WHAT NOT TO SAY

*What to say is a personal thing. What to say in a situation that might be valid for one person will not be valid for another person.*

The Parkinson's Care Partner's Digital Toolbox

So for the people we've worked with, they'll talk about traveling and rides they plan to go on and the miles they get to decide what empowers them, what keeps them moving forward and what gives them the drive to live well despite the challenges. The best thing we can do is focus on what would best benefit them mentally.

It's a hard habit to break, but if someone close to you has Parkinson's, it's a great time to practice mindfulness. The best thing you can do is to be present in the moment and let your words reflect that. The following are words that might work better than others when it comes to communicating with the people you love and with whom you are involved.

*You know, I've heard that you can reverse Parkinson's.*

**What to say instead:**

You know, I've heard that some treatments can help manage the symptoms of Parkinson's, but it's important to remember that reversing the disease isn't possible at this time. Instead, focus on what's most important to the person you care about.

*Are you sure all of these medications are good for you?*

**What to say instead:**

I'd love to make a plan to get together next Tuesday, but I also understand if you need to cancel last minute.

*Would (insert your care partner) like me to come over on Saturday and spend some time with you so they can feel well enough to meet up.*

**What to say instead:**

Let me know if I can help or if there's anything I can do for you.

*Are you canceling on me again?*

**What to say instead:**

I'm the care partner for Ian and spend a lot of time answering questions about how to best care for someone with Parkinson's. I've found a lot of somewhat questionable information. Not so with the available information from Davis Phinney Foundation. It's great to see you. I've been so excited to tell you about (insert something interesting that they will enjoy).

*Please get me a minute.*

**What to say instead:**

It seems like a nice idea to just leave an opening for them to say what they need to say. It's natural for us to try and imagine how someone feels. It's even natural for us to WANT to know exactly what they're thinking and feeling.

*It's okay to acknowledge that you have some sort of experience with Parkinson's.*

**What to say instead:**

It's natural for us to want to connect and assure them that they're safe with you. By giving them an easy out, you're letting them become more and more unpredictable. By attempting to put a date on the calendar, you're showing that you don't think they need to spend time with you.

*Are you sure X is the right thing to be doing/eating right now?*

**What to say instead:**

You're going to be fine. I know you've got this.

*Most of us understand the intention behind, “It could be worse.” It's designed to get the person out of the moment.*

**What to say instead:**

It's a hard habit to break, but if someone close to you has Parkinson's, it's a great time to practice mindfulness. The best thing you can do is to be present in the moment and let your words reflect that.

*Thank you for.*

**What to say instead:**

Thank you for opening this discussion. Sharing your story is important. It helps others understand the challenges that come with caring for someone with Parkinson's and it can help others feel less alone in their experiences. It's okay to acknowledge that you have some sort of experience with Parkinson's. Maybe your loved one will have the opportunity to meet them in person. If you really want to connect and assure them that they're safe with you, let them know you feel that you can handle whatever they need. 

*We're certain that if it were possible to reverse Parkinson's, the person you know with Parkinson's would do it.*

**What to say instead:**

The Parkinson's Care Partner's Digital Toolbox

As the Parkinson's Care Partner's Digital Toolbox, we want to give you a list of words and phrases that work well and those to avoid using. The words that can be used to support them will make the person feel empowered, understanding and hopeful. Words like “normal” and “regular” may not be helpful or accurate when it comes to describing the person with Parkinson's. Other words like “OK” or “fine” may be a way to soften the news, but they also tell the person with Parkinson's that their perspective is not valued.

*You can say anything you want.*

**What to say instead:**

You can say anything you want. It's your experience and your perspective is valued.

*You must be logged in to post a comment.*

**What to say instead:**

You must be logged in to post a comment.

*Thank you for.*

**What to say instead:**

Thank you for sharing your story. It's amazing that you've decided to tell your story and to share your experiences.

*Thank you for.*

**What to say instead:**

Thank you for sharing your story. It's amazing that you've decided to tell your story and to share your experiences.