RANQ
Regroupement des
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Helping Young Caregivers Thrive

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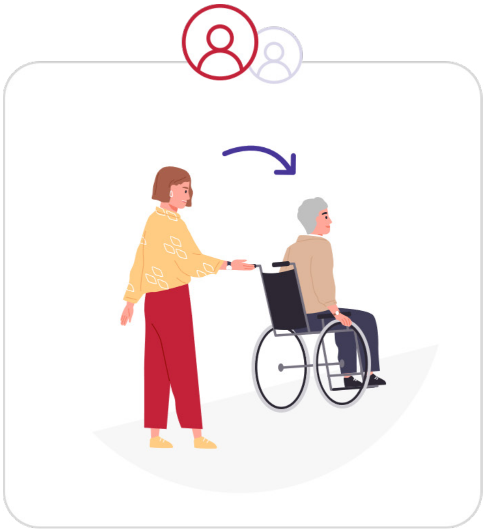
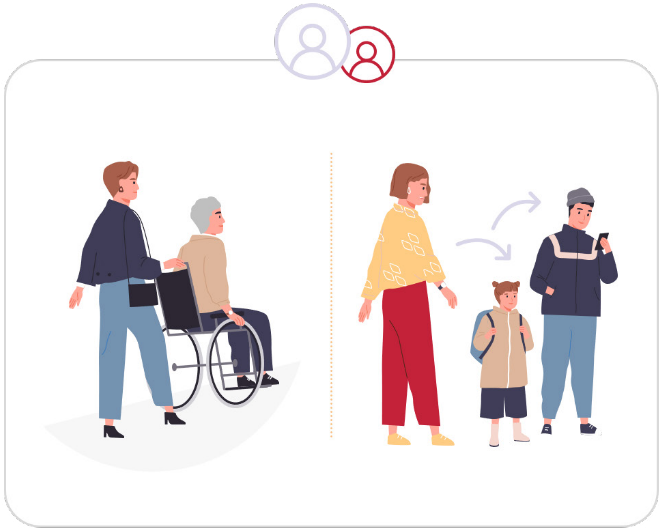
Whether you are in education or in health care, you have already met families where young caregivers (YC) are involved. They stand alongside a family member who is ill, aging or disabled. They provide daily care, emotional support, and perform household chores (young primary caregiver [YPC]) or take care of siblings when their parents, who are the primary caregivers, are unavailable (young secondary caregiver [YSC]).

Young caregiving can have negative impacts on young people's physical and mental health, but also on their long-term life plans. Although it is necessary to increase home care for the person being cared for, to alleviate the impoverishment of sick or aging people, and to better distribute care responsibilities between family members and health professionals, these interventions are difficult to implement, take time and require political will.

I am a youth just as much as others, but with different types of activities.

> *The good news is that with support, listening and understanding, the negative effects can be greatly reduced and the positive effects of young caregivers can be significantly enhanced.*





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This guide aims to raise awareness among health and education professionals about the realities and issues of young caregivers aged 6 to 25. It is intended for school personnel, health specialists and parents of young caregivers.

The first part aims to describe who young caregivers are, their responsibilities and the impacts of this additional role.

In the second part, the paragraph on approaches is intended for all professionals and adults working with young people. Afterwards, it is possible to read only the chapter that concerns you.

This guide was written following numerous readings of scientific articles and recommendations made by organizations specialized in supporting young caregivers, especially in Australia and the United Kingdom. The recommendations and situations have been adapted to the Quebec context by a committee of experts in health, education and caregiving involved in raising awareness about caregiving since 2018.

Who Are the Young Caregivers?

Between the ages of 6 and 25, any young person can become a YC, whether he or she lives in the city or the countryside, in a single-parent family or not, whether he or she is an only child or part of a large sibling group, or, regardless of the family's financial situation.

Children or young people who are caregivers can be defined as a young person under the age of 25 who provides care, services or support to a person around them who has one or more physical, mental, intellectual or sensory disabilities, whether temporary or permanent (accident, disability, illness, old age or dependency). They can take care of a parent, a grandparent, a brother or sister, or even a more distant family member, a friend, or compensate for the unavailability of the parent who is acting as a caregiver.

> *Being a young caregiver is not living in a dysfunctional family, it is living in a normal family struggling with exceptional circumstances.* (Grant, 2012)

YCs aim to facilitate the recovery of the person, the preservation or improvement of quality of life, or the possibility of dying with dignity. They may also act to alleviate the impact of illness, disability, aging or dependency of other family members.

The role of the young caregiver is an additional role, one that goes beyond the normal scope of culturally accepted responsibilities for a young person. The YC role is in addition to his or her activities as a child or youth (school, recreation, work, socialization, etc.), and as such can have both short-term and long-term negative and positive impacts on him or her and his or her future.

50 % have been doing it for more than 7 years

26 % became a caregiver between ages 6 and 12

31 % are helped by a parent

15 % are alone as a caregiver

6 → 25 years old

14 h → 27 hours of care per week

Supporting their parent, grandparent, sibling or their parent who is an informal caregiver

Disability, physical or mental illness, addiction, old age

69,8 % are girls

Many YCs keep their situation secret for fear that their parents will be blamed or that they will be separated from their family, because they are ashamed to provide adult hygiene, or because they want to protect their family from stigmatization (prejudices about mental health problems, dependency, disability, etc.).

What Do Young Caregivers Do?

- Perform household chores
- Grocery shopping, cooking
- Administer medications or provide medical care
- Provide personal hygiene care
- Take care of siblings (homework assistance, meal preparation, etc.)
- Pay bills, do administrative work
- Seek care and support for the sick person
- Provide interpretation (minority language, aphasia, sign language, etc.)
- And most importantly, provide emotional support

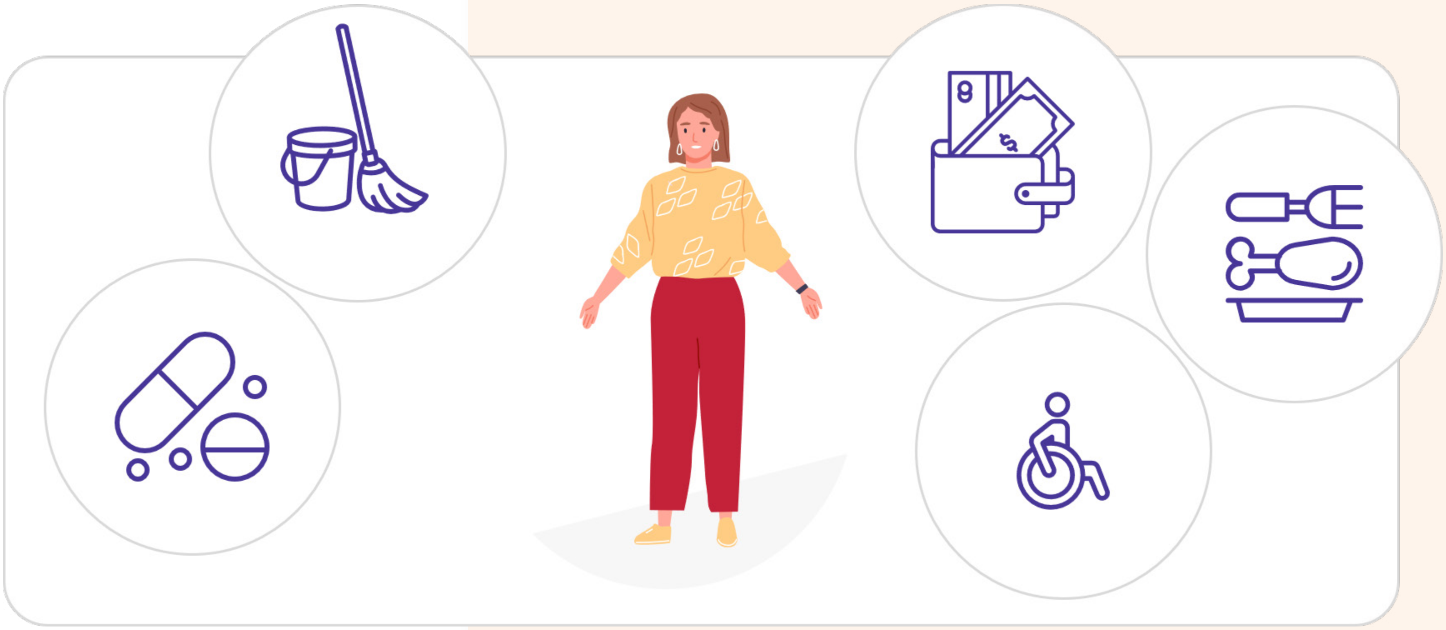
Are You a Parent or a Guardian of a Young Caregiver?

You may feel guilty about your child's situation. Know that no one chooses to be sick, disabled or aging. **Young caregivers act out of love for their family:** value their contribution and their good deeds.

To support them, listen with empathy, be mindful of the impact that caregiving can have on them, and help them explore the positive aspects that caregiving can have on their lives. If you are the person being cared for, talk to health care professionals about your young caregiver's responsibilities so you can receive more care. If you are a caregiver yourself, find out what help is available from local organizations. School is important to your child; you can help them talk to their teacher to explain the situation and find support or accommodations. Finally, you can encourage respite periods where your young caregiver can see friends, participate in recreational activities, etc.

Did You Know?

- YCs, like adult caregivers, do not recognize themselves as such because of the belief that what they do is normal, natural.
- Some YCs do not want to be labelled, either because they do not feel that caregiving fits their role or because they fear being stigmatized.
- YCs have different contexts of life, extra-familial or caregiving responsibilities and want these varieties of talents and situations to be recognized. Above all, they want to be young.



Positive and Negative Impacts of Young Caregiving

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- Feeling of being useful
- Compassion and empathy
- Strong family bond
- Greater maturity
- Feeling prepared for adult life: know-how and interpersonal skills
- Develop a partnership with the healthy parent
- See school as a way to better support their family in the long term
- Increased self-esteem

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- Physical health issues: headaches, 60% have sleep disorders, back pain, poorer lifestyle habits, and 30% have eating disorders
- 60% are more likely to have a mental health disorder or anxiety, 34% have self-harming behaviours, and 36% have suicidal thoughts (Cree, 2013)
- 12% use psychoactive products
- Short-term family impoverishment, limited job prospects
- Worrying about the health of the person being cared for, fear of not doing enough
- Isolation, risk of intimidation
- Behavioural problems: feelings of injustice, anger
- School difficulties, absenteeism, dropping out[1]

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[1] For more information on educational outcomes, see section: Being a Young Caregiver at School

Supporting Young Caregivers: Everyone's Business!

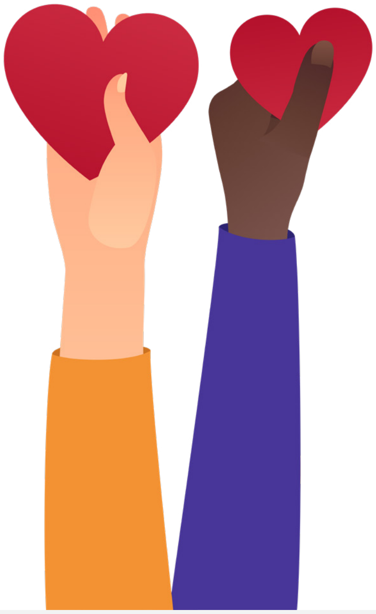
Some Important Approaches and Insights

- Be able to name the situation, acknowledge their involvement, but also make them understand that the emotions they are experiencing are normal, without making them feel different or problematic.
- Enable them to be actors in their own lives, without absolving governments of their responsibility for the care of the most vulnerable.
- Young caregivers appreciate family interventions, which increase services for the person being cared for and promote good communication within the family.
- YCs want the positive aspects of young caregiving to be valued.
- A young person experiencing a difficulty has the right to confidentiality and information.
- YCs like to be appreciated for who they are, and not for what they do. They appreciate support that allows them to be young: expression of emotions, leisure activities, socialization.
- YCs like to realize that other young people may be experiencing similar situations and share with them.
- Above all, they want to be heard and understood, without judgments or assumptions about the situation and its implications.
- Various evaluation tools exist[2], but none is adapted to the Quebec context. However, it should be noted that an intervention is required, particularly if the young caregiver is no longer able to mention the positive aspects of young caregiving.

Being a Young Caregiver in the Health Care System: How Can Health Care Professionals Support the Young Caregiver?

Doctors, nurses, social workers, occupational therapists, researchers … behind your sick, aging, disabled or dependent patients, there is often a YC.

Don't wait for your patient to tell you. The fear of being a burden to the young person, the feeling that they are not a dysfunctional family but a family in an exceptional situation, the lack of knowledge about the role of the young caregiver, the cultural differences regarding children's family responsibilities, or the fear that the child will be removed from the family all contribute to the silence.



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[2] See references at the end of the document.

Ask questions to find out if a young person lives with the person to be helped, how he or she contributes to the situation, and how he or she experiences the illness, disability, dependency or aging of his or her relative. These questions allow for a non-judgmental dialogue. For researchers interested in the health of young people, taking this variable into account would not only make it possible to obtain Quebec data on YCs, but also contribute to the development of knowledge on the role of YCs and the impacts that this can have on their health.

It is true that the involvement of YCs reduces hospital visits and delay entry into long-term care. They are also an important source of information on your patient's health, a factor in quality of life, and are actors in therapeutic compliance. However, it is important to assess the needs of the young caregiver, his or her ability to continue in this role without jeopardizing his or her youth, mental and physical health, as well as his or her academic and professional future. Often, the presence of YCs is only revealed at the time of a crisis: detecting them beforehand would prevent urgent situations that can create trauma. Even though there is no evaluation grid[3] adapted to the Quebec context or support services specific to YCs, there are many existing services that can help them (CLSC programs dedicated to young people, organizations that support caregivers, youth organizations or homework assistance, etc.).

Here are also some guidelines for working with YCs (youngcarersnetwork.com.au and the-ria.ca/resources/young-carers-project).

- Listen to them: young caregivers spend time with your patient on a daily basis and see how things are going.
- Explain to them the treatment plan, medical terms, and prognosis of the disease in an age-appropriate way or discuss it with your patient so that they can do it themselves at the most appropriate time. Be honest and transparent when answering their questions.
- Inform them about resources or people to contact in case of an emergency or crisis.
- Provide them with information about relevant community and school resources.
- Try to understand their emotions, validate their normalcy and make time for them to express themselves.
- Do not underestimate your impact as a professional and trusted adult.
- Educate your colleagues and your institution about young caregiving.

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[3] See references at the end of the document.

Being a Young Caregiver at School

Emphasize the importance of school

Most YCs (85.3%) (Lakman, 2017) believe it is very important to succeed in school. In a majority of cases, school is seen as a place of respite, with caring adults and predictable routines. In the longer term, it is also an opportunity for them, through education, to have a good job and to be able to contribute financially to their family. Being a young caregiver during childhood also increases the possibility of being a young caregiver in adulthood.

Nevertheless, 68% fear doing poorly in school, 27% have significant academic difficulties, about 10% develop problematic behaviours, and many are unable to continue to higher education. In Canada, researcher Vivian Stamatopoulos (2018) notes a 10% absenteeism rate among YCs, with nearly 21% missing 1-2 days monthly, 5.5% being absent 5 days a month, and 11.7% missing 3-4 hours of school per day. While most would like to have support from their teacher, 31.4% feel they only have a little support. However, this is not related to a lack of will, but rather to a lack of knowledge about caregivers in general and the specific situation of YCs (61.3%). And yet, most of the measures that can support them already exist for certain student populations or could be easily put in place.

What could this change for your school?

In Australia and the UK, many schools have implemented approaches to support YCs, some of the results include:

89 %	identified more YCs
94 %	noted in increase in YC well-being and confidence
60 %	noted an increase in academic performances
74 %	noted a decrease in absenteeism
✓	Most noted an improvement in behaviours

Teachers: empathetic adults

The YCs reported that knowing a teacher who is aware of the situation, who believes them and who listens to them can have a major impact on their lives. It is not easy for young caregivers to disclose their situation: they are afraid of not being believed, they don't have the words or all the information; they may feel like failures if they ask for help or feel disloyal to the person being helped. They are afraid that their parents will be blamed and that the family will be separated. Finally, they fear the label of caregiver that might be used against them to intimidate or mock them.

Some guidelines to facilitate the disclosure of the young caregiver's situation:

- Be empathetic, listen, believe him or her and respect his or her right not to tell you everything.
- In the absence of peers, ask informally how he or she is doing, ask about tardiness and the reasons for it, or ask about grades.
- Offer him or her a listening ear on a regular basis. Even if he or she doesn't take advantage of your offer right away, he or she may use it later.
- Acknowledge his or her concerns and emotions about the situation, and do not try to reassure him or her about the progress of the loved one's health problem.
- Focus on his or her perspective and experience rather than his or her relative.
- Ask him or her what he or she needs and find out what you can do for him or her.
- Is he or she looking for a listening ear, an opportunity to vent emotions, a mentor or stimulation?
- What information is he or she willing to share with you, and to whom? How can you inform your colleagues of this situation?
- If possible, help him or her meet other youths who are going through something similar so that he or she feels less lonely (organize a meal). Or refer him or her to community organizations that can support him or her.
- Don't judge him or her by the reactions of other family members, everyone may react differently to adversity.
- Talk to him or her about the possibility of talking to the school nurse, psychologist or other resource person at your school.
- Discuss his or her mode of transportation, especially in the event of unforeseen circumstances. What alternatives are available?
- Educate your institution and your colleagues about YCs or invite specialized organizations to do so.
- As a trusted adult, believe in your ability to make a difference for this young person.

Promoting student retention and achievement:

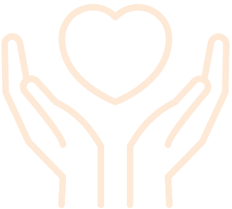
- YCs need flexibility and adaptability.
- Sharing class notes, online tools, or class recordings can lessen the impact of absences.
- Offer tutoring during mealtimes rather than at the end of the day. Find out what devices or resources are available for homework assistance.
- Be understanding and flexible about assignment due dates, the YC role has a lot of uncertainty and last-minute upsets.
- Allow the YC to stay in contact with his or her family during school hours if he or she is worried.
- Eventually, suggest a personalized support plan.
- If a punishment is necessary, favour the lunch period, so as not to break the family routine and increase the YC's anxiety.
- For parent or family meetings, if transportation is not possible, consider video conferencing, or consider travelling to the home if the family agrees.

YCs are more likely to be bullied

With less socialization time, they may feel different, have difficulty with social skills, be more isolated or sensitive. They are often more mature and may be teased by their peers. The disease can result in a significant loss of income, and YCs may put their needs after those of their families, and their clothing may be of poorer quality or out of style. Similarly, the stigma of mental illness, dependency, disease or disability can lead to being ostracized or ridiculed.

A caring environment: so that the YCs and their parents can talk about it and be recognized

Ideally, all school personnel should be committed to listening and responding to the needs of YCs in order to encourage them to stay in school. This commitment by all is also intended to enable YCs to enjoy school time and to have equal opportunities with their peers.



Changing schools and school transitions are anxious times for a young caregiver. You can also make a difference by reassuring him or her, and by making the new school or teachers aware of the realities of young caregivers.

How to detect a young caregiver?

Is the student:

- Often absent or late?
- Often tired, depressed, anxious or introverted?
- Being bullied?
- Worried about the health of a loved one?
- Secretive about his or her family life?
- Under the care of youth protection programs?

Does the student:

- Have difficulty making or keeping friends? Is he or she isolated?
- See a sudden decline in academic performance?
- Seem very mature for his or her age?
- Have difficulty concentrating?
- Not participate in school trips or extracurricular activities?
- Often turns in work late or sloppy?
- Have physical pain (headaches, back pain, etc.)?
- Have any behavioural issues?
- Show signs of physical neglect, malnutrition, or clothing neglect?
- Never have parents present at parent-teacher meetings? Or do his or her parents have little or no communication with the school?
- Not pay expenses for school activities?
- Have a sibling who is registered as a student living with a disability or health problem?

The involvement of as many school personnel as possible, from the onset of young caregiving awareness, is critical to ensure that as many YCs as possible are detected. It may also be necessary to reassure teachers. Often, they are already familiar with certain situations and know how to cope with them. Although supporting the development of young caregivers is everyone's business, it may be appropriate to designate an adult as the point of contact for young caregivers, who will be more aware of the issues and resources available.

Various measures can make a difference, such as allowing another family member (even a minor eldest brother or sister) to take the place of the parent when meeting with teachers. Allowing students to contact their families during school hours can reassure them and prevent presenteeism[4]. Access to a computer can also help them in their search for information or support. The health care network still relies heavily on faxes, which are more difficult to find in the community. Offering to fax a medical request to a YC can save time. YCs often do not have the time, financial resources or transportation to engage in sports, creative or social activities outside of school. Developing these activities on school grounds, during lunch breaks, would promote healthy lifestyles, creativity, and playful respite time for YCs.

Participate in awareness: The first week of November is National Caregiver Week. This is an opportunity to communicate about the realities of young caregivers, to thank them for their commitment to their families and to talk about the positive aspects of supporting young caregivers. Similarly, there are themed days or weeks, relating to mental health, disabilities or certain illnesses. Reducing prejudice and stigma would allow YCs to live in a more caring environment and reduce the risk of bullying. In fact, local anti-bullying plans should include young caregivers as a risk factor and ensure better detection and response.

In addition to raising personnel awareness, school establishments can create opportunities for disclosing the situation. For example, by asking the youth if a family member has a health problem, disability, or dependency. An anonymous suggestion box would also allow YCs to be considered within the institution and to suggest actions that could support them. In many neighbourhood schools with large English or Allophone populations, registration materials are translated into several local languages. Thus, rendering the registration process, website and various documents accessible to people with disabilities (deafness, visual impairment, etc.) would promote family involvement and reduce the responsibilities of young caregivers.

These initiatives are opportunities to promote your school and its commitment to equal opportunity and student retention. Talk about it around you, on your website or on your Facebook page.

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[4] Presenteeism refers to being physically present at school but being too preoccupied with the family or caregiver situation to be focused and attentive to what is being said in class.

Resources

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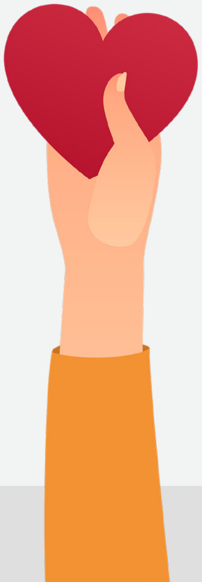

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