

Young Carers Voices – International perspectives

*Day 1 – Thursday
8th June 2023*

Thursday 8th and Friday 9th June

*The introductory
film will begin at
4:50pm BST*

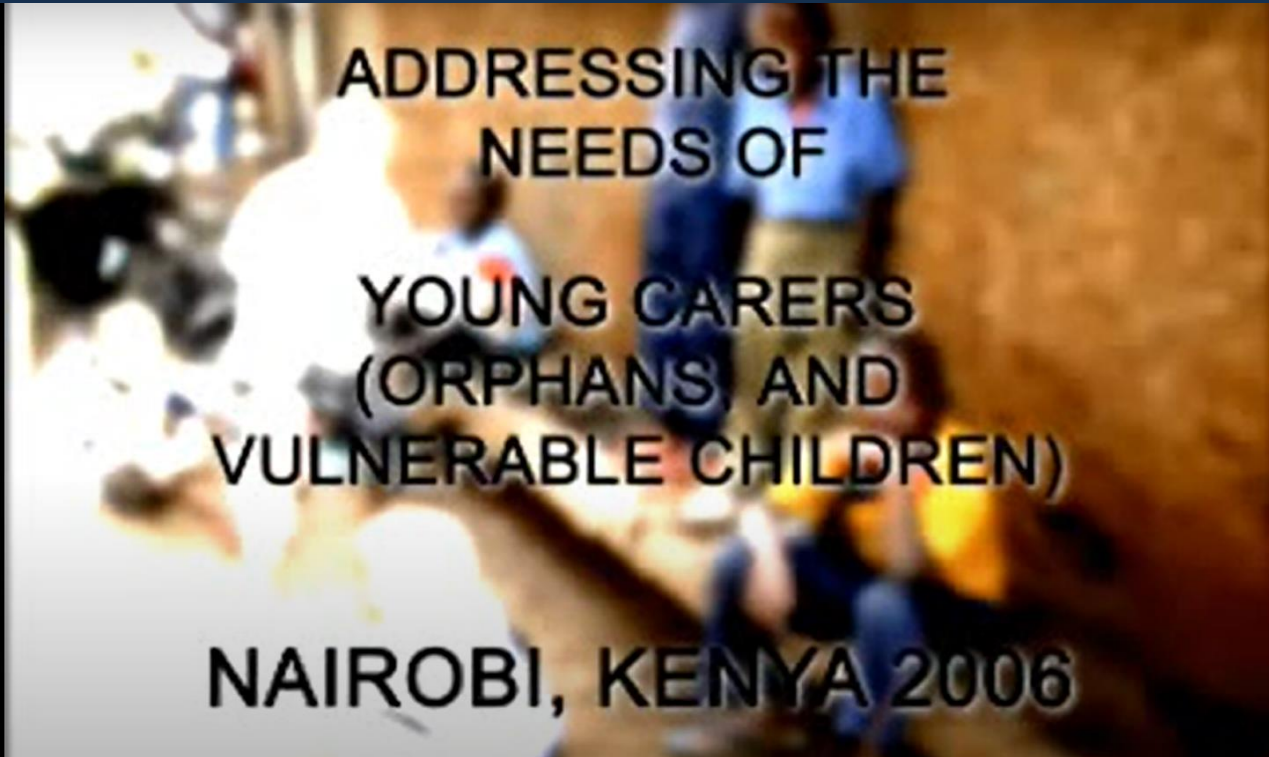


Photographer credit: Jessica Howarth

Young Carers Voices – International perspectives

Thursday 8th and Friday 9th June

Introductory film – Where the Commonwealth young carers journey began...



Young Carers Voices – International perspectives

Thursday 8th and Friday 9th June

Hello

Jambo

Kon'nichiwa

Bonjour

Ciao

Namaste

Hei

Helô

"We want a strong national young carers network so Government can hear us and so we can have a BIG SAY in what happens and be involved in making decisions about policies."

Rebecca, Rwanda

www.carers.org/youngcarersvoices

Housekeeping

- This session will be recorded and will be available next week along with the slides at www.carers.org/youngcarersvoices
- Please keep yourself on mute if not speaking
- Do introduce yourself in the chat and create links
- If you are on Twitter - #youngcarersvoices @CarersTrust @YCAAlliance @commonwealthsec @CwIthSocWk
- If you want to share anything after the event or have any more questions - youngcarersalliance@carers.org
- All presentations will be available after the event from www.carers.org/youngcarersvoices



Jamboard

- We will be using Jamboard to capture follow-up questions/comments/pledges.
- Feel free to use post-it notes as we go through the event
- Please use the link in the chat to access
- Quick questions which can be answered via the chat can be posted in the Zoom chat.

Day 1 - Agenda

- Welcome and setting the scene
- Welcome from the Commonwealth Secretariat
- Keynote – Professor Saul Becker
- Voices from Rwanda
- Voices from Italy
- Voices from Canada

- Oritsé Williams
- Voices from France
- Voices from UK
- Voices from the USA
- Wrap-up



Portraits:
Max Alexander/Hospice
Toronto;
Max Alexander/The
Children's Society

Follow-up
questions/comments/pledges – Go to
the [Jamboard](#) (Link is in the chat)

Welcome from the Commonwealth Organisation of Social Work



Sylvia Daisy
Chair
Commonwealth
Organisation of Social
Work

*"We should have our
physical health and
emotional needs
acknowledged and
assessed."*



Welcome from the Commonwealth Organisation of Social Work



Welcome from the Commonwealth Secretariat



The Commonwealth



Layne Robinson,
Head of Social Policy
Development
The Commonwealth
Secretariat

*"We should have our
physical health and
emotional needs
acknowledged and
assessed."*

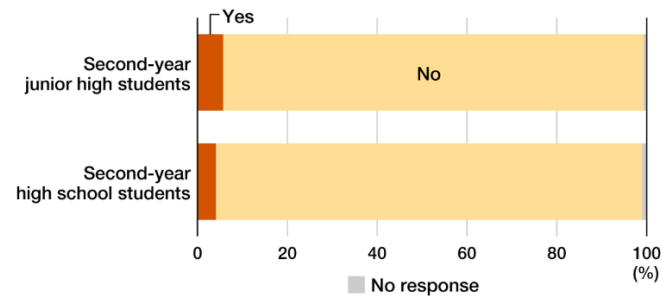


Setting the scene...



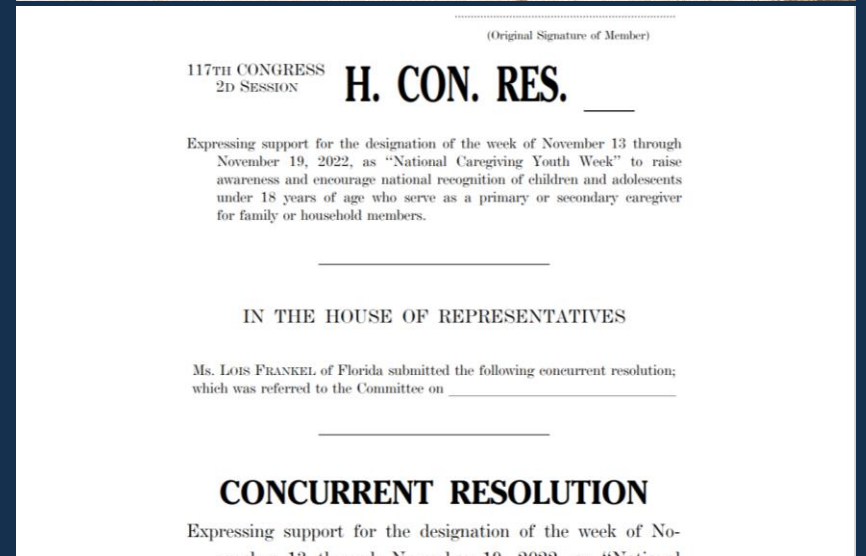
More than 45% of young carers said they looked after a family member on almost a daily basis and 17% said they cared for someone three to five days a week. On average, students spent four hours a day on caregiving, while 10% answered that they spent over seven hours on care daily.

Do You Care for a Family Member?



Created by Nippon.com based on a Ministry of Health, Labor, and Welfare research report into the conditions of young carers.

nippon.com



Commonwealth Young Carers Charter

- The work started with a symposium in 2006
- Young carers wanted their voices heard and needs recognised by governments
- Consultation with young carers across 10 Commonwealth countries has led to a draft charter
- Aim is to be signed off at Heads of Government meeting in Samoa 2024



THE COMMONWEALTH CHARTER FOR YOUNG CARERS



Young carers from across the Commonwealth have developed this Charter, grounded in the United Nations Convention on the Rights of the Child.

Young carers in every country look after someone in their family who has an illness or a disability or other condition. Sometimes they look after the whole family. Young carers are children and young people first and should be free to develop emotionally and physically and to take full advantage of opportunities for educational achievement and life success.

"It is important to involve young carers in all aspects of policy making and decision making. We have a voice - listen to us!"

AS YOUNG CARERS FROM AROUND THE COMMONWEALTH WE ASK THAT WE:

Are listened to and our views and culture are respected.

Understand how we feel and what we need.

Do not face discrimination as a carer or for our family situation.

Young carers should be treated equally... no one should be judged because of their family situations.

Have our physical health and emotional needs acknowledged and assessed.

Have a right to an assessment of our needs separate from the needs of the person we care for.

It's hard ... trying to find a balance in life - juggling everything we have to do.

Being a young carer can be challenging and sometimes we all need a little support and time out, just to be ourselves and relax.

Have the right support given to the person we care for, so we don't have to provide excessive care which impacts on our own health and wellbeing.

Have practical support and help offered including respite care.

Are protected from psychological and physical harm.

Have the right to education, time to focus on our studies and be offered real choices in accessing further education and future aspirations.

Adults who work with us should know about who we care for and how it might affect us.

Have the right to relax, play and take part in a wide range of cultural and artistic activities.

We want schools to respect and understand the issues we have to deal with at home!

Have a home that is suitable and safe for us and our family.

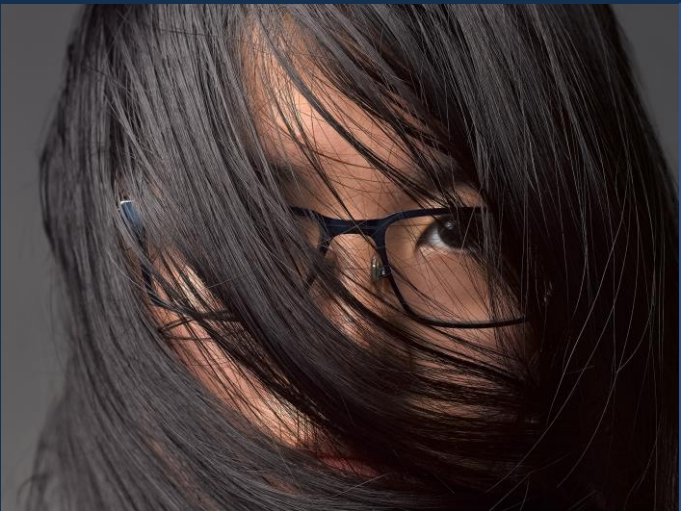
The 10 charter requests:

- Respected and heard
- Do not face discrimination
- Acknowledge health & emotional needs
- Right to assessment of own needs
- Support for the person being cared for
- Practical support & help
- Protected from psycho-logical & physical harm
- Right to education
- Right to relax
- Home which is suitable & safe

To find out more about the Commonwealth Young Carers Charter: View the charter at - [Young Carers - COSW](http://YoungCarers-COSW)
DavidNJones@PeopleNeedPeople.org.uk

How can the charter support the work you are doing in your country???

Keynote speech



Professor Saul Becker,
Pro-Vice-Chancellor for the
Faculty of Health and Education,
Manchester Metropolitan
University

*“We should have a right to
an assessment of our needs
separate from the needs of
the person we care for”*

**Keynote speaker – Professor Saul Becker,
Faculty Pro-Vice-Chancellor & Founding Director of the
Institute for Children’s Futures, Faculty of Health &
Education, Manchester Metropolitan University**



The Commonwealth



0:00 / 8:36



Young Carers Voices - Rwanda



Pierre Celestin
Bimenyimana; Hopes and
Homes for Children

*"We should have the right support
given to the person
we care for, so we don't have to
provide
excessive care which impacts on our
own health and wellbeing."*



INGABO ZACU
UMUTAMENWA

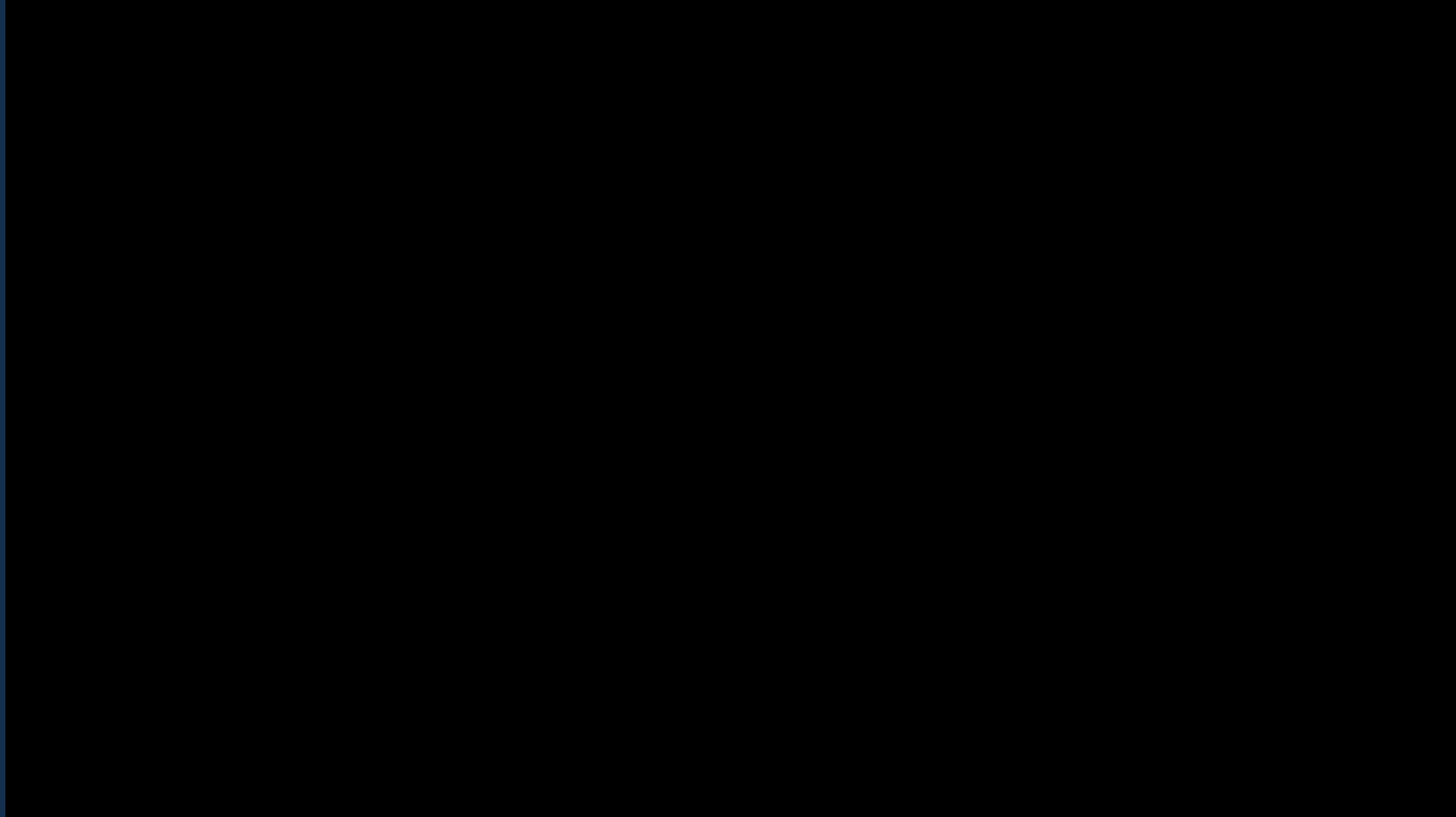
Young Carers Voices - Italy



Licia Boccaletti
Anziani e non solo

"We should have the right support given to the person we care for, so we don't have to provide excessive care which impacts on our own health and wellbeing."

Young Carers Voices - Italy



Young Carers Voices - Canada



AMI Quebec; Hospice
Toronto; Canadian Centre
for Caregiving Excellence;
Young Caregivers
Association

"We should have practical support and help offered including respite care."



Young Carers Voices - Canada



Samiha Rahman

Young Carer



Young Carers Voices – International perspectives

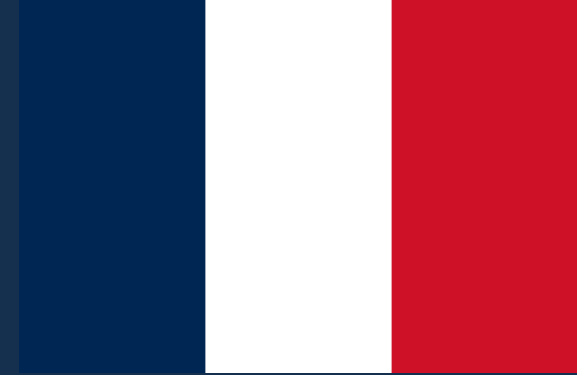
Thursday 8th and Friday 9th June

*A message
from Oritsé
Williams*



Singer-songwriter;
Member of the band JLS;
Former young carer;
Commonwealth Young Carer
Champion

Young Carers Voices - France

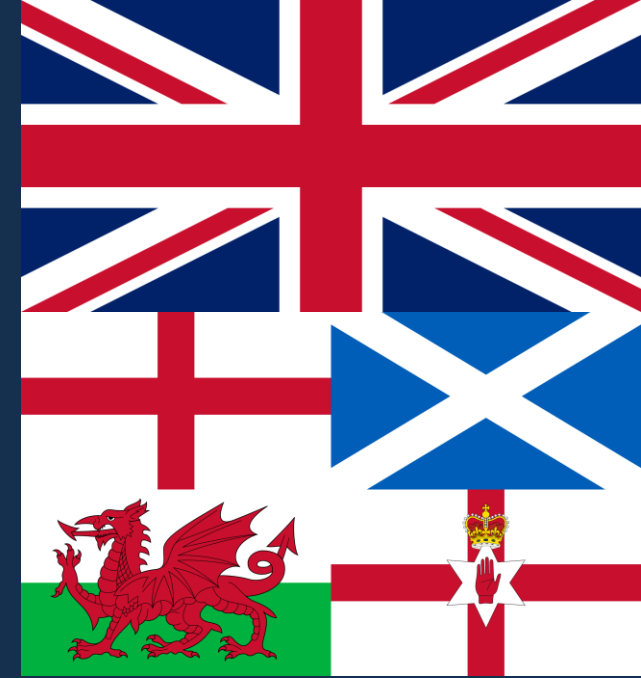


Amarantha Barclay
Bourgeois
Association nationale
Jeunes AiDants Ensemble

*"We should be protected from
psychological and physical harm."*



Young Carers Voices - UK



Action for Children and Carers Trust

"We should have the right to relax, play and take part in a wide range of cultural and artistic activities."

Young Carers Voices - England



Holly (20) and Ruby (17)
Young Adult Carers



- In England, the term 'young carer' usually goes up to 18 years old – we have a term called 'young adult carer' for carers aged 16 to 25.
- According to the 2021 census, the number of young carers in England and Wales is just over 127,000 – but it is believed that there are many more than that
- Research has shown there could be as many as 800,000 young carers.
- In the census, there were nearly 7500 young carers who were 5, 6 or 7 years old. There were also nearly 15,000 children caring for more than 50 hours every week

What issues are young carers facing?



56%

OF YOUNG CARERS AND YOUNG ADULT CARERS SAID THE TIME THEY SPEND CARING HAS INCREASED IN THE LAST YEAR



56%

SAID THE COST-OF-LIVING CRISIS IS EITHER 'ALWAYS' OR 'USUALLY' AFFECTING THEM AND THEIR FAMILY



47%

NOW CARE FOR MORE PEOPLE THAN THEY USED TO



44%

'ALWAYS' OR 'USUALLY' FEEL STRESSED BECAUSE OF BEING A YOUNG CARER OR YOUNG ADULT CARER



45%

WHO WORK 'ALWAYS' OR 'USUALLY' STRUGGLE TO BALANCE CARING WITH PAID WORK



40%

OF YOUNG CARERS AND YOUNG ADULT CARERS SAID CARING 'ALWAYS' OR 'USUALLY' AFFECTS HOW MUCH TIME THEY CAN SPEND WITH THEIR FRIENDS



40%

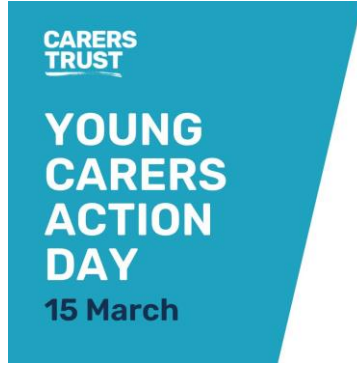
EITHER 'NEVER' OR 'NOT OFTEN' GET HELP IN EDUCATION TO HELP BALANCE CARING AND SCHOOL, COLLEGE OR UNIVERSITY WORK

"Caring never stops. Especially when it's time to sleep, your brain constantly worries about how tomorrow will be, hospital appointments, money etc. It's in overdrive."

What young carers want:

1. More mental health support for young carers
2. Support with their money and finances
3. More support with their education
4. Support to have a break from caring

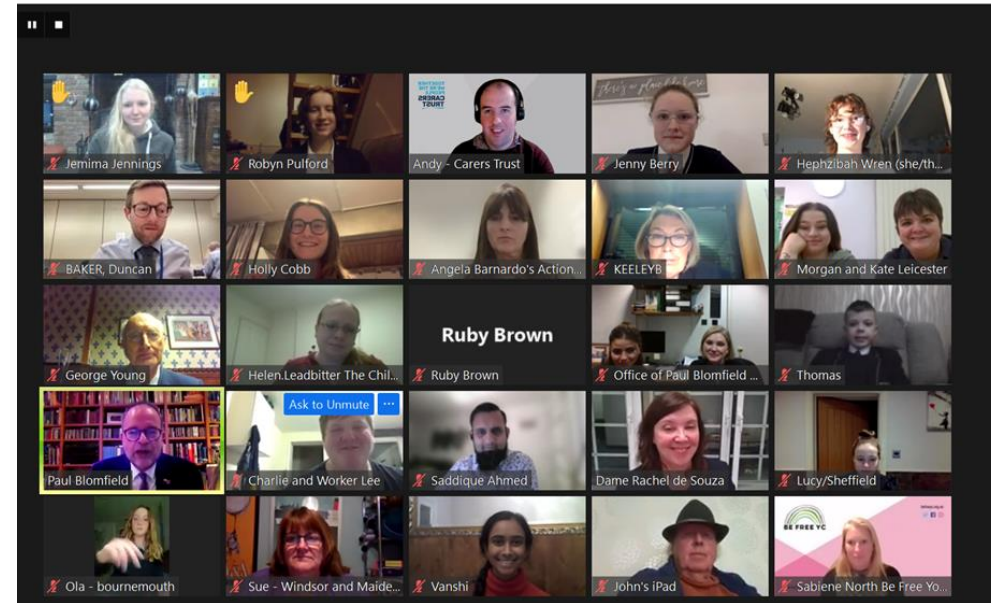
Work to improve support for young carers



#YOUNGCARERSACTIONDAY



APPG inquiry into life opportunities for young carers



It is good to see in the charter that there are lots of things which are similar to what young carers in England have said they want (e.g. education, time to relax.)

We also like that it makes it clear that young carers need to have their voices heard.

Next steps

In the UK, the plan is to use the principles within the charter to produce our first ever UK-wide covenant for young carers and young adult carers

Young Carers Voices – Northern Ireland



Aisling Reynolds
Service Co-Ordinator – NI Regional Young Carers
Action for Children





*Action for
Children*



Action for Children Young Carers

EVERYONES
RESPONSIBILITY



for Children

Young Carers – Everyone's Responsibility

**Aisling Reynolds-Manager
Regional Young Carers
Northern Ireland**

What areas do we cover?

Action for Children

Belfast HSCT
South Eastern
HSCT
Southern HSCT



Barnardo's

Northern HSCT
Western HSCT

Young People from our Young Carers Inclusive Group (YCIG)



Young Carers Inclusive Group (YCIIG)



Northern Ireland
Assembly

Young Carers Inclusive Group have met on with MLAs (Members of Legislative Assembly to discuss being a young carer. They have also spoken to MLAs about their recommendations for change in the future for young carers.

Young Carers have been invited by several Political Parties to meet in the future to discuss further.

Young Carers Inclusive Group (YCIIG)



children's law centre

Young Carers Inclusive Group met with the Childrens Law Centre and advocated on their behalf to have specific information regarding being a young carer and their rights within law within Northern Ireland.

Young Carers in Education

Official Launch date: 26th January 2023 in Belfast and 14th March 2023 in Craigavon.

Advocating and increasing the awareness of Young Carers in Education and what support and improvements need to be made by the Education Authority.



Summary Results

Below is some of the key information contained within the report

104 Young People completed the survey

School Awareness	Number of Young People	Percentage
Yes	44	43%
No	35	34%
Not Sure	25	24%

Supported	Number of Young People	Percentage
Yes	16	16%
No	66	64%
Sometimes	22	21%

“They know my mum is ill and that I struggle so they support me coping with my mum being ill but not as a young carer for my mum. They don’t see the emotional support I give as caring. They know life is tough for me but not as a young carer! They are not aware of young carers! Most people think there are people to help mum but do not know my life is affected daily helping my mum in different ways. No one sees that I’m there to help mum when she is in pain, upset and how I can’t have a normal day or life. I don’t have the freedom of not having to worry when I come home from school, we can’t just go out. I don’t get out much”

Current Unpaid Young Carers

According to the 2021 Census there are currently 2600 Young Carers from the age of 5 and 14

2588 young carers according to the census.

We are currently unable to explore this further passed the age of 14 years, due to the next age range in the census being 15-39 years

Current Carers Allowance for 2023 = £76.75 Per Week

$$£76.75 * 261 = £20031.75 * 52 =$$

Our Young Carers this year will save the Government **£1,041,651**

Recommendations

Below are the recommendations that have been gathered from the research.

- Awareness Raising – E Learning Module (Mandatory) co-produced by EA and AFC for all school staff to help identify and support young carers.
- To have a better understanding of being a young carer and support them in education.
- Flexibility required within schools in relation to attendance and homework.
- Better communication between schools and young carers support services.
- Student Teacher Training.
- School Admission Forms to ask if any new admissions into their school are young carers.

How we help

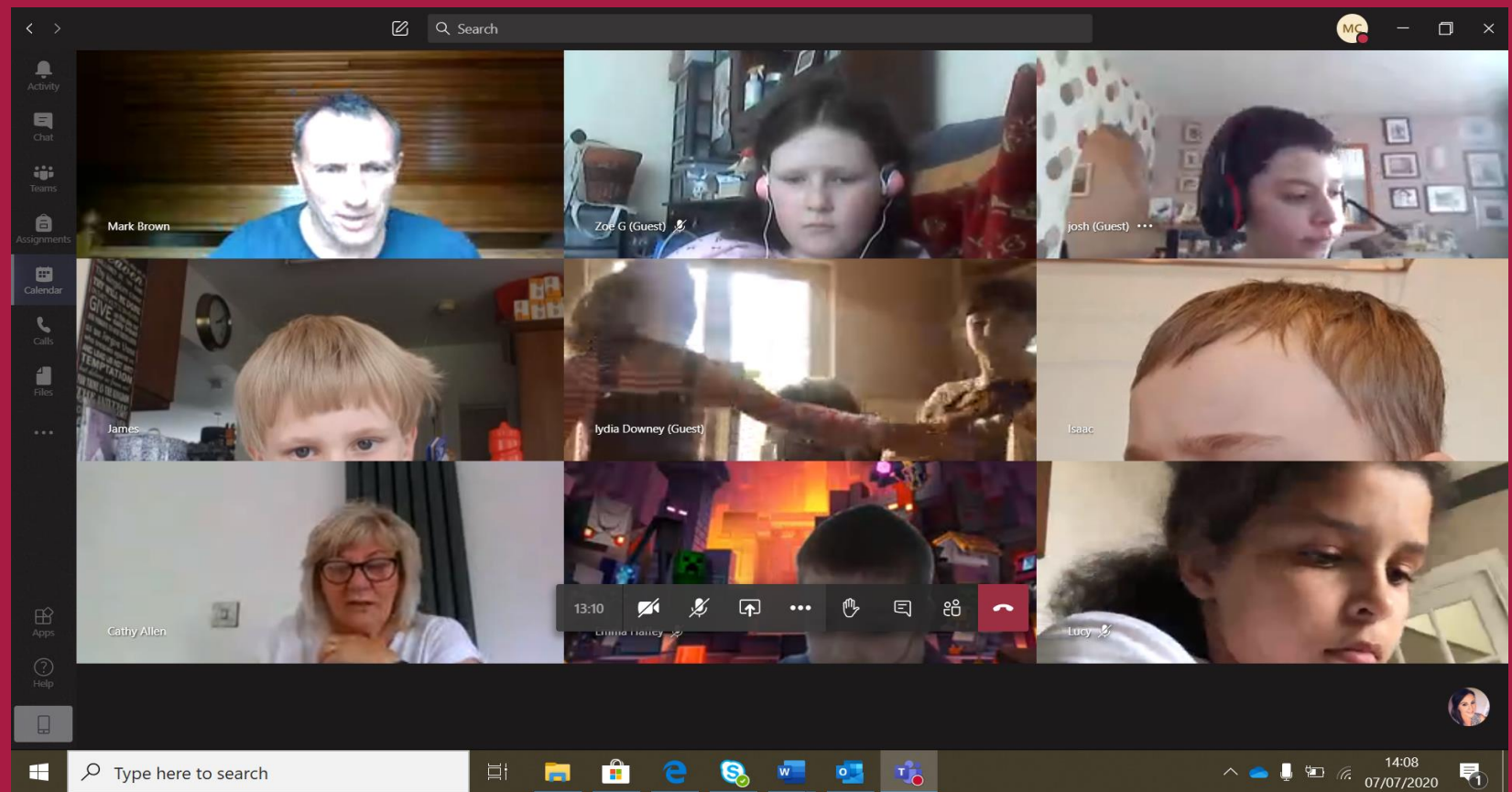
Activities

Groups

1-1

Family Fun Day

Advocate on behalf of young carers





We are family



Our vision

Every child and young person in the country has a safe and happy childhood and the foundations they need to thrive.



Our mission

We protect and support children and young people by:

- Providing practical and emotional care and support.
- Ensuring their voices are heard.
- Campaigning to bring lasting improvements to their lives.

Young Carers Voices – Scotland



**CARERS
TRUST**
SCOTLAND

Ruth – Young Adult Carer;
Nicola – Carers Trust
Scotland

*“We ask that we are listened
to and our views and culture
are respected.”*



**CARERS
TRUST**
SCOTLAND

 @CarersTrustScot
 @carers

Young carers in Scotland

Ruth Williams

Young Carer & Young Adult Carer Advisory Group, Carers Trust Scotland

© Carers Trust

carers.org



Young Carers Voices – Wales



Make time for young carers – Carers Trust Wales Youth Council

**YMDDIRIEDOLAETH
GOFALWYR
CYMRU**

**CARERS
TRUST
WALES**



“ GWNEWCH AMSER I
OFALWYR IFANC

MAKE TIME FOR
YOUNG CARERS ”



Young Carers Voices - USA



American Association of
Caregiving Youth; Professor
Melinda Kavanaugh (YCARE)

*"We should have the right to education,
time to focus on our studies and be
offered real choices in
accessing further education and future
aspirations."*





American Association of
Caregiving
Youth

US Caregiving Youth Project

Connie Siskowski, RN, PhD

President and Founder - AACY

connie@aacymail.org

aacymail.org

What is AACY?

American Association of Caregiving Youth (AACY)

- Florida based non-profit corporation established in 1998
- The only organization in the US dedicated to addressing Caregiving Youth issues
- Created affiliate model as non-profit franchise
- Established the Caregiving Youth Institute in 2014 – 4 in person conferences; 2 virtual
- National and international partnerships



Caregiving Youth Project (CYP)

- Established in 2006 - Boca Raton Middle as first school
- Addresses the needs of pre-teens, teens, families, and professionals through education, awareness, research with direct and indirect services
- Works within systems of healthcare, education, and the community

Why Children are Caregivers

- ♥ **Economic influences**
- ♥ **Cultural variances**
- ♥ **Multi-generation households**
- ♥ **Delayed childbearing**
- ♥ **Grandparents as parents**
- ♥ **Aging population**
- ♥ **Advances in technology care at home**

Comprehensive CYP Services

- ♥ **In School – eligibility screening, Skills-Building groups, Lunch and Learn sessions**
- ♥ **At Home - link families with resources, providing computers, tutoring, mentoring, respite and solutions for special needs, earn Community Service Hours**
- ♥ **Out of School - overnight camp, bowling, dining, Holiday celebration, educational and fun activities**

Questions at Camp Treasure

Questions ^{hanya} 11-9-16
If you help someone with
medicine and you give them
more than what you need
will it harm them?

How to remember that a person
has problems but looks like a normal
person.

How can I get someone out of
bed if they don't have anything to help them
with

When you lost your love ones,
will it effect your life?

What happens when
they need help but you
can't help them?
(What can you do?)

If you help someone with medicine and you give them more than what you need will it harm them?

How to remember that a person has problems but looks like a normal person.

How can I get someone out of bed if they don't have anything to help them with

When you lost your loved ones, will it effect your life?

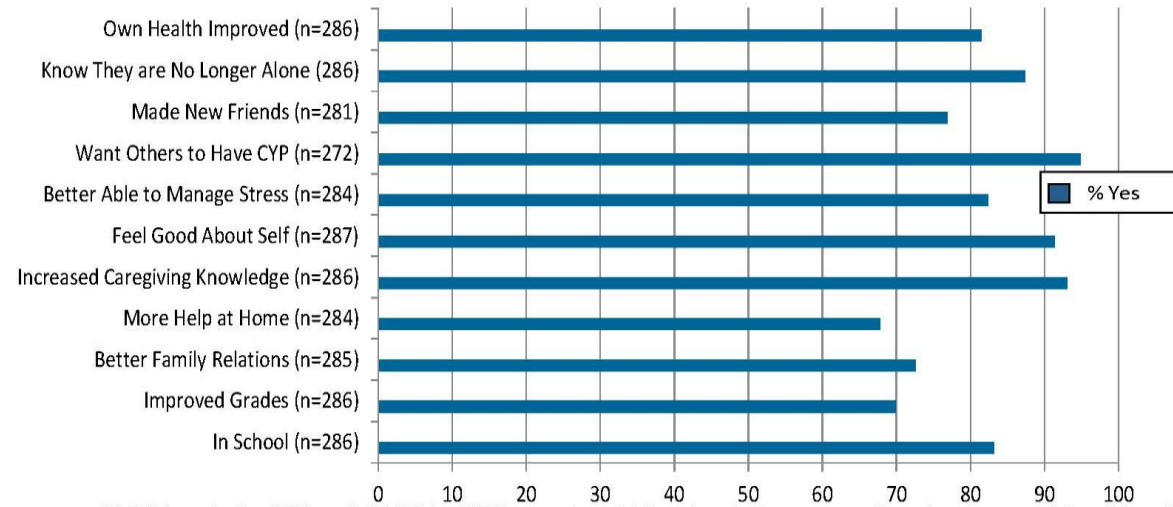
What happens when they need help but you can't help them? (What can you do?)

End of the Year Feedback 2022



CAREGIVING YOUTH PROJECT (CYP) RESULTS 2021-22 End of Year Feedback from 288 Respondents

How the CYP Helped Them Provide Care for 417 Individuals!



Respondents were 63.3% female (n=237) and 67.8% (n=283) were in middle school. There were 5 no longer caregiving. Not all students responded to every question. Some respondents answered via telephone interview. CYP services provided are needs-driven so not all students received the same supports or had the same opportunities to meet caregiving youth from other schools. Qualitative results are also available.

The Caregiving Youth Project in Palm Beach County, FL is the direct service program of the American Association of Caregiving Youth® which is headquartered in Boca Raton, FL; 561-391-7401; www.aacy.org





American Association of
Caregiving
Youth

US Caregiving Youth Project

Connie Siskowski, RN, PhD

President and Founder - AACY

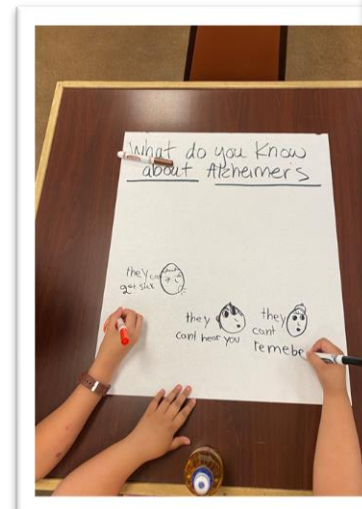
connie@aacymail.org

aacymail.org



YOUTH CAREGIVING: TRAINING, SKILLS, & SUPPORT

Multidisciplinary Caregiving Education, Support, and Training



Young Carers Voices: International
Perspective

June 8, 2023

Melinda S. Kavanaugh, PhD, LCSW

Professor, Social work
Helen Bader School of Social Welfare
University of Wisconsin - Milwaukee





YOUTH CAREGIVING: TRAINING, SKILLS, & SUPPORT

Feasibility of a multidisciplinary caregiving training protocol for young caregivers in families with ALS

Melinda S. Kavanaugh, Megan Howard & Lori Banker-Horner

To cite this article: Melinda S. Kavanaugh, Megan Howard & Lori Banker-Horner (2018) Feasibility of a multidisciplinary caregiving training protocol for young caregivers in families with ALS, Social Work in Health Care, 57:1, 1-12, DOI: [10.1080/00981389.2017.1378284](https://doi.org/10.1080/00981389.2017.1378284)

Research Article

For reprint orders, please contact: reprints@futuremedicine.com

Skill, confidence and support: conceptual elements of a child/youth caregiver training program in amyotrophic lateral sclerosis – the YCare protocol

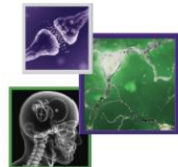
Melinda S Kavanaugh¹, Young Cho², Dominic Fee³ & Paul E Barkhaus³

¹Helen Bader School of Social Welfare, University of Wisconsin-Milwaukee, PO Box 786, Milwaukee, WI 53201, USA

²Joseph J Zilber School of Public Health, University of Wisconsin-Milwaukee, Milwaukee, WI 53201, USA

³Department of Neurology, Medical College of Wisconsin, Milwaukee, WI 53226, USA

Neurodegenerative
Disease Management



Modular, hands-on, caregiving skill and support program for children and youth

Each module is designed for the illness/injury care needs - **ALS, Alzheimer's disease, Cancer etc.**

Modules are delivered by trained health care professionals, who go through the YCare professional training

Participants can touch, use, ask questions about - any tool, device or care process – makes it fun

Research based - Data collected at each session to ensure fidelity to program, and appropriateness of content

YCare is delivered in small, peer-engaged groups

Using small peer engaged groups allows the youth:

Know they are not alone

- There are youth like you all over the U.S.

Opportunity to talk to other youth who have a family member with illness/injury

- share stories and learn from each other
- ask how others deal with illness/injury, caregiving and the loss of a family member

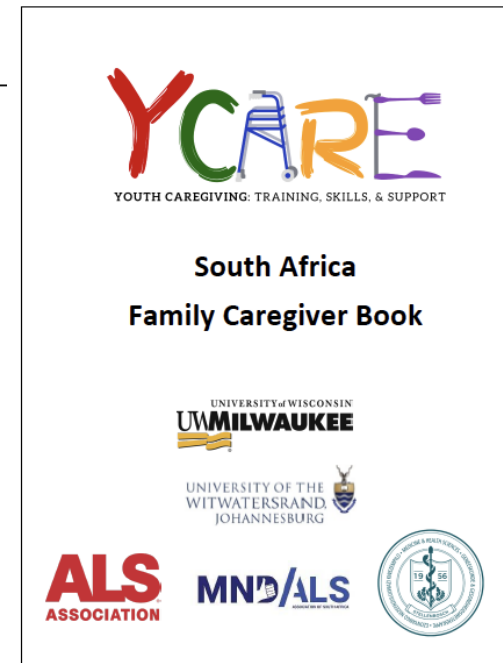
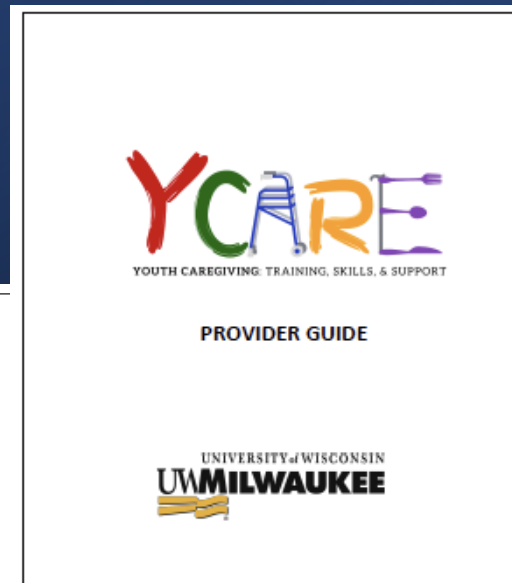
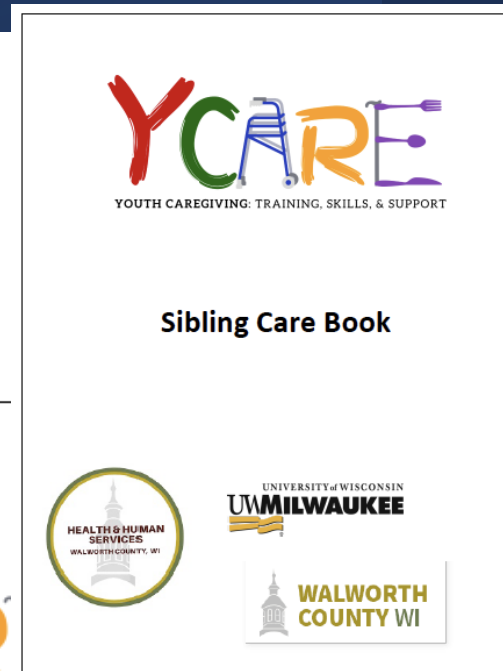
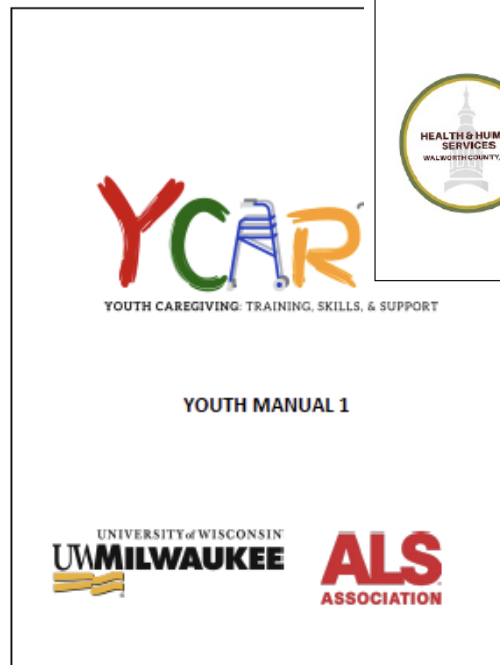


YCare uses professional training and handbooks

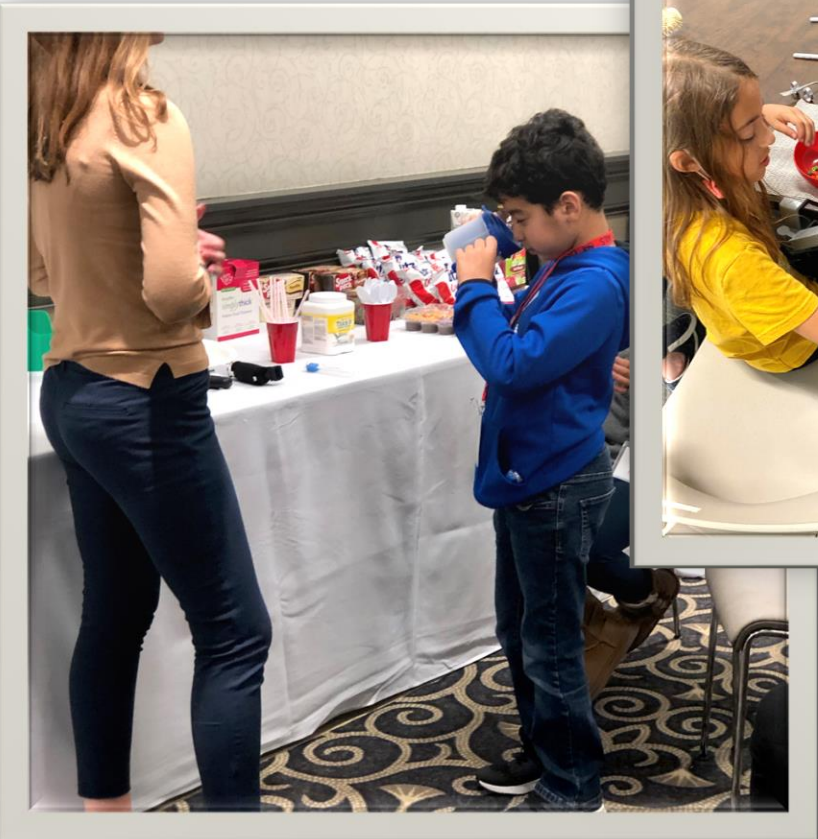
Handbooks and provider training guides created for each training

- ALS
- Siblings as caregivers
- Alzheimer's disease
- Cancer care

- International – South Africa YCare




Examples of modules: Basic care, Feeding and Communication




Basic Care Skills

Both the **physiotherapist** and **occupational therapist (OT)** will show you some ways to help your family member with things like dressing, eating, and going to the bathroom.




What you will learn:


- Dressing:** Getting a shirt on, putting pants over feet, putting on socks and shoes, buttoning and zipping, tying shoes
- Bathroom:** Getting up and down off the toilet safely
- Transferring:** Using transfer boards to help someone get in and out from chairs, beds, etc.




Can you name any of the items above?



- You will learn what happens when muscles in the mouth and throat do not work well.
- How to change food textures:
 - Less chewing
 - Small bites
 - Avoid crumbly/chewy/crunchy foods
- Ways to help with feeding:
 - Chair position
 - Go slowly, give small bites and sips of food
 - Use special cups and straws
 - Use a small sponge to check for food between cheek and gums



Above: Universal cuff, non-slip matting, and adaptive knives (reflex slicing knife)



Above: One way valve straws, sippy cups with bendy straws, and a plate guard



Health care professionals

- YCare trained over 80 health care professionals (PT, OT, SLP, Social work, respiratory, neurology)
- Go through a ½ day training in young carers, caregiving and the YCare model

Thank you

Thank you to the many children, youth and families who participated in the YCare sessions.

The ALS Association, Wisconsin chapter, for the initial development and constant collaboration.

To the many health care professionals across the United States who worked so closely with us to develop YCare.

Melinda S. Kavanaugh, PhD, LCSW
kavanaugh@uwm.edu

Day 1 – Thank you!

Tomorrow's programme

- New Zealand
- Australia
- India, Nepal and Bangladesh
- Kenya
- Japan
- Nigeria

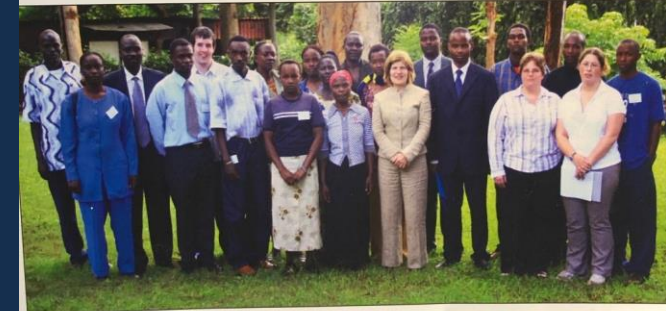
www.carers.org/youngcarersvoices

www.youngcarersalliance.org

[Young Carers – COSW](#)

An International symposium held in Nairobi 8th – 10th May 2006 for Practitioners and Policy Specialists on addressing the needs of Young Carers (Orphans and vulnerable children).

A newsletter written by young carers attending the symposium.



"It is important to involve young carers in all aspects of policy making and decision making. We have a voice listen to us".

Young Carer

"We should have a home that is suitable and safe for us and our family."