

YOU'RE DOING GREAT!

MAKE
TIME FOR
YOURSELF

EXPRESS
YOURSELF

HAVE FUN!

Be CREATIVE

WE'RE
LISTENING
TO YOU!

DO
WHAT YOU
LOVE!

— WE —
HEAR YOU

WE'RE HERE
TO HELP!

SUPPORT MATTERS

A GUIDE FOR YOUNG CARERS
AND THEIR ALLIES

A BY US FOR US® GUIDE

WE CARE

Young Carers Are:



children, youth & young adults who experience an



alteration in our family



roles as a result of a family member's




exceptional needs or our unique family situation

Young carers have many different experiences. You could have a sibling, parent, or older adult living in your home with a physical or developmental disability, mental health, addiction or language barrier issue, or a chronic or life threatening illness.

Amy Townsend, Fitsum Areguy, Angele desRoches & Zarra Amatulli
Young Carers & Members of The Young Carers Project

2012 – 2013



Sometimes when you are a young carer, you end up feeling alone, like the people around you don't understand what you are feeling, thinking and dealing with. We created this guide because you are not alone.

There are many other young carers dealing with situations that are similar to yours in some ways and different in other ways. Our group met to talk about our experiences. We explored the impact of being a young carer on us as individuals, on our relationships with our friends, families and others, and on our life choices and situations at school, work, and in the community. This guide includes issues, perspectives, and hopes for the future directly from young carers.

Some of this may fit for you and some of it may help you realize how your experiences are unique from others. The point is to talk about these issues and what you need to feel supported and acknowledged. This is for you.

There are sections in here that you can share with other people in your life, if you want to, so they can understand how to support you. These are lists of tips that you can add to so they really fit your situation.

Our hope is to increase awareness about young carers so that you have more options for community supports. This guide is a step toward that. If you have thoughts or experiences to share with us after reading it, we would love to hear from you. Your voice can make a difference!

Holly Mathers

Young Carer & Chair of The Young Carers Project



Chapter 1 You

Caring for your family member is something that may be part of your life for a long time, continuing to shape who you are even when you are an adult. Here are some areas that may have personal impact for you right now.

IDENTITY

Adolescence and young adulthood are key times to figure out who you are. All of your experiences can shape your identity, and being a young carer is no different. You may be very capable and self-motivated because you've been taking on a bigger role in your family. You could be super responsible or very rebellious, maybe being the peacekeeper in your relationships or creating conflict because of the stress in your life. Most likely you will feel and act differently depending on the situation and people you are with.

At times, being a young carer can help you learn about yourself. You may decide to pursue a career helping people because you know you're good at it, you've developed a strong sense of empathy, and you want to continue to make a difference in people's lives. Other times, being a young carer might keep you from expanding your horizons. Maybe you spend so much time thinking of others that it's hard to find time to focus on yourself, your goals and accomplishments, and new experiences. It can also be difficult to feel empathy when you hear about other people's problems that seem minor in comparison to your situation.

EMOTIONS

Being a teen or young adult is an emotional time for most people. Pretty much everything in your life is changing, from your brain to your body to the way you see yourself and interact with others. On top of that, being a young carer can sometimes feel like an emotional rollercoaster. You may feel devotion, love, hate, guilt, envy, concern, acceptance, jealousy, anger, gratitude, resentment, fear, shame, embarrassment or other emotions at any given time depending on your situation. These feelings can be overwhelming and confusing. Disconnecting and bottling up your feelings might be appealing when it's hard to deal with them, or you think others won't understand. You may want to talk about your feelings but aren't sure who to trust. Remember that emotional ups and downs are natural. There are no "wrong" emotions to feel, it's how you handle them that matters.

STRESS

Being a young carer can add extra stress to what is already a really stressful time of life. Family members might lean on you for support, which can feel like a lot of pressure. You may also put pressure on yourself to meet the demands of school, friends, clubs, work, and family responsibilities. It can be tempting to get caught up in trying to find solutions, even when there may not be clear problems that can be solved.

“At that time in your life it’s not fair, shouldn’t be like that—responsibility trumps almost everything, every piece of your wellness wheel.”

-Young Carer

Dealing with emotions, like guilt, can stress you out. You might not think you’re doing enough or feel bad when you take time to focus on yourself or have good things in your life that your other family members don’t. Just like with emotions, feeling stressed at times is normal and what matters is how you deal with it.

THERE ARE NO
"WRONG"
EMOTIONS

SELF-CARE

When you’re caring for someone else it can be easy to ignore your own needs. You might be aware of what your needs are, but sometimes they take a backseat to the well-being of the family member with more urgent needs. Other times, you might not even know what your needs are because you’re focused on so many other things. You may decide to “do you” at times but find it stressful because you feel guilty.

When you are juggling a lot of responsibilities it can be hard to find time for hobbies or fun social activities. These activities can be positive outlets for you and maybe you make as much time for them as possible. Or, you might

avoid them all together because your family responsibilities can be unpredictable and you feel like you can’t commit on a regular basis, don’t want to bail on others at the last minute, or feel guilty for doing something for yourself. It can sometimes be tempting to choose potentially harmful activities as an escape, like using drugs, drinking, hurting yourself, or taking part in aggressive activities. Positive self-care can provide other options.



Chapter 1

Ways to Cope

Everyone copes with stress, emotions, and challenges differently. How do you cope? Are your coping strategies actually helping you deal with the situation? We've got some suggestions if you're not sure where to start or are looking for new ideas.

- Find at least one safe person outside of your family you can talk with about your life. If you're not sure who to reach out to, look for someone who you feel comfortable around, is a good listener, has time, and will focus on you. Tell them what you want from them—do you want them to listen, provide advice, challenge, motivate, or mentor you?
- Share your needs with your family if possible. Depending on your family dynamic, this can be really hard. Remember that they won't know what you think, feel, or need unless you tell them.
- Talk to your family doctor or another health care provider about your own health and well-being.
- Take (or make) time for yourself because you matter too:
 - › *Try to do one thing each day that you enjoy. Taking even 10 – 15 minutes for yourself can be a step in the right direction and help you start to recharge.*
 - › *Plan for breaks from your responsibilities, especially when the situation is chronic and long-term, and make sure you have a safe place you can go to relax.*
- Channel your energy and emotions into something positive:
 - › *Learn something new or join a group activity or club.*
 - › *Express yourself through art, dance, poetry, singing, or drama.*
 - › *Find a fun activity you can do with someone in your family.*
 - › *Advocate for causes you believe in.*

CHANNEL
YOUR
ENERGY!



"[I] never found time to tell people what was going on."

-Young Carer

- Stay healthy mentally, physically, and spiritually by scheduling in time for a walk, run, bike ride, sport, or workout.
- Some people find it helpful to focus on the positives and what they do have in their lives:
 - › *Pay attention to the small things that are going right in your life like cooking tasty food or doing something nice that makes a stranger smile.*
 - › *Think about all the happy times you've had with the person with exceptional needs in your family and remember that deep down inside they are still that person.*
 - › *Use humour to help you make the best of a difficult situation.*
 - › *Look forward to the future. This can help you get through a tough time and realize it won't always be this way.*
- You may feel that you need to do everything or be everything to everyone. Try not to be too hard on yourself and reach out for help when needed.
- Give yourself permission to laugh, have fun, and be silly sometimes.
- Develop a plan for emergency or crisis situations that might come up. This can help ease your mind.
- Have a plan to avoid coping strategies that feel good in the moment but may hurt you in the long run. Instead of using strategies like hurting yourself, drinking or using drugs, try:
 - › *Creating a list of positive activities and doing something from that list instead, like listening to music, journaling, or watching a funny movie.*
 - › *Calling, texting, or video chatting with a caring friend or family member.*
- Take positive action on the things you can change to make you feel better.
- Get some help. Sometimes you'll feel upset about what's going on. If you feel like this is getting overwhelming, it's time to talk to your family doctor, school counsellor, another adult you trust, or call a local help line.
- Remember that taking time for yourself and seeking help from others is important. You don't have to feel guilty about that.



Chapter 2

Your Relationships

Relationships are a huge part of everyone's life. As a teen or young adult, you may be trying to rely less on your family and build stronger relationships with others. As a young carer, this can be really complicated if you feel pulled in different directions.

FAMILY

Relationships with family members can be tough and being a young carer adds to that. Sometimes dealing with a challenge together or experiencing a crisis can bring families closer and make relationships and bonds stronger. Other times it can cause tension, like when family members disagree about how to handle a situation or if it should be discussed with others outside the family.

You might not always get the attention you need or want from your family. Maybe you think you can't raise your issues because they don't seem as important as everything else that's going on. Or, you may exaggerate an issue or problem to make it seem as important as the other issues your family is dealing with.

Roles and boundaries can become blurry. You might find your relationship with your parents is different than your friends' relationships with their parents. Your parents may treat you differently, expect you to take on more responsibilities, or share too much information with you. Maybe they expect you to always be there to help, even if the situation

is chronic or long-term. This can bring up angry and resentful feelings and make it hard for you to plan for your own future. Things can be complicated with your extended family too. They might make your life easier by helping with care responsibilities, doing household tasks, or being someone you can talk to. Other times, they could judge or give unwanted advice without actually offering to help, which can be frustrating.

FRIENDS AND OTHERS

As a young carer, friendships can be really hard. At times, you may have so much to deal with at home that you don't have the time or energy for relationships with people outside your family. Some friends might not understand your situation, while others don't care, or tell you you're too negative when you're just telling the truth about your life. Because of this, you might pick and choose what you tell your friends; you may even drift apart. This can make you feel alone and misunderstood. Maybe you avoid social activities and drama by never fully committing to plans or cutting out needy friends. You might try to make friends with



“There is shared energy when there are shared experiences.”

-Young Carer

people who are “drama-free” and stay away from conflict with friends so you won’t get blamed for it. Other times, it may seem easier not to have many friends.

and find the support you need and want in the community. It sometimes makes parents scared to let people outside of the family know what’s going on because they don’t want to be judged or criticized.

“[I] Ran away from home a couple of times and after a few hours had to (out of sense of duty) call [home] to make sure they were okay and that all of their needs were being taken care of. [I] always went back because no one was consistent enough to let [me] have a break.”

-Young Carer

It may seem like people are always watching and judging you and your family. They might think that you have a broken family without knowing anything about what is going on. Some people have expectations of you because of your age and do not understand your unique role in your family.

When you open up to someone you might worry that they think you are making things sound worse than they are because they don’t see the issues your family member is dealing with. This can make it really hard to open up

Adults outside your family, like coaches, camp counsellors, teachers, neighbours or family friends, can be important in your life. When these adults show they care about you and your situation, you will be more likely to bond with and respect them. They can provide you with the

attention, motivation, and praise you feel that you’re not getting at home. Because of this, you may look up to them as role models and try very hard to please them, so they will be proud of you. It can be tough to find friends and adults outside your family that give you what you’re looking for when not everyone understands your situation, your family wants to keep things private, or people are not available when you need them. When you are able to find people you can depend on, they can have a huge impact on your life.

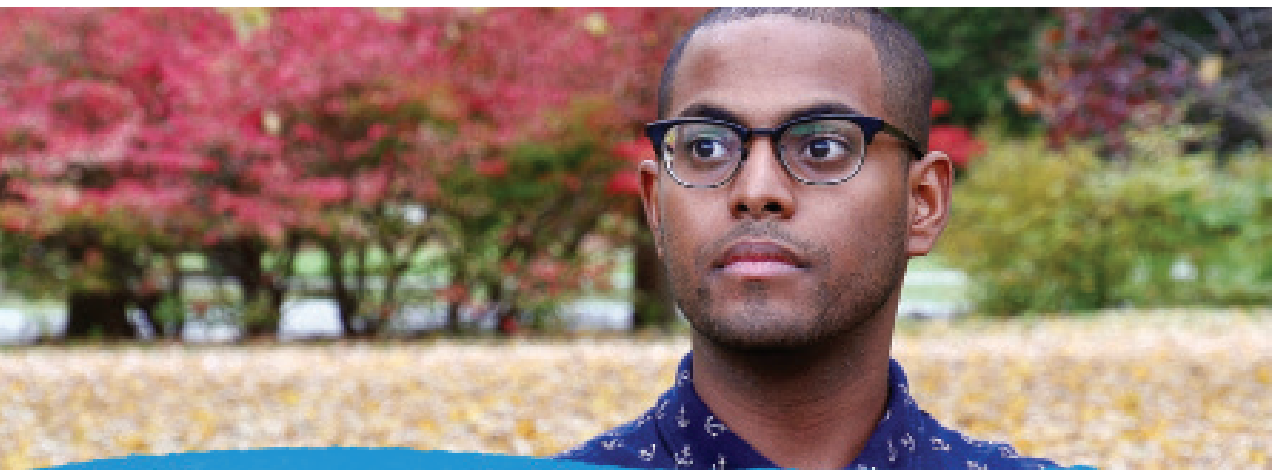


Chapter 2

Ways to Cope

Relationships are a necessary part of life, even though they can be complicated. Are you getting what you need from your relationships? There are ways to help create stronger relationships in your life.

- Talk to trusted family members and friends about what you're going through, even though it might be hard to open up. You may be surprised by how supportive people will be if they understand your situation and what you need.
- Find family members and close friends who want to help out. Many people do want to help, but just don't know how. For example, when you have plans with friends, arrange for someone to cover for you at home if needed. This can help to ease your mind and make sure you don't have to change your plans if your family member needs help.
- Be selective about who you spend your time with. Good relationships are safe, healthy and positive. Look for and spend time with people who let you act your age, be yourself, and feel good. This could be a friend, teacher, camp counsellor, or family member.
- Connect with people that understand what you're dealing with through blogs, chatrooms, forums, and other online options.
- Use technology to keep the people involved with your family connected and updated, create a care schedule, or coordinate anything else that's needed.



"People care; they just don't know what to do."

-Young Carer



Chapter 3

Your World

You don't live in a bubble. There are a lot of other things around you that can have a big impact on your life. Here are a few to think about.

SCHOOL

School can be a challenge when you are a young carer. You might use school as a distraction, or focus on it because it helps you cope with your situation. Maybe you don't have the time, energy or interest you need to do well in class. Your stressful family situation can make it hard to focus or interfere with your sleep and studying so you don't get the grades you want.

If you have trouble at school, people may think you are not smart. But, just because you're not getting good grades, doesn't mean you don't have the potential. The skills you learn from being a young carer are also important. You may not realize it now, but they can be skills your peers don't have and can help you in other areas of your life.

Managing when you are at school can be hard. For example, you may not have the opportunity to stay in touch with home due to cell phone rules. It can be very distracting

wondering how things are going at home while trying to focus on school. Finding people you can talk to can also be tough.

School counsellors, teachers, and other support staff don't always know what you need and may not be around every day. If you don't have somebody who understands, you may feel really alone. When you do find someone you trust, school can be a safe and supportive place.

HEALTH CARE

Dealing with the health care system can be really overwhelming. It's scary when someone you love is sick. It's often hard to understand their illness, mental health issue, or disability and how to help them. You might deal with doctors, nurses, pharmacists, and others who do not want to tell you information because they don't understand your role in your family, or who give information in a way that you don't understand. This can leave you frustrated, concerned, confused and feeling left out of important conversations. However, there are some health care professionals who truly care and will take the time to address your concerns.

CULTURE

Your culture greatly impacts the role and expectations that you have in your family. Your culture includes your individual family, your school, your community, your ethnic background, or other influences in your life. For example, you may have a different support system or level of privacy living in a small town versus living in a big city.

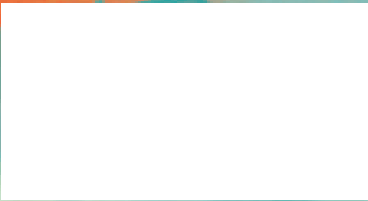
You might find yourself becoming a young carer if your family moves to a new country. They may rely on you for help with almost everything from banking to contacting service providers and healthcare organizations to making sense of bills and other mail. This can happen when your family has difficulty communicating due to language differences, or does not yet understand the processes of the new country. A lot of responsibility can then fall on you to become their voice and guide. You may feel pulled in different directions because your family may want you to stay close to your heritage and traditions but you might really want to fit in with your peers and community by forming your own identity.



Chapter 3

Ways to Cope

- Knowledge is power! Learn as much as you can:
 - › Check out YouTube videos and relevant websites for young carers.
 - › Talk to librarians to get help finding good information.
 - › Ask your family doctor or other health care provider any questions you have. Bring a list of your questions with you to appointments.
 - › Call 211 or visit www.211.ca for free and confidential information about Canadian health and community services available in your area.
- Support matters! Connect with people when you can:
 - › Join a support group on your own or with your family if available locally or online.
 - › Contact a community organization relating to the issue your family is dealing with.
 - › Think about finding a different health care professional, if yours isn't helpful.
 - › Find a trusted person who can be there for you.
 - › Be open and talk about your needs - exceptions can often be made at school if teachers are aware of your situation.



A young carer is anyone who is living with a family member with an exceptional need. This can be short-term or long-term and include an illness, disability, mental health issue, addiction, language or cultural barrier, or other unique situation.

If you know a young carer, you might feel like there is nothing you can do to make their situation better. The reality is that young carers really need you, even though they might not say it, and there are lots of things you can do to help them feel more supported and less alone. Some ideas are:

- Be their safe person:
 - › *Be compassionate and empathetic.*
 - › *Check in with them on a regular basis to find out how they are doing. You can do this in informal settings, like when you're travelling together in a car or going for a walk. These kinds of informal check-ins can help young carers open up freely without feeling pressured.*
 - › *Let them know that they can talk to you about anything. Even if they don't take you up on your offer, keep reminding them so they know you are being genuine. Sometimes young carers are protecting themselves by not opening up right away, so don't take it personally. You never know when they might finally reach out.*
 - › *Be supportive, nonjudgmental and try not to pry for information. Just listen to what they feel comfortable sharing.*
- › *Focus on their perspective and experiences rather than on their family members.*
- › *Ask the young carer what they need and want from you. Are they looking for someone who will simply listen to them and let them vent, a mentor, or someone who will challenge them?*
- If you can, help them meet others who have similar experiences so they feel less alone.
- If they are ready, help facilitate opportunities for them to learn new things, improve their coping strategies, increase their support system, and have some fun.
- Offer to help out with their responsibilities at home, if possible, so they can take time for themselves.
- Help them find a safe place where they can go to relax when they need a break from their responsibilities at home.
- Don't underestimate the impact you're having as a caring adult.
- Share this information with your colleagues, other community members, and young carers.

TIPS FOR SCHOOL STAFF

You can play an important role in the lives of young carers as a supportive, stable and caring adult. There are many issues that can come up at school that you can help address. Here are some points to keep in mind:

- Every school has young carers. Find out who they are and invest some extra time in them. Get to know their name and story, make time for them, and be encouraging. A little positive attention and understanding can go a long way.
- Educate other staff on the young carer experience to help raise awareness about the ways it can impact their lives both inside and outside of school.
- Explore who the young carer would like to have as their go-to people at school and how to access them.
- Do the best you can not to judge young carers based on your knowledge of, or interactions with, their siblings, parents, or other family members. For example, their sibling might have a disability or mental health issue that causes them to act out in class, but that doesn't mean that the young carer will as well.
- Be understanding and take steps to make your classroom or office as safe as possible for young carers. School may be the only place that young carers have time away from home or a predictable routine and you may be the only adult they have outside their family that they can trust and open up to.
- Make time in your schedule to consistently check in with the young carer.

- Be flexible and accommodate their needs when you can:
 - › *Set aside time outside of class to help them with homework.*
 - › *Provide extensions if they've been dealing with an emergency.*
 - › *Be understanding when they miss school to help their family.*
 - › *Explore how they can stay connected with their family during school hours when needed.*
- Don't underestimate the impact you're having as a caring adult.
- Share this information with your colleagues, other community members, and young carers.

TIPS FOR HEALTHCARE PROFESSIONALS

Some of your patients have young carers in their families. They are often involved with aspects of their family member's care and can be impacted by the situation in many ways themselves. Consider the following:

- Be honest and transparent with them when they ask questions about their family member's health, care plan, and other needs.
- Provide information that is age appropriate so they can understand what is going on and how to properly care for their family member if they need to. Provide information about what to expect in the short and long term, including future care needs, if applicable.
- Develop crisis plans with them for emergency situations, including people who can be called any time of day or night.
- Provide young carers with information about relevant community supports.

- Don't underestimate the impact you're having as a caring adult.
- Share this information with your colleagues, other community members, and young carers.

TIPS FOR ORGANIZATIONS

If your organization works with young carers and their families, these suggestions can help you better meet their needs:

- Ensure your website has information that is interactive and accessible for individuals of all ages.
- Provide safe and comfortable programs or places where they can share their experiences and feelings and connect with other young carers. Ask young carers what location works best for them.
- Create opportunities for young carers to connect. Awareness campaigns or fundraising events are a great way to help young carers meet others who are in a similar situation in an informal environment.
- Post information about local crisis lines and provide resources to young carers about what to do in emergency or crisis situations.
- Train staff to understand and support young carers and their needs.
- Consider providing support online for convenience and privacy.
- Create low cost or no cost recreation opportunities, so they have a safe and supervised place to be themselves, have fun, and relax.
- Don't underestimate the impact you're having as a caring adult.

- Share this information with your colleagues, other community members, and young carers.

TIPS FOR COMMUNITY MEMBERS

Our communities can be positive places for young carers and their families. This can happen in a variety of ways:

- Explore ways to support young carers.
 - › Mobilize spiritual communities, neighbours and others to provide practical and emotional support for young carers and their families.
 - › Offer after-hours supports.
- Consider extending your support services to include weekends and evenings.
- Create on-call support options.
 - › Provide safe and comfortable spaces in community organizations and healthcare locations for young carers.
 - › Participate in fundraising and public awareness activities and events that support young carers.
- Don't underestimate the impact you're having as a caring adult.
- Share this information with your colleagues, other community members, and young carers.

**DON'T
UNDERESTIMATE
YOUR IMPACT!**

Resources

To order additional copies of this guide, contact:

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