

The **POWER** of ATTORNEY PROJECT

Family Members and Advanced Directives...What Does Grief Have To Do With It?

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- Our guest expert today is Eleanor Silverberg. She has her masters in social work, a bereavement management certificate from the University of Toronto, and is author of a book called Caregiving with strength. Welcome Eleanor.

Eleanor- Thank you for having me.

Mary- Tell us a little bit about your career and about your book.

Eleanor- Well I think I can start it off with my training. I am a social worker. I am a caregiving expert and a grief specialist that works in private practice as a self-development coach specifically for care providers for the chronically ill. Based on my self-help book Caregiving with Strength, that was just published this year, I train family caregivers through a program that I have created in the element of a regiment that strengthens their resiliency and well-being. The feedback I get a lot specifically from people who enter into one of my programs is that they do not have the skills anymore that they need to have which is really alleviating a lot of the anguish in family caregiving of the chronically ill, for example people with Alzheimer's, Parkinson's, MS. The spouses and adult children are giving me that feedback and one of the elements of the strength building regiment is dealing with the loss and grief that they experience while providing care. So in order to facilitate the loss and grief, I developed the three A approach component specifically for caregivers. There is lots of grieving from having a family member who has fallen ill. So in the book, the three A approach to caregiving has been further developed to be used as a self-monitoring, coping tool. There's more information about this on my website www.eleanorsilverberg.com or you can reach out through the website www.caregivingwithstrength.com .

Mary- Thank you for that. Now I have a question for you. How does your grief work relate to advanced directives?

Eleanor- We think of grief as mainly associated with death but there are many situations and certainly circumstances where there is a grief reaction because we are reacting to a loss. Addressing a loss and applying the three A approach, one of the guiding assumptions is where there is adversity, there is loss. That can also include the prospect of future loss in other words the prospect of not having the capacity to attend to daily living activities. It can bring on a painful reaction. Let's call it an anticipatory grief reaction. It is defined as a multi process phenomenon which prepares individuals for the death of a terminally ill person and it facilitates adaptation but we can even bring that definition of anticipatory grief further by including those who are falling ill such as those who are developing Alzheimer's, dementia or other life threatening illness. This also includes the family members who really cannot bear the thought of losing a family member in general but also to an illness. People have this reaction even with just the idea of getting ill and we live on top of that; in addition to that. We live in a culture that lives in denial and avoidance so it would make sense that living under those circumstances and it's almost encouraged to repress, that people would avoid anything related to what would have to be done in law even if it relates to something that is happening in the future and is not happening in the present day.

Mary-Thank you for that. My next question is what would be helpful for family members to address the grief or this issue?

Eleanor- As I was saying, we live in a culture that does not encourage grief, and well it has a low tolerance of losses. Very much like the keep a stiff upper lip kind of thing. Facing the pain rather than resisting or avoiding the pain would help and that's where the three A approach component that I had mentioned comes in. It could be helpful because these components work simultaneously by acknowledging and facing the pain involved in the notion of falling ill in the future rather than denying that or resisting it. It may be unpleasant but unpleasant feelings are a part of who we are. It's almost denying who we are when we deny our grief or we don't face realities. They may be avoided but that doesn't mean they disappear. The chance of the occurrences happening are very real and the feelings that we feel at the idea of getting sick are real and the pain if it isn't expressed or shared or the reality isn't faced this can manifest in other ways...so you would feel better in other ways because it's better for one's well-being.

Mary- And my next question is, what therefor are the ultimate benefits?

Eleanor- Well, emotionally feeling positive and getting your affairs in order. You may feel lighter...the advantage of not having to deal with these issues in a time of crisis when one does fall ill and when everyone is upset and not thinking clearly. I'm going to refer to an article that I came across called the town where everyone talks about death. This is real and is in Wisconsin where now it is a comfortable conversation and that is because of one fellow in town, a doctor Bud Hammond a medical ethicist and he was called for years with people thought to be extremely ill, and he would sit down with family and try to figure out what to do and the discussion was excruciating because of the stress being palpable and most of the time at the crucial moments, the patient had been sick for years and the conversation could have been earlier so what he did was started training nurses to ask people ahead of time if they had an advanced directive and then the idea caught on. I think it's very much like the project that you're doing

where you are encouraging advanced directives and getting more and more people knowing about it. There was an added benefit about more people filling out these advanced directives is that when it did come time at end of life the health care costs were far less because what people chose to do cost less money. There are people contacting this doctor about this initiative about getting these advanced directives.

Mary- Yes and you know that's an interesting story. Imagine a whole town where people have had those difficult conversations, at the kitchen table or going for a walk and that is a town with courage and just imagine if everyone in a family worked through those topics or just imagine on the street you live on or if anyone in close proximity had those conversations what a better world this would be. You know you have to say to those people that they had great courage and once the ball got rolling I bet that became a topic of conversation on the park benches...you know did you get your paperwork done?

Eleanor- Well you know Mary, it's like I mentioned earlier, we live in this culture that does not talk about death. It's almost like a talk that is unmentionable and the reason is that people are encouraged to be emotionally strong instead of feeling the feelings...when rather it's okay to not feel okay and if we could share more and once we get these conversations going you are opening so much more up that is healthier as opposed to being more trapped and repressed and having these conversations be okay is something we have to work on. We have to open it up and keep opening it up and it is a reality that our culture is more repressed and encourages more repression and this is probably why we don't have too many advanced directives because facing the reality, that anticipatory grief, is too difficult. We are very attached as well. What do you think of that?

Mary-I think that's so real and the point that you speak to about the anticipatory grief is so real especially as our population ages and what we read about the statistics going to happen with Alzheimer's and dementia. My mom had Alzheimer's and the grief that I went throughwell every day I lost a little bit more of her and you were grieving while you were caring for them. You lost today what you had yesterday.

Eleanor- I also draw from personal experience taking care of my father who had dementia and my mother who had cancer and it's so hard to witness it but if you can process the grieving while you are caring it can leave you lighter and with more comfort and truth. You aren't hiding anything. It's really out there and whatever is out there does not hurt you inside like with headaches, body aches etc, which is a physical manifestation of that grief feeling.

Mary- Well Eleanor I would like to thank you for joining our project. Would you please share with people how they can get your book and about your website?

Eleanor- Sure. My website is www.eleanorsilverberg.com or www.caregivingwithstrength.com Both those sites will take you to the same place and you will get information on my 8 week group, burnout prevention workshops, and self-care initiatives as well you can order and preview the book on that website as well so I hope you will visit and that you've benefited by my talk with Mary.

Mary-I would like to wrap up with some closing remarks and that is that Chris Kata, one of our board of directors and I would now like to share a few closing comments.

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