



APPROACHING DIFFICULT CONVERSATIONS

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Inevitably as Parkinson's progresses or as our loved ones' age we may find ourselves needing to have conversations about getting more help, driving abilities, safety concerns, moving into a retirement community or care facility, end-of-life decisions, or other difficult topics. Understandably these are not always easy conversations to have, however they are necessary ones – to keep yourself or your loved one(s) healthy and safe, reduce strain and stress on a care partner, or even for a family's peace of mind. Important to note here is that it is not JUST conversations with aging parents or those with Parkinson disease that this article refers to; it also includes adult children. It can be just as difficult to relay decisions about health, safety, and well-being concerns to adult children as it is for adult children to raise concerns to their loved ones.

So how do you talk to your spouse or your aging parent(s) about concerns regarding their safety, health, or quality of life? Or to adult children about decisions, you have made regarding your own future? In this article we will talk about how to begin those uncomfortable but important conversations.

Talking to your spouse/aging parent(s)

Have the conversation as early as possible. Rather than having a health crisis force making a decision in which your loved one will have little say, have these important conversations early. Having the conversation BEFORE there are safety, health or well-being concerns can take the pressure off making immediate decisions, allow time for your loved one(s) to learn about and consider all options, and make the best choices for themselves. The same applies to sharing your wishes regarding your future (be it selling the house, medical decisions, or end-of-life) with adult children; the earlier you start the conversation the more time you give your loved ones to share their thoughts and accept your choices.

Having the conversation early also makes it possible to **have multiple conversations** and **take a break from the conversation**. Many of the more difficult conversations result in a HUGE change and/or loss of independence for some. The probability of coming up with solutions to potentially emotional decisions in one

conversation is likely not possible. This is a process, not a one and done discussion. This may take a series of talks.

Conversations about future plans you have made, or safety, health, and well-being are not always welcomed with open arms; in fact, it can be the opposite where a loved one(s) feel blind-sided, attacked, condescended to, or hurt. This is yet another reason to have the conversation early when issues are either not present, or not pressing. This isn't always possible of course; but whether you have the conversation in advance or in the moment there are a few things as the "Conversation Initiator" you need to consider.

Are you prepared for the conversation? Do you have an idea how your loved one(s) feel about any particular topic? What is their typical conversation style? If you are an adult child, are you fully aware of what the day-to-day of your loved one(s) is? Have you thought about what your concerns are? As you consider these questions it may be beneficial to create a list of your concerns. For example, are you worried that driving long distances or at night is no longer a safe environment for them? Have their health conditions become more difficult for them or you as a couple to manage? Are they having trouble with activities of daily living, such as dressing, bathing, or managing their medications? Is the spouse/care partner struggling to manage their own health and well-being as well as their loved ones? Are there more falls? Are issues with cognition that may make it unsafe? Discussing concerns with other family members or peers (other care partners or adult children) and getting their perspective may bring more awareness, though it is important not to "gang up" on your loved one(s). Write down observations so that you are able to keep on track and focused, these types of conversations are sensitive and often emotional.

Taking the time to **educate yourself** and learn more about supports and solutions to identified safety, health, and well-being concerns can give you the confidence and the credibility you need to begin the conversation. Once you learn more and feel more confident about the options you will be able to have a genuine, constructive conversation. Keep in mind that exploring and learning gives you options to share and discuss, it does not mean that you are making the

final decisions. By preparing yourself with possibilities to share, you will be able to offer options to concerns that may lay ahead. By discussing options, you will help your loved one keep some control over their life and be as helpful as possible for the conversations and decisions ahead.

Talk in person, if possible. Face to face conversations are always the best option, if not a video call so you are able to see each other during the discussion. Choose a time when all involved are rested and more relaxed; and location where you can talk without being interrupted.



It is so important to **listen to your loved one**. Recognizing and admitting that things have changed or progressed, that they might not be able to do what they once did, or that they or their loved one needs more specialized assistance than you/they are able to provide isn't easy. It is a loss. A loss of independence, a loss of sense of self, a loss that can take time to come to terms with. There will be anxieties, concerns, worries, and (in some cases) objections. It is important to acknowledge these feelings, not minimize them. Asking questions in an empathetic and calm manner will show that you care and are trying to understand the fears and frustrations they may feel. By trying your best to put yourself in their shoes it will come from

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a place of empathy and the conversation will have a caring tone versus controlling. It may not change the outcome of the end decision, but it will help your loved one know that they have been heard and respected.

Remember, it is their decision. Unless your loved one or you are a danger to themselves or others, or your health is compromised (care partners, this means you too) it is up to them to make choices they deem best for themselves. Voicing concerns and asking questions is natural and healthy if done in a respectful and non-coercive manner; however ultimately the choice is theirs to make.

Starting that conversation. Beginning the discussion is the hardest part, open ended questions are the best way to encourage conversation. Here are some conversation starters.

- » How is it living at home alone?
- » Do you still feel safe? (This might include stairs, taking medication, safety in the bathroom, kitchen or outdoors)
- » Have you thought about support coming into the supported living or long-term care? For example, if you (or I) fell or got sick and couldn't take care of yourself or I wasn't able to help with what you needed?
- » How would you or we pay for it?
- » Ever wonder about getting a helping hand with housekeeping and laundry?
- » Would you feel less stress if you didn't have to worry about the house?

Talking to your adult children

In the previous section we talked about initiating the conversation sooner rather than later. The same applies to sharing your wishes regarding your future (be it selling the house, medical decisions, or end-of-life) with adult children. The earlier you start these conversations the more time you give your loved ones to process and become accustomed to your decisions. As before, depending on the decision or decisions this likely isn't just one conversation, rather an ongoing conversation over time.

It can be challenging and emotional for adult children (or other loved ones) to engage in conversations about end-of-life and/or accept the reality of your changing needs and progressing Parkinson's. This is anticipatory grief and is natural for a parent-child relationship as the parent ages.

Understanding your adult child/children's communication style can help you prepare to initiate the conversation. Is it a one-on-one conversation? Is it a family-style meeting? Making yourself notes on what you want to say/share can be helpful in keeping you on track. Your family may have questions or in some cases be resistant to your decision. Everyone is entitled to their own feelings. Questions are often a person's way of understanding, so considering questions asked purposefully and thoughtfully can go a long way. That said these are YOUR decisions, wishes and choices and you should not be persuaded, coerced, or guilted into changing them.

An IMPORTANT note on that last sentence. We all know life happens and things change, so it is important to understand that some of the choices you determine early on, may not be feasible in the future and as such new plans and/or conversations may need to be had. For example, you may want to stay at home and not move into a retirement community or care facility; however, declining health/cognition may make it unsafe to stay at home or put your loved one at increased risk of stress, burn out, or injury.

Finally, a caution on information/conversation overload. Sharing information upfront can be helpful, however a lot of information all at once may be overwhelming. It is a human reaction when feeling overwhelmed to become defensive. It will put an end to that conversation and make it difficult to start again. As mentioned earlier it is best to have multiple, smaller, meaningful conversations over time, allowing the information to sit and be processed and pick it up again later.

As Desmond Tutu wisely said, "there is only one way to eat an elephant: a bite at a time." What he meant by this is that everything in life that feels overwhelming and even impossible can be gradually accomplished by taking on a bit at a time rather than taking on the whole thing all at once.