Native Women's
Association of Canada

NWAC
Understanding From Within Project

Understanding from Within: Developing Community-Driven and Culturally Relevant Models for Understanding and Responding to Neurological Conditions among Aboriginal Peoples

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Background

- The project was one of thirteen that were funded as part of a four-year National Population Health Study focused on filling gaps in knowledge about individuals with neurological conditions, their families, and caregivers.

- It is important to note that of the thirteen funded projects the UFW project is the only project that sought to examine neurological conditions through the lens of Aboriginal realities, culture, and worldviews.

Background

- Goal of the UFW research project was to develop a better understanding of how Aboriginal peoples conceptualize neurological conditions and the impacts on their families and communities, and the resources and supports needed to provide culturally safe and appropriate care.

Background

- The following 14 conditions were selected, according to NHPSNC specifications, based on the lack of knowledge and potential population disease burden: Alzheimer’s disease and related Dementia; Amyotrophic Lateral Sclerosis (Lou Gehrig’s disease); Brain Tumours; Cerebral Palsy; Dystonia; Epilepsy; Huntington disease; Hydrocephalus; Multiple Sclerosis; Muscular Dystrophy; Neurotrauma (including brain and spinal cord injuries); Parkinson’s disease; Spina Bifida; Tourette Syndrome.

Background

- The UFW team expanded the scope to include any condition to impact the brain, the spine, or the nervous system. In doing this research the team spoke with participants (co-researchers) who lived with a condition or cared for someone with one of the conditions listed above plus the following conditions that were not originally mandated: Migraine headaches, Stroke, Ataxia, and Trigeminal Neuralgia.

Background

- To ensure that the project remained transparent and accountable to Aboriginal peoples and communities it formed an advisory committee made up of representatives from the First Nations, Métis and non-Aboriginal experts in their field from various jurisdictions across Canada. The advisory committee was engaged at the onset of the project through to the analysis and dissemination phases of the project.

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Methods

- The research was qualitative in nature and used an Indigenous Research Methodologies (IRM) approach to guide the design, collection of data, and analysis of the research.
- Two methods were used to collect information: In-depth interviews and research circles (focus groups). A total of eighty people participated in the research, 69 women and 11 men. In-depth interviews and talking circles were undertaken with key informants (22), with Aboriginal peoples living with a neurological condition (18), and with Aboriginal peoples caring for someone with a neurological condition (40).

Methods

- Narrative analysis emphasizes a story based approach to understanding a given phenomenon by taking as its object, the “story” (Liamputtong and Ezzy, 2005). This is consistent with, and respectful of, the oral tradition of storytelling as a method of transferring knowledge among Aboriginal peoples (Kovach, 2009).
- Collective Consensual Data Analytic Procedure (CCDAP) described by Bartlett et al. (2007) was also employed as a method for the second level of analysis for the in-depth interviews. This collective process allowed the team to elicit input from a wider group of experts (in this case the entire research team and some members of the AC) to help ensure that the research finding remained relevant and that respectful inclusion of Aboriginal experts was gained.

Methods

- The UFW research project was implemented in three stages:
- 1) a systematic literature review of available knowledge that addresses neurological conditions in Aboriginal communities and an environmental scan of existing services available to Aboriginal peoples affected by neurological conditions.
- 2) an examination of how Aboriginal peoples conceptualize neurological conditions and the impact on their families and communities, and the needed resources and supports to provide culturally safe and appropriate care.
- 3) a review of how the findings might be translated and applied to policy, programming, and practice was conducted.

Results

- Major themes and sub themes emerged in the research, along with a series of recommendations intended to improve relations between the medical community and Aboriginal peoples, and to promote the importance of Aboriginal control of health care services.

Summary of Results

- Colonization was a major cross-cutting theme
- Spiritual, mental, emotional, physical, and environmental impacts
- Family, community and life impacts
- Healthcare, knowledge and information gaps
- Risks and protective factors
- Recommendations

Results

- **Impacts**
- The range of impacts that emerged was extensive. Research participants spoke about how they were impacted personally (as someone with a condition) and collectively (through family and community experiences), and told stories about how the impacts of neurological conditions are interconnected. One key informant noted that there is still so much the medical community does not understand about neurological conditions and how they impact the Aboriginal community.

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Results

- The results of the study indicate that the legacy of colonization in Canada can lead to increases in some risk factors for neurological conditions, and compounds the effects they have on individuals. Racism, stereotyping, discrimination and stigmatization can create barriers to accessing vital services. However, through sharing circles and interviews co-researchers shared common stories of resiliency. The perseverance of Aboriginal women in the face of systematic cultural destruction echoed through their outlook on neurological conditions, giving them an advantage in dealing with the incredible challenges of their or their loved ones’ diagnoses.

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Key Informant

- *Let's get to the issue at-hand which is: What can we do together or what can your agency do to help us out? So, if you were visiting with a neurological ward, I'm sure that the staff there would say to you: "Well, why don't Aboriginal people do this and that and this?" And then, they'll say: "Ok, now what can we say or do to actually help the people here who are actually Aboriginal and have neurological disorders." And, that would be a new question…they'll say: "I never thought about that!" That's neglect and I mean neglect, it's actually part of history of neglect where institutions and policies are set-up without consideration of us. So, they have to be reminded but, that's actually part of our* ***colonial*** *experience. And, it must not continue, and if they continue to do that then we will stop and come back when they are ready to talk or, we will work against their current lack of policy, which is a form of violence and racist. It's a* ***colonial****, racist, thing for them to not consider us because we are an important part of the population.*

Results

- ***Spiritual Impacts***
- Some participants described how, over time, they lost touch with their culture and traditions and as a result were unable to draw on them to cope with their condition. Participants who were able to connect with Elders and traditional healers as a source of support talked about finding solace in being able to revitalize their traditions.

Spiritual Impacts

- This participant spoke about the need to accommodate Aboriginal spiritual customs such as smudging within the health care system:

- *So, I think if they're gonna have sections for Aboriginal people, have a room where you can smudge at any time where you don't have to get the firemen to shut off the- you know, like have it set-up for people, you know. And, and we need that definitely*

Results

- ***Mental Impacts***
- Neurological conditions impact mental capacity and can change how people manage in their day-to-day lives. Some participants talked about the impacts medication had on their mental capacity. Both caregivers and those with a condition spoke about the need for more information related to what they should expect, and how the condition can progress.

Mental Impacts

- A couple participants with epilepsy spoke of how the seizures, along with the medication, severely impacted their short and long-term memory. As one patient describes,

- *The side effects of the medications are that I am constantly tired, I have no energy, I can't sleep at night, I have put on 70-80 pounds, lack of memory; like an 80 year old person. The medicine and the seizures take a little bit of my memory at a time.*

Results

- ***Emotional Impacts***
- Being diagnosed with a neurological condition or caring for someone with a neurological condition can be overwhelmingly emotional. For many Aboriginal women the emotional impacts were the most debilitating.

Emotional Impacts

- One mother describes how she felt when her daughter was diagnosed with a neurological condition:
- *I'll go back to the diagnosis part and the time following that when a lot of the symptoms were starting to appear. A huge part of that for me was, it's almost like I felt like being attacked, it’s almost like- Well it is like something is attacking S----- and hurting her and there's absolutely nothing that I can do about it. That helplessness and anger that I felt, even though I understood and I read up about everything.*

Results

- ***Physical Impacts***
- Some of the women interviewed who suffered pain as a result of their condition spoke of how it impacted every part of their lives, particularly in terms of not being able to get enough sleep and being physically, mentally, emotionally, and spiritually exhausted.

Physical Impacts

- The following is a quote by a participant with trigeminal neuralgia, a neurological condition that causes extreme pain:

- *It's a nerve disorder that causes extreme stabbing pain in parts of my face. The pain is so bad sometimes, that no amount of Advil or Tylenol can touch it. I've had days where I can't eat, I can't talk, I can't even lay down because any movement sends shooting pain throughout my head and face. I take upwards of 30 pills a day to manage the pain. I'm not pain free, but they do help. Living with this condition has impacted every aspect of mine and my family's life.*

Results

- ***Environment***
- For those living in areas with severe environmental contamination for example, traditional practices such as fishing and hunting became a risk factor for certain neurological conditions.

Environmental Impacts

- One participant shares concern regarding environmental impacts in her community:

- *I think like our reserve has had neurologic problems since the ‘70s, but prior to that though because our system has been polluted by mercury. And these are third generations now, these young women sitting here. I was the second generation; my parents were the first generation. So it’s a ripple effect, they’ll see this for a while because mercury is still in our system, in our river system.*

Results

- ***Family and Community Impacts***
- Living with a neurological condition or caring for someone with a neurological condition affects and connects everyone around that person. Family can contribute significantly to the recovery process. Some interviewees talked about how their neurological condition negatively impacted their relationship with family.

Results

- ***Life Impacts***
- Both caregivers and those living with a condition spoke about how the condition interfered with their work life. Some talked about having to relocate their families because it was cheaper than renovating their homes. People talked about how doctor’s appointments took them away from their home, sometimes for extended periods of time; they talked about the time and expense involved with each medical appointment.

Results - Gaps

- ***Healthcare Gaps***
- The high number of undiagnosed neurological conditions in the north is in part due to the fact that many health insurance policies do not support all the costs associated with accessing services. Researchers heard stories about transportation and accommodation costs deterring or delaying patients’ access to health and other services.

Results - Gaps

- ***Knowledge and Information Gaps***
- A common story researchers heard was related to the lack of “easy to understand” information about their condition. Participants described not knowing what to expect, how to manage their conditions, and how confusing new technical terms were, and that the language used during medical appointments was confusing and made them feel helpless and isolated.

Results – Risk Factors

- ***Risk Factors***
- When looking at risk factors amongst the Aboriginal population, the prevalence rates appear to be higher among Aboriginal people than the general Canadian population. Research participants spoke about genetic risk factors (e.g. Epilepsy and Seizures); and lifestyle (unhealthy diet, alcohol and drug use, and smoking), and spoke about having to deal with multiple issues and conditions. Diabetes, cardiovascular disease, obesity and other injury were most commonly reported.

Results – Protective Factors

- ***Protective Factors***
- Some research participants talked about how they were able to tap into an internal strength in order to cope with their condition, yet others talked about how they lacked coping skills. Sometimes experiencing difficult circumstances can build confidence and resiliency; one participant relayed a story of how her being a residential school survivor allowed her to overcome her fear of public speaking.

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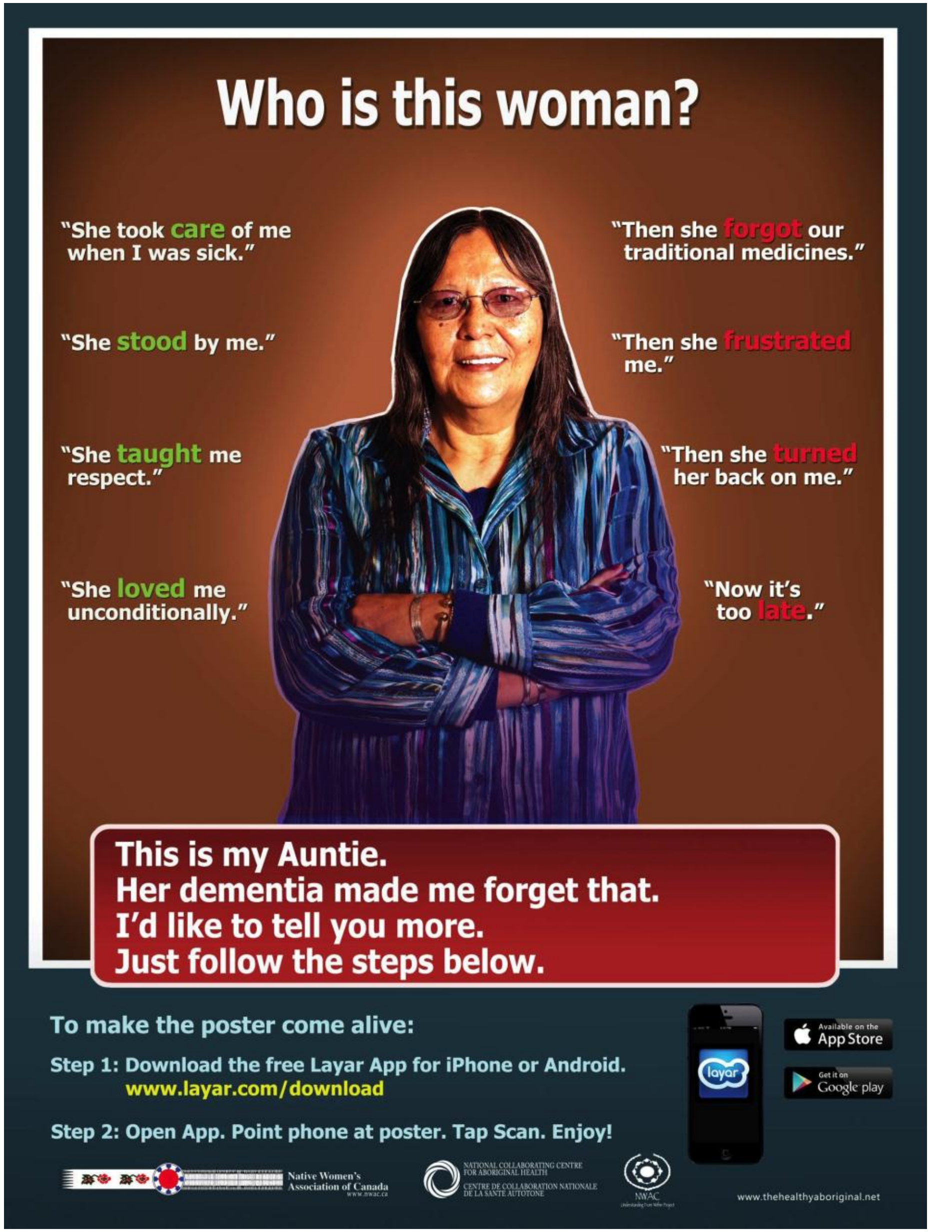
Recommendations

- **Improved Relationships**
- *Provision of Aboriginal Patient Advocates*
- *Promote the use of plain language*
- *Respect for traditional ways*
- *Implement a national cultural competence program for all health care providers*
- *Provision of dedicated space for spiritual ceremony and cultural practices*

Recommendations

- **Aboriginal Driven Health Services**
- *Bring more services to the community*
- *Aboriginal health programming for Aboriginal people by Aboriginal people*
- *Aboriginal engagement in Aboriginal health policy*
- *Aboriginal specific data collection*
- **Research Needs**
- *Aboriginal men’s health*
- *Interactions of co-morbidities with neurological conditions*
- *Aligning impacts with available supports*
- *Examine how Aboriginal specific risk factors differ from mainstream*
- *Examine relationship between risk factors and prevalence*
- *Examine conditions that cause higher morbidity rates*
- *Relevance, subpopulations, violence*

Community Resources



Who is this woman?

"She took **care** of me when I was sick."

"She **stood** by me."

"She **taught** me respect."

"She **loved** me unconditionally."

"Then she **forgot** our traditional medicines."

"Then she **frustrated** me."

"Then she **turned** her back on me."

"Now it's too **late**."

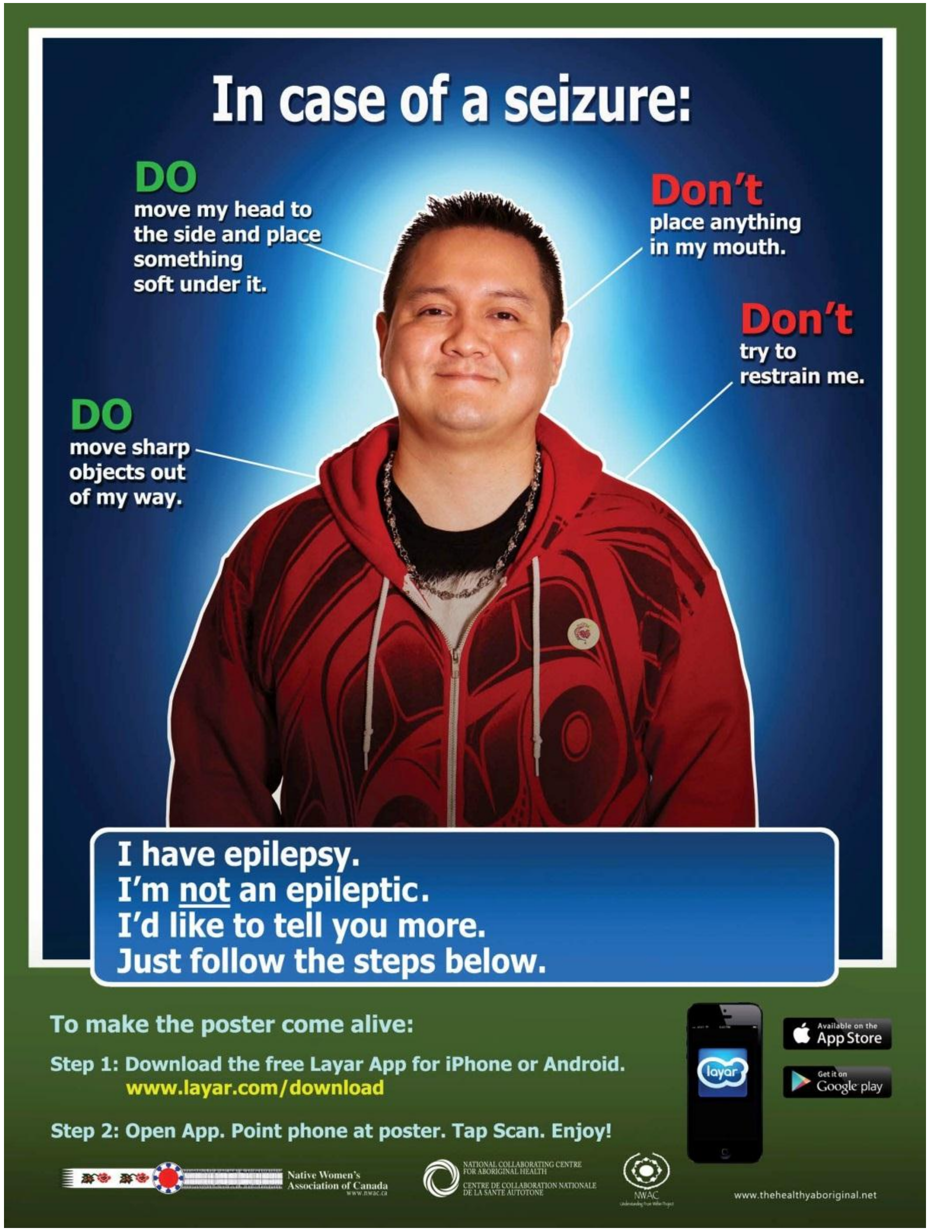
This is my Auntie.
Her dementia made me forget that.
I'd like to tell you more.
Just follow the steps below.

To make the poster come alive:

Step 1: Download the free Layar App for iPhone or Android.
www.layar.com/download

Step 2: Open App. Point phone at poster. Tap Scan. Enjoy!

www.thehealthyaboriginal.net



In case of a seizure:

DO move my head to the side and place something soft under it.

DO move sharp objects out of my way.

Don't place anything in my mouth.

Don't try to restrain me.

I have epilepsy.
I'm <u>not</u> an epileptic.
I'd like to tell you more.
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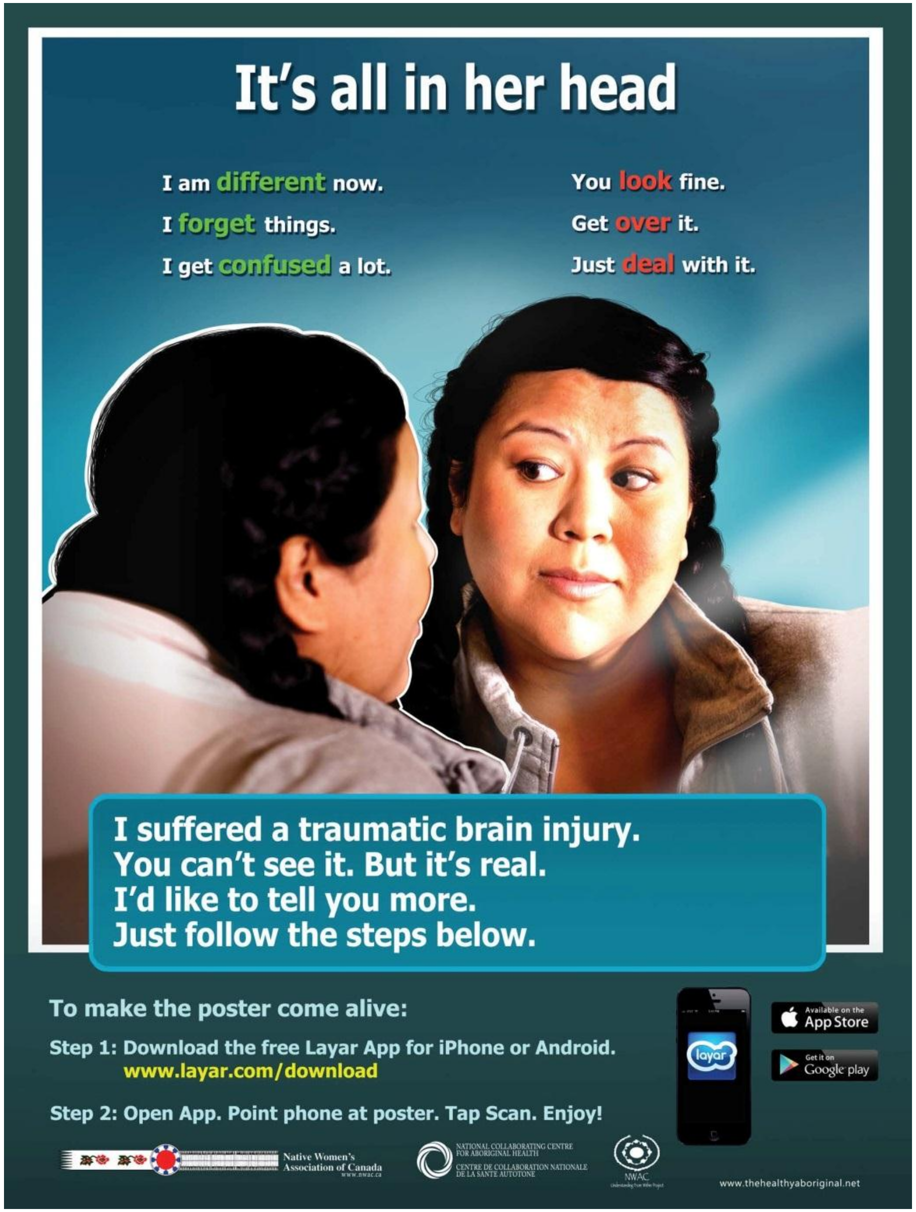

It's all in her head

I am **different** now.
I **forget** things.
I get **confused** a lot.

You **look** fine.
Get **over** it.
Just **deal** with it.

I suffered a traumatic brain injury.
You can't see it. But it's real.
I'd like to tell you more.
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NATIONAL COLLABORATING CENTRE FOR ABORIGINAL HEALTH
CENTRE DE COLLABORATION NATIONALE DE LA SANTE AUTOTONE

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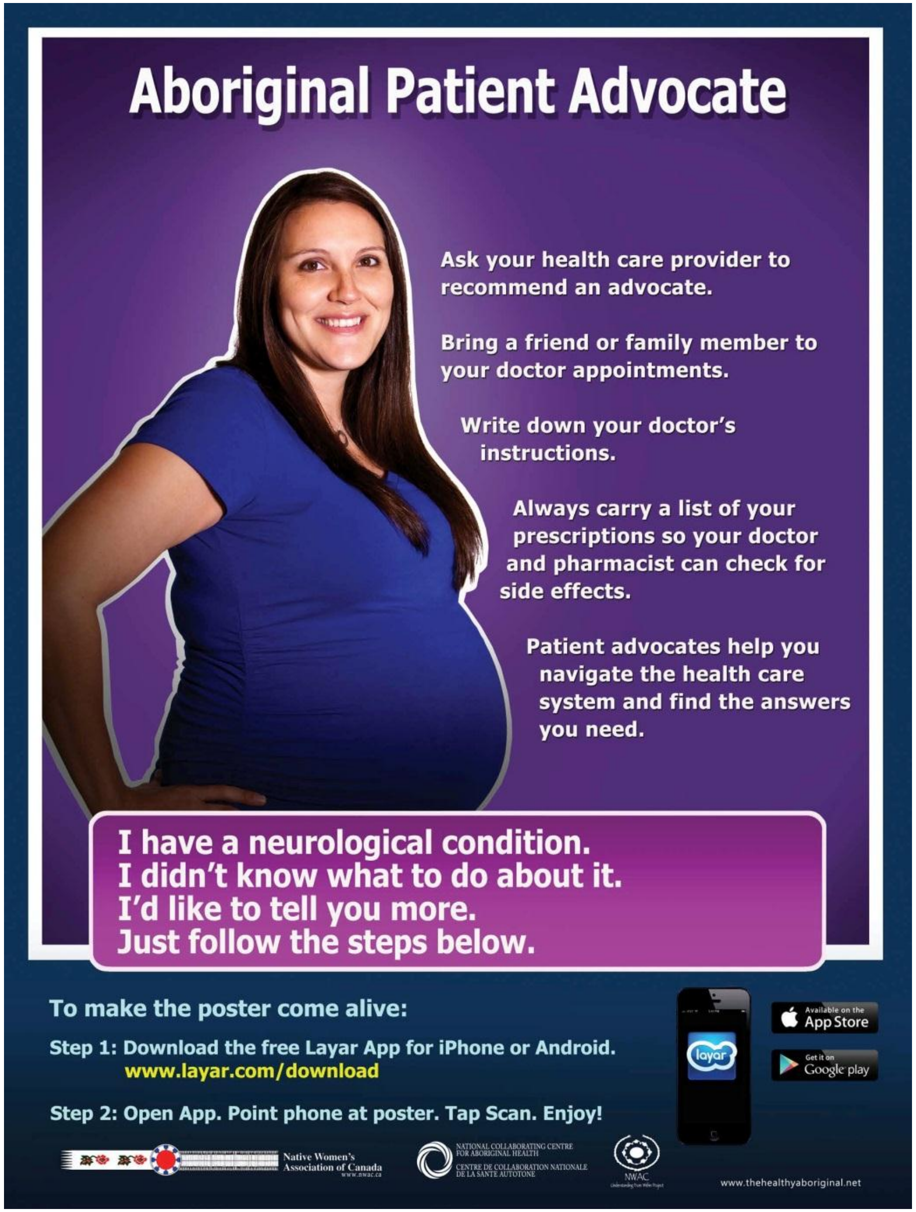

Aboriginal Patient Advocate

Ask your health care provider to recommend an advocate.

Bring a friend or family member to your doctor appointments.

Write down your doctor's instructions.

Always carry a list of your prescriptions so your doctor and pharmacist can check for side effects.

Patient advocates help you navigate the health care system and find the answers you need.

I have a neurological condition.
I didn't know what to do about it.
I'd like to tell you more.
Just follow the steps below.

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Thank You /Megweetch

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