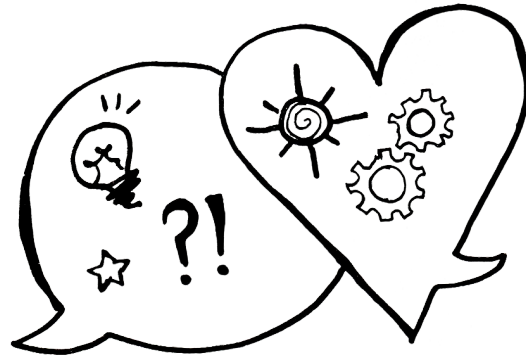


# ENGAGING WITH YOUNG CAREGIVERS: A TOOLKIT FOR PROFESSIONALS



Created by Young Caregivers Association

**YOUNG**   
*caregivers*<sup>™</sup>  
ASSOCIATION

Lead.  
Support.  
Empower.

# WHO ARE WE?

Young Caregivers Association is a registered charity dedicated to the recognition, support, and empowerment of young caregivers. Our work began in 2003 as a project involving the Alzheimer Society of Niagara. With funding from Ontario Health, and a strong relationship with the Alzheimer Society of Brant Haldimand Norfolk Hamilton Halton, we were the first organization in Canada to support young caregivers in rural and urban communities.

Our service model, Powerhouse, is a program designed to support young caregivers and their unique needs through peer support, specialized programming, and counselling. Powerhouse programs are ran in person in the Niagara, Hamilton, Brant & Haldimand-Norfolk regions of Southern Ontario, but our online services are used by young caregivers everywhere.





# ABOUT THIS TOOLKIT

It is not unusual for professionals working in education, social work, mental health, addictions, child protection, community services or health care to come into contact with young caregivers without knowing. We are working to build awareness and provide education to professionals so young caregivers no longer feel dismissed, disrespected, or invisible, especially while at health care appointments with the person they care for.

## **What professionals have told us about engaging with young caregivers:**

- *I feel uncertain about what to ask.*
- *What do I do if support is needed?*
- *Engaging with young caregivers is not my mandate.*
- *How do I begin a conversation about caregiving with children?*

This Toolkit was created with young caregivers to raise awareness and to support professionals, like yourself, who engage with children, youth, adults, and families. Using our evidence-based ways of leading, supporting, and empowering young caregivers, this Toolkit provides everything you need to get started!



# WHO ARE YOUNG CAREGIVERS?



Young caregivers (or young carers) are children, youth, and young adults who provide care for a family member due to a chronic illness, physical or intellectual disability, mental health concern, addiction, or socioeconomic factor (e.g., language barrier, incarceration, etc). Young caregivers can support their family members through personal care (e.g., bathing, grooming), medical care (e.g., giving medications, tube feeding), caring for siblings, and providing emotional support. Young caregivers are an important, but often invisible, part of the caregiver population. Handling the condition or disease of a family member creates a ripple effect throughout the family unit. This ripple effect might require children in the home to be turned to for help with caregiving tasks and household responsibilities, even more so when resources are not accessed or available.

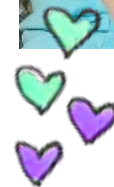
Research shows that, without support, young caregivers may experience challenges including social isolation, lack of peer support, low self-esteem, depressive symptoms, anxiety, and other mental health challenges. Despite these risks, there are many upsides to being a young caregiver. We acknowledge that young caregivers can have a higher understanding of family bonding and empathy and gain competencies such as independence, resilience, wisdom, and responsibility. With support and empowerment, young caregivers can learn to be resilient, learn how to cope with stress, and grow into strong adults.



# WHAT YOUNG CAREGIVERS DO

A young caregiver can do many different tasks to support their family. They can include:

- Household tasks such as cleaning, washing, cooking for the family, and paying bills
- Personal care like giving medications, helping with mobility, bathing, and assisting with washroom use
- Providing emotional support for the family member requiring care, and for the family as a whole
- Helping supervise siblings which could include meal preparation, making school lunches, and providing physical/personal care for brothers and sisters
- Providing interpretation for their family member at appointments due to a language barrier or hearing impairment
- Attending appointments and hospital visits with their family member in order to assist them



# WHY YOUNG CAREGIVERS ARE HIDDEN

There are many reasons why young caregivers are not recognized which results in a lack of support offered to them. Here are some reasons why this population may remain hidden:

- Our society often views family caregivers as being adults and don't consider the children and youth in the home
- Young caregivers can be very loyal to their families and feel guilty asking for help
- Many young caregivers are not aware that they are even caregivers (as their situation is just seen as life as they know it); therefore they just do what needs to be done
- Parents who require the care do not have their parenting needs considered by the supports they receive
- Some young caregivers and parents do their best to keep their situation a secret out of fear of stigma or unwanted interventions
- It may be difficult to engage with families depending on their circumstances
- The needs of the family may only be identified when there is a crisis
- Professionals are very busy and focused on the client/patient and don't have the mandate to ask the children in the home how they are doing



# YOUNG CAREGIVERS NEED SUPPORT, NOT STIGMA

Many young caregivers and their families have told us that they are secretive about their situation for reasons that include fear of stigma, being bullied or judged, and having unwanted interventions. What we know is that family caregiving isn't black and white. It takes a community to support families and we need to work together to ensure a whole-family approach.

Without a system and policies in place to support young caregivers, professionals can do their part to ensure everyone is given equal opportunities to thrive. It is important for professionals to be aware of young caregivers in order to identify them, and hopefully provide them with support.

It is our hope that this toolkit will provide you with the information and strategies needed to feel confident when interacting with and supporting young caregivers.





# CAREGIVING THROUGH A CULTURAL LENS

We live in a multi-cultural society. Caregiving can be a complex subject for many cultures - especially when the discourse around caregiving becomes too heavy in child protection or too academic. Many cultures do not see caregiving responsibilities as a “label” or “role” - it's just a part of their culture and identity. It is a more respectful and productive use of time to meet them on their cultural level rather than force a label or discourse on them for mandated purposes. You can do this by asking about their views on caregiving, looking at their family history, and having in-depth conversations about their cultural identity. As a professional, it is your responsibility to adapt the conversation to fit their cultural background.

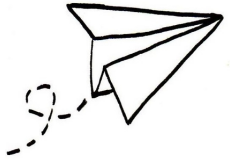
**For example:** For cultures that consider caregiving the "norm", it may be useful to refer to "young caregivers" as “youth who are helping you” or "youth who are helping the family”. Changing simple language can lift the stigma, remove the label, and help conversations be accessible and welcoming.





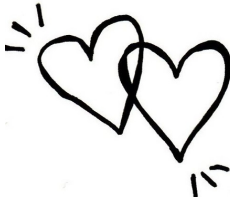
# A THREE-PRONGED APPROACH

Young Caregivers Association has created a three-pronged approach used to engage young caregivers of diverse backgrounds. The three-prongs of this are “LEAD, SUPPORT, EMPOWER”.



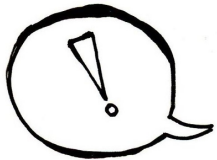
LEAD

**Lead** a conversation about caregiving (these prompts are yellow). This section contains conversation prompts and questions that will encourage engagement. The questions provided are just starting points and require appropriate follow-up questions.



SUPPORT

**Support** the young caregiver in the moment and identify their needs (these prompts are pink). This section contains mindfulness tips as well as suggestions for simple coping skills.




EMPOWER

**Empower** the caregiver through tangible activities that gets them to think about their experiences and takes your conversation further (these prompts are green). This section contains easy hands-on activities that allow them to be in complete control and learn something new.

The following pages contain examples of **LEAD**, **SUPPORT**, **EMPOWER** in action that professionals can utilize with young caregivers.



# LEAD, SUPPORT, EMPOWER IN ACTION



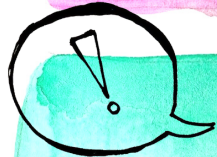
## Do you think you are a caregiver?

Some people don't consider themselves a caregiver, even if they appear to be. Identifying whether or not they acknowledge this part of their life will help you determine how to talk with them about their responsibilities.



## Making a Mantra:

Have the young caregiver think of 3 positive words to describe themselves. This can be unrelated or related to caregiving. Have them repeat the words in mantra form: "I am \_\_\_\_, I am \_\_\_\_, I am \_\_\_\_".



## Inside The Box:

For this activity, you only need paper and drawing utensils. On a piece of paper, draw a box. If you're really crafty, you can make it look like a big shoe box that you can place items in. Have the young caregiver imagine that they have placed their worries in a small box. What would that box look like? After, the caregiver can complete another box filled with activities they do to make themselves feel better.




Unique. Sacrifice. Improvise. These are words used to describe families who have to change so much in their lives to care for each other. We strive to get through our everyday lives. I can only speak for myself but being a young caregiver and in Powerhouse, I have learned to empathize for everybody around me.

- Young caregiver and member of Powerhouse

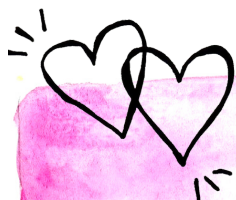


# LEAD, SUPPORT, EMPOWER IN ACTION



**Do you see caregiving as a positive or negative part of your life?**

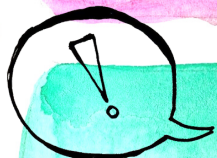
This should result in a conversation about the best and hardest parts of being a caregiver. Hopefully by the end of the conversation, they are able to see that there are both struggles and benefits in being a young caregiver and that it is okay to talk about both.



## **Don't Get Mad - Get Mindful:**

Have the young caregiver stand up straight and stretch out their body. Have them focus on one part of their body at a time. Whenever they are upset, they can practice this.

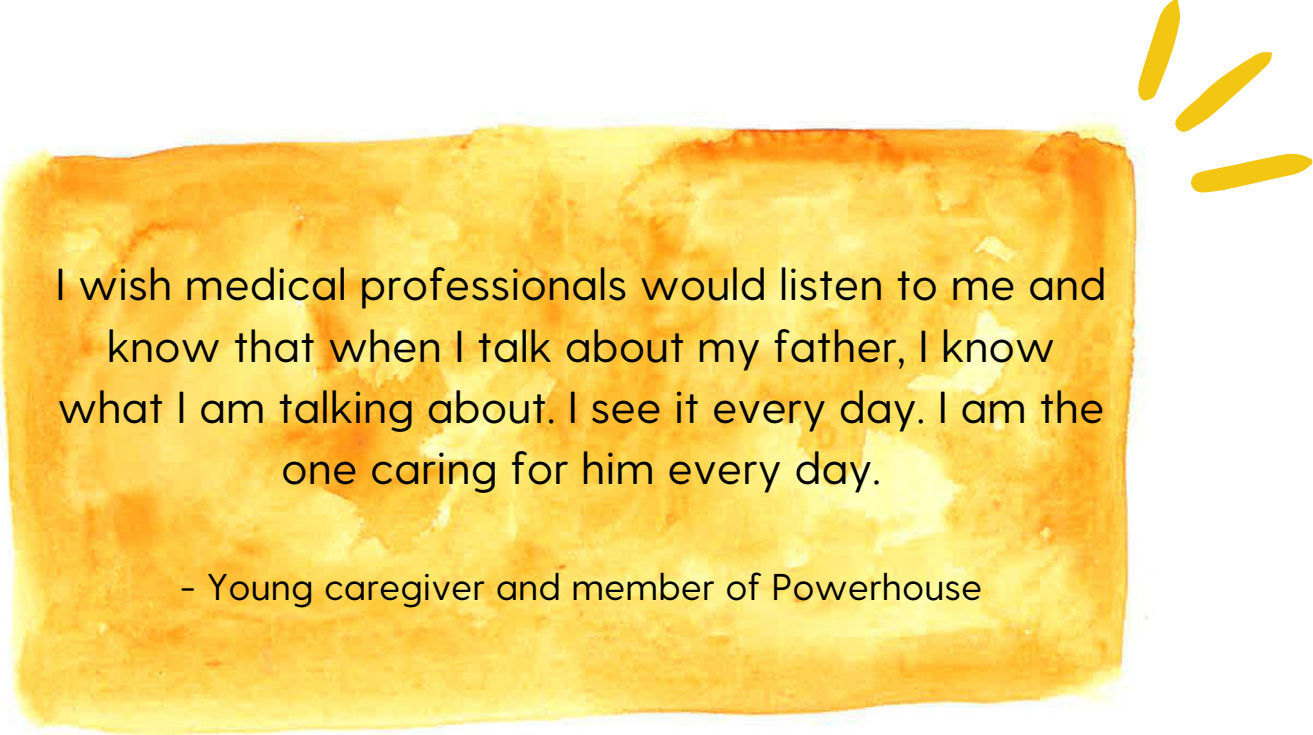
**Instructions:** *Close your eyes. First wiggle your toes. Then bend your knees. Move your fingers and then clench a tight fist. Breath in and inflate your belly. Then breath out, and let your fists go.*



## **Outside VS Inside:**

Draw two blank faces (outlines of a head) on a piece of paper. Label one "How I Look Outside" and the other "How I Feel Inside", and have the caregiver fill in the self-portraits. A follow-up conversation should be had about how being open about feelings can be a valuable coping skill.

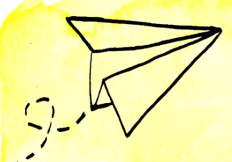




I wish medical professionals would listen to me and know that when I talk about my father, I know what I am talking about. I see it every day. I am the one caring for him every day.

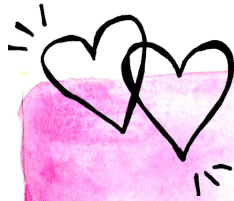
- Young caregiver and member of Powerhouse

# LEAD, SUPPORT, EMPOWER IN ACTION



**Who do you feel closest to in your family? Why?**

If it isn't the person they help care for, why is that? This conversation will help discover if there is feeling of attachment, resentment, guilt, or other complex emotions that can come from caring for a family member.



## **Communal Coping:**

Have the young caregiver create a list of enjoyable activities they have in common with their care recipient. From that list, encourage them to brainstorm 5 healthy, stress-relieving activities they can do together.



## **Stress Dough:**

You will need: 2 cups flour, 1/4 cup oil, food colouring. To make the dough, add flour to a large bowl. Then mix oil and food colouring. Combine ingredients and knead until stretchy. Now the stress relieving dough is formed! This can be used as a stress ball or a fidget/anxiety tool.






It's called Powerhouse because you learn to have power over your emotions.

- Young caregiver and member of Powerhouse

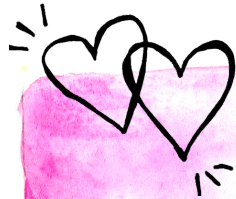


# LEAD, SUPPORT, EMPOWER IN ACTION



**What do you do when you feel like you can't help anymore?**

This opens up a conversation about the impact of caregiving. It can also determine if they experience exhaustion and stress and how they deal with it.




## **Breathing Star:**

Draw out a star on a piece of paper. Practice breathing together. Tracing the star with your fingers, begin breathing. On the lines, take inhales. When you reach the points, exhale. Repeat if necessary. They can do this whenever and wherever they find themselves needing to calm down.



## **Wrinkled Heart:**

Cut a heart shape out of paper. On the front, write "young caregiver". Ask them to think about the complex feelings they get when they help their family. Whenever they say one, they wrinkle a piece of the heart. To open it back up, they must say things they do or people that help make them feel "whole" again. Discuss that even though the heart is still wrinkled, what matters is that it can always open back up. "Wrinkles" make us who we are; a wrinkled heart is not a broken heart.

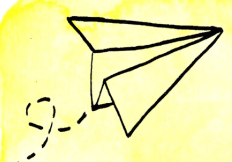


Having to help and deal with my brother and step mom on a day to day basis has added so much extra stress and little to no time for myself. Powerhouse has opened me up to so many opportunities that I can now do.

- Young caregiver and member of Powerhouse



# LEAD, SUPPORT, EMPOWER IN ACTION



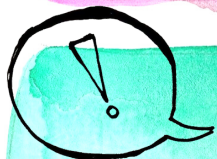
**How has helping  
(insert care  
recipient) changed  
your life for the  
better?**

Caregiving is not a responsibility that we can take away, so it is important to encourage them to view their caregiving experiences in a positive way.



## **Gratitude Steps:**

Put four lines of tape on the ground; each of which they will eventually step on. Have them take one step at a time. The first step is something about themselves they are grateful for, the second step is what they are most grateful for, the third step is who they are most grateful for, and the fourth is a unique part of their life that they are learning to be grateful for.



## **Sunny Side Up:**

Have the young caregiver draw a big sun with thick rays. In each ray they should write a gift that caregiving has given them (e.g., wisdom, confidence, maturity). In this way, they are decorating the sun with positivity. If you have materials you can cut the middle of the sun out of yellow paper and have them write the "gifts" or "benefits to caregiving" on clothespins to attach around the circle to create sun rays.





As much as I want a life outside of my home, I know sometimes I can't because there is always so much responsibility and so much to do. Yes I get angry and upset that I can't just have a normal, less stressful life, but I learned that this is for my family and it is completely normal to feel this way.

- Young caregiver and member of Powerhouse



What are some ways you encourage your (care recipient) to be independent? (Example: teaching them how to make tea, etc)

Can their care recipient be more independent? Why or why not? A lesson in empowerment will not only help them - but it will also help them empower their care recipient in hopes that they both can have time to themselves.

# LEAD, SUPPORT, EMPOWER IN ACTION



## The Weight We Carry:


Slouched over, have the young caregiver begin to imagine putting down weights and taking bags off their shoulders. Each time they "let go", they must say something they feel is weighing them down. Every time they take off a weight, they can begin to rise. Once they reach the top, have them think of one weight their care recipient carries, and whether or not they can help them without "slouching" back down.



## Acts of Kindness:

On a blank piece of paper, have the young caregiver write "notes" or short letters to some of the people in their lives expressing positive affirmations. Have their "project" be slipping these notes into places where their loved ones will find them. For example: "You are brave", "I love and appreciate you", "Thank you for \_\_\_\_\_". A secret act of kindness helps others feel loved and happy, and they help the giver feel good as well.






My sister needs help because she has autism. I help her do her chores, and I teach her things (speech, how to play fair, and many more). It makes me feel happy and helpful. Powerhouse makes me feel happy. Now I feel like I am her own hero and that I can do anything!

- Young caregiver and member of Powerhouse



# LEAD, SUPPORT, EMPOWER IN ACTION



**If you didn't have to help (care recipient), what would you be doing?**

Do they blame their care recipient for not getting to do more of the things they love? Connect them to their passions, hobbies, interests, and remind them that they have an identity outside of being a caregiver.



## **First Thought Reflections:**

Have the young caregiver sit and close their eyes. Ask them to complete the following sentences about themselves as quickly as they can, with the first thought that comes to them: *I am... I am good at... I will get better at... I love to... I've always wanted to... One day, I am going to be...*



## **Me Tree:**

The first step is to draw the trunk of a tree followed by bare branches. At the base of the tree have the young caregiver write all the things that make up who they are (the roots). In the trunk, have them write things they cannot change about their situation. On the bare branches draw big leaves and write in each one all the things they wish to change or improve. Their finished tree represents who they are, what makes them unique, and what changes they can make.




I wish my teachers could understand my caregiving responsibilities. I wish they could see my other homework.

- Young caregiver and member of Powerhouse

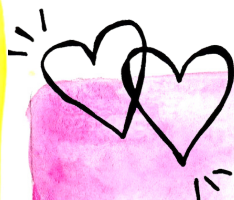


# LEAD, SUPPORT, EMPOWER IN ACTION



**What does your life look like in 5 years?**

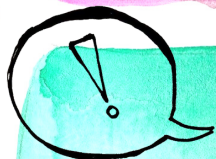
What role will caregiving play in their life in the future? There is life beyond caregiving, and as professionals, we can provide hope and compassion to young caregivers by helping them envision the future, rather than fear it.



## **A Moment of Mindfulness:**

The future is scary and can cause us great stress. Encourage them to take 1-5 minutes to meditate.

Support by speaking: *Sit up straight, close your eyes, stretch out your body, and try to clear your mind. If a thought comes, acknowledge it, and let it pass. Keep breathing and focus on the movement of your belly with each breath.*



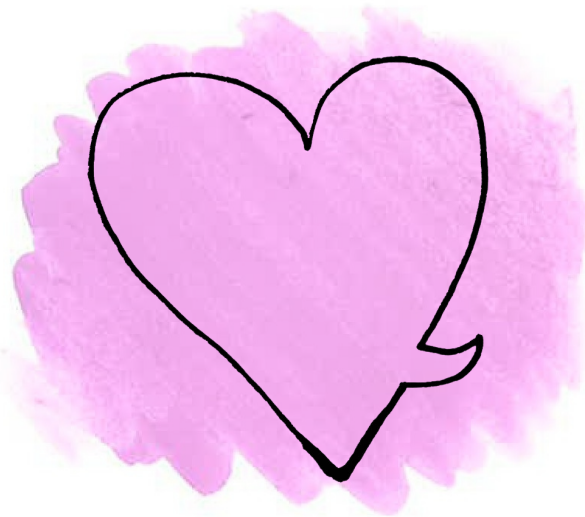
## **On A Mission:**

Have the young caregiver write 10 things they want to accomplish in their lifetime, along with a letter to their future selves with their favourite life lessons. Seal it in an envelope for them to open on a later date of their choosing.



# SITUATIONAL SUPPORT

Caregiving is unique and situational. With the multitude of different circumstances in households that impact young caregivers, it is important to respect specific young caregiver scenarios. With consideration of what we know as the most common experiences of the young caregivers we support, we created the following "tip" sheets.



# YOUNG CAREGIVERS & GRIEF: PALLIATIVE CARE



When anticipating death is the reason for care, it is beneficial to prepare the young caregiver to cope with grief. However, grief can start before death as they begin to lose the person they knew and adjust to their changing state of being (e.g., no longer being picked up by that family member from school). Some tips to help young caregivers handle grief are:

- Validate their various feelings and allow them the space to show their emotions openly
- Encourage them to talk to you, family, friends, other professionals, or even their loved one
- Try to talk clearly and honestly about death
- Respect their cultural and familial beliefs about death
- Try not to glorify where their family member is going (afterlife, heaven, etc.) to avoid confusion and fantasies of trying to somehow "get" to their family member after death
- Remind them that death is a natural, non-optional part of life
- Let them be kids and encourage play; play can be a way for kids to process tough situations and have moments away from troubling mindsets
- Connect them with appropriate counselling services





## YOUNG CAREGIVERS & DEMENTIA

Dementia is a complicated reason for care. Adults can more easily understand the condition and are better able to separate who their family member was before the condition, from who they are now. To help support young caregivers caring for a family member with dementia, try your best to:

- Remain positive during interactions and validate their feelings and experiences
- Check in often as dementia situations are different on a daily basis
- Supply them with mindfulness and coping skills they can use during tough moments with their care recipient
- Encourage positive memories; for example, have them create a "box" of memories and items associated with their family member
- Understand that the young caregiver might experience grief, even though there is no death - memory loss is worthy of grieving and should be treated as grief
- Be honest with them and give them realistic expectations of the care recipient
- Connect them with Dementia related services in their area

# YOUNG CAREGIVERS & DISABILITIES



Young caregivers who have a family member at home with a disability can experience negative feelings such as guilt, resentment, loneliness, shame, and confusion. There can also be positive feelings such as pride, happiness, support, and love. To ensure young caregivers stay positive about their family member with a disability, professionals and adults should:

- Be clear and concise about the family member's disability
- Check in with the young caregiver's personal feelings often
- Give them praise unrelated to their family member; for example, instead of "You're so good at helping your sister!", try comments such as, "You are so talented at drawing".
- Allow them time away from their family member
- Encourage them to find healthy coping skills both inside and outside of the home
- Connect them to support systems relevant to their life situation
- Remind them of the positive aspects of having a family member with a disability, such as the ability to understand and empathize with others on a greater level



## YOUNG CAREGIVERS & MENTAL HEALTH

Mental health is a growing reason for care in our society. It is important to break down the stigma around mental health. Empower the young caregiver to be able to take care of their own mental health when their family member relies on them for emotional support. Some tips on working with these young caregivers are:

- Check in with them regarding their own personal mental health
- Check in with them regarding their family member's mental health
- Remind them that it is not their sole responsibility to take care of their family member - prompt them to brainstorm other adults who can help support this family member
- Connect them to appropriate services, programs, groups, and counselling services for their own well-being
- Have them picture their own mental health as a cup of water: If the water is not good, it cannot be shared with others. This will help them realize that in order to help their family member, they must prioritize and take care of their own mental health



# YOUNG CAREGIVERS & ADDICTIONS



Young caregivers who support someone with an addiction sometimes do not know or understand the full extent as to why they help this person. If the young caregiver is particularly young, they might talk about their reason for care as a chronic illness such as back pain or stomach pain. If they do understand the addiction, they might be ashamed or talk about it in inappropriate ways. To support these specific young caregivers:

- Actively listen when they talk about their family member
- Ask appropriate contacts (such as schools or their social workers) about any of the young caregiver's background information that may be relevant to your interactions
- Try not to make assumptions or explain the condition in inappropriate ways
- Respect what they know or do not know about their family member
- Ensure their safety by checking in with them often
- Watch for lack of hygiene, consistent hunger, or other signs of negative impact on the young caregiver's well-being
- Connect them, and their family, to resources that will positively support them



## YOUNG CAREGIVERS & CHRONIC ILLNESS

Young caregivers that have a family member with a chronic illness typically know and see the illness first-hand. Illnesses can include cancer, diabetes, arthritis, and many more. Chronic illness is a significant reason for care because it can require all types of care - personal care (providing medicine, feeding, bathing, dressing), emotional care (being a support system) and/or practical care (laundry, supervision, dishes, picking up extra chores). To support:

- Answer their questions about the illness honestly and compassionately
- Help them learn the importance of accepting the things they cannot change
- Let them be kids and encourage play; play can be a way for kids to process tough situations and have moments away from troubling mindsets
- Find the middle ground between "matter-of-fact" and age appropriate information
- Validate their worries and allow them the space to show their emotions openly
- Have them practice mindfulness and coping skills for moments when their family member has illness "flare ups"
- Set them up with illness-specific support systems



# YOUNG CAREGIVERS AT SCHOOL: SUPPORTING A STUDENT



Young caregivers have so many responsibilities, that occasionally their schoolwork can be put on the back burner. This contributes to the stigma that young caregivers are lazy or troubled - when in reality, the opposite is true. If you work with a young caregiver in a school setting, here are some ways to ensure they are better supported:

- Offer programs DURING school in case after school programs are not possible for them
- Validate their role at home and check in with them
- Hold homework clubs to leave sufficient time for their at-home tasks
- Offer academic accommodations when appropriate (e.g., deadline extensions)
- Listen to them and provide simple, age appropriate coping skills such as deep breathing, fidget toys, and stress balls
- Encourage them to connect with other students in similar positions
- Connect them to school resources and staff that can help them
- Ensure a welcoming and inclusive classroom setting
- Encourage play as it is a way for kids to process tough situations and have moments away from troubling mindsets



# YOUNG CAREGIVERS WITH NEWCOMER FAMILIES

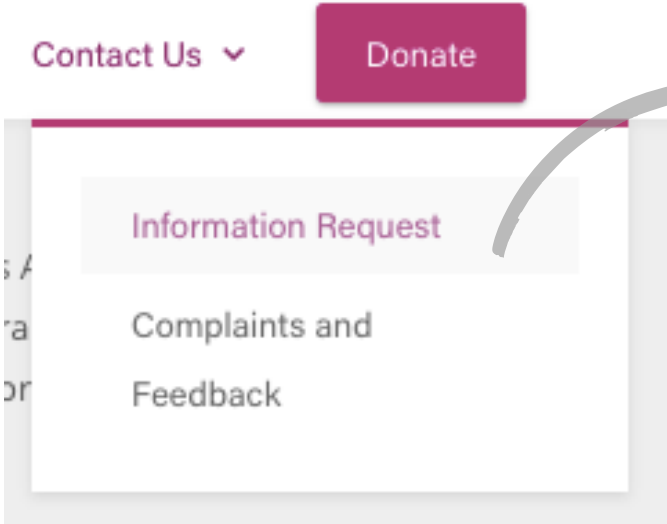
It is a regular expectation in many cultures that children contribute to the success and well-being of their families. Newcomer families are not a uniform group and have different levels of access to supports and services, along with different levels of comfort. Here are some important things to consider when working with newcomer young caregivers:

- Families new to Canada may have existing difficulties that are made worse by the stress of immigrating; for example, mental health issues triggered by the stress of immigrating
- Many children and youth are relied on for their ability to translate at appointments
- Young caregivers can experience a role reversal or distorted relationships that are inconsistent with cultural expectations
- Young caregivers may experience more serious isolation due to the isolation experienced by being a newcomer
- Newcomers may experience racism, educational gaps, language barriers, culture shock, and conflicting values that may affect participation in services
- Cultural awareness and sensitivity are needed when engaging with newcomer young caregivers



# MAKING A REFERRAL:

Refer young caregivers to us. Please go to our website - [youngcaregivers.ca](http://youngcaregivers.ca) - click "contact us" and choose "information request form". On the form, please be sure to click "refer a young caregiver" and provide us with the information needed to contact you. For families and young caregivers who cannot reach our in person services, we have virtual programs and counselling available, as well as an accessible micro-site: <https://powerhouse.youngcaregivers.ca/>



**Reason for contact**  
check all that apply

<input type="checkbox"/> To register my child/family	<input type="checkbox"/> To register myself as a young caregiver
<input checked="" type="checkbox"/> To refer a young caregiver/family	<input type="checkbox"/> To receive information about services
<input type="checkbox"/> To request a presentation	<input type="checkbox"/> To become a volunteer
<input type="checkbox"/> To join the Board of Directors	<input type="checkbox"/> Register for an virtual program
<input type="checkbox"/> other (please specify)	

**Referring Agency \***

**Referring Contact \***

<input type="text"/>	<input type="text"/>
First	Last

**Referring Contact Email \***      **Referring Contact Phone**

<input type="text"/>	<input type="text"/>
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Thank you for your support of YCA and your interest in supporting young caregivers and their families. To stay up to date on our efforts and to see young caregivers in action, please stay connected to us on social media.

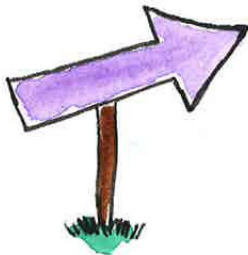


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Lead.  
Support.  
Empower.



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