

Rachel Dolhun, ([00:25](#)):

Hi. I'm Dr. Rachel Dolhun, a movement disorder specialist, and senior vice president of medical communications at The Michael J. Fox Foundation for Parkinson's Research. Welcome to Ask the MD: In Conversation, where I talk with community members about important topics in Parkinson's. Today, we'll be talking about sleep. Good sleep is an important part of keeping our bodies and our brains healthy, but it can be hard to come by. Many of us have trouble falling asleep or staying asleep. Some people even act out their dreams. They yell, kick or punch while sleeping. This is called REM sleep behavior disorder, or RBD. For some people RBD can be part of Parkinson's. It can be one of the earliest signs of disease happening years or decades before diagnosis, but it can also happen years or decades into life with Parkinson's too.

Rachel Dolhun, ([01:25](#)):

Not everyone with RBD goes on to develop Parkinson's, but scientists are learning more about this connection to develop better treatments and ultimately prevent Parkinson's. For more on these topics, we are talking with Terry Goldin, who's been living with RBD since 2012 and his wife Holly. They're joining us from Wilmette, Illinois. Welcome Terry and Holly, thank you so much for being here.

Terry Goldin ([01:54](#)):

Thanks, Rachel. I appreciate the invitation to be part of this program.

Rachel Dolhun, ([02:01](#)):

So let me get started by asking, I know you're both empty nesters, you're both retired. How do you keep yourselves busy?

Terry Goldin ([02:10](#)):

Both of us are very... To start with, we're very athletic. Both of us are into yoga, we both play tennis, we play golf, we downhill and water ski and bicycle a lot. We just try to stay active.

Rachel Dolhun, ([02:27](#)):

Yep. And you have to be well rested for all of that activity, right?

Holly Goldin ([02:31](#)):

Absolutely.

Terry Goldin ([02:31](#)):

Yes.

Rachel Dolhun, ([02:32](#)):

So important to talk about sleep, and what we're going to focus today on is acting out dreams. And Terry, I know you act out your dreams. So I'd like to start by asking you to tell us what that feels like and what that looks like for you.

Terry Goldin ([02:45](#)):

Well, I used to play a lot of basketball, then I finally wore out my hips and had to get them replaced, but I still dream about playing basketball, and it's the excitement of it. One of my incidents that opened up my eyes that I had a problem was, I was dreaming about playing basketball and stealing a pass. And I jumped in front of somebody and caught the ball in my dream. It turned out that I tackled a glass lamp on my nightstand, and it was quite disturbing, a little scary for my wife.

Holly Goldin ([03:26](#)):

Very.

Terry Goldin ([03:28](#)):

That's kind of how it all began.

Rachel Dolhun, ([03:30](#)):

Very scary, as you said. And you have other types of dreams as well, that you act out.

Terry Goldin ([03:37](#)):

Yeah. I mean, the dreams, they seem to fall into categories. Another dream is being chased by wild animals, where an animal's approaching me and I start kicking the animal to keep them off of me, and I'm actually doing that while I sleep, and my wife who's next to me, to nudge me and pull me out of it. Another-

Rachel Dolhun, ([04:01](#)):

[crosstalk 00:04:01] well, while this is happening?

Holly Goldin ([04:03](#)):

Sometimes yes. That will wake me up. But even if I'm not directly impacted, I can feel him in bed, kind of running or pushing or kicking, and that will often wake me up.

Terry Goldin ([04:16](#)):

Right. Another type of dream that I've had commonly is being in espionage, where I'm running away from somebody and trying to escape, and I might throw myself out bed when I'm diving for something in my dreams to get out of the way of somebody shooting me.

Rachel Dolhun, ([04:35](#)):

Yes. These can be really frightening.

Terry Goldin ([04:36](#)):

[crosstalk 00:04:36].

Rachel Dolhun, ([04:38](#)):

Yeah, really frightening for you Terry, to be having these sorts of dreams. But Holly, from your perspective, what is this like, as somebody who shares a bed, a spouse or someone, obviously very concerning and worrisome.

Holly Goldin ([04:51](#)):

Very worrisome. Initially really worrisome. Once we identified the condition and he started getting treatment for it, less so, and as you've lived with it for all these years, it's not as jarring as it was earlier on when it was so unexpected. And I'll add, now that he's on what I consider a good medication program for this, those bigger incidents are very infrequent.

Rachel Dolhun, ([05:25](#)):

We want to get into the diagnosis and the treatment of course. But just to stick with you for a second, tell us a little more about what it's like to be sharing a bed with somebody, to be [crosstalk 00:05:34], and at first not certain why.

Holly Goldin ([05:37](#)):

Yeah. It's challenging for sure, and it's disturbing to my sleep. I wake up... Fortunately, I'm a pretty good sleeper, so I can usually get back to sleep without too much trouble, and now it's kind of a, "Okay, wake up," and then he'll wake up, he'll stop and-

Terry Goldin ([05:57](#)):

And one of the worries is, I can turn either way in the bed. I can dive out of the bed and that saves her from getting hurt, but I might hurt myself, but I could be facing the other way, and I have been known to hit her.

Holly Goldin ([06:12](#)):

Yeah. I think about the way I'm facing as well, that if something happens and I'm facing Terry, well, then I might get hit in the face, but if I'm not facing Terry, it's not as bad.

Terry Goldin ([06:23](#)):

When I face Holly, I try to tuck my arms under my head so they're not loose. So I have to consciously pull them out of that position, hopefully she catches me.

Rachel Dolhun, ([06:37](#)):

A lot to think about as you go to bed and in your positioning and taking all these safety concerns into account for both of you, and Holly, you mentioned too that you were concerned at some point that, like many people, you might have to sleep apart for both of your safety. How this might impact your relationship or your marriage?

Holly Goldin ([06:55](#)):

Absolutely. And I think, had we not been successful with treatment, that might have been a necessary solution because I might not have been able to get enough sleep or adequate sleep. So I'm happy-

Terry Goldin ([07:09](#)):

Or enough security.

Holly Goldin ([07:10](#)):

Or enough security, right. But I worried if I moved to a different bed, and now he's experiencing these things on his own, is he more likely to get hurt if I'm not there to wake him up when he's on this path of moving around too much?

Rachel Dolhun, ([07:24](#)):

Yeah, it's a valid concern.

Holly Goldin ([07:26](#)):

It is. And as I'm talking to you about it, I'm thinking, "Wow, this sounds terrible." But it was more scary, and now the fact that it's less frequent has made it manageable, I guess I would say.

Rachel Dolhun, ([07:42](#)):

And I think the point you made earlier too, that you have a name for it, and you have a treatment for it. So let's talk a little bit about how you figured out what this was and what doctor you got to and how you went down a path toward the right treatment.

Terry Goldin ([07:56](#)):

And I'll be perfectly honest. Holly is the more studious person of the two of us. So when I had this thing, she immediately went online and started looking it up and exploring what other people said.

Rachel Dolhun, ([08:11](#)):

This can be a good thing or a bad thing. The internet does have a lot of misinformation, so you want to be cautious about that.

Holly Goldin ([08:18](#)):

Absolutely. And when it happened once I thought, "Oh, this is just a weird thing that happened." And I didn't really think anything of it. But when it happened a second time, and there was probably maybe a few months between those two incidences, I thought, "Okay, this is now a pattern, and I wonder if this happens to other people too." So interestingly, and I know the internet can have a lot of misinformation, but as soon as I put in a search box, acting out dreams, information about RBD came right up. So it reassured me that he is not the only one experiencing this, I'm not the only one experiencing this, and eventually took us to a physician at Northwestern who had experience with RBD, and did diagnose it.

Rachel Dolhun, ([09:07](#)):

That's right, and it's so important that anybody who's experiencing something like this, whether it's acting out dreams or any kind of sleep change gets to you a doctor who specializes in this area, a sleep doctor, who can take you through what's happening, what this might be, and formally diagnose it. Tell us a little bit more about that experience for you, Terry. What was the diagnosis process like?

Terry Goldin ([09:30](#)):

Well, we looked up this doctor who specializes at a very prominent local hospital, and at my first appointment, I started describing him what was going on, and it just was classic, as far as he was concerned. I mean, everything I described was an indicator that I had this condition. For me, it was kind of a good feeling, that somebody was able to so quickly diagnose it. Now, when they told me that it was

also a potential indicator for getting Parkinson's in the future, or increased my odds of it, that was also interesting. But I felt more reassured that somebody had identified what was going on with me, and that they were able to control some of the problematic symptoms that came out of it.

Rachel Dolhun, ([10:26](#)):

As you mentioned, this can be one of the earliest signs of Parkinson's in some people, so I'm sure very worrisome and concerning to learn about that risk. I want to talk a lot about more in just a second, but to stay with the diagnosis of RBD for a moment, tell us then, once you said, "This sounds like RBD," did you have to go through a sleep study, did you ultimately go on medications, did you have to make other adjustments to your bedroom?

Terry Goldin ([10:57](#)):

One of the first things we did is, we did a sleep study. And I believe the doctor was looking for symptoms of RBD, which I'm not sure you would see in one night. He Was also concerned about my ability to sleep soundly, and to determine if I needed any additional measures to help me sleep properly, and they did determine that I did not have sleep apnea.

Rachel Dolhun, ([11:19](#)):

Yeah. Just for our listeners, an overnight sleep study, which isn't the most comfortable thing in the world where you go and... Either you can do it at home or go to a lab type of facility, and get hooked up to all kinds of recording machines and devices to see what it's like when you're dreaming. And this can help us confirm REM sleep behavior disorder, but Terry also, as you're pointing out, look for other sleep conditions that might be cause for acting out dreams or might otherwise interrupt your sleep.

Terry Goldin ([11:50](#)):

And the doctor, I'm sure could see small movements during my REM sleep phase that would confirm that while normal people don't have this issue, your body is basically paralyzed to movement, whereas a person with RBD, your body moves with your dreams.

Rachel Dolhun, ([12:13](#)):

That's such an important point, and thank you for doing my job for me, explaining what RBD actually is, and you're right. Normally when we sleep, our brains prevent our muscles from moving, so that we can't throw our lamp across the room, or get out of bed and run across the room. But in people with RBD, those brain signals don't work properly, and so the muscles can move, and we can act out our dreams.

Holly Goldin ([12:39](#)):

One thing that the doctor said, I think, when we had the follow-up visit is, even though I might not notice this every night, or Terry wouldn't notice it every night, he might just sleep through some of, it's probably happening much more frequently on a very small scale, and it's only the bigger incidences that get to the point where it wakes one of us up.

Rachel Dolhun, ([13:03](#)):

So important to treat, and there are good treatments for it, but Terry you're on some of these medications.

Terry Goldin ([13:09](#)):

Absolutely. I'm taking a pretty large of melatonin, which is pretty benign, but it does subdue my movements. I'm taking a drug every evening called clonazepam, which I like to joke with my friends, on a heavier dose could be used as an animal tranquilizer, when they want to tag animals, but for I'm such a light fit.

Rachel Dolhun, ([13:39](#)):

[crosstalk 00:13:39] those doses, but yes, so melatonin, a hormonal supplement that can be available over the counter, and then also clonazepam, it's prescription medicine.

Terry Goldin ([13:51](#)):

And I'm taking a steroid nasal spray once a day, just to keep my sinuses clear all day and all evening, to sleep better.

Rachel Dolhun, ([14:02](#)):

And these medications have worked pretty well for you?

Terry Goldin ([14:03](#)):

They've worked very well. I started on a little lower dose of melatonin, they raised that one up, but as far as the clonazepam, they kept it where it was. They've been very effective in reducing the number of large incidents, or more noticeable incidents.

Holly Goldin ([14:23](#)):

The doctor stepped up that dose of melatonin, "Try this for a week or two, then report back. Let's increase it a little more." We're at the point where we are now, and I think it's 15 milligrams of melatonin.

Terry Goldin ([14:38](#)):

Yes, it is, yeah.

Rachel Dolhun, ([14:38](#)):

Just gradually getting to that right dose for you?

Holly Goldin ([14:39](#)):

Right. I feel like it hasn't eliminated the problem, but it has greatly reduced it. So, I can live with that.

Rachel Dolhun, ([14:49](#)):

And you made some adjustments to your sleeping space and your bedroom as well, is that right?

Terry Goldin ([14:55](#)):

Well, yes. In a way. We ended up purchasing nightstands that had rounded corners. So, if I did fall out of bed and hit my nightstand, I wouldn't be hitting a sharp edge.

Holly Goldin ([15:09](#)):

And we went to a platform bed, so it's lower to the ground. It's not one of those super-duper low ones, because we thought, "We're getting old. We're not going to be able to get out of that bed so easily." But-

Terry Goldin ([15:19](#)):

For a little while I had one of these things that we put on children's bunk beds, to keep you from falling out of bed, but I think I've graduated back to not... My incidents of falling out of bed is so low, that I just felt that it was a better off thing.

Holly Goldin ([15:36](#)):

Having that made it hard to get out of bed when you need to go use the restroom at night or something, so there's a trade off by using that. So we gradually stopped using that, but it's still in the closet, if we need to go back to it.

Rachel Dolhun, ([15:47](#)):

It's a balancing act, like you mentioned, of being able to sleep in the same bed, but also again, paying attention to your safety and the quality of your sleep. So I want to get back to this point, Terry, that you mentioned about learning that RBD, REM sleep behavior disorder, can be a risk for Parkinson's. Obviously very concerning, very worrisome to learn that, especially right after you were diagnosed with RBD. So tell us a little more about that.

Terry Goldin ([16:17](#)):

Well, when I learned that I had this condition of RBD, and that it had a higher incidence of being a precursor to getting Parkinson's, it isn't always the case. In one sense it worried me, but in the other sense, it made me feel more comfortable that somebody knows what I have, and then if it does lead to... When I go to my doctor, a large amount of the time is spent checking my movements, checking my reactions to see if there are any signs of Parkinson's, and so far, since I've had this condition, my doctor's never told me that he's seeing a condition that could indicate that I have this onset of Parkinson's.

Terry Goldin ([17:18](#)):

I also feel that if I do eventually develop Parkinson's, that I'm immediately closer to the experts, and I don't know if they go searching for the right people to deal with it, and I could be on a hopefully cutting edge of something that could help treat Parkinson's or help lead towards solving it.

Rachel Dolhun, ([17:41](#)):

And what you're talking about is, you got to a Parkinson's doctor so that you could get regular evaluations, and see, as you mentioned, if signs or symptoms of Parkinson's were developing over time, which you haven't seen any evidence of yet after about a decade of living with this, is that right?

Terry Goldin ([18:00](#)):

That's right. Another thing, and this is only maybe Terry Goldin's personal theory, is that I eat well, I eat properly, I sleep properly, I do a lot of physical activity, a lot of exercise. Maybe that has something to do with why Parkinson's is not displaying itself in me-

Holly Goldin ([18:23](#)):

Or yet, anyway.

Terry Goldin ([18:24](#)):

Yeah. Or yet, exactly.

Rachel Dolhun, ([18:26](#)):

Yeah. And that's not just your personal opinion. I think research is showing that exercise is one of the best things that we can do for our bodies and for our brains, and there is some suggestion that it could potentially delay the onset of Parkinson's, if it is going to happen. And in people who have Parkinson's already, of course, it's one of the best things that you can do for managing symptoms, and also potentially slowing the changes that happen over time. So, Terry, one of the other things that you also did, you got to the right doctors, you maintained your vigorous exercise schedule, but you also joined research, and you joined a study called the Parkinson Progression Markers Initiative, or PPMI. And this is a study that's looking at people who have REM sleep behavior disorder, whether they have Parkinson's or not, to see exactly how Parkinson's comes on and changes over time, so that we can develop better treatments for the disease, but also ultimately hopefully, prevent it from happening. So tell me more about why you chose to participate in research, why PPMI?

Terry Goldin ([19:36](#)):

Well, initially, when I was diagnosed with RBD, I was working full-time, like everybody else I felt I had a lot of pressure and a lot of obligations, etc., so my doctor asked me if I wanted to continue to be part of research. My answer at that time was, "Unfortunately I'm too busy." Since I retired, when I was 65 years old, I felt I had the extra time to devote, and it's that much of an obligation. I mean, I go maybe once or twice a year for a battery of mental and physical tests and things like that. It was something I felt was a good contribution just to study me, to share the information that they're finding out about my condition with other doctors. The PPMI I was referred to by my doctor, they asked me if I could join it, and then when I was ready, I felt I had the time, it's a great organization.

Rachel Dolhun, ([20:51](#)):

And Holly, how do you feel about Terry participating in research?

Holly Goldin ([20:56](#)):

Well, I think it's great that he's doing it, both for the benefit of the research, in terms of learning more about Parkinson's, which you have all the statistics on what percentage of people develop Parkinson's in general and all of that. It's something that is prevalent, and so the more we learn about it, the more we can learn to prevent it or treat it better. And to a question that you asked a while ago about how do I feel about the risk of, this is hanging out there that Terry may develop Parkinson's, I'd also say that a lot of people might develop Parkinson's who don't have this knowledge that they're at risk for it, and therefore there might have symptoms that develop that they're not paying attention to, and by the time they go get treatment for it, they're well into it.



Holly Goldin ([21:45](#)):

In this case, we're aware that there's a risk and he sees very well qualified doctors, he's part of this research study. I feel like we'll know very early on if that's where he's headed and when it begins, and that can be nothing but a benefit to us.

Terry Goldin ([22:05](#)):

Right. And I feel one of the other advantages of being in a research program is being exposed to even more high tech measures of detecting Parkinson's [crosstalk 00:22:19]. Such as, I had an opportunity to get an MRI of my brain, a data scan, they did a lumbar puncture to check my spinal fluid. These are all things that really, when you get a yearly checkup to look at RBD, they're relatively expensive measures that they would not justify for a once a year checkup. But being in the program, I'm exposed to some of these other higher technologies.

Rachel Dolhun, ([22:48](#)):

It gives you that closer look and that closer contact, as you mentioned, with researchers and doctors who are in this area.

Terry Goldin ([22:58](#)):

Exactly.

Rachel Dolhun, ([22:58](#)):

Which is, it's one big thing that both of you took on, as a way to kind of manage the worry and living with RBD, as a potential risk for Parkinson's, but are there other ways that you may manage this worry about living with RBD? Holly, you in particular?

Terry Goldin ([23:15](#)):

Holly, probably more than I, because I don't worry so much.

Holly Goldin ([23:18](#)):

I'm definitely the worrier of the two of us. I think it's like many things in life that we all live with risks of varying kinds. This is his risk, there's not a family history of that, and he doesn't have a history of cancer in his family or diabetes, or other things that many other people worry about. So, this is just the thing we have to deal with. I try not to think about it all the time, have it become such a factor in our day-to-day lives that it doesn't let us enjoy what we have. But it does factor into things like, we love to travel and let's do it now while we can, who knows if 10 years from now, we're still going to be in that position? But that's true of many conditions, not just Parkinson's.

Rachel Dolhun, ([24:11](#)):

You both have such great outlooks about this. Terry, what would you tell other people who are living with REM sleep behavior disorder?

Terry Goldin ([24:22](#)):

I would say that your biggest contribution would it be to join a thing like PPMI to participate. I look forward to my once or twice a year visits there. I know it's a pretty intensive day of getting MRIs and data scans and lumbar punctures and things like that, but in the end it's about six hours of activity doing

very interesting things. So it's not that difficult to be helpful, and what they could learn from me hopefully will help solve the mystery.

Rachel Dolhun, ([25:06](#)):

What would you say to anybody who's on the fence about joining research?

Terry Goldin ([25:10](#)):

If you have the time, again, being retired, my time is pretty loose, I would say, join the program. It's just a very worthwhile contribution that is not so involved, that you have to give up a ton of time.

Rachel Dolhun, ([25:29](#)):

And Holly, what would you tell other loved ones or spouses of people who are living with RBD?

Holly Goldin ([25:35](#)):

I would say, make sure you're getting good treatment from somebody who has expertise in this area, because the treatment has been, I'd say life-changing. I mean, it was life-changing to find out that he had this, and equally life-changing to get some treatment that really has helped, and I think probably most people with the condition can be helped with treatment. I think too, the participation in a research study is proactive. You have a choice when you have something like this in your life, you could just kind of sit back and wait for it to happen, or you can be proactive and work toward its better outcome. And why not? Again, the time is a big factor. If you're working and if you don't live near a major medical center where you can go do this, it would be much more difficult, but we live in Chicago and he's retired, so there we go.

Rachel Dolhun, ([26:34](#)):

The initial step into PPMI is only an online survey. So some people will then go on to be invited to come into clinic, into a medical center like you do Terry, but not everyone. So the time commitment may be even more or less to begin with, in joining PPMI.

Terry Goldin ([26:53](#)):

Absolutely.

Rachel Dolhun, ([26:55](#)):

On that note, Terry, I would ask you, how does it feel to be part of something like PPMI, which may have the potential to really change how Parkinson's is seen and how it's cared for, and potentially even make the disease something of the past?

Terry Goldin ([27:10](#)):

Well, I only hope that what they learn from me can help solve the puzzle. I'm not convinced I'm going to have Parkinson's, but if I do, I feel like I'm in very good hands.

Rachel Dolhun, ([27:29](#)):

And you bring everything you can.

Terry Goldin ([27:34](#)):

Yeah. I'm just proud to be part of the research, and it's not like I have to commit weeks and months and stuff like that, it's only a couple of times a year and responding to some surveys and things like that.

Rachel Dolhun, ([27:55](#)):

Researchers are so grateful for your contributions because they couldn't do it without you and without your contributions and your time. So thank you much for participating in research, and also Terry and Holly for sharing your experiences with us today.

Holly Goldin ([28:11](#)):

Thank you.

Terry Goldin ([28:11](#)):

Thank you, Rachel.

Rachel Dolhun, ([28:14](#)):

If you act out your dreams, whether you have Parkinson's or not, you can help research. The Parkinson's Progression Markers Initiative or PPMI, is learning more about the connection between REM sleep behavior disorder and Parkinson's. These insights could lead to better treatments and cures. For more on REM sleep behavior disorder and Parkinson's, download our free guide at [michaeljfox.org/rbdguide](http://michaeljfox.org/rbdguide).