CARING FOR A LOVED ONE WITHOUT ISOLATING YOURSELF

A demanding role

Caring for others without forgetting yourself

As we get older, we face many changes that require us to adapt, such as retirement, bereavement or moving to a new home. Becoming a caregiver can be one such change. This demanding role, which is often taken on without any preparation, can lead to stress and isolation.

To stay healthy and maintain a good quality of life, it is important to continue to have other roles and activities that matter to us. This leaflet offers some ideas on how to achieve this.

What is a caregiver?

Any person, regardless of their age or background, who provides support to one or more people in their immediate circle who have a temporary or permanent disability of a physical, psychological, psychosocial or other nature. They share an emotional bond, whether family-related or not, with the person they are helping.

The support provided is ongoing or occasional, short-term or long-term. Under Quebec law, the role of a caregiver is performed on a non-professional basis, in a free, enlightened and revocable manner.

Source: Act to recognize and support caregivers, RLRQ c R-1.1 (Québec). https://www.legisquebec.gouv.qc.ca/fr/document/lc/R-1.1?langCont=en

Am I a caregiver?

It is essential to recognize our role as caregivers, as this role often develops gradually. It may take us a while to realize that we have become the main source of support for a loved one with increasing needs. We then risk burning ourselves out without even thinking to ask for help.

With the proper help, we can continue to enjoy social activities, meaningful relationships, and voluntary or professional engagement, all of which are essential to our well-being. Setting aside these moments for ourselves also helps us to maintain a meaningful personal connection with the person we are caring for.

Becoming aware of our role as a caregiver means:

- Making this new role part of our identity.
- Taking on and managing our new responsibilities more effectively.
- Recognizing our own needs, which are different from those of the person we are caring for.
- Raising awareness and engaging those around us as allies.
- Sharing tasks to reduce the burden and the risk of burnout.
- Breaking the isolation and taking care of our own health.
- Accessing community resources sooner.
- Ensuring our role is recognized by staff at community organizations and within the health and social services network.
- Assert our rights (financial support, time off work, etc.)

Some people are reluctant to identify themselves as caregivers for fear that professionals will ask them to do more, particularly when resources are limited. That is a valid choice. However, it is essential to establish boundaries while still utilizing the available resources.

Tools to help us explore this role in greater depth

Reflex-aidance: thinking about informal caregiving before you have to face it. (In French only for now)
https://observatoireprocheaidance.ca/interactive/Outils_VF2_RVB_Interactif.pdf

Self-assessment questionnaire on the well-being and mistreatment of caregivers, designed to help us reflect on our role and the context in which we carry it out.
https://www-tc.pbs.org/wgbh/caringforyourparents/handbook/pdf/cfyp_self_assessment.pdf

Key figures on caregivers aged 65 and over in Quebec (ISQ, 2023)

Women and men are getting involved

- Among people aged 65 and over, **around one in five (21%) is a caregiver**.
- From the age of 65, women and men are involved in equal numbers.

Caring for more than one person at the age of 65 is common

- **63%** care for 1 person
- **23%** care for 2 people
- **14%** care for 3 or more people

Weekly time commitment

- **16%:** 10 am to 7 pm
- **23%:** 20 hours or more

Work and caregiving

- **More than half** of caregivers aged **65 and over are employed**

A variety of support options

Among those aged 65 and over, the support provided includes:

- **73%:** Transportation
- **48%:** Household chores
- **36%:** Organizing care
- **33%:** Home maintenance
- **32%:** Banking
- **29%:** Personal care
- **17%:** Medical treatment and care

Gender-specific **differences observed:**

- Women aged 65 and over take on a greater share of household chores, organizing care, banking and personal care.
- Men aged 65 and over take on a greater share of household maintenance and transportation.

Effects on social involvement

- **The majority** of caregivers aged 65 and over **cut back on their social and leisure activities** (69% of women, 57% of men).

How can caregiving affect our health?

Caregiving can have **positive effects**. It also has **negative consequences**, particularly when needs increase and support is slow to materialize.

POSITIVE HEALTH EFFECTS

Caring for a loved one can:

- Give a sense of purpose and personal fulfilment
- Bring a deeper meaning to one's life
- Help develop new skills
- Strengthen the bond with the person being cared for
- Enable you to become a partner with healthcare professionals
- Provide a sense of recognition and appreciation

NEGATIVE HEALTH EFFECTS

As the burden grows heavier, the difficulty of balancing different roles and financial worries can increase. This situation can have several effects:

Psychologically: Stress, sadness, guilt, low self-esteem, emotional exhaustion with irritability, anger, loss of joy, loss of motivation, anxiety or depression.

♡ **Physically:** Fatigue, sleep disturbances, cardiovascular disease, and weakening of the immune system.

Socially: Less time spent with one's partner, family, friends, volunteering or leisure activities, which can lead to isolation.

The quality of our social network and active involvement in our community have a direct positive impact on our health.

This is true at any age, but staying socially active becomes even more important for healthy ageing.

5 steps to organizing your support network so you can continue your social activities

1

Identifying as a caregiver

- Recognizing our role and its impact on our lives.
- Let everyone around us and those close to the person we are helping (family, friends, neighbours, maintenance staff, members of the community) know about our role. Exchanging contact details where necessary.
- Reflect on how our personality, culture, religion or values influence our ability to ask for and accept help.

2

Becoming aware of the emotions that influence our request for support

- The emotions experienced in our role as caregivers are varied : anger, sadness, shame, despair. These emotions can hold us back and limit our ability to ask for help.
- Guilt is common: the feeling that we are not doing enough, that we are not measuring up, or that we are failing to alleviate the suffering of the person we are caring for. It can also come with a sense of sacrificing our own life, our aspirations or our well-being.
- Certain fears fuel our reluctance to ask for support: fear of bothering others, of imposing ourselves, of being turned down or of appearing demanding.
- Naming our emotions, recognizing their effects, showing kindness towards ourselves, accepting our limits and expressing what makes us feel good are essential steps in maintaining balance.

3

Identify and prioritize the social activities that matter most to us

- Make a list of the activities that bring us the most satisfaction.
- Take the necessary steps to ensure we can continue with them, with the support of our friends and family.
- Be persistent, and explore other options if our initial attempts do not work out.
- Assess the financial impact of informal caregiving and take steps to access available support (e.g., employment service cheques, tax credits).

4

Identify and ask people in our circle for help, based on their strengths and availability

- Identify people in our circle (family, friends, neighbours) whom we can ask for help, approach them, and see how much time they can spare.
- Divide tasks according to each person's strengths and availability, and regularly adjust these arrangements.
- The support requested may relate to:
    - personal care
    - daily activities and transportation
    - financial and legal matters
    - emotional support
    - Companionship or respite care
- Express our gratitude to those who help.

5

Identify and make use of community resources as early as possible, without waiting to reach exhaustion

- Seeking help promptly prevents this task from adding to your other responsibilities and being seen as a burden.
- Choose accessible, local resources that meet all our needs. Community organizations offer services such as psychosocial support, respite care, training and information.

Caregiving and immigration: a reality often experienced differently

The term "caregiver" is not commonly used among some immigrants, who view family support as a natural duty. This support is rooted in the values of solidarity and gratitude, whereas financial assistance from the state can be viewed negatively. This presents a challenge for immigrant caregivers: recognizing the burden they bear and accepting help from those around them, while respecting their cultural values.

Caregiving at a distance

Thanks to new technologies, it is possible to help a loved one even if you live in a different town, region or country. For example, you can arrange certain medical appointments, offer emotional support, help with managing finances, or pay occasional visits. This makes it possible to stay in touch with loved ones and to strike a better balance between personal and professional life. That said, distance can also lead to feelings of helplessness, guilt or stress. It can be more difficult to know how things are going on a day-to-day basis and to have direct control over their care. There is also a risk of emotional exhaustion.

Helpful resources to explore

HELPLINES, INFORMATION AND REFERRAL SERVICES

- **Appui—Caregiver Support Helpline:** Helpline (1-855-852-7784), email (info-aidant@lappui.org) and chat, offering a listening ear, information and referrals 7 days a week (8 am–8 pm). https://www.lappui.org/en/about-us/contact-our-caregiver-support-helpline
- **211:** Directory of local social and community services.
- **Info-Social - 811:** For questions relating to the psychosocial aspects of health.

PSYCHOSOCIAL AND COMMUNITY SUPPORT

- **Proche aidance Québec :** Brings together community organiations offering support, respite care, guidance and advisory services.
- **YWCA Montreal:** Workshops, activities, reducing social isolation. https://www.ydesfemmesmtl.org/en/community-services/caregivers
- **Respite Services:** https://repit-ressource.com/en/home-care-services/caregiver-support

SPECIFIC ISSUES

- **Mental health:** Peer Support Helpline (1 800 349-9915)
- **Federation of Quebec Alzheimer Societies:** https://alzheimer.ca/federationquebecoise/en
- **Alzheimer's Society:** https://alzheimermontreal.ca/en/supporting-a-loved-one
- **Parkinson-Québec:** https://parkinsonquebec.ca/maladie/proche-aidant
- **Parkinson Montréal-Laval:** https://parkinsonmontreallaval.ca/en

ONLINE EDUCATIONAL PROGRAM

- **You and Me as Life Goes On program** https://www.lappui.org/en/practical-advices/register-for-training/you-and-me-as-life-goes-on

Words from our elders

Testimonial from Nicole, 68 | Caregiver for her mother

“At one point, I just couldn’t cope anymore: the care, the shopping, the appointments… I asked for financial help from my brothers who live abroad. Someone now comes once or twice a week to take my mum to her appointments, cook meals or just spend time with her. As for me, I’ve been able to take on my role as a daughter again. And my mum now has her daughter back. We now spend quality time together.

After several years of caregiving, I’ve learned to become my own best friend. I stop if I find myself overwhelmed. I find a solution. I speak up. I ask for help.”

Testimonial from Georges, 85 | Caregiver for his spouse

“I’ve been playing tennis all my life. Despite my knee pain, I’ve adapted my game. Twice a week, I meet up with my friends for a match, after which we chat over a drink.

My wife, Yvonne, is suffering from advanced heart disease. As she has already had a few falls at home, she needs someone to keep a close eye on her. Together, we decided to ask for help from a community organization in our neighbourhood so that I could continue playing. Our children also offer support.

These moments do me good. I come home energized, with stories to share. For me, keeping up with tennis is also about looking after myself … and maintaining a healthy balance for both of us.

Chaire de recherche Marguerite-d’Youville d’interventions humanistes en soins infirmiers de l’Université de Montréal

Proche aidance Québec
Regroupement d’organismes engagés pour les personnes proches aidantes

PARKINSON MONTRÉAL LAVAL

Appui proches aidants

RÉSEAU RÉSILIENCE AÎNÉ·ES MONTRÉAL

Société Alzheimer MONTRÉAL

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