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## The Art of Receiving Care

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*It doesn't come easily to me. Being on this side of things.*

The first time we meet, it is on the computer. I feel uneasy, as she goes through her list of questions. Her head is not the size of her real head, and I can't see her shoulders or her elbows. Her eyes seem tired, yet alert. I sense she has been through this routine many times. While she is polite, the exchange feels distant. We are far away from each other. She asks me many questions I don't like, such as: "Do you have any dangerous behaviours? What is the name of your disability income support worker?" I hesitantly answer her questions so that my predicament can be detailed and categorized. I dislike it when people type down the things that I say. I don't know what will happen to the words that come out of my mouth. She later tells me they will be stored in a secure online system. This does not make me feel any better.

She is the case manager. I am the case, apparently. Though I don't look like a case, and I certainly don't fit into one. It's not that she isn't kind. Because she is. But perhaps her kindness makes this whole exchange more eerie. Am I supposed to feel comfortable being asked about my mental health history by a stranger?

When our session is over, I close the screen. I can sense a cluster of eyes staring me down. I am being watched. I begin obsessing about what I said and what she said and what we did not say together. Why would she ask to speak to my disability income support worker? Why does she want to ask my psychiatrist questions?

Days later, I decide how I actually want to respond to her questions. I don't want her to have the name of my disability income support worker. And I don't want her to talk to my psychiatrist without my consent. I do my best to articulate my concerns, and she retreats easily. She tells me what she meant by her questions. Maybe I misunderstood. She agrees to my terms, and I start to feel a little less like a case. She says she wants me to feel in control, whatever that means.

I suppose it is happening clumsily, learning the art of receiving care. It is different, being on this side of things. I was once the one asking questions. And, though I have had a psychiatrist for years, this system of information gathering somehow feels different.

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I gather information about my workers with my senses. Are they safe? Are they trustworthy? How do they see me? I try to see them without seeing them as my workers. Since they are also human. I feel their eagerness to be of help and their wish for me to avoid harm. I like them, for even though we are on different sides, we are on the same side ... I think.

I have lots of supporters now. I am embarrassed to list them all. It was only recently that I was welcomed into a community health centre. I had been on the list for at least two and a half years and had been struggling with a lack of support. My new worker connected me with a number of supports, including a case manager at another organization.

I didn't want to take too many services or be a "drain" on the system, but I hesitantly accepted the care that was offered me. I was already getting help with cleaning and a lot of support from my family with basic tasks. Now I have workers who assist me in other ways, like finding my way around the hospital. Some of my supports are meant to help me do more things on my own. I receive this help so that I can progress towards the person I want to be. Or is it the person I am expected to be?

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I struggle to write about my experiences receiving care. I want to write something beautiful. I want to be grateful. But, when I sit with the experiences of being a care recipient, I am uncomfortable. I don't know what's expected. I don't know who I am in this relationship. There are moments I feel I am not welcome as I am, such as when the woman at the hospital asked my Primary Care Coordinator why I needed support, as if I wasn't there. I answered the question myself. I wanted her to know that I was there.

When I meet my case manager in person, we talk about my life. She speaks with a soft voice

and looks at me in just the right way. It almost feels as if I am meeting a friend for a walk, but it doesn't. We talk about what I want and what I don't want. She says all the right things in response to what I say. She has learned these things along the way. I do not have a problem with the things she says. They are usually good things to say. But I wonder if they come from a script of what you are supposed to say to people like me.

I wasn't always the way I am now. I was once the person providing care. I graduated from law school and had a management-level job. After that, I was a support worker and then a peer supporter. Over time, my mind became more sensitive, and I struggled more with the basics. My journey, though difficult, was not a downward slide, but a deepening. While I experienced a loss of status, it also led me to the path of being a writer. My brain is more attuned to poetry these days.

I feel the world differently now, and that's not a bad thing. But sometimes it feels like it is. The person I used to be was not sitting across from a case manager answering questions about her disability income support worker. That person knew the questions to ask. She knew what to look for. And how to look back without looking down.

I remember meeting with youth I supported and asking them questions. Did I always help people feel comfortable? Was I always easy to talk to? I fumbled at times, and I am sure I had lots to learn. But I really cared.

I tell myself that I am comfortable being the person receiving this care, but am I really? It feels

like the difference between a worker and everyone else is what they write down. They have a template. There is space for your name and room to write down your perceived mental state. There is also space for what you want and what you don't want and whether you are getting what you want and avoiding what you don't want. In this space is your life. Condensed. Compartmentalized. Codified. You will never see the words written about you, but they form a trail. This trail can be followed by the other workers who are allowed to trail you. There's no need to be suspicious. This is just a way of making sure you get the care you deserve, right?

Am I getting the care I deserve? Yes, I am mostly getting very good care. Despite my own discomfort, I want it on the record that I'm grateful. My workers are kind. They really can be adept at providing care. I don't want to complain about the support I am receiving. It is helping me have the things I want. I just wish I was the one writing the notes.

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There is a meeting happening. The workers are talking about the clients. They are talking about what is moving along and what is moving along too slowly. They are helping each other move things along. In this meeting, they talk about the people who are receiving care. I don't know if they ever mention my name. But I'm there, in the background. I am one of many clients whose details have been summarized and placed into boxes. You can't place a person in a box, but you can place the details of their life into a box.

I am not invited to the meeting. I wouldn't want to be there anyway. It's only a shadow of myself that is present. This shadow can't talk or move her eyes. She can only exist silently within the terms of the arrangement.

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There is a way of speaking where you don't speak to change what's happening. You speak what's happening. When I hear someone speak this way, I listen. It feels like no one is trying to change me. And, when no one is trying to change me, I am welcome as I am—which is the best invitation to change.

We sit in my living room. She is new to her role and open to me, Carol. She has perceptive eyes that are gentle, yet affirming. I find her presence grounding, without expecting me to be grounded. Her voice has a softness to it. I watch her lean out of her comfort zone to learn something new. Her humility helps me feel at ease. I tell her how hard it is for me to join a new group and how I don't know how to date with so many restrictions. And do I even have the energy for a partner? We talk about my goal of cooking and how it just feels too much for me right now. We talk about how hard it is for me to go grocery shopping. She is steeped in compassion, and it doesn't feel like she is staring at me. She is sitting with me. When she says things, they are not the right thing or the wrong thing. They are her thing. And that truth rings clear and makes me feel at ease.

After we talk about what it is like to be me, she says this helps her understand. When we get to the next steps, she says she will help me organize my refrigerator. Then we can talk more about me cooking soup. I don't mind that she is an occupational therapist who is helping me. Or that I am the client who is being helped.

She wants me to have an easier time doing the things that matter to me. She doesn't speak as if there's something wrong with me. Instead, she looks at the world around me and how I am in the world and sees how to create more harmony.

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I move around the city more easily now. Most of the time, I take public specialized transit for people with disabilities, though I only have support under certain conditions. I do this, because I get painfully overwhelmed when I take regular transit. When I am inside a Wheel-Trans vehicle, I do not want to tear my eyes out. I see the city around me from my back seat. Sometimes the drivers are kind. Sometimes they are rushed.

I remember one of the drivers very well. He called me Carol Anne, as he narrated the city from the front seat. When he welcomed me, I felt like a special guest. I leaned back and saw the city through the eyes of a warm stranger. His voice was animated by the world around him. He treated his cab as a limousine. I don't even remember much about what he said, but it was how he said it that meant something. I felt valued. When I made my way out of the vehicle, we said goodbye as if we were old friends. He taught me something

about offering care that day. Because I felt no hesitancy in receiving it.

I am aware of the privilege of being able to receive so much care. Not everyone has access to the supports they need, and sometimes people are mistreated or dehumanized when they do receive supports. I think of all the people who deserve to be welcomed and wish we would ride in that Wheel-Trans vehicle together.

What needs to happen so that more people can receive quality care?

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I am also trying to receive care by taking care of myself. There are many ways I already do this. And I have recently started making sandwiches again, thanks to my occupational therapy sessions. There are a lot of steps to making a sandwich. You need to buy the ingredients and put them together in the right order. My occupational therapist teaches me that when you go through a task, it can be handy to break it down into small steps, like this:

1. Buy gluten-free bread.
2. Buy cucumber.
3. Buy cream cheese.
4. Put the gluten-free bread in the freezer.
5. Put the cucumber and cream cheese in the fridge.
6. Take the gluten-free bread out of the freezer.
7. Put the gluten-free bread in the toaster oven.



8. Take the cucumber and cream cheese out of the fridge.
9. Take the gluten-free bread out of the toaster oven and put it on the counter.
10. Open the cream cheese container.
11. Get a knife.
12. Spread the cream cheese on the bread.
13. Slice the cucumber into four slices.
14. Put the cucumber on the bread.
15. Put the other piece of bread on top.
16. Enjoy!

Now I realize why it takes so much motivation to make a sandwich. Eating takes a lot of motivation in general. I am not sure I understand why preparing food is so demanding. It takes so much energy to put the soup in a bowl, and place it in the microwave. I am uncertain about how I am going to get to the point of cooking regularly. Was it a bad idea? I move my occupational therapy appointment back. Hoping that in a few weeks I will feel up to the task.

I want to end this piece with the accomplishment of making soup. I want to narrate making soup and describe the delight of eating it. Then this piece will be complete. I will have received the care that I was given and produced something valuable that I can share with someone else.

Maybe, in a few weeks, I will make soup. Or three months. Or a year. Maybe I will be able to start doing more of the things I want to do. Like go to the queer social group I signed up for. Or go on a date. But right now, I feel that keeping up with what I already do is an amazing feat. I live

on my own, with practical and financial help from my parents. I visit friends. I exercise regularly. And work hard on my writing.

I cannot tell you about the Moroccan tomato soup I plan to make again one day. I can't even think how many steps are involved in making this soup. Have I failed at the art of receiving care? Should I try harder to become the person I am expected to be?

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It is a fierce lesson to lose many of the abilities you once had. When I was younger, I was considered impressively capable. I was sure of myself in the way insecure people are. I knew how to shake hands with the "brightest," even as my spirit grew dimmer.

Still, I have a rich life, and I know joy down to my bones. I can listen to a tree unfold from my toes to the top of my head. I can climb inside caves and revel in being filthy and wet. I receive gifts I could not even begin to tell you about with words, just by being in the forest. I am not built wrong. I am just created for a different world than the piercing city I find myself in. The frenetic noise gathers inside me, making it more difficult to do the things I want to do.

That said, I can only meet life here. The things I struggle with are teaching me to be more fully human. Perhaps the lessons from being on this side of the exchange are even deeper.

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I did not make soup by myself. But I did not give up. I asked for help.

The spicy soup is simmering on the stove. It is a Moroccan tomato soup, like I used to make. My friend and I, we made it together. I appreciate the care she puts into assisting me. Her good humour and natural ease help me meet the task at hand. She chopped the garlic. I chopped the onions. She pointed out that one of the cans of tomatoes expired in 2020. I lined the new cans of tomatoes on the counter. She suggested we put the parts we wouldn't be eating in a bowl. Then the parts we would be eating in a pot. She stayed with me for moral support while I went through each step on the list I had printed out. She didn't expect anything of me, but she was confident that I could do this.

It wasn't a glamorous thing, me slowly slicing the onions with a dull knife. The onions were hard to cut, and it took me a long time. My friend helped peel off the top layer of the small ones. The onions in the soup were a little hard to chew. I'm not sure why. No matter. The spicy soup is simmering on the stove. I did not make the soup by myself. My friend and I, we made it together.

Once the soup has simmered, I decide that—though it is not perfect—it is tasty. I place it in plastic containers. I put some of the containers in the freezer and some of them in the fridge. My sink is filled with dishes I will finish tomorrow. Or the next day. I feel a sense of satisfaction because, with some help, I made it up my summit of chili powder and tomatoes. My hands smelling of onions. I will tell my occupational therapist of this

accomplishment, and she will be happy for me. My difficult feat written down in a computer system somewhere. She will document my progression to the person I have set out to become. It will only be a few lines. There will be no way to fit the tomatoes and onions inside. But, maybe next time she comes over, I will invite her to taste a spoonful of soup.

### **About the Author**

**Carol Krause** feels most alive crawling through caves. Her poetry collection, *A Bouquet of Glass*, is published by Guernica Editions.