

The **POWER** of ATTORNEY PROJECT

Being an POA (SDM): An issue of rights vs. duties

Welcome to the Power of Attorney Podcast which is part of our Conversations that Matter Podcasts. My name is Mary Bart, Chair of Caregiving Matters. This podcast is intended to provide general information only and is not intended to be a substitute for seeking personalized legal, financial or other advice. This podcast raises issues that our audience can further explore on their own in their own local communities with their own local experts. This project will help to be a call to action for families to solve their issues, find solutions to their problems, and have greater peace of mind.

Mary – Today’s topic is called “ Being a POA” or what is properly called a substitute decision maker... An issue of rights versus duties. Our guest expert is Dr. Michael Gordon. Welcome Dr. Gordon.

Dr Gordon – Thank you for having me.

Mary – Could you share with us a bit about your practice, Dr. Gordon?

Dr. Gordon – Well, I’m a geriatric medicine specialist. I’m at the University of Toronto as a professor of medicine and I’m a staff geriatrician and program director of palliative care at the Baycrest Geriatric Health Science Centre. I’ve been here for almost 40 years. My practice is academic geriatrics, which means not only do I do clinical geriatrics which means looking after patients, but I’m involved in teaching, writing and collaborating with other academic physicians in the fields of geriatrics, neurology, and family medicine through the University of Toronto.

Mary – Thank you very much. We are so honored that you are participating in this program. I would like to begin with a couple questions. My first one is, the difference between a right and a duty?

Dr. Gordon – These terms often get mixed up; especially the term rights. One often here’s people say they have a right to do something or they say this is an issue of human rights. The important thing to understand is to have a right means somebody else has an obligation to fulfill that right. When most people say they have a right they mean that somebody else is supposed to make sure that that right can be fulfilled. A very simple example would be, in Canada, everyone has a right to health care services as defined by the Canada Health Act. That means all provincial governments, by the structure of our health care system, are obligated to fulfill the health care needs as defined to the people who are residents of the provinces as defined by who is able to be provided with health care. There’s a right of getting health care services and that means government is obligated to fulfill those rights. In contrast, a duty in a sense isn’t a legal term. One might say it’s an ethical term but it means that somebody has an obligation to do something. For example, in almost all cultures there’s a duty of parents to look after their

children. There may also be laws that determine what the nature of “looking after” means but the major propelling force is that sense of obligation which is virtually universal. When it comes to decision making for example, for another person, as in a substitute decision making, it’s very important to understand the difference between the rights and the duties that are embodied with that concept.

Mary – Okay. Let’s take this a little bit further. Why is this difference important?

Dr. Gordon – Well, in practice, especially when children, or another family member for example it could be a spouse, is fulfilling the role of a substitute decision maker, that is usually defined within a legal framework that says if the patient is not capable to make health care decisions, then either by designation through a document or according to the Health Care Consent Act, another person is designated as a substitute decision maker. That means this person is now in the position of making those decisions on behalf of the person whom they are representing. Often, what one hears people say, is that “now that I am the substitute I have the right to make decisions” and they interpret that right to make any decisions that they want. The way I describe it is like what the Health Care Consent Act gives you is the right to fulfill your duties under the act and the duties say you are to make decisions to the best of your ability based on the last expressed wishes of the person you are acting for. If you decide to make decisions that are different, you are not fulfilling your duty and the Health Care Consent Act gives you the right, but it’s the right to be the person who fulfills their duties.

Mary – That’s very interesting. Is this a role people are prepared to take on?

Dr. Gordon – I think what happens is if somebody is requested and it’s often part of a family discussion or sometimes it’s not even discussed, it just happens either because people don’t think it should be discussed or they’ve never discussed it and then it goes according to the consent act which designates the algorithm of who’s first, who’s second, or third unless this person has discussed it, they may not fully understand the implications of becoming the substitute decision maker. The problem is, it’s a very difficult position because you’re trying to make a decision based on either what somebody told you they want; either verbally or written which makes it a little bit easier, or they have to do it based on indirect evidence as to what they likely would have wanted because of various conversations or things they’ve indicated in discussions and the person has to be able to say “I am going to do this even if it’s not something that I think should be done based on my values but it’s not my values that matter but the values of the person I am representing”. Not everybody is fully prepared to do that because they may have a hard time doing something that goes against their own personal values even though that is not the nature of their duty. The duty is to fulfill the wishes of the person they are acting for.

Mary – That’s a really important point. Thank you for sharing that. If you’re going to designate someone as your substitute decision maker how should you do it?

Dr. Gordon – What I recommend. Well the first thing you should do is indicate that you are making plans. I call it having the conversation. I’ll make up a scenario and I just did this recently myself and I also helped friends, colleagues and patients do it. I say “look, I want to make sure that, should something terrible happen to me, and it’s something that will not resolve, to the point where I can no longer make decisions about my own health care, I want you to be able to make those decisions on my

behalf.” The first question is, ‘do you think you want to take that on?’ Now some people may say they’d rather not. They don’t have the emotional makeup to do it. It’s too difficult. They live far away. It’s too complicated. I went through this not long ago with my best friend who lives in New York and I was explaining to him because he has very little family that he should do a written advanced directive, also called a living will, so that should something happen to him people will know what to do and he asked if I would be his substitute because we’ve been friends for 50 years. I said yes and he made it out and I helped him word it and unbelievably, within 6 months he had a devastating life threatening illness and I found myself in a position almost on a daily basis for a few weeks having to make decisions on his behalf based on my best understanding of what he would have wanted. He recovered, eventually, from a very long illness but was left with significant disabilities but not cognitive impairment. He still has full faculties. The last time I saw him he said to me “if anything like this should happen again I’m asking you please to let me go. Can you promise me?” I had to be able to say, even though he’s my dearest, best friend, if I’m going to take on this role that yes I will let him go. Now that is a difficult position to be in because you may have to say about a loved one that you told me you didn’t want any more treatment and I am agreeing with the physicians that there will be no more treatment. So first you have to have the agreement that the person will do it. Then you should put together in a sense a list or a collection of your most important wishes and values. Sometimes you may need assistance from a physician to help you determine what it is you want and what the implications are and then put it in a format either written or verbally communicated that says should I be in that position, and the doctor says to you they would like to put in for example a permanent feeding tube and the individual says no they do not want a permanent feeding tube then you have to be able to say no, my friend, mother or father absolutely rejected the idea of a permanent feeding tube. You have to be able to understand what was indicated and then be able to carry out those wishes.

Mary – That is so important. I see this all the time where people struggle trying to figure out what to do and if they had had those conversations, they would have had the proper guidelines to fulfill their duties. That is an amazing example with you and your friend. Another question for you Dr. Gordon. If you have designated a substitute decision maker and you have important wishes about your end of life, how should you communicate your wishes to your substitute decision maker?

Dr. Gordon – According to the law, if you communicate verbally that’s acceptable. The person is allowed to say when asked, in a conversation that I had with say my mother, father, my best friend, this is what he indicated and it’s a system of trust. The physician is supposed to trust what you’re saying but nowadays, many people feel more comfortable, and it depends on the jurisdiction, if there’s been some written communication that can be used to demonstrate that this is what the person really wanted. The problem with the written advanced directive is a problem with the language where sometimes things get interpreted by the nature of language in terms that the person may not have meant them to be. Especially if there’s a legal conflict where the person chooses to try and ignore what was said they will then use a legal challenge which can start reinterpreting words and that is something that’s not hard to do. What I suggest is, if you are going to or you’re concerned that the person may not be able to fulfill their duties for whatever reasons, then one approach is to write it down but write it down with the assistance of a physician to use terminology that cannot be misinterpreted or challenged. There’s no

foolproof way of doing it but the main part of the equation is that you believe you chose somebody who really wants to follow your wishes and it may not be a family member. A family member may have too much emotional investment to follow your wishes or may have religious beliefs that are different from yours and find that they're not capable based on their beliefs to do something even though they may not be your beliefs. We see this quite often where there's been a disconnect in religious beliefs between one generation and another. Sometimes it is better having someone who is not a family member but who is close and reliable and has indicated their ability and desire to do what the person wants as is the case with my best friend and I had to deal with family members who started questioning some of my decisions and all I had to say was this was what ----- asked me to do and I will do it according to his wishes. It's not a simple thing although in many circumstances because the closeness and willingness of the substitute to do what the person wants as part of their duty, obligations and love then it doesn't cause a problem. There are many situations in which there are serious problems and these are often taken through the legal system.

Mary – My final question for you Dr. Gordon is what do you do if your substitute decision maker will not follow your wishes?

Dr. Gordon – Hopefully this doesn't happen too often but unfortunately it happens often enough. I'm going to describe what I think you should do and use an example of a case that I dealt with which has already worked its way through the legal system so it's already in the public domain. In a written advanced directive by a parent which was done at a time that there was no suggestion that she was not capable of writing it and expressing her wishes, but what she did not do was discuss those wishes with her children, so the advanced directive was stored somewhere undiscussed. Ten years later, she happened to have a terrible medical event which resulted in poor blood and oxygen supply to her brain and she was left in a state of almost permanent unconsciousness but because the children had no way of knowing that she had an advanced directive, a feeding tube was put in place while she was in another jurisdiction. When she came back to Ontario in Toronto and ended up in her own institution, the written living will was discovered and in it it said quite clearly for anyone who had read it, that written in it she did not want to prolong her life and was not there for comfort and she used the word artificial which is what feeding tubes are called for artificial nutrition. When this document was produced to the physicians and to the ethicist which I am, we told the children we have a duty as an institution to not ignore her wishes and to request from the children to heed her wishes and therefore to discontinue the artificial nutrition and hydration which was the feeding tube. The children's response was, they could not do that because they felt if they did that they would be responsible for killing their mother. When it was explained to them that the living will or advanced directive that their mother made should compel them according to the law to follow her wishes, and when she wrote this she understood it would mean that she would die they said we can't do it. Unfortunately, it worked its way through the court, and the various legal levels and the first level which is the Health Care Consent and Capacity court, which after examining the evidence and reading the documents, decided that her wishes as written should be respected. Therefore, the tube feeding should be discontinued. The children challenged that ruling and it went through the next level which happened to be the Superior Court of Ontario. Once it goes into the court system, and you have lawyers arguing they look for reasons to dispute what the interpretation

was from the consent and capacity board and as it turned out, they raised enough doubts to through what some may call ultimate legal ease so that the judge. actually surprising almost everybody from the institution including the legal advisors, ruled that there wasn't compelling evidence to suggest that when the mother made her advance directive that she actually understood what she was saying. Now that's a pretty big jump because the whole idea of advanced directives are that you are supposed to do it when you are capable and there was nothing to suggest that she was not capable. So, when one says you didn't understand, now you are going to something that is very subtle because then you say well the language wasn't clear or say the lawyer didn't explain it, so what I tell people to do is you make it as absolutely clear as you can. You discuss it with the people you are asking to act on your behalf. You document that you had that discussion and if you have any doubts about them following your request, you find somebody who's not emotionally involved to do it or as I know it, some lawyers are now doing to make sure that the wishes of their client will not be misinterpreted , they are doing a video of the discussion. That is an extreme because that suggests a doubt of what peoples' inclinations are and a lack of trust and the last thing you want is not to be able to trust the person who in fact you are entrusting your wishes to. It's complicated but most of the time it works well if you've had the conversation and it's somebody who cares for you enough and is able to say "I will do the best for you because you are my mother, my father, my best friend (whatever the case may be) and I understand that is my duty and the law allows me to fulfill my duty"

Mary – Thank you Dr. Gordon for sharing all of these insights in this conversation and for sharing some of your experiences that I'm sure you see on a daily basis and for sharing your wisdom with this project. Thank you so much for joining us.

Chris - Mary, who are our initial project supporters?

Mary – We wish to acknowledge that this project is funded in part by the government of Canada's New Horizons for Seniors Program. Our other initial supporters include Care Connect, The Care Guide, The Healing Cycle Foundation and Scotiatrust. Caregiving Matters is an internet based registered Canadian Charity dedicated to educating and supporting family caregivers. 90% of our work is done online and by leveraging technologies. 10% is done by producing local educational events. We leverage technologies in everything that we do ensuring greater reach and sustainability. I trust that we have given some of the highlights of our exciting new initiative. If you are interested in speaking with me about the project, please let me know. We look forward to your questions and your ideas.

Chris - Mary, if listeners have questions, what is the best way for them to contact us?

Mary Bart- You can contact me directly Mary Bart, Chair of Caregiving Matters at 905-939-2931. My email is mary@caregivingmatters.ca and our website is www.caregivingmatters.ca