

THE BIG 16: WHAT TO SAY (AND WHAT NOT TO SAY) TO SOMEONE WHO HAS PARKINSON'S



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What would you say to a friend or family members who just told you they have Parkinson's?

If you're like most people who are faced with that news, your hope is that you'd have the right reaction, say the right thing and be the exact kind of support they need at that moment.

However, as a human being, you'd be trying to balance all of that while trying to make sense of the questions and emotions that you're feeling at that moment too. It's also very possible that the last thing that person wants to hear will come rushing out of your mouth before you have a chance to stop it.

We've worked with thousands of people who've had to break the news that they have Parkinson's to a loved one. Sometimes it doesn't go quite the way they hoped, and not because the person they chose to share the news with was insensitive or intentionally trying to be hurtful. In a moment like that, people often confuse what's helpful for the person with Parkinson's with what feels helpful to them.

Which is why we want to give you a menu of words that work and words to stay away from.

WHAT TO SAY AND WHAT NOT TO SAY TO SOMEONE WHO HAS PARKINSON'S

What Not to Say

You don't look sick.

What to Say Instead

You look really good. Is that how you're feeling?

The truth about Parkinson's is that some days a person with Parkinson's may not display any of the signs we've come to interpret as sick. That doesn't mean that they aren't feeling symptoms that we just can't see.

For example, they might have a smile on their face when they're talking to you but their toes are curling so badly they couldn't take a step forward if they tried. Or maybe you're even out for your weekly run together and they seem fine but they can barely concentrate on what you're saying because they're worried their right leg will just give out... again.

Parkinson's is 24/7 so honor that. By saying to someone that they don't look sick, you're reducing Parkinson's to its outward manifestations and minimizing the array of symptoms someone could be feeling at any given moment. That's why a statement that highlights how good they look followed by something that underscores the hidden nature of many Parkinson's symptoms can go a long way to letting the person know you appreciate the depth of what they're dealing with.

What Not to Say

How are you feeling?

What to Say Instead

It's great to see you. I've been so excited to tell you about (insert something interesting that they will also think is interesting.)

How are you feeling sounds like a reasonable question. And most of the time it is, especially if you're talking to someone who just had the flu or broke their arm. However, it's a completely different situation when you're talking to someone with a chronic illness.

First of all, you don't want to be another one of the many people who've already asked them the same thing that day. Second, when you ask this question, you're keeping Parkinson's front and center.

Instead of doing a temperature check every time you see them, focus on how happy you are to see the person and help them focus on something other than how they feel.

What Not to Say

You seem great. Your Parkinson's must be getting better.

What to Say Instead

I love your shirt. That color looks great on you. I've missed you.

Parkinson's does not get better. It's degenerative, meaning that cells will deteriorate over time. There will be some days that are better than others and by all means, celebrate those days, but their Parkinson's will not get better. If it's been a while since you've seen them, it's better to focus on something other than Parkinson's.

What Not to Say

Are you canceling on me again?

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.

People living with Parkinson's deal with symptoms on a daily basis that some of us may never understand. Depending on where they are on their path, how they will feel on certain days will become more and more unpredictable. By attempting to put a date on the calendar, you're showing them that you care and want to spend time with them. By giving them an easy out, you're letting them know that you appreciate the challenges they may face on any given day and you'll be there whenever they feel well enough to meet up.

What Not to Say

I know how you feel.

What to Say Instead

I'd love to know more about Parkinson's if you're up for talking about it.

It's natural for us to try and imagine how someone feels. It's even natural for us to WANT to know how they feel. We want to get close to them and build a connection. Instead of building solidarity when you say that, what you're really doing is minimizing the other person's story. If you do not have Parkinson's but the other person does, you can't know how they feel.

If you really want to connect and assure them that they're safe with you, let them know you feel honored that they trust you enough to share with you and then let them take it from there.

What Not to Say

My second cousin's neighbor's uncle has Parkinson's, and he seems to be doing fine with it.

What to Say Instead

I have some understanding of Parkinson's because my _____ had it; however, I know it's really different for everyone. What's your experience with it so far?

It's okay to acknowledge that you have some sort of experience with Parkinson's. Maybe your experience is a distant connection or maybe it's through a not so distant family member. There's no sense in pretending you know nothing about Parkinson's if you do; however, if you do know something about it, you also know that it plays out differently for nearly everyone. If you're upfront about the knowledge you do have with them, and then ask them about their experience, you will open the door for a more productive and supportive conversation.

What Not to Say

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

What to Say Instead

Would it be helpful if I came over and helped with your laundry and some housework tomorrow?

Would (insert your care partner) like me to come over on Saturday and spend some time with you so he or she can go out and take care of themselves for a while?

It seems like a nice idea to just leave an offer open-ended, but what that really does is put more work on the person living with Parkinson's. If you make a direct ask, it's easier for them to assess whether or not that would be helpful and give you a yes or no. Making things easier for them is a gift they will thank you for.

What Not to Say

It could be worse.

What to Say Instead

I'm really sorry you're going through this. Is there anything that makes you feel better?

Most of us understand the intention behind, "It could be worse." It's designed to get the person out from under catastrophic thinking and make them see it's not so bad compared to other negative health conditions; however, what it does is minimize whatever pain, sadness, isolation or frustration they may be feeling.

Before you let this one slip, simply let them know you're sorry and ask them if there's anything that makes them feel better. Even better, when they say "X seems to make me feel better", offer to do it with them.

What Not to Say

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

What to Say Instead

I want to help in any way I can.

When you're facing a big challenge, and you know that barring a cure you're going to be living with Parkinson's for the rest of your life, hearing someone treat it as though it's a broken bone that will heal is not helpful.

Instead, acknowledge it and then let them know they can count on you during the ups and downs of the journey.

What Not to Say

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

What to Say Instead

I'm so impressed with everything you've been doing to take care of yourself. What do you think has been the most helpful?

The problem with this question is twofold: 1) It has an accusatory tone, and it assumes they're doing things without putting any thought into them, and 2) It assumes you know more than they do about what is good for someone with Parkinson's.

A more helpful approach might be to ask them what they've done that's been the most helpful. That will perhaps prompt them to really think about all of the things they've tried, assess what's working and generate new ideas on their own.

What Not to Say

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

What to Say Instead

It sounds like you're doing everything you can and you have a great team behind you.

In our work with people who have Parkinson's, we've yet to meet someone who enjoys taking all of their medications or someone who doesn't worry about everything they have to put in their body to feel sometimes only marginally better. They wonder if these medications are good for them. They wonder if the side effects of the medication will make some things worse. And they are working closely with their doctors to find the right combination of everything to suit their needs.

Putting them on the spot with a question like this is not going to help them. A better route may be to simply acknowledge everything they are doing to live well and see where that conversation leads.

What Not to Say

Have you tried X?

What to Say Instead

Anything else.

This question comes from our desire to be helpful. Resist this temptation to immediately start working on how to fix the situation or problem solve. If someone has Parkinson's, it's quite likely that they've already spoken with dozens of doctors and they've been thinking of nothing else since their symptoms began. They have probably thought about every pathway, considered many therapies already and have a trusted circle of people they like to run their ideas by. The only time, "Have you tried X?" works is if they've made a direct ask such as, "I feel like I'm out of ideas. Do you have any thoughts about something I haven't considered yet." Aside from that, it's best to take that question off the table.

What Not to Say

I don't even know what I'd do if I had Parkinson's.

What to Say Instead

Nothing. Just listen.

It's a hard habit to break, but if someone close to you has Parkinson's, it's a great time to practice focusing on what they need and listening when they feel open enough to talk about it instead of thinking about how you might react if in the same situation.

What Not to Say

We're never given more than we can handle. Or it's sister, everything happens for a reason.

What to Say Instead

What's the best way I can support you right now?

These are phrases that people use a lot when something bad happens or when someone is facing a big challenge. In fact, they're said so often that it's easy to default to them in situations like this. That's a problem. Hearing a platitude is often the least helpful thing you can say to someone facing a challenge like Parkinson's. It's simply too dismissive. Here's the thing that most people miss: the person who is experiencing the pain or loss or sadness can say these words all they want because 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 support them right now instead.

What Not to Say

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

What to Say Instead

What are you most looking forward to?

There are people out there who preach that they have and can reverse Parkinson's. Some claim that they had Parkinson's once and now they don't. From what the vast majority of research says, that is not true. While we are big on hope at the Davis Phinney Foundation, we're even bigger on living well today, no matter what challenges you face.

We're certain that if it were possible to reverse Parkinson's, the person you know with Parkinson's would already be investigating that path. We're also certain that one of the best things you could say to someone who has Parkinson's is, "What are you most looking forward to?" If they're like many of the people we've worked with, they'll talk about [traveling](#) and [rides they plan to go on](#) and the [miles they hope to log this year](#). What fun might you have if you joined them on their next adventure?

What Not to Say

Just think positively.

What to Say Instead

I wish I had something smart and helpful to say right now but I'm at a loss.

If you're one of those people who truly want to be helpful but you have no idea what to say, say that. Tell the person that you really want to be helpful and say the right thing but you have no idea what that is. Saying you don't know what to say is always better than throwing something out there you can't take back.

Knowing what to say and how to say it is not easy. We hope this menu will serve as a good reminder of what words might work better than others when it comes to communicating with the people you care about most.