

SUPPORTING CAREGIVERS UNDER THE AGE OF 25

RISE-UP: Recognizing, Identifying and Supporting the Engagement of Youth Providing Care

A toolkit for Canadian healthcare providers to recognize and support **young carers***

* Caregivers under the age of 25 are referred to as young caregivers or **young carers**

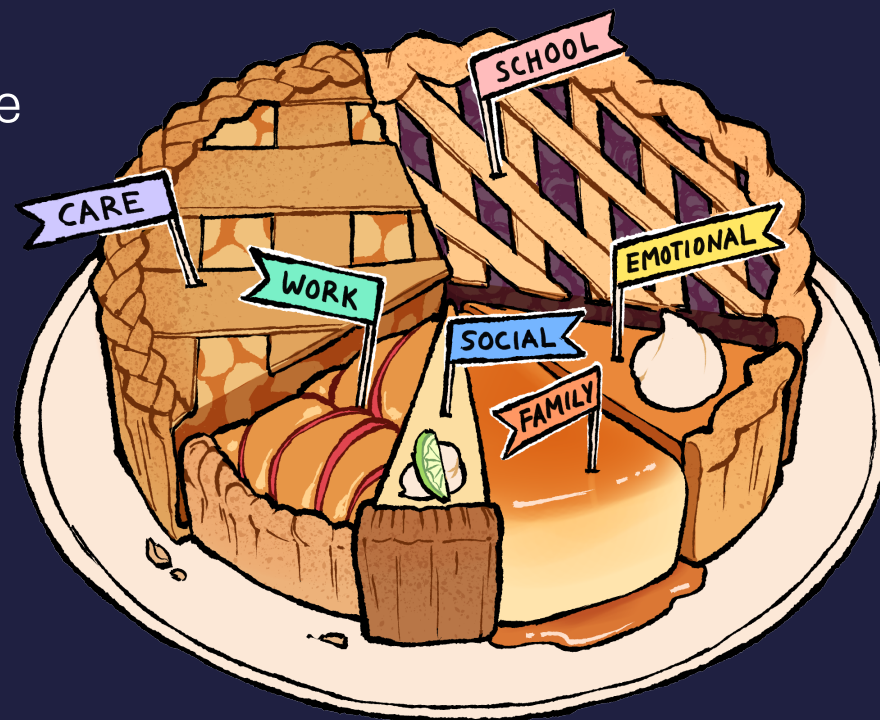


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How to navigate this toolkit

Click on the...

- i. Table of contents headings
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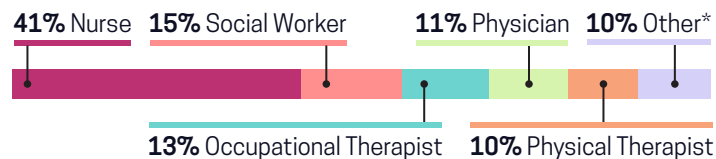
About the toolkit

A survey was adapted¹ and sent to healthcare providers across Canada to assess their ability to identify, recognize and support young carers in their practice.

This toolkit was informed by the survey results and created through a series of co-design workshops with young carers, healthcare providers and caregiving organizations.*

Survey results are embedded throughout the toolkit, and are highlighted in **pink**. Other research sources are indicated with a superscript. An example is shown below:

Clinical roles of healthcare respondents n = 450



*Other includes: Pharmacist, Speech-Language Pathologist, Respiratory Therapist, Mental Health Professionals

Clinical settings



* This toolkit is part of a research project at the University Health Network called **RISE-UP**.

RISE-UP:
Recognizing, Identifying and Supporting the Engagement of Youth Providing Care



How can I use this toolkit?

As a healthcare provider, you can use this toolkit to:

- i. Recognize the vital care that a young person may be providing as your patient or for your patient – via **Recognizing Young Carers: PIE**
- ii. Learn how to empower young carers and connect them to resources to support their needs – via **Supporting Young Carers: PASS**

Who are young carers?

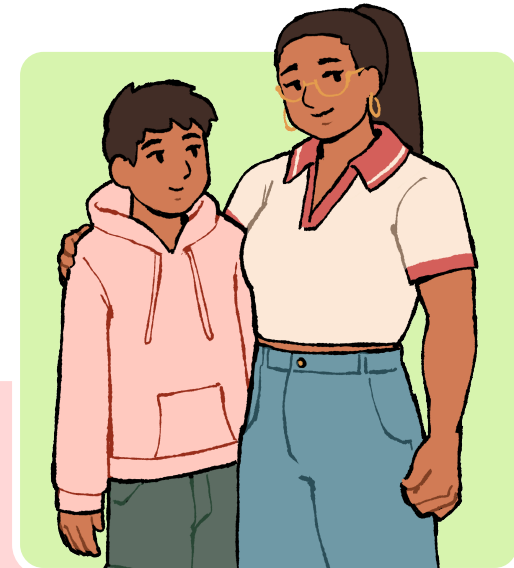
Young carers are people under the age of 25 who provide significant and ongoing unpaid care and support to a family member or loved one.²

Over **1 million** youth

ages 15 to 24 in Canada are estimated to provide caregiving support.²

What differentiates young carers?

Young people can take on significant care responsibilities, but are often not recognized for their caring roles. This lack of recognition, combined with the challenges that come with being a young person (for example: school, work, social life, family dynamics and life transitions) represent the unique challenges and difficulties of being a young carer.



Overview of PASS the PIE

Recognizing young carers: **PIE**



The “**PASS the PIE**” acronym will help you learn about the roles, responsibilities and nuances that come with being a young carer.

Recognize the young carer using PIE:

P Proximity

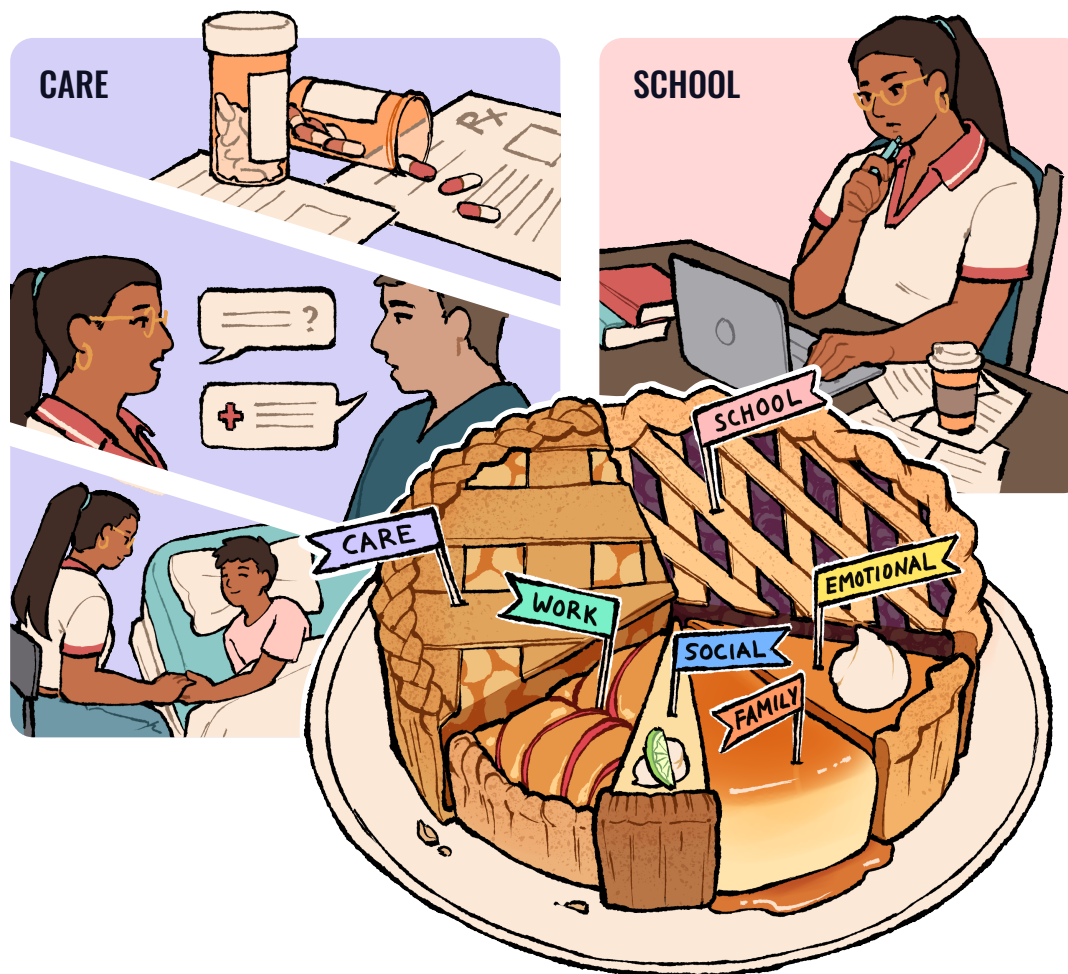
I Intensity

E Effect

Learn about the significance of each word on the following pages

Young carers often have a lot on their plate. It can be an unmanageable amount. Learn about the different pieces of **PIE** is on their plate.

PASS the **PIE**!



Overview of PASS the PIE

Supporting young carers: **PASS**

Support the young carer using PASS:

P Partner

A Affirm

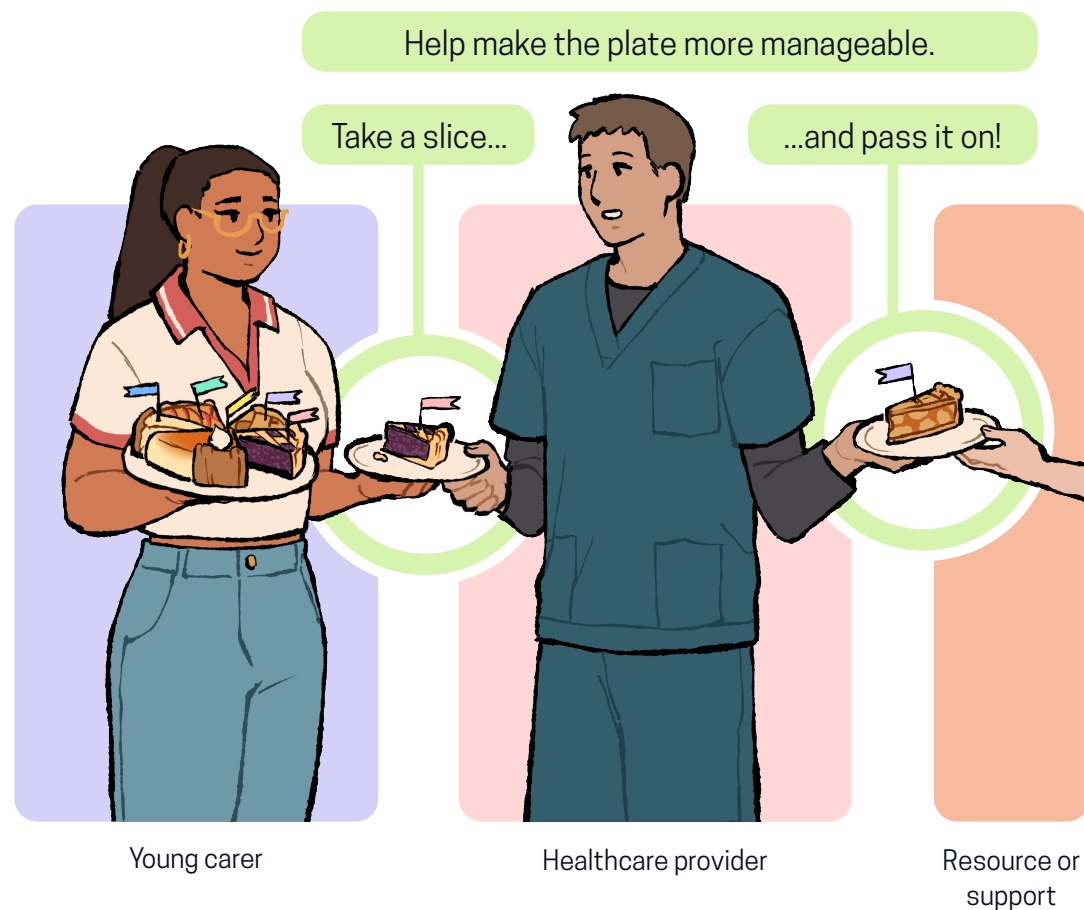
S Systems

S Support

Learn about the significance of each word on the following pages

Help young carers manage what is on their plate and **PASS** those slices to resources that can support them and their loved one.

PASS the **PIE!**



PASS the **PIE** *Recognize the young carer, learn what is on their plate*

P Proximity



Guiding
Question

**Who is within close proximity
to the patient?
Who provides care support?**

Ask yourself the **Guiding Questions** to learn how to recognize a young carer and their care responsibilities in your practice.



Family dynamics and cultural nuances

A young carer may be providing care on their own, or they may be caring alongside other members of their family unit.

When asking about care settings and needs, consider the whole family unit, with awareness to how different family members may be addressing different care needs. Cultural identities can shape care dynamics, and it is important to understand how personal and family values can impact care responsibilities.^{3,4}

Young carers may not self-identify as a caregiver. Asking about care and support without assigning a label of "caregiver" can help facilitate a conversation without stigma.

PASS the PIE *Recognize the young carer, learn what is on their plate*

Intensity



Guiding
Question

How intense are the responsibilities of the young carer?

What are young carers' responsibilities?

The following are some examples.



In healthcare

Attending appointments, coordinating care, **interpreting across a language barrier in healthcare interactions***, paperwork, **providing informed consent as substitute decision maker***



At home

Emotional support*, physical care tasks (medication administration, suctioning, wound care, and more), sibling care

** Tasks that are the most frequently identified by surveyed healthcare providers as being done by young carers*

Understanding the intensity of their care tasks can help to pinpoint where support may be needed. It can also help to avoid adding further care tasks that the young carers cannot take on. Ask the young carer:

How do you feel about providing care and helping out?

Do other people in your family provide care too?

Does it feel overwhelming?

Do they help you, and could they help you?

Learning about how a young carer feels about their care support is an important part of respecting their autonomy. They may want access to resources that can help reduce their care responsibilities, or resources to help them manage the impact of caregiving on their life.

PASS the PIE Recognize the young carer, learn what is on their plate

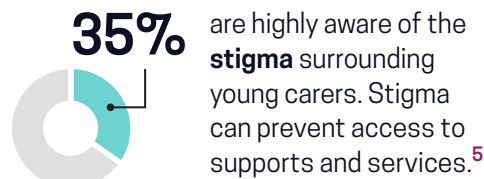
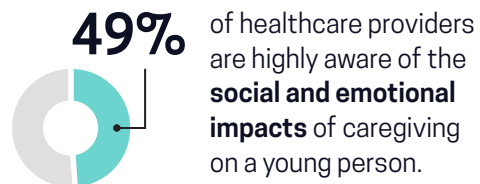
Effect



Guiding
Question

What is the effect of caregiving on the young carer?

Are you aware?



There is an undeniable impact of health struggles on families, and siblings and children are no exception. It is important to acknowledge how a caregiver and patient can support each other. Care is not unidirectional. Some young carers have shared how caregiving can positively impact them—such as feeling more mature and having a deeper relationship with their loved one.

Caregivers of all ages can struggle. It is important to understand the unique impacts of being a caregiver as a young person, especially without visibility or support.

Potential effects

The following are some examples, and not an exhaustive list.



Educational

Barriers to pursuing further education, dropping out, falling behind in school



Personal

Burnout, exhaustion, social isolation, deteriorating mental and physical health, strained family dynamics



Financial

Reduced work hours, loss of employment

PASS the PIE *Support the young carer, pass along their slices*

Partner



Guiding
Action

Understand the expertise young carers have as caregivers. Where appropriate, partner with them as a member of the care team.⁶

Use the **Guiding Actions** to appropriately engage with and support young carers, while being mindful of the intricate dynamics that can accompany caregiving.



Privacy and confidentiality

Ask the patient who they would like to know about their care and treatment—this may be a young carer!



Communication

When the person you are communicating with is a young carer, inform them about the treatment plan, medical terms and prognosis.

Treat them as a member of the care team.



Family partnership

Partnership also extends to families as a whole. Some families may want support in sharing age-appropriate information with younger siblings and children. Where available, social workers can help.

PASS the **PIE** *Support the young carer, pass along their slices*

Affirm



Guiding
Action

**Listen to their story without judgement.
Affirm their experiences.**

How do you support young carers?

See how one nurse from the survey responded to this question:

"Providing emotional support [by] giving them a listening ear, offer reassurance and validate their feelings"

Even though young carers may be at bedside in hospital or attending appointments with their family member or loved one, they may not feel seen as a caregiver.⁷ Ensure they feel heard and valued as a member of the care team. If a young carer shares with you their feelings or challenges as a caregiver, validate these feelings and affirm the importance of their support.

Affirming the roles and responsibilities of young carers is an important part of recognizing their care contributions.⁸ As a healthcare provider, sharing with a young carer that you see and acknowledge their care contributions can be a meaningful action.

PASS the **PIE** *Support the young carer, pass along their slices*

S

ystems

&

S

upport

Survey respondents familiar with the term “**young carer/caregiver**” were

6.1x more likely to be able to support young carers in their practice.

Awareness building is an important step to better supporting young carers.

Caregivers play an instrumental role in our health systems.

An integrated, accessible healthcare system takes work off of a caregiver's plate.



Guiding
Action

Work with the young carer and the healthcare team to determine what type of support is desired.

You are likely meeting young carers at a very difficult time. This means that they are unlikely to ask for help for themselves because they do not want to add to their family's plate, or they may see their struggles as less important.

Ask the young carer, “**What do you need?**”. It may be as simple as a note excusing their absence from school.


There are different areas where young carers may need support that a healthcare provider cannot help with (for example, long-term leave from school). Work with the young carer and their family unit to determine how they want to be supported.

Use the [resources section](#) to connect young carers to relevant resources and supports that can address their needs.

Resources

Resources are categorized by province. However, some online resources can be accessed outside the province.





As of **2024**, resources are up to date.

Click on this icon  to access the resource link.

Surveyed healthcare providers shared their thoughts on resources for young carers:

Resources identified as helpful for young carers included:
Peer support
Phone helplines
Mental health support

Healthcare providers recognized a need for more **health literacy** and **culturally competent** resources.

Region	Org	Resource	Condition	Age	Link	Young Carer Specific	Navigating healthcare	Emotional Support	Life Skills*	Informational Support	Session (online /in-person)	Online resource	Helpline
Alberta	CA	Caregiver Coaching	All	All			✓	✓	✓		✓		
	CA	Community Resources (database)	All	All			✓	✓		✓		✓	
	CA	COMPASS For Caregivers	All	All			✓	✓	✓	✓	✓	✓	
	CA	Resources	All	All			✓	✓		✓		✓	
	MHL	Could My Parents Be/Have Series	Mental Health	Teen		✓		✓		✓		✓	
British Columbia	FCBC	Caregiver Coaching	All	All			✓	✓		✓	✓		
	FCBC	Young Caregivers Resources	All	All		✓		✓	✓	✓		✓	
	BCSS	Supporting a Loved One	Schizophrenia	All			✓	✓		✓	✓	✓	

***Life skills** = time management, setting boundaries, communication skills, etc.

CA = Caregivers Alberta
MHL = Mental Health Literacy

FCBC = Family Caregivers of British Columbia
BCSS = British Columbia Schizophrenia Society

Region	Org	Resource	Condition	Age	Link	Young Carer Specific	Navigating healthcare	Emotional Support	Life Skills*	Informational Support	Session (online /in-person)	Online resource	Helpline
Ontario	HB	Sibkits	Pediatric acquired brain injuries, disabilities, complex diagnosis	Kids	↗	✓		✓		✓		✓	
	HB	Sibling Support Program	Disabilities, complex/dual diagnosis	7-18	↗	✓		✓	✓	✓	✓	✓	
	HT	Young Carers Program	All	<18	↗	✓		✓	✓	✓	✓		
	OCO	Caregiver Coaching Program	All	All	↗		✓	✓	✓	✓	✓		
	OCO	Healthcare Journey Binder	All	All	↗		✓			✓		✓	
	OCO	Helpline: 1-833-416-2273 (CARE)	All	All	↗			✓					✓
	OCO	Young Caregiver Discussion Forum	All	15-25	↗	✓		✓	✓	✓		✓	
	OCO	Young Caregiver Peer Support Group	All	15-25	↗	✓		✓			✓		
	YCA	How To Advocate For Yourself	All	5-25	↗	✓		✓	✓	✓		✓	
	YCA	Knowledge Centre	All	5-25	↗	✓		✓	✓	✓		✓	
	YCA	Powerhouse Program	All	5-25	↗	✓		✓	✓	✓	✓		
	YCA	Resources For Young Caregivers	All	5-25	↗	✓		✓	✓	✓		✓	
	YCA	Young Caregiver Identification Checklist	All	5-25	↗	✓				✓		✓	

*Life skills = time management, setting boundaries, communication skills, etc.

HB = Holland Bloorview Kids Rehabilitation Hospital
HT = Hospice Toronto

OCO = Ontario Caregiver Organization
YCA = Young Caregivers Association

Region	Org	Resource	Condition	Age	Link	Young Carer Specific	Navigating healthcare	Emotional Support	Life Skills*	Informational Support	Session (online /in-person)	Online resource	Helpline
Ontario	CAMH	Guides & Publications	Mental Health	All	↗			✓		✓		✓	
Quebec	AMI	Family Peer Support	Mental Health	18+	↗		✓	✓	✓	✓	✓	✓	
	AMI	KARE: Magazine for Young Carers	Mental Health	13+	↗	✓		✓	✓			✓	
	AMI	Navigating the Healthcare System	Mental Health	All	↗		✓			✓		✓	
	AMI	SOS - Famille	Mental Health	18+	↗			✓			✓		✓
	AMI	Young Adult Support Group	Mental Health	18-30	↗	✓		✓	✓		✓		
	AMI	Young Carers Resource List	Mental Health	All	↗	✓	✓	✓	✓	✓	✓	✓	✓
	ARB	Family Peer Supporters	Mental health	All	↗			✓		✓	✓		✓
	ARB	Online Training	Mental health	13-25	↗	✓		✓		✓	✓	✓	
	CAP	Tools and Resources	Mental health	All	↗		✓	✓	✓	✓		✓	✓
	LAP	Tools and Support for young people	Mental health	Kids	↗	✓		✓	✓	✓		✓	
	LAP	FAMILLE+	Mental health	7-11	↗	✓		✓	✓	✓	✓		
	LAPPUI	Caregiver Helpline	All	5-25	↗		✓	✓		✓			✓

*Life skills = time management, setting boundaries, communication skills, etc.

CAMH = Centre for Addiction and Mental Health
AMI = AMI-Quebec

ARB= Arborescence
CAP = CAP santé mentale

LAP = LaProche
LAPPUI = l'Appui

Region	Org	Resource	Condition	Age	Link	Young Carer Specific	Navigating healthcare	Emotional Support	Life Skills*	Informational Support	Session (online /in-person)	Online resource	Helpline
Canada	AS	Young Caregivers Resource Centre	All	<30		✓		✓		✓		✓	
	CCCE	Canada-wide Caregiver Resources Hub	All	All									

***Life skills** = time management, setting boundaries, communication skills, etc.

AS = Alzheimer Society of Canada
 CCCE = Canadian Centre for Caregiving Excellence

Financial resources

- BC [Overview of Financial Resources](#)
Family Caregivers BC

- ON [Financial Support](#)
The Ontario Caregiver Organization
- [Home and Vehicle Accesibility](#)
March of Dimes

- CAN [Health Equipment Loan Program](#)
Canadian Red Cross
- [Overview of Caregiver Benefits](#)
National Senior Strategy
- [Travel Support for Medical Appointments](#)
Hope Air

Integrated Youth Services Network

For youth aged 12–25, integrated mental health and substance use services are a growing resource. They are available in certain regions.
[Click here to learn more.](#)

- MB [Huddle](#)

- NS [IWK Health](#)

- ON [Youth Wellness Hubs](#)

- SK [Homebase](#)

Want to learn more about caregivers as a healthcare provider?

Caregiver-Centered Care Education
Supporting Family Caregivers in Healthcare

Toolkit Design and Illustration

Nichole Zhou
flaticon.com (for icons)

Project Leads

Dr. Karen Okrainec
Isabelle Caven

Project Team

Aysha Afzaal
Zhenxiao Yang
Nichole Zhou

Co-design Support

Melissa Frew
(Healthcare Human Factors)

Collaborators



Study Co-investigators

Sue Bookey-Bassett
Jill Cameron
Shoshana Hahn-Goldberg
Yona Lunsky
Kristine Newman
Marianne Saragosa

Young Carer Advisors

Alexandre Grant
Nicholas Goberdhan
Samiha Rahman
Amanda Ramkishun
Kristie Mar
Tyler Redublo

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