

S2E1 - Puzzle Pieces

Transcript

Judith: [00:00:02] Sometimes when I'm looking at a puzzle, I can look at all of the pieces, and if I have studied the picture, I can actually then, say, pick up a piece and know where it belongs. So when it comes to working on that section of the puzzle, I know what I have and what I don't have.

Narrator: [00:00:21] I don't think I'm particularly good at solving jigsaw puzzles.

Judith: [00:00:24] Well, the key for solving a lot of different puzzles is sitting back and thinking first.

Narrator: [00:00:30] Right, right. Which I imagine is probably a lot easier when the puzzle is on a table in front of you as opposed to inside of you.

Judith: [00:00:41] I have a little story about that if you have a minute.

Narrator: [00:00:47] Canadian Patient Safety Institute presents *Patient*, a nonfiction medical podcast about people trying to fix modern health care from the inside out. I'm your host, Jordan Bloemen. Judith Maxwell is a note taker.

Judith: [00:01:21] I'm a very organized person.

Narrator: [00:01:24] This is a profound understatement.

Judith: [00:01:26] And as you probably have gathered from all of my notes.

Narrator: [00:01:31] And notes are really useful when the only clues in the mystery that you're trying to solve are happening to you. This season of *patient*, we're going to do things a little bit differently. We're telling one story across three episodes, and that story is a mystery. You could say that it's a puzzle, which is fitting because its protagonist is Judith Maxwell, a solver of puzzles.

Judith: [00:02:03] After a while, I decided that I had to keep really good tabs on things in case I needed to give that information to a physician so that they would be able to help me, which obviously for eight years, nobody was able to.

Narrator: [00:02:16] Eight years ago. So let's start there.

Judith: [00:02:20] I think how it started was sad, actually. I will tell you how the story started. I have type two diabetes. It's not serious; it's mild. In 2008, in the summer or July, my family doctor decided he wanted to do the best he could for my type two mild diabetes and sent me to the clinic at the local hospital. The doctor there spent ten minutes with me and said she would like to double my medications.

Narrator: [00:03:00] Judith has type two diabetes, which can be a very serious condition, if not a relatively common one. Roughly one in three people will develop it in their lifetime. And she had been on medication for her diabetes, taking several common drugs, the doses of which were increased when her family doctor sent her to see a specialist.

Judith: [00:03:19] He doubled the metformin, doubled my Crestor, and gave me Diamicron. And with that, I left. But I went to England with my granddaughter for my final trip to my birthplace, and I was very sick. I would wake up in the middle of the night, take my blood sugar to see what was happening. When I came home from that holiday, I realized then that it was the medication. I went back to see my family doctor and said, "No, I'm sorry, I can't take all this extra medication." I said I was just going to stop it. I think it took a while for my body to return to normal, but by then I was having other reactions.

Narrator: [00:04:12] Judith was taken off the doubled medication, but she was still experiencing symptoms. So Judith's doctor put her on a new medication, a collection of medications to treat the symptoms she'd experienced in London.

Judith: [00:04:23] Eventually, I had the atrial fibrillation reactions. It was funny because it was New Year's Day and they were celebrating a little there, but that would be the first time that I had a serious A-fib like that. When I had A-fib attacks, it was always at night and often very early in the morning. I would get absolutely incredible readings from a blood pressure monitor that I was using, read something like 210 or 194 or over 190. And we called the Ontario helpline who said, "Get into the emergency department."

Narrator: [00:05:10] So on New Year's Eve 2009, Judith had her first serious A-fib attack, which is shorthand for atrial fibrillation. A-fib is essentially an irregular heartbeat. It's the abnormal firing of electrical impulses that causes the atria, which is the top chamber of the heart, to kind of quiver or fibrillate. Signs and symptoms of an A-fib attack include palpitations, the sort of flip-flopping feeling in your chest weakness, fatigue, lightheadedness, dizziness, and confusion. And it's important to note that there are a couple different types of -fib attacks.

Judith: [00:05:44] A little bit of information you can look up yourself. There are two types of A-fib. There's the regular A-fib that goes on constantly that you may never, ever know you have A-fib. It's just that your heart, it would be fluttering away on a regular basis. That's the best way I can describe it.

Narrator: [00:06:03] And then there's the other kind of A-fib, the kind of A-fib that Judith had.

Judith: [00:06:08] It's called paroxysmal A-fib. And that A-fib, the best example is written up in the Mayo Clinic. Look up paroxysmal A-fib. And it's occasional. Now, fluttering A-fib, you should be checked up and you should take medication for. And usually it's a blood thinner to ward off a heart attack.

Narrator: [00:06:38] So there are several different types of A-fib, each with different frequencies and intensities of the regularity of the heartbeat. And Judith is diagnosed and prescribed medication to treat her paroxysmal A-fib. And as is the case for many people with A-fib, the regularity of the attacks meant she began visiting the hospital more and more often.

Judith: [00:06:59] I would go into the emergency maybe four to six times a year with A-fib. And it always happened between midnight and about three in the morning. And I got to the point where before I went to bed at night, I would set out my clothing. We would make sure that the dog had had her walk. And we were ready to jump into the clothing and off to the emergency department anytime that was necessary, because it seemed to be so very urgent. And I just simply got used to this.

Narrator: [00:07:40] And while things have been confusing and scary and hard for Judith up until this point, it's right about here, right as Judith is starting to get used to those late-night trips to the ER, used to her piling-up diagnosis, when she's starting to feel like maybe she can see the solution to the puzzle of what exactly is happening to her in sight, it's right then when things go completely sideways. The rest of the story after this quick break.

[0:08:18] *Patient* is brought to you by the Canadian Patient Safety Institute. Established by Health Canada in 2003, the Canadian Patient Safety Institute works with governments, health organizations, leaders, and health care providers to engage the public and to inspire extraordinary improvement in patient safety. To learn more about CPSI, visit PatientSafetyInstitute.ca.

Chris: [00:08:40] So, you know, when you think about taking many medications...

Narrator: [00:08:44] Chris Power, CEO of Canadian Patient Safety.

Chris: [00:08:46] We know that two out of three Canadians – that's 66% of people – over the age of 65 take at least five different prescription medications. And one in four Canadians – so over a quarter – over the age of 65 take at least ten different prescription medications. So that's huge. And then you need to think about the risks of having multiple medications. And there are tremendous risks for that of, you know, different interactions happening that weren't intended.

Narrator: [00:09:16] Tremendous risk of taking multiple medications. But we're getting ahead of ourselves. I'm going to play you some tape from my conversation with Judith about the puzzle she was working on on the morning we spoke.

Judith: [00:09:27] I never forget them growing up or growing through the years. And I found a very good designer who is now dead, has been dead ten years, in the States. Charles Wysocki. They are very challenging, but they're also very humorous.

Narrator: [00:09:46] To look at a Wysocki puzzle is to look at an image you'd most readily describe as dense. They're these quaint sort of pastoral scenes and the eye doesn't really pass over them in a clean line. You find yourself jumping around, trying to make sense of all these little details. And to zoom in too close on any one, and you're lost.

Judith: [00:10:07] The confusion and depression came later. It came in about year six when I realized that I could not replace what I had lost in my lifestyle. I wasn't really doing any more art.

Narrator: [00:10:28] Let's jump back.

Judith: [00:10:30] Over the years, over the seven years, I would go from the emergency, I would spend five days in their continuing care unit.

Narrator: [00:10:40] The A-fib diagnosis and the increasing regularity of the attacks all meant that Judith was spending a lot more time in the hospital, and while she was there, doctors began noticing and diagnosing other symptoms.

Judith: [00:10:52] Such as irritable bowel and so eventually spent time separated in their special unit.

Narrator: [00:11:03] And this list of symptoms kept growing.

Judith: [00:11:06] I spent four days in hospital for observation. There were 11 medications not noticed.

Narrator: [00:11:11] And growing.

Judith: [00:11:12] They were always X-raying me. I had constant X-rays on my heart, my legs, my back because of the pain.

Narrator: [0:11:18] And growing.

Judith: [0:11:19] They sent me for an MRI for the kidney.

Narrator: [00:11:23] And this is maybe what makes solving a puzzle like Judith's so tough. It's the fact that having more clues doesn't necessarily make it easier to solve.

Judith: [00:11:31] These are all of the results of doctors trying to decide what was wrong with me, because in those seven years, seven and a half years, there was simply no diagnosis for my problem.

Narrator: [00:11:43] Finding more symptoms doesn't necessarily make it easier to diagnose.

Judith: [00:11:48] I had two colonoscopies to rule out other problems, and it was the gastroenterologist who said to me that, "Your digestive system is having a difficulty in processing medications that you swallow, so what I would suggest is that you take them sublingual or liquid. And in the meantime, because you have type two diabetes, I'm going to give you insulin." And I've been on insulin and give myself insulin ever since then. They sent me to a sleep lab... geriatric assessment. They tried to give me a [inaudible – audio is confused] Overall, I saw 22-plus positions and specialists.

Narrator: [00:12:48] All in, Judith ended up seeing a gastroenterologist, a rheumatologist, four neurologists, and another four cardiologists.

Judith: [00:12:55] Then they worried about it overall because I was very depressed.

Narrator: [00:13:06] What was it like before all this?

Judith: [00:13:07] I played golf, I swam, I had a little golf cart. I had to give up absolutely everything. I moved to Peterborough to live in a house. My friends from years before in Peterborough had moved on or died. And so having given that up, I felt very alone. I'm not one to talk to anybody, not to see anybody, but my cleaning lady came up from Bowmanville to Peterborough because she said she used to come and see me and she was worried that I might do something to myself and she said she didn't want that to happen, that she said she'd come in to vacuum the bedroom and I'd be sitting on the side of the bed in the dark, crying.

[0:14:04] My granddaughter helped a lot because she was doing her PhD in psychology and she's now graduated as a doctor. She just said to me, "Grandma, go and sit out in the sunshine, take a coffee, and watch the world walk by and keep doing something you like every day." So I followed her advice and I slowly rebuilt my life somewhat and so on. When I look back on it, it was pretty crappy for my husband, I would like to say, really crappy for my husband because he became my caregiver. And during the years of depression, he never left me alone.

Narrator: [00:14:44] In 2008, Judith went to her family doctor. And 8 years, 22 doctors, and untold diagnoses and prescriptions later, we find her here in deep depression, sitting on the end of her bed, still with no clue what exactly is causing her symptoms, what exactly is happening to her.

Chris: [00:15:06] I would suspect that it's way more prevalent than we even have any idea about.

Narrator: [00:15:12] That's Chris Power, who we heard from earlier, speaking on the depression Judith faced as a person dealing with a chronic, yet undiagnosed, illness.

Speaker3: [00:15:22] Lots of times, you know, diagnosing patients is part science and part art and part guesswork sometimes, when you really when you're stumped and you don't know. And so there's lots of trial and error that happens and different medications tried. So I think it probably happens – I would suspect that Judith's story is not a one-off at all. I think there are probably lots of them out there, but hard to know. Lots people go for years and don't realize that that's what the case is.

Judith: [00:15:55] Every once in a while, I'd fall. I don't want you to think that I'm always strong. Every once in a while, I'd say to myself, "Will this ever change?"

Narrator: [00:16:08] Eight years, countless symptoms, no answer.

Female: [00:16:11] We often, as Canadians, think of the health care system as the repair shop.

Narrator: [00:16:16] We're going to speak with academics and activists.

Female: [00:16:18] It's almost an invisible force of death and illness and the way we currently look at the system.

Narrator: [00:16:25] Patients and providers.

Female: [00:16:27] So we know how insidious and how often it happens.

Narrator: [00:16:31] To try and find the answer.

Judith: [0:16:32] And I laughed and giggled over it because there was my answer right in front of me.

Narrator: [00:16:37] Judith Maxwell, solver of puzzles, finally solves the puzzle inside her on the next episode of *Patient*.

[0:17:06] Big thanks to our sponsor, Canadian Patient Safety Institute. If you're interested in the subject of the season, you should visit the PatientSafetyInstitute.ca and search "five questions to ask about your medication." You'll find a checklist of five essential questions to ask when your doctor or health care provider starts, stops, or changes any of your medications. It's interesting and relevant to the story we're telling. Check it out.