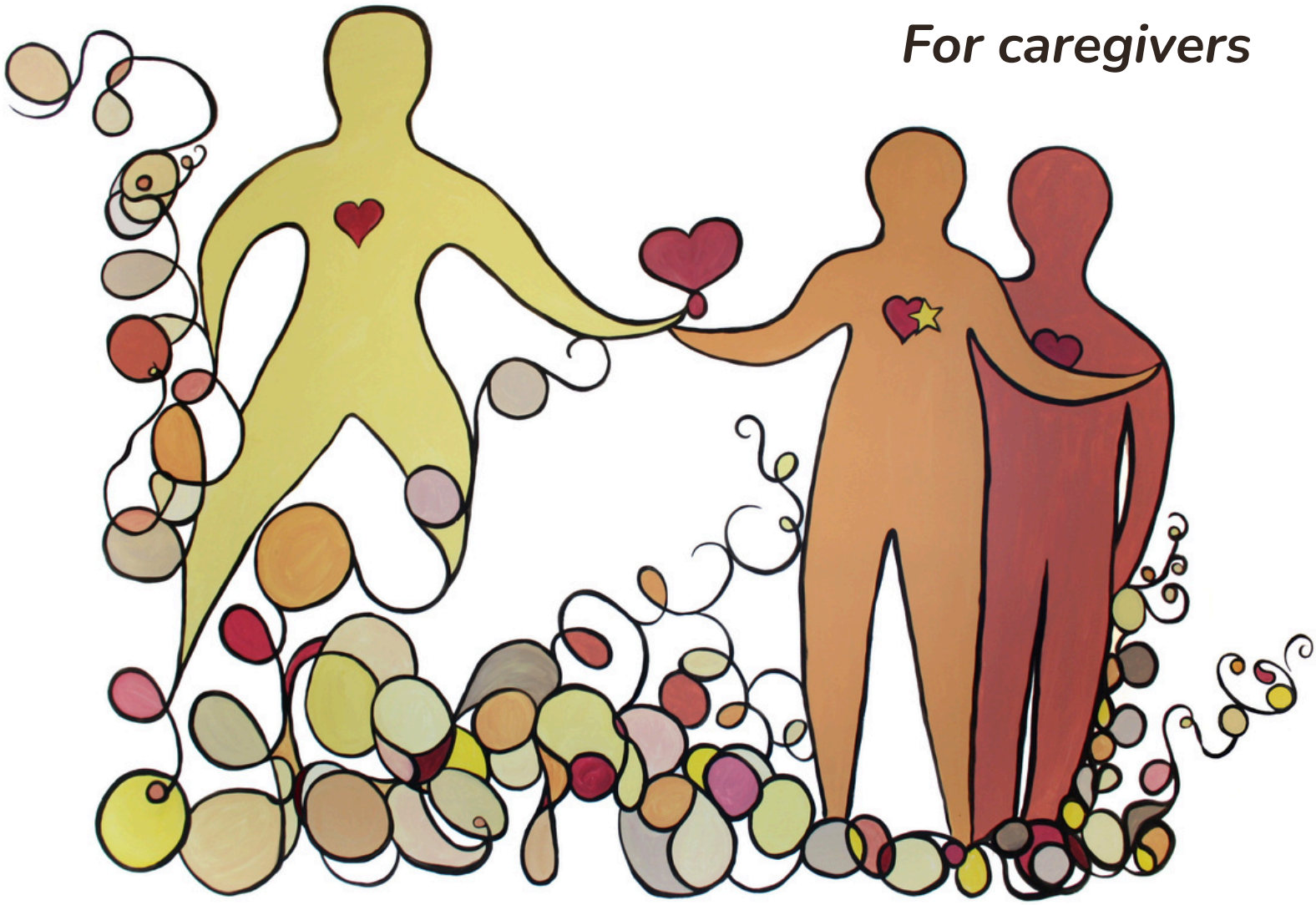
MAGAZINE

STRONG HEARTED CAREGIVER PARENTS

For caregivers



QUIZ!

Are you a caregiver?

Being a parent and also being a caregiver..

HOW TO CARE FOR MYSELF!

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How do you feel about the support you provide to a person living with an intellectual or physical disability, or an autism spectrum disorder?

- I feel like I'm the only one helping
- I feel overwhelmed by everything I have to do and I have no time for myself

There is help available!!

This magazine will help you learn more about caregiving and show you where to find support.

QUIZ

ARE YOU A CAREGIVER?

1 Does someone in your life (child, sibling, parent, friend, etc.) live with an intellectual or physical disability, or an autism spectrum disorder?

- ◯ Yes — 2 points
- ◯ No — 0 point

2 Do you think that the challenges of the person living with an intellectual or physical disability, or an autism spectrum disorder, has an impact on you?

- ◯ Yes — 2 points
- ◯ At times — 1 point
- ◯ No — 0 point

3 Do you worry about the person you care for when you're not around?

- ◯ Yes — 2 points
- ◯ At times — 1 point
- ◯ No — 0 point

4 Does the person living with an intellectual or physical disability, or an autism spectrum disorder, need help with certain tasks (such as assistance with eating, adapted transportation, hygiene support, help with school difficulties, increased supervision, etc.)?

- ◯ Yes — 2 points
- ◯ At times — 1 point
- ◯ No — 0 point

5 Do you have to accompany a person living with an intellectual or physical disability, or an autism spectrum disorder, to numerous appointments on a regular basis with various professionals (such as an occupational therapist, physiotherapist, social worker, specialised educator, etc.)?

- ◯ Yes — 2 points
- ◯ At times — 1 point
- ◯ No — 0 point

6 Do you need to take care of a person by preparing their meals, giving them their medications, helping them dress, on a regular and detailed basis, etc.

- ◯ Yes — 2 points
- ◯ At times — 1 point
- ◯ No — 0 point

7 Have you ever had to postpone your activities due to your responsibilities toward a person living with an intellectual or physical disability, or an autism spectrum disorder?

- ◯ Yes — 2 points
- ◯ At times — 1 point
- ◯ No — 0 point

8 Have you ever been forced to reduce your working hours, quit your job, or even lose your job in order to care for a person living with an intellectual or physical disability, or an autism spectrum disorder?

- ◯ Yes — 2 points
- ◯ At times — 1 point
- ◯ No — 0 point

9 Has your relationship been impacted by the time you devote to a person living with an intellectual or physical disability, or an autism spectrum disorder?

- ◯ Yes — 2 points
- ◯ At times — 1 point
- ◯ No — 0 point

10 Is it difficult for you to find time for activities, sports, or to see friends because you provide support to a person living with an intellectual or physical disability, or an autism spectrum disorder?

- ◯ Yes — 2 points
- ◯ At times — 1 point
- ◯ No — 0 point

11 Have you noticed that your other children have experienced jealousy or reacted strongly because of the time you dedicate to a person living with an intellectual or physical disability, or an autism spectrum disorder?

- ◯ Yes — 2 points
- ◯ At times — 1 point
- ◯ No — 0 point

RESULTS

Calculate your total points (Yes = 2 points; At times = 1 point; No = 0 points).

Between 0 and 1 point: You may not identify with the definition of caregiving, but keep reading the magazine! It's quite possible that some people in your circle are caregivers without realizing it.

Between 2 and 11 points: You might be a caregiver for someone in your circle. Your responsibility load is significant. That said, it's more common than you think! However, few parents identify as caregivers.

Between 12 and 22 points: You are clearly a caregiver. These responsibilities can weigh heavily on your shoulders, although there are many positive aspects to caregiving (such as developing a strong bond with the person you're helping or feeling a sense of purpose, for example).

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WHAT IS A CAREGIVER?

Did you know?

More than one-third of Quebec adults (2.4 million) are caregivers. Of this number, 35% do not identify as such, which complicates the search for and access to support services specifically intended for caregivers. [2]

A caregiver is:

- A "caregiver is someone who provides support to one or more individuals in their circle who have a temporary or permanent disability of a physical, psychological, psychosocial, or other nature, regardless of their age or living environment, with whom they share an emotional, familial, or non-familial bond" [1]
- Being a parent of a child with special needs
- Sharing life with a partner who has a disease or disability that requires assistance
- Hosting or living with a parent or family member who cannot live alone
- Ensuring the well-being of a loved one living in a care facility by visiting them
- Providing meaningful, continuous, or occasional support
- Adapting one's daily life to ensure the well-being of a loved one
- Cutting oneself off from social networks and depriving oneself of outings
- Having to balance family and work obligations with the role of a caregiver
- In some cases, quitting one's job to care for a loved one
- Taking care of transportation, assistance with personal care, household tasks, emotional support, and coordinating care and services

1. Definition taken from the APPUI Caregiver Support website
2. See “Statistical Survey on Caregiving in Quebec” at L'APPUI

BEING PARENT WHILE BEING A CAREGIVER

Families of individuals with intellectual, physical disabilities, or autism spectrum disorder are similar to all other families in many ways.

However, the family of a person with a disability differs in terms of the greater intensity, variety, and longevity of the effort required to care for the individual.

Indeed, in addition to having to "work harder" (intensity) than a typical family (e.g., providing more daily care for activities such as eating, hygiene, mobility, etc.), families of individuals with disabilities must also address a greater number of areas such as rehabilitation or stimulation (variety).

Furthermore, many of these families provide lifelong support to their child (longevity), as the individual is unable to achieve the independence typically reached in adulthood. [1]

“Parents supporting a child or children with a temporary or permanent disability are part of the **1 500 000 caregivers in Quebec**. They are both parents and caregivers.

Upon reading these words, some of you may react: “I’m just a mom!” – “I take care of my daughter, it’s normal, I’m not a caregiver, I’m just her dad.”

You’re right. First and foremost, you are moms and dads, connected to your child by an emotional bond that no label can fully define.

But your role goes far beyond that. You provide «continuous or occasional support, short-term or long-term (…) with the aim of maintaining and improving [your child's] quality of life.» You are a mom and also a caregiver. You are a dad and your situation is that of a caregiver too. This is your reality.
You can refer to the law! [2] ”

1. www.laressource.ca/images/ressources/ENQUETE_SUR_LES_SERVICES_RECUS_ET_LES_BESOINS_DE_1.pdf
2. www.lappui.org/fr/je-suis-aidant/etre-proche-aidant/les-multiples-visages-des-proches-aidants/etre-parent-proche-aidant/

TESTIMONIALS

Anne-Renée, Alex's mother

"At some point, it gets confusing to know what counts as being a parent or a caregiver" she admits. "I always compare it to if I had a neurotypical child."

Alex is 16 years old. He has a rare genetic syndrome known as 1P36 chromosomal deletion, which results in both physical and intellectual disabilities.

"My child experiences a lot of frustration" she explained. "Because he knows he has limitations. That frustration leads to anxiety, which shows up as aggression." His parents therefore need to assist him with a wide range of basic daily tasks. Every day. In fact, in 16 years, she and her partner Dany have never gone out on a date as a couple. [1]

Marie-Claude, Joanie's mother

Marie-Claude is a teacher and the mother of Joanie, a young adult with cerebral palsy. Joanie does not walk or speak.

Marie-Claude's concerns take many forms: caring for her daughter, the multiple hospital appointments, the lack of resources, complicated paperwork, financial difficulties, the loss of services at age 21, the lack of sleep, and so on. In this whirlwind, Marie-Claude tries not to lose her footing.

"Every two weeks, I give myself two days to focus only on myself. Because otherwise, it would just be the two of us. I would never exist on my own. Even when she's not here, there's an emptiness around me; I feel a bit lost." [3]

Kym Thúy, Valmond's mother

Life gave Kim Thúy a different kind of son, an autistic son.
"When a baby starts crawling, you crawl too to spot electrical outlets, dangers, to keep them from getting hurt. With Valmond, I have to get inside his head and see life the way he does. To understand what feels hostile or difficult for him, what bothers him, what causes him pain."

Caught up in this wave of adjustments and learning, Kim never really questioned whether she had become a caregiver. It was only six years after her son was born that the thought even occurred to her, she says. [2]

Geneviève, Xavier's mother

Geneviève, a history teacher at Collège Brébeuf, is the mother of Xavier, 17 years old. An autistic young man without intellectual disabilities, Xavier is passionate about history and is starting his college studies.

"It's only recently that I realized I am a caregiver, though I still have many questions. We are raising a child who is a bit different, but does that make us "caregivers"? For me, a caregiver was someone who takes care of an elderly person or someone at home who needs help with cleaning or grocery shopping; it was someone who provides assistance so that their loved one can live their final years with dignity. That's not what I do with my child. He is not losing his independence. I am helping him toward independence. I don't know..." [4]

Marc-Antoine, runner and Noah's father

"With Noah (6 years old, living with Down syndrome), we had to consult a wide range of professionals […]. At each visit, we had to listen and try to bring that expertise back home. The specialists gave us assignments, which were very important, because it's at home that the child makes progress. It meant building our toolbox while learning to be parents. Perhaps in that sense, we became caregivers."

"During the week, however, we try to maintain a structured learning environment for him, to continue a bit of what happens at school, wearing our hats as both close caregivers and teachers. I think the term "close caregivers" really captures our roles as parents of a child who is different." [5]

TRANSLATED FROM:

1. www.journalsaint-francois.ca/proche-aidance-la-mission-dun-parent-denfant-handicape
2. www.lappui.org/fr/actualite/entrer-dans-sa-tete/
3. www.lappui.org/fr/actualite/la-tete-a-la-bonne-place-preparer-la-rentree-dun-enfant-different
4. www.lappui.org/fr/actualite/on-existe-a-deux/
5. www.lappui.org/fr/actualite/des-plans-avec-noah/

TAKING CARE OF YOURSELF

Since I have became a caregiver, do I feel that:

- my role weigh more and more on me?
- it is too much, it is beyond my strength?
- I no longer have a life, I feel alone?
- I feel guilty about considering institutional care?
- I find it difficult accepting or asking for help?
- I afraid of the future, my finances are in poor shape?
- I lost the person I care for and it's hard to cope with it?
- I need to talk about my experiences, but those close to me are tired of hearing me?

If you answered yes to one or some of these questions, you can contact the organization Les Aidants du Haut-Saint-Laurent to learn about the services that may be available to you or that best match your needs.

When we think about others, we often take less time for ourselves. Yet, taking time for yourself is essential for your physical and mental health. If you take care of yourself first, you will be more willing to help your loved one.

Find what makes you feel good

Do you enjoy reading? Would you like to learn how to play the piano or draw? Take 30 minutes to relax in a bubble bath? Go ahead, treat yourself!

- Find what helps you unwind, learn new things, and feel accomplished. Nurturing your interests is a way to give yourself a break.
- Once you've found what motivates you, make it a habit and make sure to set aside time for this activity.

Do not neglect your social life

Sometimes, being a caregiver isolates us from others. The responsibilities you have don't always allow you to participate in activities or go out with your friends. Yet, it's so important for your well-being!

- Schedule one or more moments in your day that will allow you to be with the people you love.
- Can't free up time? Use technology! A coffee over FaceTime or Messenger with a friend can be just as refreshing!

Ask for help

Asking for help is not a sign of weakness. The most difficult part is asking!

- Could an organization near you offer help with cleaning or meals? Could a family member step in to do the grocery shopping during a busy week for you? Would the person you're helping be able to receive assistance from the CLSC?

**At the end of the magazine, you will find resources that could be helpful to you.

Learn to respect your limits and to say no

We often notice our own limits when we surpass them. To better recognize them, we must learn to listen to ourselves and pay attention to the emotions that certain situations provoke in us. For example, if a situation makes you uncomfortable, it probably means that a limit has been exceeded. Your feelings are yours, they are very valid and cannot be denied!

- Clearly naming your limit will do you good because it is an act of self-respect first. The other person may react, and that's okay. It takes everyone time to adapt to changes. What matters is that you acknowledge what you feel, because it is completely legitimate.

Move!

Two thousand years ago, someone said, "A healthy mind in a healthy body." It must make sense because we still hear it today!

- Taking care of your body is just as important as taking care of your mental health. You don't need to go to the gym five times a week! Even a 15-minute walk can make a difference, as long as it aligns with your energy level.

Don't ask too much of yourself

Give yourself some "wiggle room"! Like everyone else, you only have 24 hours in a day, and the accumulation of tasks doesn't always allow you to do everything.

- When it piles up, take the time to set your priorities and do what you can in order. And remember, just being there for your loved one is already extraordinary!

LES AIDANTS DU HAUT-ST-LAURENT

Our Mission

Our organization's mission is to prevent burnout and provide support and tools to caregivers, enabling them to better fulfill their role and improve their quality of life.

Client group - All Caregivers

Caregivers responsible for a person under 65 years old:

- Living with an intellectual disability
- Living with a physical disability
- Living with an autism spectrum disorder
- Residing in the territory of the Haut-Saint-Laurent

This magazine is aimed at **All caregivers**, but we also support **Caregivers of seniors** and individuals in **Post-caregiving** situations.

AVAILABLE SERVICES

Support

- Individual support and referrals
- Assistance and guidance through procedures

Meals

- A monthly gathering dedicated to caregivers, centered around sharing a meal.
- Informal meetings where conversations flow freely based on participants' interests, in a non-judgmental space.
- Offered in an open format.
- Participation is by registration and facilitated by a staff member from the organization.
- The location changes each month to explore the flavors of the region.
- Each participant is responsible for covering the cost of their own meal.

Cozy-coffees

- A way for caregivers to share their experiences and personal stories with other participants.
- These groups provide a safe space that values respect, confidentiality, and non-judgment.
- They are offered in an open format, require registration, and are facilitated by a staff member from the organization.

Reflective Workshops

- These workshops help break the isolation caregivers may experience, offering tools to lighten their daily lives and strengthen their resilience.
- They provide an opportunity to share personal experiences with others who are going through similar situations, all within a confidential, respectful, and inclusive space.
- They also offer a moment to recognize one's own strengths, limits, and needs.

RESSOURCES

Les Aidants du Haut-Saint-Laurent

www.aidantshsl.org

Appui proches aidants

www.lappui.org/fr/je-suis-aidant

Proche aidance Québec

www.procheaidance.quebec

Huntingdon CLSC - Psychosocial Intake ID-ASD
450-829-2321 extension 1299

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