

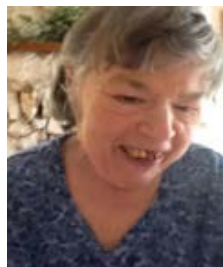
PATRICIA, NEIGHBOUR! THE SIGNIFICANCE OF A VALUED ROLE, WELL CRAFTED

by Janet Klees

Janet Klees is from Toronto, ON Canada. She has been thoughtfully involved in the lives of people with disabilities, their families, and allies in community for over 30 years. She has been the coordinator with the family-governed Deohaeko Support Network almost from its beginnings 25 years ago when families designed and built a housing co-operative where seven of their sons and daughters with disabilities now call home. They have built and sustained vibrant and diverse roles and lives within the cooperative and the broader community. At the same time, Janet became involved in work with other families in consulting and teaching roles internationally with a focus on individually-designed arrangements ensuring that each person lives a meaningful, involved and secure life within their communities. Recently, Janet has taken up the role as Executive Director of a family support organization in an effort to bring her ideas and approaches to a broader level. She continues to dedicate some of her time to teaching and sharing her experiences.



Patricia Wessel recently marked her 77th birthday with three parties, organised and attended by different groupings of friends, neighbours, church members, co-volunteers, and people who support her in her full life in her community of Kamloops, BC. She is a quiet but active woman who marks her days with full and engaged roles as homemaker, quilter, Sewing for Children group member, music lover, church member, Senior Community Centre member,



power and importance of intentionally crafting and supporting valued roles for and with people over the course of their lifetime. As active and involved as Patricia is right now, this was not always so. While Patricia currently holds a number of valued roles in her community, the transition from Patricia merely living

in a house to being a contributing, nourishing neighbour is important as the turning point towards her good life. Although Patricia has lived in the same house for 30 years, she only began to enjoy the benefits of the ordinary and familiar role of 'neighbour' three years ago.

Before that time, Patricia's home was a group home, and in that small distinction, her house was seen as quite different from those in the rest of the neighbourhood. In other homes, people came to live together through family relationship and choice. Patricia and her former housemates were grouped to live together based on their common experience of disability. This distinction had Patricia and her housemates live in a neighbourhood, but not really regarded as neighbours.

In addition, until a few years ago, Patricia was seen as a woman who did not speak, who was best not to be challenged lest she break down into uncontrollable anxiety, who needed never to stray from her routines and their safety to the point that she only wore certain colours and only occupied certain spaces, often at home, that she knew well.

Over the years, her housemates moved on or passed away, and the people who plan for

and know Patricia best determined that this house of many years should provide her with continuity for the rest of her natural life. And so, after some 27 years, the group home in Kamloops became a place of real home for Patricia.

For a woman who treasures routine, stability, and things she can rely on, the gift of home is a rich treasure. The people who care for Patricia and want the best for her were determined that she use this treasure well. They wanted to think deeply about Patricia and her life. As well as asking how she might best fill her time, they began to ask who she was, who she would be and what she could offer - to herself, her sister, her neighbours and her community. They began to see her potential as a sister, church member, quilter, music lover and more.

Because of Patricia's 30 year preoccupation with this home and space, these people took much time to understand how she could come to deepen and grow, especially in those roles rooted in the things she loved best - homemaker,

host and neighbour. They began to understand that it was important to have this place in her neighbourhood, but also that simply being here - eating her meals, sitting in her garden, listening to music in her living room, paying attention to her budgies - was not bringing her purpose, or meaning, or people in the full life in which they knew Patricia would thrive.

They moved beyond the idea of Patricia simply being present in her home to imagining how others in her neighbourhood, neighbour-

hood, and in any neighbourhood, might hold the roles of homemaker, host and neighbour for themselves. Without limiting the ideas to Patricia, they listed all of the activities that

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people in the neighbourhood might take on as homemaker - tidying, cleaning, decorating, baking, organising, enjoying the space, gardening, planting, and more; as host - inviting, welcoming, greeting others, cooking, serving, clearing, cleaning up, taking photos, sharing photos, sharing memories over the fence, and more; as neighbour - helping, chatting, keeping in touch, being positively nosy, asking after a neighbour, running an errand for, giving a lift to, fundraising for a good cause, helping with garbage, dog-walking and house-sitting, sharing garden produce, and more.

Next, they carefully selected activities that would most interest Patricia, which would

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bring her into the most regular contact in a positive way with her neighbours, which would allow others to see her for herself, which would allow her to make a contribution to her neighbours and neighbourhood, and which would then allow her to fully embrace the most positive definitions of the words Homemaker, Host and Neighbour. They embarked on taking these on in simple, small steps that fit Patricia best, and allow her to feel comfortable with each new activity before she took on the next. This was a slow, cautious

process which Patricia led by others being attuned to how fast, how slow and when to take another step.

This process of following Patricia's lead in exploring roles of homemaker, host and neighbour has taken over three years to date, but no-one is really counting. The journey itself

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is a wonder and a revelation, and things are going along exactly as fast as they should. Life is deepening and unfolding, and haste would only make people miss the fullness of the roles that Patricia holds and the grace with which she holds them.

What exactly does it look like to see Patricia in her life right now? Let's just focus on the simple role of "nourishing neighbour". Patricia is now identified as the neighbour who lives at 5325 Bogetti Place. People started to notice and meet her when she began regular walks in her neighbourhood with stops along the way to learn people's names and chat. She notices when neighbours are in their driveways, in their gardens and is helped to time neighbourhood walks in order to say hello to neighbours by name, to ask after their babies, dogs and kids, to stop and look at their flowers and new cars. She has become nosy in the most positive way and helps to share good news with others around the neighbourhood. Patricia knows all of her neighbours by name and they know her, many stopping by for tea, treats and a chat at many times during the

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week. Some neighbours have become good friends. Patricia came to know Ashley and Dan,

the couple across the way, from when they were pregnant and she was later able to welcome their new baby, Riley, with a special gift. Recently Riley brought one of his first Valentine's to her. Dan has shovelled Patricia's driveway through the winter, and Patricia in turn is helped to make baked goodies for Dan's bag lunches.

Patricia has a deep friendship with Sigrid, another

single senior in her neighbourhood. Sigrid comes by to share dinner with Patricia a couple of times a month, and then drops in just to say hello, or check on something that does not feel right - she thought she saw smoke one time. Neighbours Jen and Brent have also become firm friends based on a common love



of gardening and now Patricia is helped to plant heritage seeds from Jen, who is a city horticulturist.

Patricia is helped to make Christmas cards and baked goods, and uses many neighbourhood walks to distribute them. While sourcing fresh fruit for her winter canning, Patricia has met many people then gifted back canned

preserves and pies to their original donors. Last summer, Pa-

tricia was helped to host Patricia's Spring Fling Garden party, and a Christmas Open House

which may well become annual events, as many people came along to share food, hospitality and good cheer as neighbours. Clearly this valued role of neighbour has brought Patricia friends and other relationships, purpose, identity, a chance to make a meaningful contribution and many new experiences.

Furthermore, when any of her neighbours show up at her home - which

they do frequently for one reason or another, Patricia is able to step into the role of host. It turns out she is thrilled to have others in her home - contrary to early opinions! She likes to have others admire her handmade quilt (the outcome of another role choice that she had been helped to take on), taste her latest kitchen treat, help out with the crop of apples being peeled in her kitchen, and appreciate her taste in music.

Intentional plans to support Patricia in her roles as homemaker, host and neighbour are not static, and the activities do not grow boring. Support people and neighbours bubble over with new ideas - what if we were to help Patricia make a quilt for Riley's birthday, turn one of her rooms into a quilting planning room, invite a neighbour or two over on the morning that her friend comes over to play guitar for her and make music? What if...

LESSONS FROM PATRICIA

So let us be clear on what we have to learn from Patricia and those who assist her to take up valued roles in her community.

1. Craft a Valued Role by Intention. The shift from being a neighbour simply by living in a house among others to holding a dynamic and mutually enjoyable role as neighbour did not come about by luck or accident, but by intention. This means that it is not simply good

enough for people to be present in a given situation in order to fully take on the opportunities of the role in that place and time. We must be thoughtful and intentional about our planning and our actions to make things happen.

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2. Role-thinking leads to Relationship and Good Things in Life. The main reasons for thinking in terms of social roles is that themes of contribution and relationship are naturally woven into this kind of thinking. A role is not intrinsically good or bad, but a valued social role can bring about degrees of purpose, identity, contribution and relationship in powerful and life-defining ways.

3. Embed the Valued Role within a Context. This means that crafting a valued role is most successful when imbedded in a context:

- The role takes place in valued and typical community life and spaces (not pretend, is not a group of disabled people, nor mere community presence),
- Ensuring that some of the significant activities of the role happen frequently, regularly and predictably,
- Ensuring the role is thoughtfully crafted and deepened, and
- Ensuring there are other people available during significant parts of the times and places when the role is engaged.

4. Start with the Person. We can see that the valued roles of focus for Patricia were based on genuine interests (homebody, food and cooking, music, loves to observe others in a group),

on her contributions (loves to help others, able to make others feel welcome, helps gentle people's fears of disability and difference, has a home with meeting space, extra time on her hands) and her experiences (lives in this

role of neighbour was so much fuller with the realisation that a deep role has contribution at its heart. In addition, the offering is genuine, authentic and based on who they are in an essential deep place. We need to really know

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the person in order to bring this out. The true power of a focus on contribution,

neighbourhood, also has a garden, has followed 50's music forever). This is how you find the role - you start with the person. At all times resist fitting the person into something that you think is great.

however, is that it moves from simply being in an activity that might be done alone, to a situation which involves another person and therefore forms the basis for relationship. Every act of contribution involves another person. In the end, the true gem of a focus on valued roles is that it is a powerful way to bring relationship into someone's life.

5. Look at What Typical Others Do. Where do others who have this interest gather? What are others doing who have this interest? What roles do people who share this interest hold? What are other 21-year-olds doing when they are not working? What do other 50-year-olds do on Sundays? What are neighbours doing in this community? Based on the kinds of things the person is interested in, search for these in ordinary community life as shared by ordinary others. Look in the newspaper, bulletin boards, social media, the news and more to find

7. One Person at a Time. People are so obviously unique and different in their personalities, life journeys, experiences, skills, and more that the only way to authentically help someone to fully engage in a valued role is one person at a time. Five people who hold the same general interest or positive experience will take on a role in five different ways based on who they are, the opportunities in their particu-

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lar neighbourhood or community, the unique qualities of their particu-

lar interest, the others who are already engaged and their own experiences and personalities. To plan for all five people - in this role or any other - at one time is foolhardy at the least, ineffective at best, and harmful to both image and the perceived contributions of the person at worst

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6. The Heart of Role is Contribution. It is clear that so many new ideas came forth when others who supported Patricia began to see her as a person with something to offer. The

8. Define Roles Broadly. It is important at the outset to choose a role that is broad enough

to be familiar to others; to have many, many lesser roles, activities and expectations attached to it so that it can grow with the person, and to expand to allow for a variety of places to happen.

Broadly-defined roles are ones that people can grow into and layer on, and can become life-defining (neighbour, artist) rather than weak roles (spectator of local soccer games). To be narrowly

defined as the neighbour-hood garbage bin collector leaves

one without too many directions to take this further. But recognising that the broader role is "good neighbour" and that "garbage bin collector" is one small expression of that larger role, allows us to then ask (without taking away one's purpose and enjoyment of collecting garbage bins), "what are other activities and ways that he could be a good neighbour around here?"

9. Find Ways to Deepen Roles. The layering and deepening of a role can significantly enhance the experience of holding it. A role that has many related activities attached becomes obvious to others, shows authentic affinity for the interest defining the role and for the role to become life-defining, or a significant part of one's identity. This deepening the role can be achieved by:

- Adding layers of related activities over time - brainstorm all of the ways that people might typically act or work in this role, and take on the ones that make sense
- Expecting and allowing the role and its related activities to take place over time - think in years, not weeks - so that people become familiar, the various activities can be increased; contribution might be offered in different ways over time

- Ensure that some of the regular activities take place with the same core of people over time
 - Along with contribution, build in commitment and responsibility - opportunities for a person to take pride and ownership in what they are able to offer
- Planning and using typical, familiar and image-enhancing role communicators and

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indicators (uniforms, identifying t-shirts, backpacks, etc.)

10. Roles are Powerful. Even When Not Actively Engaged. Role identifiers or communicators work even when the person is not actively engaged in the role. This is the magic of a valued role! It continues to announce identity, contributions and expectations even when you are not actively working at it. These might include:

- Things people are wearing, e.g. a uniform on the way home, a t-shirt on another day, a team baseball cap
- Things that people carry with them, e.g. a photo of the person receiving an award for environmental work, a business card identifying them as artist or entrepreneur
- Things in and around one's home, e.g. photos of past events together around the living room, jars of jam in the kitchen begging for a comment, a gardening magazine subscription on the coffee table so others can see what the person is interested in
- How the person is introduced or talked about, e.g. "my son, Tom, the local librarian"
- Things that others say or bring into conversation, e.g. ready stories to tell about the evening at orchestra practice, or tasks that might be set aside for the person.

11. Plan the Role and the Support for the Role. After you identify the possible role based on knowing the person:

1. Set it into context - name the role, articulate the nature of the contribution, find out

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where this can take place, with whom and on what frequent and regular basis (Place, Presence, Role, People = Building a Context for Relationship)

2. Notice in that place: what needs to get done, who does it, and what pieces this person could do (even with assistance). Notice all of the roles and activities in that setting and imagine which of the tasks this person can do, and don't expect the other party to be able to figure this out.
3. Get the asking right - Know when you are asking to take part and when you are offering a service or resource. Ask a question to which the answer is likely to be YES - small, achievable and well-supported.
4. Start small and successful - being a regular at weekly meetings, joining the walking group for monthly hikes and taking a weekly painting class gives you lots of opportunity to look around and imagine how the person can next contribute. E.g. helping set up for the meeting beforehand, bringing snacks on the monthly hike, taking photos of the painting class for the local newspaper and considering what other activities might be related to the role.
5. Demonstrate ongoing vigilance so that you keep open to opportunities to add to the role or even enter into a new one as a result (neighbour to friend to church fund

raiser) and ready to step in when extra support is needed.

6. Remember your role - the support person is the bridge to role and relationship, and not the holder of the role or the relationship itself. You should be replaceable by another. Support the other party.

12. Music to Your Ears.

It is good to

understand the indications that you are on the right track. Know success or good “notes” when they are present. Listen and look for:

- When someone says they missed her when she was away last week.
- When you don't have to explain what you are doing - it is obvious because the person's role is familiar.
- When they start thanking her for the contribution, and not the support person
- When you have another community member (neighbour, co-worker, volunteer, marathon walker) to work alongside
- When there is a common project for a group or many to work on together (a fundraiser, a local tea, a celebration)
- When the support person can change without any fanfare because it is all about the person with a disability and the group or other party - not about who is providing support.



This is what Patricia and her neighbours are teaching us every day: That Patricia's presence makes a positive difference in her neighbourhood, that what Patricia has to offer is more important than what she cannot do, that who Patricia is more interesting than who she is not. Patricia is teaching her neighbours to listen to the spaces in between, to new ways of being with one another, and to the enormous capacity within themselves to become the caring, kind neighbourhood they wished they could live in.

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Read: “Our Presence has Roots” and “We Come Bearing gifts” available for purchase in our online bookshop www.belongingmatters.org

Watch: A number of Janet's presentations, e.g. “Upholding the Sanctity of Home”, in our online video gallery Talks That Matter.

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