishes and substance of the advance care directive and have them provide assurances as much as anyone can that they understand what is being asked of them and that they are willing and able to respect those wishes even though the wishes may be in conflict with their own beliefs and values and emotional capabilities. As one can imagine, that is a very difficult discussion for most family members to have.

For physicians, with the increase in number of elders in one's practice, it may be prudent to explore some of the wishes and values that the patient may have especially as they relate to artificial nutrition and hydration. It is not difficult using very commonly understood terms and scenarios, for example, to have a person comment on whether or not they would ever want to live no longer being able to enjoy the taste of a favourite, or in fact of any, food for the rest of their lives. Many when asked directly quite naturally and spontaneously express to the doctor, and ideally in front of

^{14.} Friedberg v. Korn, supra, footnote 4.

their loved ones, their preferences not to be provided with a feeding tube. This can be the beginning of an important conversation as part of advance care planning.¹⁵

7. Guidance for Lawyers Carrying out the Creating of an Advance Care Directive

The ruling of the Superior Court of Justice in this case should give pause to those lawyers whose practice includes the drafting of advance care directives. It should also alert physicians who often find themselves in the midst of complex family dynamics and feuds which interfere with what physicians believe to be their professional and ethical duties to their patients. The lawyer in question who drafted FF's advance care directive claimed that she "always" had the same conversation with clients and had a template that she used to make sure all the issues of importance were discussed and that the person read the document so that when it was signed she was sure they understood it. The Superior Court of Justice was somewhat critical of her process. It was stated that the court could not be certain, on an individual basis, of the discussion with FF and the process that went into the explanation of the meaning of the terms being used. Therefore the court could not be certain that FF really understood and appreciated the terminology used in the document, as was claimed by her children. Even though good arguments were made as to the validity of the assumption that FF did understand the language and the meaning of what she was signing, the judge accepted the doubt that perhaps that this was not the case and thereby over-ruled the decision of the CCB. This decision raised serious questions about the weight put on advance care directives by most lay people, lawyers, physicians and ethicists.

8. Does the Rasouli Case Have Anything to Add to This Conundrum of Law and Ethics?

The recent judgment of the Supreme Court of Canada in the Rasouli case from Ontario¹⁶ has allowed an SDM to refuse her

16. Rasouli (Litigation Guardian of) v. Sunnybrook Health Sciences Centre, [2013] S.C.J. No. 53, 2013 SCC 53 (S.C.C.).

^{15.} Michael Gordon, "Artificial Nutrition and Hydration: Is it really what you want?", Canadian Virtual Hospice (February 12, 2014), online: Canadian Virtual Hospice ."

husband being designated as suitable for palliative care: he had been in a minimally conscious state for almost two years, and required treatment in an intensive care unit ("ICU"). The rationale, in essence, focused on the need for consent to change the mode of treatment from intensive care to palliative care as deemed clinically appropriate by the treating physicians which according to the *Health Care Consent Act*, 1996 could be refused by the SDM based on her understanding of his strongly held religious beliefs. ¹⁷

Unlike the Friedberg case, there was no advance care plan or advance care directive, only the word of the SDM and evidence to the patient's over-whelming religious beliefs. Even had an advance care directive existed, it might well have contained words to the effect that "all efforts must be continued within the spirit of my religion to keep me alive under all circumstances" (there are many religious people who adhere to the "sanctity of life" precept). Of course, the concern of the medical profession and many ethicists and health care administrators is that such a basis of decisionmaking can make it almost impossible to discontinue what is believed to clinically non-beneficial therapies if they conflict with religious values of instructions. The previously well-reported Golubchuk case¹⁸ from Winnipeg, has a lot in common with the Rasouli case. In June, 2008, after seven-and-a-half months on lifesupport, Samuel Golubchuk died of natural causes. But this was after a very heated conflict between individual physicians and the patient, his family and their lawyers and the hospital's administrators and the College of Physicians and Surgeons of Manitoba. That he died before the case moved up the legal ladder means no ruling about his situation was ever made. The Rasouli case in Ontario, however, has many issues in common with the Winnipeg case.

9. Why Have a Health Care Consent Act?

Of great interest to all those involved in end-of-life care and planning is an assumption that, if one takes the time and effort to sign an advance care directive, it is assumed that those instructions and wishes will be respected. It would be very prudent for anyone executing such a directive to discuss its contents with those who are

 Golubchuk (Committee of) v. Salvation Army Grace General Hospital, [2008] M.J. No. 54, 2008 MBQB 49 (Man. Q.B.).

^{17.} Zev Schostak, "A Wake-Up Call for Our Community: Take Control of Your Health Now", *Jewish Action* (October 29, 2010), online: Orthodox Union http://www.ou.org/jewish_action/10/2010/a_wake-up_call_for_our_community why we must be proactive in our own h/>.

expected to carry out the directions so that there is no misunderstanding as to what is meant by the statements used in the directive. If, at the end of all of these steps, it becomes known that there are ways around such carefully thought-out instructions through various legal attacks, it might become less compelling for individuals to take the steps to outline their wishes. It would also be prudent to discuss the advance care directive with one's primary care physician to confirm that not only are the concerns and requests valid, but to enable the doctor to attest to the individual's understanding of those wishes.

10. Guidelines for a New Advance Care Directive Process

There have been many attempts to create advance care directives that truly capture a person's wishes and values so that anyone trying to adhere to them will have little in the way of doubt as to their meaning. One such attempt that gained a good deal of popularity and traction in Ontario some years ago was the "Let Me Decide" kit developed by geriatrician Dr. William Molloy. 19 In many ways, Dr. Molloy was ahead of his time, as his approach (perhaps too detailed) did involve the physician in the process to be sure that what was requested was understood and left little room for misinterpretation by well-meaning family members who were not able to abide by their loved one's expressions of preferences.

For lawyers who are committed to helping their clients achieve their goals, it might be prudent to take the following steps in order to assure that their client's wishes are clearly expressed, that those who might have to carry them out know about them and are willing to do so, that the language used is clearly understood by the client and that issues that might be brought up in any challenge to its content will be addressed by the document and the process of providing, reviewing, accepting and signing it:

- 1. Document the meeting with the client and in detail the issue of an advance care directive that was discussed;
- 2. Explore the salient wishes of the client that are to be included in the directive and the main philosophy behind those wishes (no suffering, not to prolong life if no chance of return to level of function that will allow for socialization, communication, enjoyment of food taken through the mouth, etc.);

William Molloy, "Measuring capacity to complete the 'Let Me Decide: Advance Care Directive' - SIACAD" (February 22, 2013), online: Let Me Decide http://letmedecide.ie/index.php/education-and-resources.

- 3. Document if there are any religious considerations that should be taken into account and, if not, state clearly that no religious dictums, practices or traditions should be brought into play on the treatment decisions that are being considered;
- 4. Refer the client to a physician, or more than one physician depending on the circumstance, to do two specific things:
 - (a) Assure the client and lawyer that the client is capable of making an advance care directive;
 - (b) Explain the medical meaning of terms so that, when instructions are being given, vague or euphemistic terms such as heroic are not used but specific interventions are prohibited such as artificial nutrition and hydration (specially call it "feeding of liquid foods through a feeding tube inserted directly into the stomach") and stipulate if that means on a permanent or on-going basis or temporary basis because of an inter-current illness or surgery, which might be the case.
- 5. After the document is complete and edited properly (whether a custom-drafted document or a pre-printed form such as that provided in the "Let me Decide" kit), review its content with the client, have the client sign it, and in the notes to the file, indicate that the client reviewed the document and could explain in clear language what was being requested.

Some might advise that in addition to the suggestions above, a video recording of the whole process might provide the best assurance that the client's wishes would be respected when the time comes.²⁰

II. CONCLUSION

The concept of the advance care planning through verbal or written advance care directives is very attractive for those who desire to maintain some element of control over their final period of life. For those with strong feelings about limitations to medical treatments in an era of apparently endless technologies, an advance care directive might provide solace that an end can be expected and organized that will be as *natural* as possible without unnecessary

Sarah Burningham, Christen Rachul and Timothy Caulfield. "Informed Consent and Patient Comprehension: The Law and the Evidence" (2013), 7 M.J.L.H. 123, online: http://mjlh.mcgill.ca/pdfs/vol7-1/vol7_issuel_Burningham.pdf>.

suffering or unwanted prolongation through the application of medical technologies.

To discover that the law doesn't necessarily support what most people would deem adequate steps to assure that such wishes are respected is very disquieting. For physicians and lawyers who generally recommend to our patients and clients that an advance care plan and advance care directive might achieve their end-of-life goals, it may be necessary to re-think the process to assure ourselves that those to whom we, in good faith, entrust our wishes will not be able to find ways to ignore them whether for their own purposes or presumably for the *apparent benefit* for the person on whose behalf they are supposed to be acting.