S1E1 – HeartBeat

Transcript

Narrator: [00:00:01] So I was wondering if we could kind of loop back a little bit. If you could take me through what happened on that morning.

Mary Anne: [00:00:13] It actually didn't start – you mean after she died?

Speaker3: [00:00:18] Yeah.

Mary Anne: [00:00:19] Martha was scheduled to work a shift in the hospital, and when she wasn't up to have coffee with her father in the morning, he went to her bedroom to wake her up, and that's where he found she was dead. She had tried to get out of bed and fallen on the floor, and she hadn't made it to the door to call for help. That's how sudden an adverse reaction can be. The result was just catastrophic and total.

Narrator: [00:01:01] Canadian Patient Safety Institute presents *Patient*, the nonfiction medical podcast about the people trying to fix modern health care from the inside out. My name is Jordan Bluman.

Mary Ann: [00:01:27] So yeah, if you can picture one of those little old ladies driving a scooter, you know, with a scarf flying in the background, and usually they have a cigarette hanging out of their mouth. Well, that's me except for the cigarette part.

Narrator: [00:01:40] This is Mary Ann Murray. The first time we spoke, she was just coming in from her garden.

Mary Ann: [00:01:44] Well, I grew up in farm country, so I can't compete with the professionals who grow vegetables, so I just grow flowers. Two years ago, one of our girls got married actually in the backyard with the big tent wedding. And yeah, it was lovely because it started to rain a bit, and so we had to move where the ceremony was being held. So we just went out the front and cut all these hydrangeas and they actually made an aisle going down inside the tent, which looked just lovely.

Narrator: [00:02:16] Could you define that term?

Peter: [00:02:17] Well, a “never event” is a term used in the patient safety industry to define a series of events that should never happen.

Narrator: [00:02:26] That's Dr. Peter Pisters. He's the president and CEO of the University Health Network in Toronto. Before that, he was a cancer surgeon, a researcher, and a professor.

Peter: [00:02:34] If you went onto University Avenue and you surveyed laypeople and you asked them the question, “Is there ever a time in clinical medicine where a team should operate on the wrong body part?” it's very clear that an average layperson would look at us and say, “No, that should never happen.”

Narrator: [00:02:54] A never event. An event that should never have happened. In 2002, something happened to Martha, Mary Anne's daughter. Never event. The trouble with a never event is you never know how to figure out how exactly it happened, because based on every policy and rule in place, it was never supposed to.

Mary Anne: [00:03:17] Martha was the eldest of our children, and she was probably the most passionate and compassionate person that I know. And she was studying nursing, wanting to help those who were sick and in need. And so, you know, she was focused on her school. She worked part time. She helped out around the house and spent a lot of evenings doing homework with her little sister. Martha was diagnosed with having bipolar disorder, which means that she was having trouble controlling her emotions. She would get really happy, really high and really low and depressed. And, you know, it happens a lot. And she was put on lithium to treat mood swings.

Narrator: [00:04:14] Lithium is a chemical often used as a medicine to treat mood disorders. We don't have a perfect sense of how it works, but over 50 years of use has earned it a reputation as an effective mood stabilizer. It's considered safe if administered and used correctly, though the doctor needs to know your medical history before prescribing it as it can cause issues for people with heart problems. Also, global advisory: I am not a doctor or health care provider of any kind. Please don't make any medical decisions based solely on this podcast. Let's get back to Mary Anne.

Mary Anne: [00:04:45] When Martha died, it was a shock and we didn't know what happened. And we wanted to understand what had gone on. You know, we knew that she had started taking this drug. We thought she was taking it as prescribed, which she was. We didn't think that she was taking anything else, which she was not. So we were waiting for answers and we initially didn't get any. For months, no one contacted us, no one told us what had happened. It took months and months to get a copy of her autopsy report and to find out that her death had

simply been classed as a natural death and the case had been closed. That wasn't good enough for us.

Narrator: [00:05:36] Mary Anne and her family started gathering Martha's medical files. They started asking questions.

Mary Anne: [00:05:41] We thought, we can't change what happened, but we can do what we can to try to help prevent this from happening again.

Narrator: [00:05:52] What they discovered about Martha's death doesn't unfold cleanly. The timeline is messy, but the conclusions that they reached are, at this point generally agreed upon. For this all to make sense, there's a few things that you need to know. In the year prior to her death, Martha had undergone multiple EKGs, which is a test that checks for problems with the electrical activity of the heart. Martha had experienced bouts of accelerated heart rate during these tests, which were accounted for by anxiety. Because of this rationale, her test results were considered to be normal. Eleven days prior to her death, Martha's lithium prescription had been increased by her psychiatrist. During the last year of her life, Martha had multiple care providers. Like many people, she had a psychiatrist treating her mental health needs, a cardiologist looking at her heart, et cetera.

Mary Anne: [00:06:37] So we started gathering together her medical files and we started looking for answers.

Narrator: [00:06:46] And they started making noise, stories running in the *Toronto Star* and on the CBC about Martha, events actively lobbying the coroner's office to reopen the investigation, which eventually, after the pressure mounted, the coroner did. And they found something. The year before her death, Martha's cardiologist had ordered a test. It revealed that her accelerated heart rate wasn't the product of anxiety, but of a congenital heart defect, a problem with the structure of the heart that's present from birth.

Mary Anne: [00:07:17] Just because someone has a mental health diagnosis doesn't mean that they can't also suffer from diabetes or from a heart problem or from, you know, some other physical illness.

Narrator: [00:07:28] But Martha's cardiologist never saw the results of that test for reasons that we're going to get into later. But what that means is that Martha was never informed that she had a congenital heart defect. It means that a note was never added to her file. So when her psychiatrist went to up her lithium dosage in response to her mental health needs, Martha didn't

know that she was in danger because she didn't know that she was at risk for the kind of heart-related side effects lithium can cause.

Mary Anne: [00:07:55] What did they call it? She had a fatal cardiac event, meaning that her heart just stopped.

Narrator: [00:08:05] Martha's heart was defective, and she was prescribed a drug that was dangerous for people with heart defects. And that's why she died. Which should feel like an answer, even though it didn't.

[0:08:33]*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 inspire extraordinary improvement in patient safety and quality. To learn more about CPSI, visit PatientSafetyInstitute.ca.

Male: [00:08:54] No, I agree with you. I mean, I think that this really addresses, you know, also a higher-level issue in our system related to care coordination and to, many times, the fact that we continue to dichotomize the treatment of physical illness and mental illness, not only among different providers, but frequently in different organizations altogether. And when an individual is seeking care in two different organizations and those organizations don't share the information and there's no holistic picture of the patient or a unified list of medications, we can run into challenges like this, where adverse effects or drug-drug interactions can come into play.

Alice: [00:09:40] A lot of times, I think, patients leave the hospital or their doctor's office not really understanding fully what medications they're supposed to be on. And so when it comes to filling a prescription in the community, sometimes we're not given the information of why things are changed.

Narrator: [00:09:58] This is Alice Watt? She's a medication safety specialist with the Institute for Safe Medication Practices and a clinical hospital pharmacist.

Alice: [00:10:05] I think the bottom line is, according to the WHO, unsafe medication practices and medication errors are a leading cause of injury and avoidable harm in health care systems across the world.

Narrator: [00:10:17] So Mary Anne had discovered that the cause of her daughter's death was a reaction caused by a mood stabilizer that reacted negatively with an existing heart condition. She knew the what, but not the why. Why didn't her cardiologist see the test results showing

that Martha had a congenital heart defect? Why didn't her psychiatrist bump into a cardiac warning in her records?

Mary Anne: [00:10:38] Why? I think it's the way the system went. The cardiologist didn't read the reports because she didn't come back to see him. She thought that no news was good news, so she didn't come back for a follow-up. He, in his practice, waited for the patient to be in front of him before he read the report. He was cautioned by his college that when you order tests, you have an obligation to read the results and be proactive to contact the patient if the results are negative. But that's not what happened; that's not what the practice was at that time. And it's probably likely that he's not the only person in this country that was following that kind of practice. So even though there was a note in her file not to give her lithium, there's nothing that says another doctor has to obey something someone else has written there. I think people try to do their best, but when their best results in failure, then it should be reported, and let the powers that be see, well, is this a trend that's happening? Is there alerts that we could send out? What can we do to help reduce the number of these harm events that are happening across this country?

Narrator: [00:12:07] The cardiologist waited for their patient to come back before looking at test results, and Mary Anne assumed that no news was good news. Chalk it up to a bad procedure. Systems error. Bureaucratic catastrophe. So where do you go from there? Can any amount of insight or understanding heal something like this? This isn't the cute podcast host thing where I ask the question just so that I can answer it. I genuinely don't know the answer to this. So that's what I asked Mary Ann. What do you do after something like this happens?

Mary Anne: [00:12:50] Yeah. Well, I think, you know, we took a look. We thought, “What was she trying to do?” And she was trying to help people who were ill. So you think, “Well, if it was reversed, what would she have done if it had been me?” I mean, I'm doing this because she can't, but that's what she would do. So you think all you can do is try to improve things so that it doesn't happen to others. I think that, unfortunately, has become her legacy. There's no justification when someone dies and it's covered up and they just call it a natural death and they make no changes or recommendations for changes. It's just not acceptable. You know, Martha died as an outpatient of a hospital. And until I called about – it was more than a year later – they weren't aware that the patient had died.

Narrator: [00:13:51] So Mary Anne started there. You see, when Martha died and her death was labeled the result of natural causes, it meant that there was no reporting. None of her health care providers knew that one of their patients had even died. Can't really prevent a problem from happening if nobody knows that it happened. Mary Anne was about to embark on

a deep dove into the world of patient safety, this emerging scientific field she knew essentially nothing about. But she had to start somewhere, so she started with reporting.

Male: [00:14:21] I think that what we often see still in our environment is confusion about the terms “quality” and “safety.” And sometimes we see people, even experienced people, using those terms interchangeably. But those terms, “quality” and “safety,” are not synonyms. And we need to recognize that that safety is distinct from quality. There is an overlap in those Venn diagrams, but we can measure safety and we need to carefully measure and quantify safety in the organization.

Mary Anne: [00:14:56] When harm occurs, you need to report it. That's the only way that you're going to see, how often are these occurring? What's going wrong to make these adverse events occur? And that's the only way that you're going to come up with really solid ground on how to prevent it from happening again. You know, in all other areas but medicine, we have reporting that works very well. You look at our workplace safety: you know, reporting of workplace accidents is mandatory. They collect the statistics. They can see how many times someone falls off a ladder or how many times someone hurts their index finger in a piece of machinery.

[00:15:45] You know, in cancer cases, we report how many cases of cancer occur each year. So you can see how many people are actually being affected.

Narrator: [00:15:54] So when you started getting through to people, when the right people started recognizing what had happened to Martha, what did they do? What happened?

Mary Anne: [00:16:05] Through a lot of effort and a lot of assistance, we were able to get the case reopened with a new chief coroner. And eventually, in addition to a letter of apology, we've also received seven recommendations and changes from that office. The office of the Chief Coroner in Ontario agreed to start reporting adverse drug reactions to Health Canada for the first time.

Narrator: [00:16:34] That's huge.

Mary Anne: [00:16:34] And until the questions were raised with Martha's death, they had never taken the time to report those adverse reaction fatalities to Health Canada.

Narrator: [00:16:46] The nationwide change to reporting: that's huge. But this isn't the story of how Maryanne fixed modern health care because of course it isn't. It's the story of a family that lost a daughter, that in the name of that daughter's compassion, set out to help prevent harm

from befalling others. The crux of this is that we've all been patients at some point in our lives. Martha was a patient. And because of what happened to her, Mary Anne has found this calling for patient safety, which is a term and field of study that many of you are probably bumping into for the first time here. So now we're going to define it and talk about some of the ways that advocates like Mary Anne are trying to make being a patient safer. Could you tell me a little bit about the five questions? There was like, 30 when you guys started.

Female: [00:17:47] Yeah, well, we had started, Lisa Seaver and myself, pharmacists, we did a sort of a world-wide web search of all the tools and questions that are out there. And we kind of came across just so many questions that we could ask. And we generated a list of three full pages of questions. What to do before you see the doctor or what questions to ask when you're at the doctor's office or when you pick up your prescriptions. But when we showed it to the Patients for Patient Safety Canada group, they were very kind and generous with their comments, but it was just too much information. There's no way that we could have included all these questions in the short period of time that a patient sees their doctor.

Mary Anne: [00:18:30] Yeah, it's a great program. The five questions to ask was a collaboration between the Institute of Safe Medication Practice and CPSI and patients. And they came up with this, you know, simple little poster, or you can get it in a card that you can put in your wallet so that people can know what they should be asking and understand to keep themselves safe. That has been so successful that we took it to the WHO at a launch about medication safety. It's now in over 20 languages. And, you know, people can really learn what to ask so that they know what medication they're taking, they understand what the medication should be doing, they understand how long they should take it, they understand what serious side effects they should look out for. And I think when you have that kind of knowledge, whether it's a patient or the patient's family, you become that first line of defence, and you can really help your loved ones not get into a situation where they have a really serious adverse reaction.

Male: [00:19:46] There's significant power differential, there's information asymmetry, and that definitely creates barriers with many patients feeling intimidated to ask questions.

Narrator: [00:20:01] So there's this question that kind of keeps coming up regarding, I guess, where is the line between what patients can be doing to improve their safety and what providers can be doing, and I guess by extension, the health care industry as a whole?

Male: [00:20:15] And this is an interesting conversation, also an interesting point for discussion, is regulatory oversight over safety. And if you look at two systems that serve the public, for example, the aviation industry: we have tight regulation over commercial aviation. And that's

done deliberately to ensure safety of the public. And when you look closely at the impact of organized regulatory approaches to safety, you can see that they have, together with the industry, resulted in massive improvements in the safety of commercial airline travel. Now, when you look at preventable harm that's occurring in the medical industry, you can see the estimates in Canada are that upwards of 20,000 patients may die every year from preventable harm. We have a publicly funded system in Canada. If we were running a publicly funded airline that had 20,000 deaths per year, that would be shut down immediately. A commission would be created to understand why 20,000 people were dying, and regulations would result, and that would probably include a government agency that oversees safety.

Mary Anne: [00:21:36] You know, generally, medicine is about systems. And people follow procedures and systems. So if you have errors that occur so that the patient is harmed, it's likely that the same kind of errors are occurring elsewhere and other patients are also being harmed. With Martha, I'm sure that this was not an act of intent on anyone's part. People followed their regular procedures, and this was the outcome. So it stands to reason that this was not an isolated event with one individual, that whatever happened to her probably happens elsewhere, and it probably happens fairly frequently because if the same systems are in place, the same holes in the systems are there as well.

Narrator: [00:22:33] Talking to someone about systems and policy starts to feel a little bit numbing when it's in the context of a tragedy like this. But ultimately – and I think that our conversations with Dr. Pisters and Alice and Mary Anne revealed this – if you can't approach an issue like this from a bird's-eye view, you never really going to have the data to be able to make something with so many moving parts work better. We wrapped up a conversation with Mary Anne by discussing, I guess, what's next for her. Beyond scooter rides and evenings in the garden, what does she want to see change in her pursuit of patient safety?

Mary Anne: [00:23:10] The right cultural shift is for everybody to partner together. I guess it's just unacceptable to me that these people who have been harmed – these are our teachable moments. These are the people who have given us these opportunities to learn. And we just can't bury that information. You can see why I spend so much time in solitude out in my garden. It's something I can control. This, you know, it's so difficult because I'm not a physician, I'm not a nurse, I'm not a politician, I'm not a reporter; so really, I have no ability to do any of these things myself. The only thing I can do is encourage others to do them. We're in an age of computers. We can see how many of these events are happening. We can see where they're happening. We can find the holes that are allowing them to happen. And we can help improve things. Providers don't want to cause harm. That's not why they go into health care, right? Patients want to get better. That's why they are seeking health care. We just have to move past the idea

that somehow it's shameful when mistakes happen. It's unfortunate when they happen. But we can learn so much by these human studies to prevent them from happening again.

Narrator: [00:24:41] This season of *Patient* is produced by the Canadian Patient Safety Institute. For more information on the five questions and other projects people like Mary Anne, Alice, and Dr. Pisters are all working on to improve patient safety, visit PatientSafetyInstitute.ca. *Patient* is produced by Scott Linder, Cecilia Bloxham, Carla Horan, and myself, Jordan Bloemen. Thanks for listening.