**Employment Insights with the NRTC – Episode 6**

Opening music

Introduction: Welcome back to Employment Insights with the NRTC, we're excited you joined us for this episode. Today, we were joined by our host Sylvia Stinson-Perez and our guest, Pat. Keep listening to hear about Pat's journey with an eye condition later in her career, her own challenges that arose from that, and her advice for others in a similar situation.

Sylvia: Welcome back to NRTC Employment Insights. Today, I'm thrilled to be joined by Pat, who shares a work history with me. Pat is a retired social worker and I worked as a social worker for a number of years. So, Pat, welcome.

Pat: Hello. Thanks for asking me to be here.

Sylvia: Thank you for being here. We'll just jump right into the questions.

Pat: OK.

Sylvia: Pat, share with us just a little bit about your vision loss journey. When did you get diagnosed? What could you see at that point and how does that impact your life?

Pat: Well, it would be over 20 years ago now, I was still driving, of course, and that was wonderful. I started to notice things related to driving in particular. I would be driving along the road and from my perspective, a car would suddenly leap out of a side street. What was happening, of course, with retinitis pigmentosa, with RP is, that your peripheral vision shrinks. They were just suddenly appearing in my field of vision is what was happening. But as far as I was concerned for some time, people were not being careful and they were leaping out of side streets without any respect for caution or me. So, the other thing was that I had a couple of fender benders. I lived on a cul de sac and I would pull out to the main street. And when you have all your vision don't really turn your entire head to the left or right to see what's coming. So, I wasn't doing that. I would be glancing. But of course, my glance was not taking in everything it needed to. And, you know, I would pull out in a couple of times I got dinged. So that was a clue to me that there was something going on. And I sort of offered myself up for an eye test, which I didn't have to do, but I did. And I went for an eye test and then for the field of peripheral field test and discovered at that point that I was well on the way to losing my peripheral vision. And it was at about 60 percent at that time, which sounds glorious at this point. So, I was sent to an ophthalmologist for, you know, to a specialist to have a better look at my eyes. And he diagnosed me as having retinitis pigmentosa. And I asked at that moment, “How long will I be able to drive?” knowing that that was something that would be affected. And he said, “Well, like, it's now like this minute, unless you go for biopics. I opted, so using the two eyes to the test, which I did, and passed and scraped through driving for a couple more years. So, driving was kind of the pivotal thing that was giving me the clues and that really set me on the path of understanding what was going on.

Sylvia: And you know, Pat, I will say that people with macular degeneration and glaucoma and even to some extent diabetic retinopathy report similar kinds of things. And, you know, a couple of those, they might add reading into that, too. But driving does tend to be or getting around does tend to be that first kind of clue for a lot of people who experience vision loss a little bit later

Pat: Yes.

Sylvia: So what kind of work were you doing at that time?

Pat: I was working as a social worker in a hospital setting and, you know, in the capital city of Canada in Ottawa and working in physical rehabilitation. So I was working in a stroke program and a traumatic brain injury program. And over the course of the time after my diagnosis I was also working as the clinical leader of the profession in that hospital. So when I was first diagnosed, I was a full time social worker working with families and patients, dealing with loss and physical loss and all the emotional impacts of that. And sometimes, you know, people were the vision was affected by a stroke and brain injury. So but that wasn't really on my radar as something which sort of relatable to me at that time, not initially anyway. Certainly, did become more something that I became much more aware of, obviously. And then later, as the clinical leader, I was working part time in, you know, front line practice in the hospital and part time as in a more administrative clinical practice role.

Sylvia: And that must have had some challenges. Pat, as you were experiencing progressive vision loss you have to get around a lot, moving to different areas, interacting with people. But then now you're also having to do paperwork and computer work. So what kind of tasks were specifically impacted by your vision loss? How is your job impacted?

Pat: Well, the paperwork, the sort of computer work, et cetera, as the clinical leader was actually easier because I had the central vision enough to be looking at a computer with reasonable amount of ease. So that was not impacted. What was impacted was running meetings, for example, where I would be in the lead to organize and then run a meeting of 20 social workers around a table. What I had to do was to sit at these long conference type tables. I would have to sit at the very end so that I could see the people to the right and left of the table. If I had been sitting at the long end of the table, I would have been having to move my head constantly back and forth to see who was there. And even as it was the people to my immediate right and left, as time progressed, I started to lose actually awareness of them and sometimes would even forget they were there because they were not in my field of vision. So I started losing people in meetings would be one thing and finding it more difficult that someone would put up their hand to speak. I wouldn't see it. Someone would speak and I would not immediately know where the voice came from. I would have to start using voice recognition more often to know who was there. And all that creates a lot of anxiety. Of course, when you're doing something that you've been doing very well, I thought for a long time. And then suddenly you're having to pay such very great attention to these kinds of details. Where are people? Who's trying to speak? Who's not spoken? All those kinds of things were quite impacted in terms of the patients and families, those that were sitting in front of me. Yes, that was relatively easy, too, because we were in a sort of static position. But over time, as my peripheral vision began to diminish, I would start to lose parts of their body, as it were. So a person sitting in front of me, I would see down to their knees when I had 60 percent peripheral vision. And eventually it would be that I lost their hands and then their elbows and then they would be left basically with just their head and shoulders. So, working with a lot less information about how people were coping and what their hands might be doing. Were they fidgeting? Were their feet tapping? I had all that information was lost. And again, having to rely much more on what they were saying and how they were sounding.

Sylvia: And many different eye conditions, like macular degeneration, et cetera, have peripheral loss in just different ways. In macular degeneration, you might not be recognizing faces which can be just as much anxiety producing. So, Pat, did you disclose your vision loss or that you were experiencing this vision impairment to your co-workers, to your supervisors? If so, how did you do it? How did they respond?

Pat: I kept pretty quiet for as long as I could to be honest. For all the reasons that you might imagine, just not really accepting what was happening. People weren't in many ways noticing. So, the people I did disclose to were my colleagues first, I guess. You know, at these meetings, I would let them know that I wasn't always picking up what was going on in the room visually and almost without exception, people would say, “Oh, no, I had no idea,” or “You do so well,” or “I didn't notice.” That sort of thing. To be fair, however, I didn't necessarily explain the condition. I didn't explain I have been recently diagnosed with an eye condition called this, and these are the effects of it, which will progress over time. I would say sort of vague kind of things like, you know, “I don't see very well” or “My vision is not that great now.” So pretty vague kind of things, which understandably people maybe responded in vague kind of ways as well. So, in terms of the people in sort of management upper, you know, beyond me positions, I did not disclose to them. No. I guess even though I knew I wasn't going to lose my job, there's always that sort of fear that you're going to be discriminated against, that there's going to be someone who's somehow going to say, “Oh, this person is going blind. Why are they still here?” This sort of thing. So, there was that kind of, again, another layer of anxiety about keeping the job, despite the fact that there was no reason whatsoever to think that anything was going to happen. I was in a union for one thing. And, you know, I had excellent evaluations. There was nothing on the surface that would suggest that. But still, it was an anxiety. So, I kept pretty quiet and kept pretty quiet until the kind of things that started happening more with patients. Because in a hospital, lots of people with wheelchairs, which gradually disappeared, again, from my view, a person approaching me or maybe sitting outside my office in a wheelchair, if I opened the door, there was a point at which I unless I looked down, I didn't see them. So that started to get really scary. And then I started to say more.

Sylvia: And so how many years did you work past your diagnosis before you retired?

Pat: I worked full time in the combination frontline and practice leader for ten years. And then I retired and went back part time frontline for four more years. So, 14 years.

Sylvia: OK, and so you just mentioned that you did start to say more. Knowing now what you know and just having the experience, if you could go back, would you have maybe disclosed earlier? Asked for more accommodations? What would you have done differently? What would have helped you, I guess, is really what I'm asking is. Would it have made the process easier if you had asked for accommodations or even just been more open about it?

Pat: I think one thing I would have done would be to be more specific about what was happening, rather than the sort of vague kind of statements I was making. Because, you know, even now it's I say something in a store, you know, I might bump into somebody? I say, “Oh, I’m sorry, I don't see very well.” Even if I have a cane with me. Somebody just recently said, “Oh, yes, I need some new glasses as well.” As if the things are equivalent. This is even with a white cane in hand. So I think I would be more specific. I would for those who I thought would listen or who needed to know, I would explain the condition, what happens, and that it's not static that it's progressive, and that things will get, you know, more challenging and that they should be aware of that and that I may be asking for some changes to my workstation, my office, the way I interact with patients. I might ask for the patients to be brought to me more frequently rather than go into the rooms. Those kinds of things I just, I think would have been more specific. I think that would have been more helpful to other people as well.

Sylvia: So, towards the end, when you really were experiencing more significant vision loss, did you ask for those kinds of accommodations? And did you ever get any training while you were still working, such as in orientation and mobility or with assistive technology or anything?

Pat: No, Sylvia, nothing. I didn't do any of those things. I was still in denial and just no, I can manage, I can pass, you know, I can pass as a sighted person and that's the way I want it right now. So I did that right up to, I essentially, I left my job rather than look for accommodations. I was at retirement age because it was possible to retire. I had that option. Had I been younger, you know, even ten years younger, I would have been forced either to go on disability or to really just kind of come to grips with things in a much more significant way. The cane training and the mobility training that I've done have all been since I retired at sixty-four. And even, you know, what I did. I mean, in a hospital, I was working with physios and OTs. So, the OTs in particular, you know, a couple were my good friends, were very helpful and sort of in an informal way were talking to me about scanning while staying close to the walls rather than trying to walk down the middle of the hallways, which were quite wide. So, I couldn't see both sides of them eventually. So, that's what I would do. So, I did get some informal advice from occupational therapists that I worked with. Keep close to the edge. Stop if anybody's coming. Let them pass first. Don't try and sort of jiggle your way around them. Let other people pass first. Scan constantly. Scanning is the other thing.

Sylvia: So I have to tell you, Pat, that everything you told me, this is very typical. I mean, I was the same way and I mean, I was much younger when I experienced enough vision loss that I had to ask for accommodations and learn skills. But that is very typical of what I find, you know, as a as a vision rehab therapist myself is and having worked with many, many clients over the years, is that people develop their own adaptations, just like you're talking about. Those are the kinds of things that I think we naturally figure out in some ways, too. And when we can have other people around us to tell us those things, too. That's great, but many people start adapting, probably even without realizing it. You were really starting to do some of those things before you even realized it.

Pat: Yes. One of the things that a friend told me was that in the last several years is that I was not looking at people as much as I used to. So, again, that's another thing now that I try and be very careful of, like in a grocery store in the line. I can see a face, so I try and make sure to say “Thank you.” and “Have a good day.” But looking at the person and not the ground, because the ground is where the dangers are generally.

Sylvia: That’s so true! So great, yeah.

Pat: Keeping an eye on the ground is important. But, you know, engaging with people and really looking at them as you talking with them is also important. But it's an effort.

Sylvia: And even when you can't see them anymore, it's still important. So, my next question is and I realized that you didn't have “blindness skills,” but what do you believe are the skills that really helped you continue to work and what gave you that ability to continue to work?

Pat: Well, I mean, my motivation to be employed, I was an older parent, so I had a child I was supporting. So, there was, you know, no way I was going to not work. So, the idea of not working never entered my head. So, it was how am I going to figure this out? I have to make a living. I want to work and I have a child to support. And so those were the sort of I would say, the major, major motivations. What help me, I guess, would be my partner and my music. I'm very involved in music. So that kind of kept me going. And the church and a church community, those would be the things that kept me going. So those were my supports, some personal support networks of some kind. You know, connecting with the blind, visually impaired community has again been something very recent that connecting through the daring sisters was kind of an important step for me. So though I'm not connected in Canada, I'm more connected with the group in the States, so but that's been an important group for me, too. Making sure that you are surrounded by people who are willing to kind of go on that journey with you and accommodate with you, because it's not just us, it's the people we work with or the people that care about us who are also impacted.

Sylvia: That's so true, Pat. So true. Now, so attitude and that support system. That's great. That's excellent.

Pat: Yeah, definitely. And having something that's keeping you going personally. You know, what is it for you that sort of keeping you motivated to stay in the game, to stay working? Do you need the money? Have you got people who are counting on you? What is it this, you know, do you really enjoy your work? Is there a way of adapting your work? Can you become a different kind of social could I become a different kind of social worker? If I think now, I could have. There are other things I could have done in employment wise. I could have gone into private practice and I could have worked, you know, and gone into private practice specializing in disability or vision loss. But I didn't do those things. Had I had I been younger, maybe I would have had to face up a little more quickly and maybe I would have done that. Maybe I would have sort of moved my world into a field that was more accessible for me.

Sylvia: That's great. So what, I guess finally, what advice would you give someone and I think you've said some really brilliant things, Pat. Really brilliant things. And I appreciate the authenticity, too. But my final thing is my question would be, is what advice would you give someone who, like you, later in their life or later in their career I should say not really later in life, later in your career, experiences significant vision loss that impacts their work. What are some piece of advice you would get?

Pat: Let me say, take a deep breath and kind of try to look at the situations square on as much as you can. It's not easy. And it often comes in bits and pieces, but try to be open to what is happening. Understand it. Seek out the resources that you feel at your stage in the journey that you can accept and live with. But try and be aware of what the journey might look like and where you were on in that sort of on that continuum. If you're at the beginning of the journey and you still have reasonable vision, don't sort of push it aside, try and keep in your awareness that this is a really is a, you know, a life altering change and or understanding and that don't give up, you know, just don't give up. Life doesn't end. Life doesn't end with this. It feels like it at certain points, but it really doesn't. And really seek out a community. Seek out people that are willing to support you. If you're in a sort of a relationship where the person is just sort of discounting what you're saying or is not going to be helpful, then think about what that means in your life. And try and educate people. People just don't get it often and they really just don't get it. Especially if they've they see walking around without a cane and crashing into things. But people need more information than we imagine to begin to understand what you're experiencing, and even then, it's often hard for people to really get it. So, let them know. Let people know what you're doing.

Sylvia: Yeah. That's so true. So, explain things to people the best you can and understand that it is very difficult for people. And I would also just add is that seek out training, orientation and mobility. Learn assistive technology. All of those things can make life so much easier. It's much easier.

Pat: Yeah. And I have done that. I have spoken with the tech specialist for the CNI, Canadian National Institute for the Blind. So then that person was extremely helpful, though. There are there are things out there, you just have got to find them and be persistent. Go at your own pace, but don't let don't be dragged down by your own pace either.

Sylvia: That's wonderful. Pat, thank you so much for taking your time out to share about your experiences. And I always love speaking to my fellow social workers. So, thank you so much.

Pat: It’s my great pleasure. Thank you for asking me.

Closing music