



# You and the agency: Steering the course, Volunteering as a PHA or affected by HIV

Fall 2023



## Acknowledgements

- Developed by Toronto People With AIDS Foundation (PWA)
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Presenters/Facilitators: Kyle Vose

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- Presenters/Facilitators: Kyle Vose



### Acknowledgement of Traditional Lands

- I would like to acknowledge this sacred land on which THN and all of our AIDS Service Organizations operate. It has been a site of human activity for 15,000 years. This land is the territory of the Huron-Wendat and Petun First Nations, the Seneca, the Mohawk and most recently, the Mississaugas of the Credit First Nations. The territory was the subject of the Dish with One Spoon Wampum Belt Covenant, an agreement between the Iroquois Confederacy and Confederacy of the Ojibwe and allied nations to peaceably share, and care for, the resources around the Great Lakes. T'kranto was the meeting place.
- Today, this meeting place of T'kranto (Toronto) is still the home to many Indigenous people from across Turtle Island and we are grateful to have the opportunity to live, to work, to play in this community, on these traditional lands.

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What does this mean to you as a volunteer?



## Learning Objectives

- See volunteering within their own life journey as individuals living with and affected by HIV
- Understanding of the complexities of volunteering in the HIV sector for people living with or affected by HIV
- Knowledge of key self-care issues (boundaries, disclosure, confidentiality)
- Learn about volunteer-agency relationship (including seeking help/information and self-advocacy)

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### **a·gen·cy**

a business or organization established to provide a particular service, typically one that involves organizing transactions between two other

parties.

agency is a group of people that performs some specific task, or that helps others in some way. A business that takes care of all the details for a person planning a trip is an example of a travel agency.

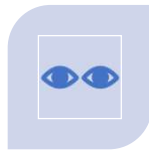
In social science, agency is defined as the capacity of individuals to act independently and to make their own free choices. By contrast, structure are those factors of influence (such as social class, religion, gender, ethnicity, ability, customs, etc.) that determine or limit an agent and their decisions.

Human agency refers to the ability to shape one's life and a few dimensions can be differentiated. Individual agency is reflected in individual choices and the ability to influence one's life conditions and chances.

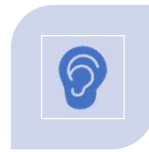
## Grounding, Breathing, & Mindfulness



MENTAL (FOCUSING  
YOUR MIND)



PHYSICAL (FOCUSING  
YOUR SENSES)



SOOTHING (TALKING TO  
YOURSELF IN A VERY  
KIND WAY)

- Mental grounding techniques use methods that are primarily of a psychological and cognitive nature; for example, counting slowly or reimagining a previous experience in great detail.
- Physical grounding techniques use methods focused on external stimuli, such as sensations and perceptions related to information that exists in the external environment; for example, exercises such as stretching or [yoga](#), concentrating on tactile sensations such as putting your hands under running water, or rubbing your fingers across different fabrics.
- Soothing grounding techniques describe methods that use kindness and positive sentiment to help induce a sense of calm and relaxation. Examples include thinking of people whom you love or repeating a positive statement to yourself.

### **Mental Grounding:**

1. Describe your environment in detail, using all of your senses – for

example, “The walls are white, there are five blue chairs, there is a wooden bookshelf against the wall...” Describe objects, sounds, textures, colors, smells, shapes, numbers, and temperature. You can do this anywhere.

2. Play a “categories” game with yourself. Try to think of types of dogs, jazz musicians, animals or famous people that begin with each letter of the alphabet, cars, TV shows, writers, sports, songs, cities.

3. Describe an everyday activity in great detail. For example, describe a meal that you cook (e.g., “First, I peel the potatoes and cut them into quarters; then I boil the water; then I make an herb marinade of oregano, basil, garlic, and olive oil...”).

4. Imagine. Use a pleasant or comforting mental image. Again, use all of your senses to make it as real and vivid as possible.

5. Read something, saying each word to yourself. Or read each letter backwards so that you focus on the letters and not the meaning of words.

6. Use humor. Think of something funny to jolt yourself out of your mood.

7. Count to 10 or say the alphabet, very s . . . l . . . o . . . w . . . l . . . y.

### **Physical Grounding:**

1. Run cool or warm water over your hands.
2. Grab tightly onto your chair as hard as you can; notice the sensations and the experience.
3. Touch various objects around you: a pen, your clothing, the table, the walls. Notice textures, colors, weight, temperature. Compare the objects you touch
4. Carry a grounding object in your pocket – a small object (a small rock, ring, piece of cloth) that you can touch whenever you feel unpleasant emotions rising
5. Notice your body: the weight of your body in the chair; wiggling your toes in your socks; the feel of your back against the chair
6. Stretch. Extend your fingers, arms, legs as far as you can; slowly and gently roll your head around.
7. Clench and release your fists

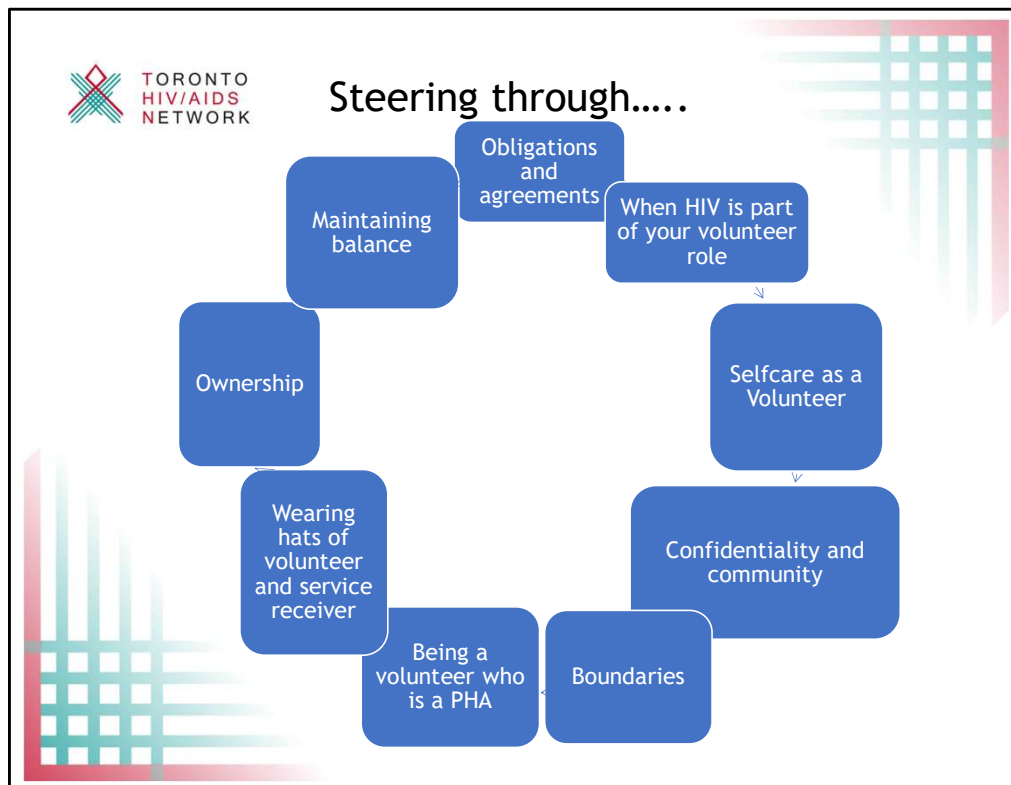


8. Jump up and down
9. Eat something in a savoring way; fully experience the food; describe the sights, aromas, textures, flavors, and the experience in detail to yourself.
10. Focus on your breathing, noticing each inhale and exhale. Repeat a pleasant word to yourself on each exhale.

**Soothing Grounding:**

1. Say kind statements, as if you were talking to a friend or small child – for example, “You are a good person going through a hard time. You’ll get through this.”
2. Think of favorites. Think of your favorite color, animal, season, food, time of day, TV show.
3. Picture people you care about and look at photographs of them
4. Remember the words to an inspiring song, quotation, or poem that makes you feel better (e.g., serenity prayer
5. Say a coping statement: “I can handle this,” “This feeling will pass.”
6. Plan a safe treat for yourself, such as a piece of candy, a nice dinner, or a warm bath.
7. Think of things you are looking forward to in the next week – perhaps time with a friend, going to a movie, or going on a hike.

Complete



## What is agency and an agency? Post to Chat

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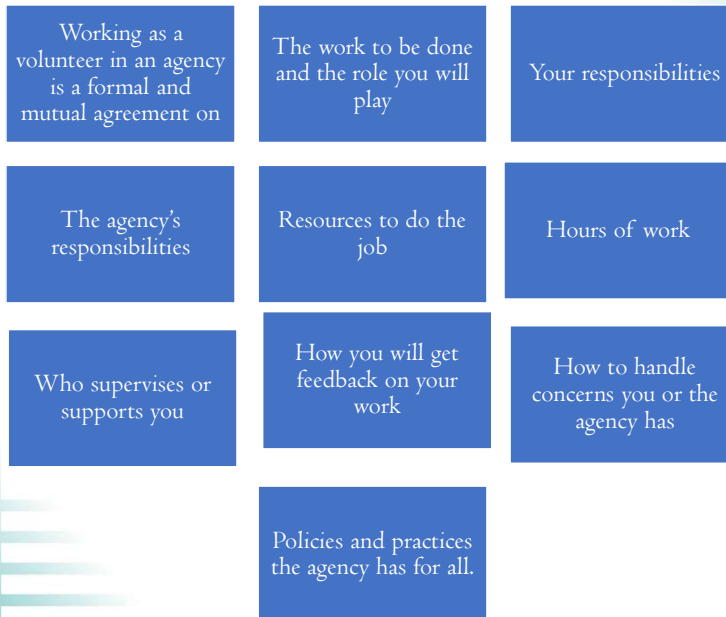
(such as social class, religion, gender, ethnicity, ability, customs, etc.) that determine or limit an agent and their decisions.

Human agency refers to the ability to shape one's life and a few dimensions can be differentiated. Individual agency is reflected in individual choices and the ability to influence one's life conditions and chances.

- You are entering into a relationship with an agency and its work
- *The agency is far from perfect and is always evolving: they will fall short, and so will you. Be understanding and stay open to communicating.*
- These main topics will probably need attention many times during your time as a volunteer.
- It is important to understand that the volunteer/client/agency relationship is a life journey for all of us



## Obligations and Agreements



- The clearer you and the agency are on your role and the agency's role the better it will be *for everyone!*
- If you come across some areas that are not comfortable for you, then continue through the discussion until you **find a mutual agreement**
- When discussing these areas, it is the best time to ask questions of your volunteer coordinator. Are there any pressing questions about this now that might help other people to understand your shared concerns?
- Your agency's Volunteer Coordinator and/or a Program Coordinator will probably be the person going through these with you
- If you have preferences for such things as how to get feedback, make those preferences clear with your volunteer coordinator; that should never come as a

surprise to other staff or volunteers.

- **Mutual respect with peers, agency staff and the people being served is key.**
- Your agency will share with you its policies and practices that its volunteers need to follow.
- *The new volunteer is really keen to start working. It is a small agency. The volunteer coordinator who also doubles as an outreach worker says, “we are so glad you are coming. It gets crazy here and I know you are agreeing to make condom packages on a Thursday, but hey, we may ask you to pitch in sometimes and do other things”*

## Being a Volunteer & a PHA

Disclosure as a PHA or not is your decision

What you share is yours to tell once told it is out of your control

Your experience is unique, others' is theirs to tell

HIV alone does not define you

Be aware of your humanness

Emotionally triggered by an experience

Support one another; Call upon services and supports.

- Being a PHA in an organization for HIV brings the personal and the professional together. Because you have a role, it is this *role* that comes first.
  - What you share about yourself is yours to share and it may get passed on
  - This includes disclosing your status or anything about your story
- You will find many times that people may ask you questions because you are a PHA – you do not have to know the answers, nor speak for all PHAs
- Your right to privacy is yours to hold
- Being a PHA may have brought you to this work, but it is not your *whole* identity. You are a person with many gifts, talents and experiences and interests for the future. It is this that you are bringing and giving.
- Being a PHA means that you will encounter people and stories that

will connect with your own. Sometimes this will affect you. This is being human. **At times like this it often is good to talk to another PHA or to a person you trust. However, share only your own feelings and story, not anyone else's.**

- **Sometimes the issue may trigger a strong emotional experience this happens when we encounter something that relates to our own story. You notice you have strong feelings . At times like this you can go to the Volunteer Coordinator or Program Coordinator for the program you volunteer in your agency and get the support you want.**

## Being an Ally as A Volunteer

Unless HIV+, we can learn about, but we cannot know what it is to live with HIV.

We can respectfully listen, learn and be supportive.

We will respect the privacy of our volunteer & staff colleagues and people the agency serves.

We may know people with HIV but we recognize that everyone experiences HIV differently.

We can contribute as part of a volunteer team that makes a difference.

- Has anyone had the experience of thinking they were acting as an ally and learning that it wasn't received in the manner intended?
- Ensuring client-centred (not taking away person's AGENCY)
- Assumption of how to be an ally focusing on one ally link but missing the many other key aspects –
- Some examples: long-term survivors/newer diagnosis; COVID-19 loss; racial identity;
- Active listening
- Asking and being open to learn
- How can I support you and what do you need rather than assuming I know what you need.



## When HIV is part of Your Volunteer Role

Sometimes the role requires the PHA to be public or “out”. This may include different levels of openness such as:

Leading peer support groups

Helping in research

Health Champions

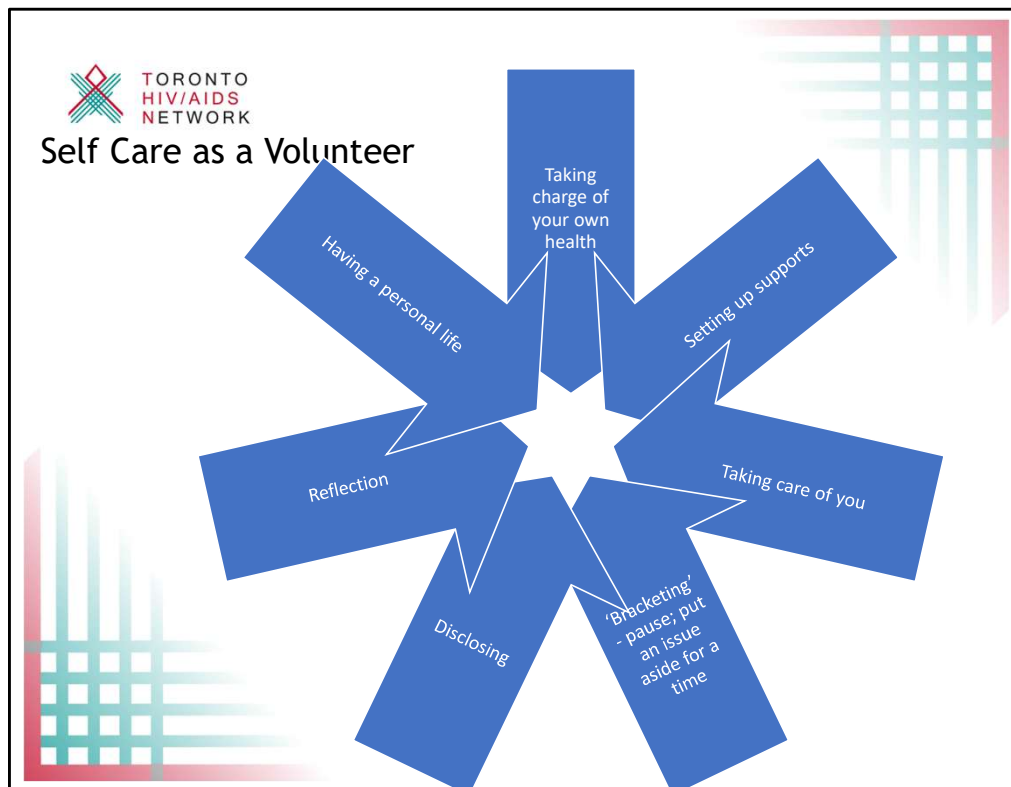
Men's Health Peer Navigator / Power Program

Media

Important to consider and set personal boundaries

Being a public PHA brings particular responsibilities and considerations:

- the release of privacy about being HIV+
- a readiness to set boundaries of what you are and are not willing to discuss publicly – Refer to their earlier discussion, the Confidentiality and Boundaries session
- a comfort with emotional vulnerability – this is very personal work
- the confidence of having your own support systems – there will always be something that challenges you
- a preparedness to receive and deal with other's opinions, sometimes stigmatizing or discriminating,
- a readiness to be the spark for someone to disclose to you and handle issues that may come up
- an ability to stay very closely in touch with all other parts of your life that bring you joy and connection – this role is not your entire life
- a readiness to say “I don't know” when people assume ***you know everything about HIV and about living with HIV.***



- It is true what they say about taking care so that you can take care of others
- Having good attention to your mind, body and spirit really is the base for bringing strong energy.
- If we ignore our own attentiveness to health, whether we are conscious of it or not, it will impact others
- You will come across lives and situations that are highly personal. Some will be wonderful and some will be stressful
- Seek opportunities to debrief after difficult situations with the Volunteer Coordinator, or Program Coordinator for program area you are in. Perhaps also with volunteer peers while attending to confidentiality.

- While the agency may support you to a certain extent, most find that having supports also outside the agency are important – *but remember to share your own story and feelings, not the stories and feelings of others*
- Taking care of you requires your attention. We can forget this sometimes. This includes not only your HIV care, but your energy and interests. This way you will be able to have a more fulfilled time as a volunteer.
- **Sometimes you will come across something that you cannot respond to immediately and your work is not finished. For example: in the middle of the work you're doing, someone tells you something that you find upsetting and can take over your attention. Learn to hold this till later when you can get the support you need to discuss it with the Volunteer Coordinator. It may be a confidentiality issue.**
- Disclosing your HIV status is entirely yours to decide. It is no guarantee that this will be kept confidential. Do this with care and after consideration.
- Take time out to reflect on your volunteer experience. Journal writing, taking time after working. All these help to deepen and make more meaning out of your time volunteering
- Many volunteers, including PHAs, make the relationship with the agency their main focus. This is good if it provides a step toward building community and building new relationships.
- However, it is only one part of you and the more joy you give yourself, the more joy that comes to others.



## Wearing hats of volunteer *and* service receiver

Pay attention to these two connections with the agency

Impact on relationships

Holding on to the right to services (gate Keeping)

How to hold both hats well but with one role at a time

- Usually as a client we go to an agency to receive but when we are part of the agency's service delivery we take on another role. This issue may differ from agency to agency
- The areas where this can get confusing is in ~~personal~~ relationships. You could end up working with someone who also provides you a service and because you are part of an agency you will also

get to learn how that agency operates.

- These new parts of knowledge about the agency and the relationships you have might require you to consider this right at the beginning when you volunteer.
- As a service user consider whether you are comfortable being both a service user and volunteer. The responsibility is yours to consider before you agree to taking on any tasks. Most particularly if you will be working in an area where you receive a service, such as a food bank or a reception desk
- Sometimes this is also a great advantage. As a peer you also offer a common understanding with some clients and can provide “a knowing” presence. For PHAs it is often very valuable to know that someone in an agency/program is also a PHA
- To hold both hats well means not being in conflict or uncomfortable. Many do wear

both hats very well. Should conflict come up talk about it with your supervisor or Volunteer Coordinator. It is not good to hold on to the conflict and hope it goes away – generally it does not.

- Because the PHA community is small, how you are and what you do will form how people think about you. This happens anyway for everyone, but in a small community it means being extra attentive
- **Slide 12 Wearing hats of volunteer and service receiver**
- *Staff and volunteers have a monthly get together and you get personally close with a staff that is your support worker. After a good time one week you have a crisis and are in need of support. You realize that your relationship with the support worker has changed and you don't know what to*

*do. What's next?*

## Ownership

OK to own your role and responsibility and have commitment, being a dependable volunteer.

Getting too attached to a program or a role. Having it become “my agency”

I cannot leave, I am working on my life

- To work in something that directly is about your life as well as others involves a relationship on many levels
- It is easy to get attached to things because the work can become highly personal. This can be great to experience while in it, but it sometimes can get way too attached. There’s a difference between being proud of the role or work and feeling you are responsible for how everything goes.
- It is common to have a relationship with the agency, rather like we do to a particular place to eat or shop. The “my agency” is an affection and we can sometimes take things personally when someone criticizes or when the agency changes something.
- It is important to remember that everything is always changing **and**



***ultimately it is up to you to work through changes.*** Attachments sometimes get very strong and if we feel a strong ownership we can sometimes feel as though we have to stay doing what we do, even if the interest has worn out. It is your life and you have the right to stop something when it no longer feeds you and to trust that others will continue addressing the needs.

- We are touched deeply by working in something that is about our lives. As we volunteer we will always be experiencing our own life and challenges and joys. This means a good thing. It is about being connected to yourself and to a community and its work. At the same time, it is important to remember that your life may outgrow this work or you may be touched deeply by something. **If you think it's time for a change or to leave your volunteer role, you can talk this over with the Volunteer Coordinator.**

## Boundaries

Parts of selfcare

In the  
workplace, In  
your role

In the  
community, In  
your personal  
life

Self-care

- Today we will only look at this topic very broadly since the separate training session went into more depth on the issue.
- Two areas are important. First there is your self care and second is your care of information of others
- Your self care includes learning to be meaningful with the time you say “yes” and the times you say “no”. Your answer is best done in the service of your health and well-being and the rest of your life. This prevents burnout, resentment and fatigue. When you start you will agree to volunteer for certain things. It is highly likely, particularly if you are enjoying what you do that you might be asked or you may volunteer for other tasks. There is always a lot to do. Always, always consider whether your “yes” is genuine and always , keep the right to say “no”. This will build a successful relationship with you and the agency and all of its people.
- Creating boundaries takes practice
- All of these areas of workplace, your role in the agency and in the

community are places where confidentiality is vital. It is highly likely you will meet people who are clients of the agency, learn information about them informally or as part of your work. Whatever you learn about someone as part of your volunteer role is to be kept to yourself, unless you are given permission. When in doubt, ask.

- Again, it is your right to privacy. Some people like to keep their private and work life separate but often, especially when living in a community, this becomes more difficult.
- As you consider and practice with boundaries – saying “yes” and saying “no” , being aware of what you do and do not want to commit to or share will start to enter your entire life. Because it is about the development of a way of seeing things and a way of being in the world you find that this practice starts to work for you in other ways at home and elsewhere.
- This is not a passive framework but rather shifts and evolves.

- **Discussion**

- *You are out at a party and you hit it off with someone emotionally and maybe sexually. The next day you go to volunteer and that person is at the agency as a client. What do you do?*

## Confidentiality and Community

About people

About your  
work

About the  
agency

About gossip  
(ill intent, not  
concern)

About others'  
disclosures

About professional  
conversations

PHA & HIV services  
community is small

Calling Community  
Member's

- About people
- About your work
- About the agency
- About gossip (ill intent, not concern)
- About others' disclosures
- About professional conversations
- PHA & HIV services community is small
- Calling Community Member's

## Maintaining Balance

We are in charge -  
making choices

Adapting to  
change. Nothing is  
stable

Being aware &  
Checking things out

Being a volunteer is  
one way to  
realize fulfillment  
in your personal  
journey

- Balance is the art of constant correction. *For example, notice how your body shifts to be more comfortable.*
- We are doing this all the time in every part of our lives so we are well practiced at this. Sometimes we get better balance in a short time. Sometimes it takes a long time.
- Let's Discuss

### Slide 16 Maintaining Balance

*You are at a volunteer appreciation party and one of your best volunteer colleagues asks you to join him on a new project in the agency. As you are*

*talking your supervisor who is thrilled with your work also ask you to*

*join*

*this new project. You really like her and feel like you are becoming friends.*

*What comes up?*

