Toronto Stroke Networks

Life After Stroke: a question guide to help you think about your needs after your stroke

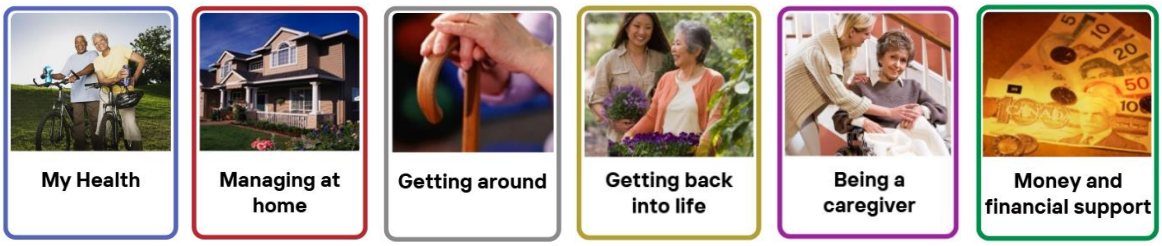
Returning to the community is an important part of recovering from a stroke. Some people living with stroke say they feel anxious and unprepared when leaving the hospital. They often say they don't know what to expect or what questions to ask.

This booklet can help you on your stroke recovery journey. It will help you to:

- Know what questions to ask
- Set goals for yourself
- Be more involved in your care and recovery
- Have a better sense of control
- Reduce your fear and anxiety

How to use this booklet

1. Click on any of the 6 topic areas below for questions that can help support your recovery and return to the community.



2. Focus on 1 or 2 areas you are thinking about now.
3. Read through the questions for you and your caregiver. You can also ask someone to read them with you.
4. Think about the questions you do not have the answers to.
5. Write down the steps you will take to find the answers.
6. Think about other questions you have and write them down.
7. Review other sections when you are ready.

While you may have other questions not covered here, this tool can be a starting point for meaningful conversations with those around you. You can also use the questions to set goals. **Keep this tool handy and refer to it often.**

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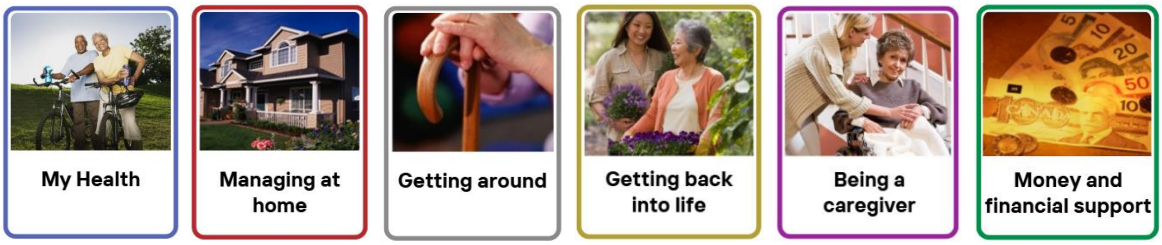
Below is an example of how you can fill it out

Understanding Stroke		**What to do next?** Write it down. Take action if you can
Do I know what the symptoms of a stroke are?	☐ Yes ☒ No	I need to look through the Guide for Stroke Recovery and talk to my doctor about all the signs and symptoms of a stroke.
Do I know what to do if I think I am having a stroke?	☒ Yes ☐ No	

Get started!

Click any image to get to questions on that topic area



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My Health

These questions help you understand important areas of health after a stroke. The questions are divided into medical health (for example: tests and medication), good health (for example: managing risk factors like high blood pressure). and mental health (for example: check if we are feeling sad or worried)

Medical

Understanding Stroke		**What to do next?** Write it down. Take action if you can
Do I know what the symptoms of a stroke are?	☐ Yes ☐ No	
Do I know what to do if I think I am having a stroke?	☐ Yes ☐ No	
Do I know what kind of stroke I had?	☐ Yes ☐ No	
Do I know what caused my stroke?	☐ Yes ☐ No	
Do I know my risk factors for a stroke?	☐ Yes ☐ No	
Do I know how to lower my risk for another stroke?	☐ Yes ☐ No	
Do I have a plan in place if I have an emergency?	☐ Yes ☐ No	

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Tests		**What to do next?** Write it down. Take action if you can
Do I know the types of tests the doctor has ordered?	☐ Yes ☐ No	
Do I know why I need the tests?	☐ Yes ☐ No	
Do I understand the results of the tests I have had?	☐ Yes ☐ No	
Are there any other tests I think I need?	☐ Yes ☐ No	

Medications		**What to do next?** Write it down. Take action if you can
Do I have the list of medications I need to take?	☐ Yes ☐ No	
Do I know how each medication helps me?	☐ Yes ☐ No	
Do I know how my medications interact with one another and/or with the food I eat?	☐ Yes ☐ No	
Do I know how and when to take each medication (for example: with meals, injection, or crushed)?	☐ Yes ☐ No	
Do I need reminders to take my medication?	☐ Yes ☐ No	
Do I need a way to organize the medications I take (for example: a blister pack or pill organizers)?	☐ Yes ☐ No	
Does the pharmacy I use deliver medications to the home?	☐ Yes ☐ No	

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Advance Care Planning		What to do next? Write it down. Take action if you can
Are my care wishes written down (living will) and/or known by my family/loved ones?	☐ Yes ☐ No	
Have I legally named someone to be my Power of Attorney for personal care and property?	☐ Yes ☐ No	
Do I have a will?	☐ Yes ☐ No	
Do my loved ones know where my important documents are located (for example: Power of Attorney, living will)?	☐ Yes ☐ No	

Good Health

Atrial Fibrillation		What to do next? Write it down. Take action if you can
Do I have symptoms of atrial fibrillation?	☐ Yes ☐ No	
Do I need to be tested for atrial fibrillation?	☐ Yes ☐ No	
Do I know what my medications are to manage my atrial fibrillation?	☐ Yes ☐ No	
Do I know how exercise affects my atrial fibrillation?	☐ Yes ☐ No	
Do I know who to speak with about atrial fibrillation?	☐ Yes ☐ No	

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Blood Pressure		**What to do next?** Write it down. Take action if you can
Do I know what my target blood pressure should be?	☐ Yes ☐ No	
Do I know how often my blood pressure should be checked?	☐ Yes ☐ No	
Do I know what I can do to control high blood pressure?	☐ Yes ☐ No	
Do I know how exercise affects my blood pressure?	☐ Yes ☐ No	
Do I know what foods will affect my blood pressure?	☐ Yes ☐ No	
Do I know what my daily sodium (salt) limit should be?	☐ Yes ☐ No	
Do I know if I should be on blood pressure medication?	☐ Yes ☐ No	
Do I have a way to check my blood pressure (for example: my own blood pressure machine or ones at the pharmacy)?	☐ Yes ☐ No	

Cholesterol		**What to do next?** Write it down. Take action if you can
Do I know what my cholesterol levels should be?	☐ Yes ☐ No	
Do I know what makes my cholesterol levels go up?	☐ Yes ☐ No	
Do I know what I can do to lower my cholesterol levels?	☐ Yes ☐ No	

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Should I be taking medication to lower my cholesterol?	☐ Yes ☐ No	
Do I know who to speak with about my cholesterol levels?	☐ Yes ☐ No	

Diabetes		**What to do next?** Write it down. Take action if you can
What should my blood sugar targets be?	☐ Yes ☐ No	
Do I know how to check my blood sugars and how often I should be checking them? (for example: use glucometer kit)	☐ Yes ☐ No	
Do I know what medications I should be taking to control my blood sugars and when to take them?	☐ Yes ☐ No	
Do I know how to control my blood sugar levels?	☐ Yes ☐ No	
Do I know what to do if my blood sugar level gets too low or too high?	☐ Yes ☐ No	
Do I know what can cause high or low blood sugars?	☐ Yes ☐ No	
Am I cooking and eating the right foods to manage my blood sugars?	☐ Yes ☐ No	
Do I know who to speak with about my blood sugar levels?	☐ Yes ☐ No	

Healthy Eating		**What to do next?** Write it down. Take action if you can
Do I need to change the way I eat to help prevent another stroke?	☐ Yes ☐ No	

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Do I know what a well-balanced meal is?	☐ Yes ☐ No	
Do I eat well-balanced meals?	☐ Yes ☐ No	
Do I know how to prepare healthy meals?	☐ Yes ☐ No	
Do I need help preparing my meals?	☐ Yes ☐ No	

Healthy Weight		**What to do next?** Write it down. Take action if you can
Do I know what a healthy weight is for me?	☐ Yes ☐ No	
Do I know how to lose weight if I need to?	☐ Yes ☐ No	
Do I know how to gain weight if I need to?	☐ Yes ☐ No	
Do I have a plan for how best to get to a healthy weight?	☐ Yes ☐ No	

Exercise		**What to do next?** Write it down. Take action if you can
Am I getting enough exercise?	☐ Yes ☐ No	
Am I doing exercises that are safe for me?	☐ Yes ☐ No	
Do I need help so the exercises I enjoy are safer to do?	☐ Yes ☐ No	
Do I know where to find exercise programs that are right for me?	☐ Yes ☐ No	

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Alcohol		**What to do next?** Write it down. Take action if you can
Do I know how alcohol can increase my risk of stroke?	☐ Yes ☐ No	
Is it safe to drink alcohol if I am taking medication?	☐ Yes ☐ No	
Do I need help managing how much alcohol I drink?	☐ Yes ☐ No	

Being Smoke Free		**What to do next?** Write it down. Take action if you can
Do I know how smoking increases my risk of stroke?	☐ Yes ☐ No	
Am I ready to quit smoking?	☐ Yes ☐ No	
Do I have the support I need to continue being smoke-free?	☐ Yes ☐ No	
Do I know where to find help to stop smoking?	☐ Yes ☐ No	

Sleep Apnea		**What to do next?** Write it down. Take action if you can
Has anyone ever told me that I stop breathing or gasp when I am asleep?	☐ Yes ☐ No	
Do I always feel tired or doze off during the day?	☐ Yes ☐ No	
Do I know who to talk to about getting tested for sleep apnea?	☐ Yes ☐ No	
Do I know what treatment is best for me to manage sleep apnea?	☐ Yes ☐ No	

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Mental Health

Depression		What to do next? Write it down. Take action if you can
Have I lost interest in things I used to enjoy?	☐ Yes ☐ No	
Have I noticed any changes in my mood, or how I act or behave?	☐ Yes ☐ No	
Am I sleeping more than usual or have trouble sleeping?	☐ Yes ☐ No	
Am I easily irritable or frustrated?	☐ Yes ☐ No	
Do I feel less motivated or interested in doing things?	☐ Yes ☐ No	
Has my appetite changed?	☐ Yes ☐ No	
Do I have difficulty concentrating?	☐ Yes ☐ No	
Do I feel alone, angry, scared or hopeless?	☐ Yes ☐ No	
Have I had thoughts about ending my life?	☐ Yes ☐ No	
Do I know where to get help if I answered ‘yes’ to any of the questions above?	☐ Yes ☐ No	

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Managing the Effects of Stroke

Perception and Cognition		**What to do next?** Write it down. Take action if you can
Do I have trouble with my memory?	☐ Yes ☐ No	
Can I focus and think clearly?	☐ Yes ☐ No	
Can I make sense of what I see around me?	☐ Yes ☐ No	
Do I know what strategies to use for my memory?	☐ Yes ☐ No	
Do I need any memory aids?	☐ Yes ☐ No	
Do I know what strategies to use to see and find things better?	☐ Yes ☐ No	
Do I need any visual aids?	☐ Yes ☐ No	
Do I know where to find help if I'm not coping with these changes?	☐ Yes ☐ No	

Pain		**What to do next?** Write it down. Take action if you can
Does pain limit or stop me from doing the things I need or like to do?	☐ Yes ☐ No	
Do I know what to do if my pain is causing other problems (for example: anxiety, poor appetite, mobility, memory problems, sleep issues)?	☐ Yes ☐ No	

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Do I know what to do if my pain gets worse, is more frequent, or lasts longer?	☐ Yes ☐ No	
If I have pain, do I know what medications I can take?	☐ Yes ☐ No	

Fatigue and Sleep		**What to do next?** Write it down. Take action if you can
Do I have trouble sleeping?	☐ Yes ☐ No	
Am I worried, anxious or is my mind racing when I am trying to rest?	☐ Yes ☐ No	
Am I too tired to do the things I need to do or enjoy?	☐ Yes ☐ No	
Do I know what I can do to sleep better?	☐ Yes ☐ No	

Swallowing Difficulties		**What to do next?** Write it down. Take action if you can
Do I have trouble chewing or swallowing?	☐ Yes ☐ No	
Do I know ways to be safe when eating (for example: sitting up, clearing food from mouth)	☐ Yes ☐ No	
Do I need food softened, minced or pureed so I can swallow safely?	☐ Yes ☐ No	
Do I need drinks thickened so I can swallow safely?	☐ Yes ☐ No	
If I have a feeding tube, do I know how to manage it?	☐ Yes ☐ No	

For the caregiver: Do I know how to help my loved one if they need help with any of the above?	☐ Yes ☐ No	

Aphasia and Communication		**What to do next?** Write it down. Take action if you can
Can I communicate my needs and wishes so that I am understood?	☐ Yes ☐ No	
Can my family and friends communicate with me?		
Do I know how to tell people that I have difficulty communicating?	☐ Yes ☐ No	
Can I join in on social situations?	☐ Yes ☐ No	
Do I need any supports to help me communicate (for example: a computer, communication board, aphasia group)?	☐ Yes ☐ No	

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Managing at Home

These questions help you think about staying safe at home (for example removing things that might cause falls). They also help you think about if you can safely do everyday activities (for example: getting dressed or going to the store) or if you need assistive devices.

Where I live		**What to do next?** Write it down. Take action if you can
Do I have concerns about living safely on my own?	☐ Yes ☐ No	
Do I need to make changes to my home so it is safe and easy to move around? (for example: railing, remove rugs or clutter, stair glide)	☐ Yes ☐ No	
Do I know what funding is available if changes are needed in my home?	☐ Yes ☐ No	
Do I need help from family, friends or neighbours to manage at home?	☐ Yes ☐ No	
Do I need extra services coming into my home to live safely?	☐ Yes ☐ No	
Do I need a way to call for help in case of an emergency (for example: medical alert device, cell phone)?	☐ Yes ☐ No	
Do I know where to get help if I can no longer live in my home?	☐ Yes ☐ No	
Am I afraid of falling?	☐ Yes ☐ No	
Do I know how to prevent a fall?	☐ Yes ☐ No	

Will I know what to do if I fall?	☐ Yes ☐ No	
Do I need any equipment to help prevent me from falling?	☐ Yes ☐ No	
Do I know what strategies to use to prevent falls?	☐ Yes ☐ No	

Self-care and day-to-day tasks		**What to do next?** Write it down. Take action if you can
Can I tell when I have to go to the washroom?	☐ Yes ☐ No	
Can I control my bowel and/or bladder?	☐ Yes ☐ No	
Do I need help with day-to-day tasks (for example: bathing, dressing, cooking, cleaning)?	☐ Yes ☐ No	
Do I need devices to manage day-to-day tasks (for example: a walker, shower chair, hand-held showerhead or one-handed devices)?	☐ Yes ☐ No	
Do I need help to manage activities in the community (for example: getting groceries, banking)?	☐ Yes ☐ No	
Do I know where to go to find help?	☐ Yes ☐ No	

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Getting Around

These questions focus on getting to the places you need to go (for example: driving or public transit). They ask if you have the equipment to get in and out of our house and move around safely.

Mobility/Getting Around		What to do next? Write it down. Take action if you can
Do I have comfortable footwear?	☐ Yes ☐ No	
Am I able to move around safely?	☐ Yes ☐ No	
Do I need help to move around better?	☐ Yes ☐ No	
Do I need any devices to get in and out of my home (for example: a railing, ramp or stairlift)?	☐ Yes ☐ No	
Do I have the equipment I need to move around safely (for example: a wheelchair, walker, or cane)?	☐ Yes ☐ No	
Do I know where I can get the equipment I need?	☐ Yes ☐ No	
Can I get funding to help pay for equipment?	☐ Yes ☐ No	
Do I know where to get help to move around better?	☐ Yes ☐ No	
Can I get to the places I need to go (for example: get to the grocery store, bank)?	☐ Yes ☐ No	
Can I get to the exercise programs that are near my home?	☐ Yes ☐ No	

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Can I get to my local programs (for example: exercise, pool, social, crafts)	☐ Yes ☐ No	
Do I know how to access on-line services if I can't get outside (for example: online banking or grocery service, Wheeltrans, Uber)?	☐ Yes ☐ No	
Do I know what my options are if I need a ride (for example: Uber, WheelTrans, or volunteer driving services)?	☐ Yes ☐ No	

Driving		**What to do next?** Write it down. Take action if you can
Has the doctor (family doctor, neurologist, physiatrist) advised me not to drive?	☐ Yes ☐ No	
Has the doctor reported me to the Ministry of Transportation to have my license reviewed?	☐ Yes ☐ No	
Do I know what steps to take to get my licence back?	☐ Yes ☐ No	
Do I need to have a driving test?	☐ Yes ☐ No	
Do I know where to go if I need a driving test?	☐ Yes ☐ No	
Do I know how much the test costs?	☐ Yes ☐ No	
Have I spoken with my rehabilitation team about ways to improve my driving skills?	☐ Yes ☐ No	

Have I spoken with my rehabilitation team about ways to adapt my car?	☐ Yes ☐ No	
Do I know which companies can help me to adapt my car?	☐ Yes ☐ No	
Can I apply for funding to help cover the cost of these changes?	☐ Yes ☐ No	
Have I told my insurance company about any changes (for example: license or car modifications)?	☐ Yes ☐ No	
Do I know what options there are if I can no longer drive (for example: Wheel-Trans, Uber, or volunteer driving services)?	☐ Yes ☐ No	

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Getting Back into Life

These questions help you think about changes in your daily life after a stroke for example, taking care of children or pets. They help you think if you can return to activities you enjoy and your relationships with family and friends.

Life roles		**What to do next?** Write it down. Take action if you can
Has there been a change in my day-to-day roles since my stroke (for example: taking care of children, doing things around the house or at work)?	☐ Yes ☐ No	
Do I know where to get advice so I can continue my roles or learn about new roles?	☐ Yes ☐ No	
Do I need to learn new strategies and skills to manage day-to-day?	☐ Yes ☐ No	
Can I get back to work, volunteer or to school?	☐ Yes ☐ No	
Do I need work retraining? (also see the section on return to work)	☐ Yes ☐ No	
Have my relationships with my partner, children, family or friends changed?	☐ Yes ☐ No	
If answered ‘yes’ to any of the questions above, do I know who to talk to or how to get help?	☐ Yes ☐ No	

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Social support and activities		What to do next? Write it down. Take action if you can
Are there activities I enjoy and want to continue but am not sure how to?	☐ Yes ☐ No	
Am I able to visit the same places as before (for example: social events or place of worship)?	☐ Yes ☐ No	
Do I want to join any social, recreational, or fitness programs?	☐ Yes ☐ No	
Do I need any equipment so I can take part in social, recreational or fitness activities?	☐ Yes ☐ No	
Are my family, friends and I coping well?	☐ Yes ☐ No	
Am I interested in joining a support group for people who have had a stroke? Do I know where to find one?	☐ Yes ☐ No	

Sex and intimacy		What to do next? Write it down. Take action if you can
Do I know if it is safe to have sex again?	☐ Yes ☐ No	
If I am unable to have sex, do I know how to be intimate?	☐ Yes ☐ No	
Am I able to express my feelings and needs during sex and intimacy?	☐ Yes ☐ No	
Do I know who to talk to about sex and intimacy after my stroke (for example: equipment, different positions or medications)?	☐ Yes ☐ No	

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Questions for partners:		
My partner's sexual behaviours are different than before the stroke. Do I know what is causing this? Am I coping well with these changes?	☐ Yes ☐ No	
Do I feel uncomfortable being intimate with my partner because I am now providing them care?	☐ Yes ☐ No	

Work, school, volunteering		What to do next? Write it down. Take action if you can
Am I able to return to work, school, or volunteering?	☐ Yes ☐ No	
Do I know when I can return to work or school?	☐ Yes ☐ No	
Do I know who can assess me to see if I can go back to work or school?	☐ Yes ☐ No	
Have I talked with my boss about what will be expected of me if/when I return to work (for example: flexible hours, work from home or different responsibilities)?	☐ Yes ☐ No	
Do I know who to talk to at my school or work about changes to make it accessible (for example: ramps, proper desk and chair, changes in equipment)?	☐ Yes ☐ No	
If I can't return to my job, do I know what other options I have (for example: train for another job, return to school, or retire)?	☐ Yes ☐ No	

I would like to volunteer. Do I know where to find information about volunteering?	☐ Yes ☐ No	

Travelling		**What to do next?** Write it down. Take action if you can
Is it safe for me to travel by car, train, boat or plane after stroke?	☐ Yes ☐ No	
Is there anything specific I need to aware of when travelling after a stroke (for example: precautions, medications, vaccinations)?	☐ Yes ☐ No	
Do I need to speak to someone to ensure things are set up at the place I am travelling to (for examples: bathroom, equipment, ramps)?	☐ Yes ☐ No	
Do I travel insurance?	☐ Yes ☐ No	
Do I know what to do if something happens while away from home?	☐ Yes ☐ No	
For the caregiver: Do I know what to do if something happens while we are away?	☐ Yes ☐ No	

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Being a Caregiver

These questions ask about the role of a caregiver (for example: if the caregiver is managing well, needing a break, and/or missing activities they enjoy).

Being a caregiver		**What to do next?** Write it down. Take action if you can
For the person with stroke:		
Do I need and/or have a caregiver to help me in my day-to-day life?	☐ Yes ☐ No	
Is my caregiver able and willing to help me in my day-to-day life?	☐ Yes ☐ No	
How is my caregiver coping? Are they showing signs of depression or burn-out?	☐ Yes ☐ No	
Does my caregiver need a break from caring for me?	☐ Yes ☐ No	
Do my caregiver and I know where to go for help if we need it (for example: family, friends, community services, respite programs or support groups)?	☐ Yes ☐ No	
Do my caregiver and I know how to access resources and services that we need?	☐ Yes ☐ No	
For the caregiver:		
Do I feel that I am managing well with looking after my loved one?	☐ Yes ☐ No	
Are there activities I enjoy but am unable to continue doing?	☐ Yes ☐ No	

Do I know how I can help my loved one to be more independent?	☐ Yes ☐ No	
Is my loved one showing changes in behaviour that put me at risk?	☐ Yes ☐ No	
Do I know the signs of caregiver stress or burnout?	☐ Yes ☐ No	
If I need help, do I know how to access resources and services to support me?	☐ Yes ☐ No	

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Money and Financial Support

These questions help you think about managing money and getting financial help (for example: if you have insurance or know how to access government programs). They help you to think about appointing a power of attorney.

Finances and income support		**What to do next?** Write it down. Take action if you can
Do I have health/disability insurance that can help pay for some of my costs)?	☐ Yes ☐ No	
Do I have short-term and long-term disability benefits through work?	☐ Yes ☐ No	
Do I know who to talk to about my work benefits (for example: human resources or occupational health)?	☐ Yes ☐ No	
Do I need financial support (for example: to look after my family, pay for medications, equipment or changes to my home or car)?	☐ Yes ☐ No	
Am I eligible for financial assistance?	☐ Yes ☐ No	
Do I know about government funding programs and tax benefits available to persons with disabilities (for example: Registered Disability Savings plan, Ontario Disability Support Program or T2201 tax form)?	☐ Yes ☐ No	
Am I able to manage my money (for example, pay bills or balance a budget)?	☐ Yes ☐ No	

Can my caregiver manage the finances?	☐ Yes ☐ No	
Do I need a power of attorney to manage my money?	☐ Yes ☐ No	
Do I know when I should call the Office of the Public Guardian and Trustee?	☐ Yes ☐ No	
Do I feel that I am being taken advantage of when it comes to my money?	☐ Yes ☐ No	
Do I know where to find help if I need resources and services to support me?	☐ Yes ☐ No	

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