

The **POWER** of ATTORNEY PROJECT

Transcript

Who is a Substitute Decision Maker (POA)?

Guest expert: Dr. Sandra Campbell

Mary- Welcome to the Power of Attorney Project 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 piece of mind.

Mary- Welcome to the first episode of our “Power of Attorney “podcasts with our guest expert, Dr. Sandra Campbell. Welcome Dr. Campbell.

Dr. Campbell - Thank you, Mary. It’s good to be here.

Mary- This is an exciting project and we’re glad that you are a part of it. So today’s topic is who is a substitute decision maker or more commonly known as a POA?

Dr. Campbell - Right...so would you like me to jump right in then to that common question?

Mary - Sure. Absolutely.

Dr. Campbell - Okay. Power of attorney or substitute decision maker really is kind of fancy terminology for people who care about and for people who are disabled or older adults. You know I, as a senior, could appoint anyone really that I trusted, through a lawyer, to work with a lawyer to make decisions on my behalf. So, it could be:

- a spouse
- a son
- a daughter
- grandchild
- niece
- nephew
- neighbours
- friends

It really can be anyone that the disabled person cares about and who cares for them and who they trust. Often these decision makers are over 65 years old and some are even over 80 years old such as a spouse. So it's a very special group of people.

Mary- Well that's very interesting and what are their challenges as a substitute decision maker?

Dr. Campbell- Well, they have a lot of challenges. It's hard to know where to begin. Caregiving can go on for more than 10 years and in fact sometimes goes on much longer. Sometimes, it's quite short, 6 months or so but it varies greatly and the age and the condition of the person providing the care of the substitute decision maker also affect the challenge. Often, the people are feeling quite burdened by their role. They may be providing very difficult physical care. They might be dealing with mental health issues. They might be having financial concerns and they will have multiple family roles. Sometimes a spouse for example, is caring for their husband or wife but they're also providing support for their children; maybe even for their grandchildren, so it can be very challenging with multiple roles. Some of the things that they are doing may include giving medication to the person as the other person may not be able to read the medication label or understand the medications and they may be driving them to appointments and to clinics, to recreational activities and to shop. They may be paying some of their bills. They may be helping them get dressed, toileting them, bathing them, accompanying them to a medical appointment to be another set of ears and eyes. They may be providing overall supervision that is making sure the person stays safe. They may be helping to feed them or to cue them when to eat. They may be doing things like putting eye drops in or dressing wounds. So there's a whole range of activities that the substitute decision makers may be taking on. On the other hand though, it can also be someone who's simply been assigned the role of making the decisions on behalf of someone if they become incapacitated and it may go no further than that so there's quite a variance in the role and in the challenges and that's only two or three categories. There are many others. For example, the person who's in this role may know nothing about disability or about aging and they find themselves just immersed in the issues of aging and the issues of disability and it can be very difficult to deal with even if you do understand and do have the knowledge of what happens when we get older. So, if they don't have that knowledge and everything comes as a surprise, it's even harder for them. They may not know much about caregiving or about the services that are available in the community. All of these things can create big challenges. Another thing that can happen is, and this I would say is particularly in the case of a son or daughter, is where there may have been a difficult relationship in earlier times. It could be a spouse as well if you have children who had very rocky relationships with their parents and then they end up a substitute decision maker for that parent or power of attorney. It can get very complicated because some of that difficulty from an earlier time can come forward in the relationship now. Usually and I would say almost always, the caregiver is compassionate and wants to help. Overtime it can still become very burdensome and the person can become overwhelmed by the responsibility and by their lack of knowing what to do and how to make things better. The caregiver themselves can become sick, or be hospitalized and these things make caregiving even more difficult. They may have their own issues to deal with. You know they may have their own mental health issues too or physical issues and they may have developed mental concerns. They may be unemployed. They may have other family issues to deal with. You've got this substitute decision maker working with the person who needs support in a

kind of an isolated environment often and with all of these challenges hanging over them. It is a very difficult job and there are thousands and thousands and thousands of Canadians who are filling this role right as we speak.

Mary- And as our population ages, there will only be more of these people and the stresses on them and our whole society will obviously increase too.

Dr. Campbell – Absolutely. In fact, if you think about it these people are often volunteering their time but often more than that sometimes people give up their jobs to provide this kind of support and so they are providing a tremendous support to our society if you just imagine what it might be like if we had no volunteer substitute decision makers and POA's what would we do? How would we help all these folks? It would be a pretty pricy situation.

Mary- I see it as virtually impossible. That would be my guess.

Dr. Campbell – Exactly. I mean there really are thousands and thousands of caregivers. I'd have to go back to my records to find out the numbers but I mean it's escalating with the aging population every year and the aging population is not going to peak for another few years. Now we've got a tiger by the tail with this one.

Mary – Absolutely and some of the most current statistics say that 1 in 4 Canadians is a caregiver; a family caregiver and within that there are a great number who are the actual substitute decision makers. Even within families you may not be the substitute decision maker but you may be the sibling of the SDM and you are still concerned with what goes on and still have a role to help as best possible I hope, so it is an issue that everyone within a family has to deal with.

Dr. Campbell – Yes and ideally you would deal with it as a team and there are professionals around that can help you with that. They will help you to plan out who's going to do what, who's going to pay for what, who's going to drive mom to the doctor? Who's going to buy the next mobility aid or whatever it is that's needed? So the family can really be a fabulous support for the senior or disabled person who really needs this kind of help. Families sometimes just don't know what to do and sometimes don't know where to turn or how to figure out how to work together. There are professionals around who can help them out.

Mary – That's so important for our audience to know because clearly not all families will get along and there will be challenges amongst the adult children so knowing that there are people and services to help them through this will help give them guidance and add some structure to what actually has to get done so thank you for adding that families can reach out to professionals to help walk them through this. No family member usually is trained for this job but there are a lot of smart experts out there that they can help and guide a family.

Dr. Campbell - That's right.

Mary – I know when I was my parent's substitute decision maker, my siblings and I we got along very well but it would have been nice if we had known more services out of the community. Many days I

thought I would go winging it and every day was a new challenge and a new opportunity. Reaching out to the social services community I think is key for families to not only survive this journey but to embrace it. So when we think about these people what should we not assume about them?

Dr. Campbell - Well, you know there used to be an idea in the literature that said that most people who are engaged in elder abuse are burned out caregivers. This is so far from the truth. This is not true. Don't assume this. You know you've got to start with the assumption that most people are compassionate and people care about their family and I am here to say that almost without exception the families that I have met are very committed to their older person. You may hear lots of criticism but really most of it is not deserved so don't assume that they are abusive in any way at all. Start with the positive. Don't assume that they know about aging though or about services though. They may have quite a lack of knowledge. What they're trying to do is help their grandparent, their sibling, or their spouse and don't assume that they can handle it all...all the time. It just gets overwhelming as you just spoke to. It's very difficult. It's one of the hardest roles in life I think. Probably, I would say, just as hard as parenting really and it's not the same at all but just as difficult.

Mary - Absolutely. So what do substitute decision makers think about? What's important to them, Dr. Campbell?

Dr. Campbell – Well I think the first thing is that they're worried about their loved one. They're worried about how much help they will get. They're worried about how much help there will be if things deteriorate. They're worried about what will happen if the person is forced to consider institutionalization and they are worried about institutionalization. There have been studies done and almost without exception, older people do not want to go into an institution and their families don't want them to need to go into an institution. Yet, it gets to be absolutely essential in some cases. There is a lot of worry around institutionalization and for the older person themselves, they're frightened of institutional care because they have heard horror stories and they've watched family members and friends and they don't understand but you know, truthfully there's just not enough money in the long term care system or in the home care system to allow older people to live with dignity with doable help from their friends and family. We've got a situation that is very difficult for people and I think that those who are younger; younger than say 75 maybe, don't really fully get it. Until you are faced with the reality of considering institutionalization for yourself or for your loved one, you don't get it. Only some people understand when they're dealing with their loved ones and they still don't really understand what is happening and there's a lot of fear around that in both the older person or disabled person and in the substitute decision maker.

Mary – Can you share with us a real life example of someone who is a substitute decision maker and what they're going through?

Dr. Campbell – Yes I can. I've worked with a lot of people who are substitute decision makers and the people they're caring for and let me say before I give you this example, that it's only one example. There are many, many kinds of situations and they're all very unique and all very individualized and of course it

depends on the level of disability that the person who is disabled is living with and it depends on the skills and the personality and all kinds of things about the care provider or substitute decision maker. So an example would be an older woman who is over 80 and caring for a disabled husband who is 85. (By the way, I do change these stories so that you couldn't identify who it was because I am bound by confidentiality) This person is caring for their spouse with early stage dementia but the older woman herself is on her own oxygen and she helps him on and off the toilet because he's got mobility issues and is unable to get on and off the toilet by himself. She helps him get dressed. She prompts him to feed himself. She takes him to a special clinic for care and she tries to persuade him to do some things for himself. I don't know whether you can picture what that would be like on a day to day, 24 hour a day, 7 day a week schedule. The first week, the first month, maybe even the first year, you can get through but after a while it starts to wear you down. She doesn't get a break. She gets frustrated and it gets so that even getting out getting the groceries can be difficult. He doesn't always agree about her ideas about care and she doesn't always agree with him and as in any typical marriage there might be some disagreements. Then there's the cost of private clinics and private services. You can bump up the care by paying yourself for some individualized care and that's a wonderful thing for a caregiver to be able to access because there's some limited number of hours available from the government services. However, the caregiver can be fairly costly in that regard but it is available and I certainly encourage people to use those kinds of services. Of course, there is this debate that goes on about institutional care and is it a good idea...is it not? Which option will we go for? How will we make it happen? Just on that front, I would just really advise people to try to talk about it. Even persons who have early stage dementia, they have lots of times when they have good brain function and are able to discuss in a rational way. Talk about it. The children of this couple; they have two and the children aren't always in agreement. One child is more worried about the older woman and the other child is more worried about the older man. So they get into some conflict sometimes. This is kind of a typical story in a way of what it looks like. Do you have any questions?

Mary – No and that's a great example because you often look at families and you go who's really helping here and how hard it is to be the caregiver essentially as you said for years and years and I think the caregivers and people who are substitute decision makers are absolute unsung heroes. So my final question for you is what do they need?

Dr. Campbell – What do they need? Well, I've talked about caregiver issues but I'm just going to summarize them here if that's okay?

- They can't get enough respite care. They can't get a break. They can't get someone to come in when they need them to be there when they need to go out and if it gets to that point. If the older person or disabled person needs round the clock care, supervision or companionship it gets so you really need to go to the grocery store to, to go and get your hair cut, to go to your own doctors' appointments so respite care is very important.
- Secondly, it's stress overload as I've already mentioned.
- Thirdly, it's trying to be able to get out and talk with other people to look after you.

- Fourth is the physical difficulty of the work. You know you may have an 80 year old woman who is trying to lift her husband on and off the toilet. It's very difficult. They may need training as to how to do it.
- Lastly, it's emotionally exhausting and I say that with an exclamation point.

So the needs are that they need information about aging, about caregiving and services. They need physical help with the work and that may come from family, neighbors or paid providers. They need relief; that is, they need respite to get a break. They need emotional support. They need to have people give them credit for doing a good job. You know, it's kind of a lonely job because you are in the home with the person most of the time. Nobody sees what you're doing. Often you may feel that nobody cares but if you see this situation you can really make the situation better if you support the person and tell them they're doing a fabulous job if they are. Of course, you wouldn't want to say that if you didn't think that. Finally they need help and support from other members of the family. So there are other needs but I think these are the ones that I would target as the most important and there are providers around that can offer this kind of thing and any of us can help our friends and neighbours with some of these things. You know, we can go over and rake some leaves or we could offer to stay with the disabled person while the caregiver goes out etc. There are a lot of things we can do. Tell them what a great job they're doing.

Mary – Those are all really good points and I'm sure people listening into this will say you know, "what can we do to help these caregivers and these substitute decision makers do a good job and stick with this job?" Just help them as best we can and I think our society recognizes the value of family caregivers but I think we can all do a good job to help them out and these substitute decision makers not only have the caring piece but many of them have the financial responsibilities of managing their money, family and legal affairs so it's almost like pieces of a jigsaw puzzle and they're all trying to figure out how to make this puzzle come together. Dr. Campbell, I would like to thank you for joining us on this episode and perhaps people would like to be in touch with you. Do you have contact information to share?

Dr. Campbell – I do and first let me say that I've enjoyed being part of this as well. Caregivers and older people are my passion and it's a joy to be able to help a bit if can. So, my contact information is:

sandra@commonpoint.ca

Mary – Wonderful. Thank you and goodbye Dr. Campbell

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, CareConnect, 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’s the best way for them to contact us?

Mary – Well they can contact me, Mary Bart, Chair of Caregiving Matters:

mary@caregivingmatters.ca

www.caregivingmatters.ca

905-939-2931