

# CAREGIVING YOUTH RESOURCE GUIDE

Raising Support and Awareness for Our Nation's Youngest Caregivers



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## INTRODUCTION

*“No child in the United States should have to drop out of school or life to provide care for family members!”*

Connie Siskowski, RN, PhD  
Purpose Statement  
2012 CNN Top Ten Hero

This Resource Guide provides background information on the evolution of Caregiving Youth recognition, support, and resources in the United States. Since 2010, the American Association of Caregiving Youth® (AACY) has focused solely on supporting children who are family caregivers, recognizing and supporting the growing population of young individuals taking on these vital roles.

This manual serves as a comprehensive knowledge base for anyone interested in understanding the unique challenges faced by students who provide care for family members with chronic illnesses, injuries, frailty, or disabilities.

*Contributors to this publication include: Connie Siskowski, RN, PhD - AACY Founder and President; Sara Poole, AACY Communications Consultant; with review by Ann Faraone, EdD - AACY Director of Education Services.*

We anticipate that you will find your journey with this special population of Caregiving Youth meaningful. We encourage and welcome your feedback: [aacy.org](http://aacy.org)

You are also welcome to contact us at [info@aacy.org](mailto:info@aacy.org) or by phone 561.391.7401 or 800.508.9618.



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# Who are Caregiving Youth?

## DEFINITION OF CAREGIVING YOUTH

Caregiving Youth are young people under the age of 18 years who provide care or support for family, relatives, or household member(s) of any age who require assistance due to chronic (3 months or more) illness, age-related decline, disability, or other health condition.

## THERE ARE OVER 5,400,000 CAREGIVING YOUTH IN THE US

- More than 70% assist a parent, grandparent, or great-grandparent.
- Many care for disabled siblings or other family members.
- 34% help more than one person in the household.

Caregiving in the U.S. 2020 - AARP Research Report - National Alliance for Caregiving (NAC) and AARP

## WHY SHOULD WE CARE?

Caregiving for a loved one is among the most demanding, challenging, and rewarding human activities. Although children are commonly thought of as the recipients of care - rather than the givers - children all over the world participate actively in caregiving every day. The US does not yet have formal policies or support systems in place for these young people as we do for adult caregivers. Furthermore, schools do not typically identify or provide support for Caregiving Youth, which puts them at risk for academic, social, and emotional challenges.

## ECONOMIC VALUE OF CAREGIVING YOUTH

A 2012 article estimates the economic value of the support Caregiving Youth provides is around **\$8,500,000,000** in unpaid labor. The estimate today would be much higher.

Armstrong-Carter, E., Johnson, C., Belkowitz, J., Siskowski, C., & Olson, E. (2023). The United States should recognize and support caregiving youth. [Journal article <https://srcd.onlinelibrary.wiley.com/doi/epdf/10.1002/sop2.14>]



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# Historical Perspective of Caregiving Youth in the United States

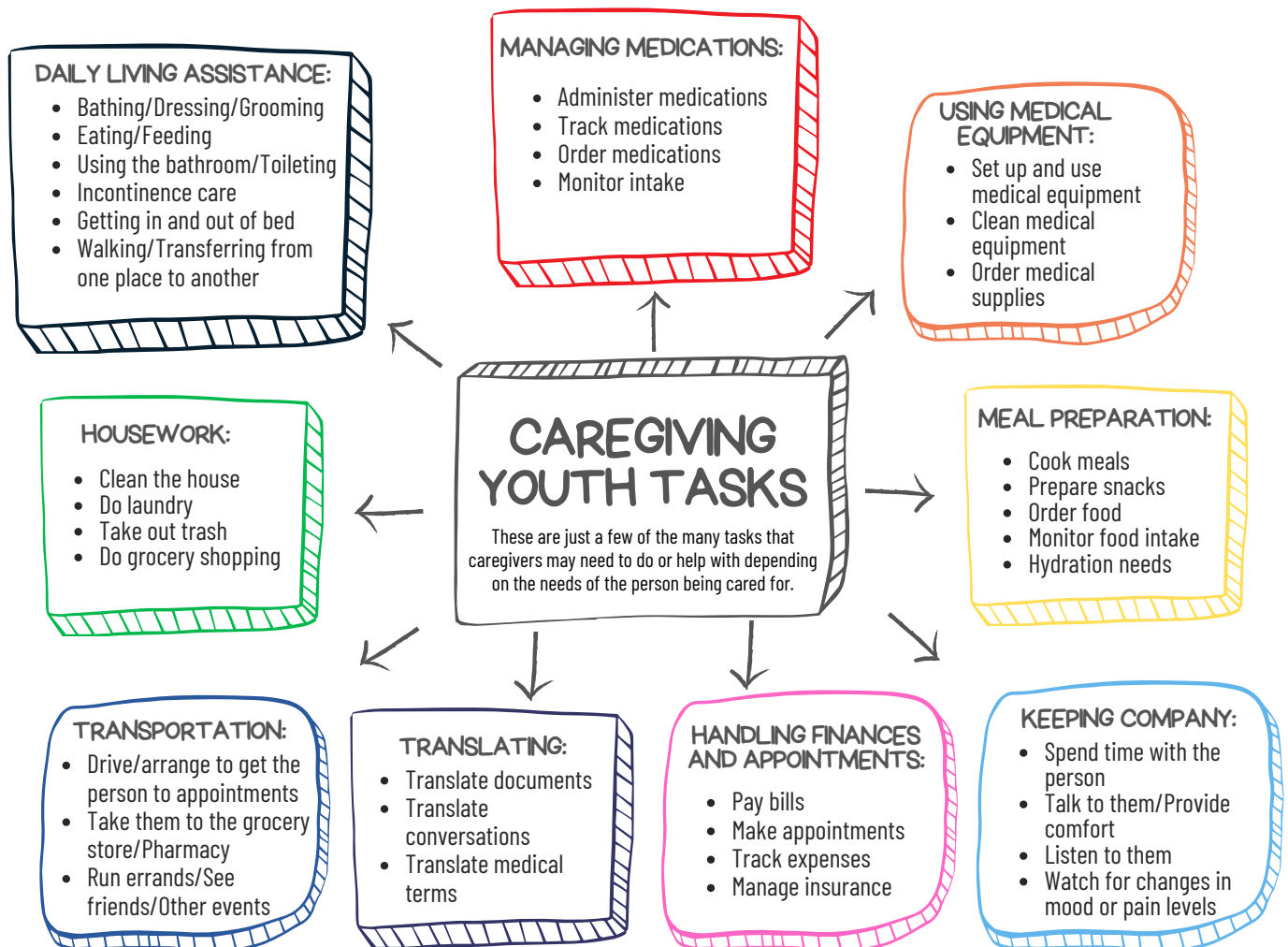
Globally, children have always played a role in supporting their families, often receiving assistance from nearby relatives. Other developed countries, particularly the UK, have recognized and supported "young carers" through legislation and policy since the early 1990s. The first International Conference on Family Caregiving was held in London in 1998, and these conferences continue to be held regularly.

- **2002:** The first US survey reflecting student voices was conducted in Palm Beach County, FL, among over 12,000 public middle and high school students. More than 25% of students in grades 6-12 reported negative impacts on their education due to caregiving responsibilities (Miller, Bunker, & Kelley-Miller, 2003).
- **2005:** An estimated 1.3-1.4 million caregiving children aged 8-18 resided in the US, with 38% caring for a grandparent and 34% caring for a parent (Young Caregivers in the U.S.; National Alliance for Caregiving (NAC) & United Hospital Fund, 2005).
- **2008:** "Not every child gets 18 years of childhood. Some have to become responsible adults well before their bodies grow into maturity." (Ryan, Contemporary Pediatrics, March 1, 2008).
- **2014:** The American Association for Caregiving Youth (AACY) received funding to launch its Caregiving Youth Institute to C.A.R.E. – Connect, Advocate, Research, and Educate. Since then, they have held four in-person conferences and two virtual ones.
- **2019:** Florida became the first state to include a caregiving question in its Florida Youth Risk Behavior Survey (23.6% of public middle school students and 16.4% of public high school students reported caregiving responsibilities) (<https://srcd.onlinelibrary.wiley.com/doi/epdf/10.1002/sop2.14>).
- **2020:** Estimates suggest 3.4-5.4 million children assist adult family caregivers, representing 7% of the 47.9 million caregivers of adults and 11.2% of co-resident adult caregiving households (Caregiving in the US 2020; National Alliance for Caregiving (NAC) and AARP).
- **2021:** US Census data reveals 7.1 million American grandparents living with grandchildren under 18, with 2.3 million responsible for their care.
- **2021:** The Elizabeth Dole Foundation and Wounded Warriors combined efforts to recognize and support "Hidden Helpers" - the 2.3 million children actively involved in caring for wounded, ill, or injured service members or veterans (<https://hiddenheroes.org/resources/hiddenhelpers/>).
- **2022:** Approximately one million grandchildren were being raised by grandparents with no parents present. About one-third of these grandchildren are younger than six years old, and half of the grandparents are over 60 years old (<https://www.gksnetwork.org/kinship-data>).
- **2022:** Nearly 25% of grandparents responsible for their grandchildren have a disability, compared to about 10% of parents of children under 18 (National Research Center for Parents with Disabilities, 2018).
- **2023:** The Caregiving Youth Research Collaborative, consisting of professionals from universities and organizations across the US and Canada, published its first white paper (<https://aacy.org/what-we-do/caregiving-youth-institute/research-collaboration/>).

# Responsibilities of Caregiving Youth

## THE AMOUNT AND FREQUENCY OF CARE VARIES.

It can be very demanding, both physically and emotionally.



It is important to note that this is not an exhaustive list of all the potential tasks Caregiving Youth take on. The majority of children receive no special education in performing these tasks. They often learn from observation, from older siblings, or homecare workers.



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# Real-life Examples of Caregiving Youth Circumstances

## CAREGIVING YOUTH STORIES

- Marie, a sixth grader, lives with two brothers, one of whom is in elementary school, and the other, Jonah, has cerebral palsy and is in need of full care. He goes to a special school and is taken curbside from his home in his wheelchair. Marie's father is in jail, and her mother is unable to provide care for her children, so they live with an aunt and her partner, both of whom work. Marie must be at home when Jonah's bus arrives to wheel him over the lawn and up small steps into their rented house. She assists with bathing, feeding, and helping to lift Jonah into bed. She has little time for herself or friends and does her best to keep her grades in school up.
- Kenny's mother is large-bodied and has diabetes and heart disease. She is raising two grandsons because their mother has addiction issues. Her husband is visually impaired and unable to drive. Kenny is in ninth grade and gets around on his bike; he plays ball with his nephews in the street by their house. Life changed for him when his mother had open heart surgery. He was the one at the hospital by her bedside, not really understanding what was happening. After her surgery, his mother developed back issues and became a regular user of pain medication. Kenny's grades in school were dropping as his home situation deteriorated. He became the "man of the house" and felt overwhelmed.
- Julia is in eighth grade and is in the care of both of her grandparents, whom she loves very much. They have an active church life, which has helped sustain the family. Her grandmother has mobility and vision issues and uses a cane. Her grandfather was the family breadwinner and worked a regular job until he was diagnosed with pancreatic cancer, and his health rapidly declined. His hospital bed now took up most of the space in their small living room. Julia was happy to spend as much time as she could with him, singing and providing comfort. She and her grandmother knew their only income, his pension money, and their savings would soon run out. Every day, Julia worried about what was going to happen to her and her grandma when his life ended.



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# Caregiving Youth Psycho-Social Impact

## THE CHALLENGES FACING CAREGIVING YOUTH

Some students who are also caregivers find their roles rewarding as they find purpose, as well as developing confidence, empathy, and valuable life skills. Others face significant challenges. Their brains and their bodies are still developing. They may have mental and physical health problems and limited educational and career options, while the stresses of balancing caregiving with other demands and the desire to be "normal."

### Some of the challenges may include:

- Feeling isolated and alone – "Why am I the only one doing this?"
- A downward spiral begins with morning caregiving taking longer than usual, so they miss the school bus and don't have other transportation.
- Limited time or resources result in a lack of sports or after-school activities participation.
- Adults in the home, especially if ill, are unable to provide homework help or emotional support.
- Nights with little sleep result in fatigue at school, compound stress, and depression, and increased worry, frustration, anger, and behavioral outbursts.
- Friends drop off because of responsibilities limiting time for fun; they cannot invite friends over to their house, and they can't go to theirs or hang out.
- They worry that they do not know how to provide care or give medicine... or when to call 911 in circumstances beyond their control or fault.
- Studies show they are bullied more than non-caregivers – or they may become the bully.
- They may not get the dental, vision, and medical care they need as attention is directed away from them, resulting in consequences for their health and well-being.
- They may feel that there is no trusted adult they can talk with, even at school.
- Grades may suffer, dropout rates are measurably higher, and post-secondary education is delayed.
- Their families fear they will all be separated if others know their circumstances.



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# Nurturing their Potential

**It's not all bad | Kids who help provide care for others tend to be really "kind kids" with a lot of potential in life.**

- They tend to mature more quickly than their peers through early responsibility.
- While sometimes referred to as "parentified," their experiences cultivate self-reliance and resourcefulness.
- They learn life, household, and medical skills that prepare them for their futures, and they are adept problem solvers.
- They gain valuable knowledge about healthcare and personal health, fostering a conscious approach to their own well-being.
- They build healthy relationships, even with adults.
- They experience purpose in their lives.
- Caregiving Youth practice compassion through their everyday actions.
- They can earn Community Service Hours for volunteer work at home; others can participate in Service Learning for school credit.
- They can use their experiences in caregiving as an asset for post-secondary schooling applications.
- Contribute to their families in ways that their non-caregiving peers do not.
- Learn empathy and selflessness, *valuable character traits*.



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# Supporting Caregiving Youth: How YOU can Help

**There are almost as many ways of supporting Caregiving Youth as there are unique circumstances among their families!**

**Become a mentor:** Share your knowledge and perspective with a Caregiving Youth during their challenging caregiving days. Your guiding hands help their minds and spirit.

**Be aware of family health circumstances:** Natural disasters can worsen chronic conditions and strain resources for families managing illness or disability, especially those managing medication or equipment needs during power outages or displacement.

**Recognize the impact:** Understand that overwhelmed parents and grandparents might not grasp the full impact of their health condition on the children.

**Amplify their voice:** Advocate for Caregiving Youth by speaking up for their needs to legislators, religious leaders, businesses, and relevant service, educational, and professional groups.

**Encourage school support:** Educate and support school personnel and anyone else involved with Caregiving Youth to better understand their situation and offer effective assistance.

**Connect them with peers:** If you can, provide Caregiving Youth with chances to connect with peers through social events or support groups.

**Offer non-judgmental support:** Be accepting of the family's health conditions and circumstances without judgment.

**Share resources:** Refer Caregiving Youth to trusted online resources that provide additional support, inspiration, and information.

**Create local support:** Consider initiating a local support program, including grief support, that could potentially expand from existing family caregiver support groups.

**Celebrate their successes:** Help Caregiving Youth recognize the importance of their contributions and celebrate their achievements and milestones.

**Provide relaxation opportunities:** Show your appreciation for their work by offering them a chance to unwind, take a break, and have fun.

**Equip academic success:** Ensure Caregiving Youth have the necessary technology and supplies to excel at school and home.

**Listen with empathy:** When talking to a Caregiving Youth, utilize active listening skills to demonstrate understanding and offer encouragement.

**Address practical needs:** Be aware of their needs and, if possible, assist with home repairs, installing ramps if a wheelchair is involved, or any other supportive equipment that might help.





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# Support for Caregiving Youth

## Special Notes:

- **It's highly unusual for a Caregiving Youth to experience no stress or worries.** Knowing you're not alone during challenging times is a great comfort, regardless of age. Frustration can build into anger, leading to disruptive behaviors at school or elsewhere. Caregiving can start suddenly, like after an accident, or gradually, as with a deteriorating health condition like Alzheimer's or Parkinson's disease.
- A major adjustment occurs when a dad who used to play games with his kids can no longer do so due to weakness or other physical limitations. A child caring for a single mom with cancer worries about what will happen if she dies. **Having future plans discussed and agreed upon can significantly reduce stress.** These plans should include a backup plan, such as emergency short-term respite care, in case the Caregiving Youth becomes ill and is unable to assist, even temporarily.
- Additional supports, like youth-directed respite care, provide a much-needed break from the worries of caregiving responsibilities. **Respite can take many forms,** including daycare, homecare health workers, or even someone to help with cleaning and laundry.
- **Socialization and play are crucial for young people's normal brain and body development, and Caregiving Youth should have ample time for both.** Meeting other Caregiving Youth to share feelings, support each other, and make new friends is incredibly helpful. Having dedicated time for fun helps them feel "normal" and not different from their peers.

**Despite having the highest number of children and adolescents providing care for family members among developed nations, the US offers the least support!** The UK boasts over 350 dedicated programs for young carers, while Australia has over 37. Even Canada offers over 30 programs, whereas only ONE program is dedicated to Caregiving Youth who assist with all types of health conditions exists in the US.



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# Advancing Meaningful Change for Caregiving Youth

- In your state: Advocate for the inclusion of Caregiving Youth in your statewide Family Caregiver Task Force.
- Work to add a question about caregiving by youth in the Centers for Disease Control's Youth Risk Behavior Survey or its equivalent to gain knowledge and understanding about this growing, hidden, and important population of children in need of recognition and support.
- The United States lags behind countries like the UK and Australia in recognizing the vital role played by Caregiving Youth. Some states even enforce laws that remove children from their homes and place them in foster care when they have caregiving responsibilities for family members with disabilities. This approach is demonstrably harmful, as studies consistently show that children thrive best when supported at home and remain with loved ones.
- A 2006 study, "The Silent Epidemic," revealed that 22% of young adults who dropped out of school did so to care for family members. Taking a proactive position and recognizing the urgency of this issue, Rhode Island's Department of Education has implemented policy changes to support Caregiving Youth in schools.
- Florida has the first US Caregiving Youth Act bill under consideration in its House and Senate. This legislation proposes the creation of a statewide task force and, echoing Rhode Island's initiative, the designation of a contact person at each school to assist students in navigating the dual roles of student and caregiver.
- Various state-regulated licensure programs review and approve the curricula of professionals. Although the process for adding new topics is often arduous, the inclusion of issues surrounding Caregiving Youth could be seamlessly integrated into existing studies for healthcare professionals, educators, and community workers, with a primary focus on those who provide pediatric services.
- Ideally, Caregiving Youth should also be incorporated into discharge planning for hospitals, nursing homes/rehabilitation facilities, and home health and hospice care. This comprehensive approach would ensure that Caregiving Youth receive the crucial support they need to thrive in all aspects of their lives.



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# Resources for Caregiving Youth

## Diagnosis Specific Organizations - Direct Services

Several direct service organizations exist for middle and high school youth who care for a family member in the United States. These organizations offer support based on the medical diagnosis and/or situation of the person(s) in need of care. Many programs for young people are part of a larger organization, and some also provide services to young adult caregivers beyond the age of 18 years. These organizations have useful resources on their websites based on their areas of expertise for Caregiving Youth or their parents/guardians and offer direct services, including in-person summer camps, meetings, and virtual support services.

### **American Association of Caregiving Youth (AACY)**

[AACY is the only organization in the US dedicated solely to addressing Caregiving Youth issues no matter the circumstance.](#) | "We champion youth who care for chronically ill, injured, elderly, or disabled family members, support their role as caregivers, safeguard, and celebrate their success in school and life."

### **Camp Corral**

[Youth who are caring for someone who is a Wounded Warrior](#) | "Transforming the lives of the children of wounded warriors."

### **Hope Loves Company**

[Youth who are caring for someone with ALS or Lou Gehrig's disease](#) | "We provide emotional and educational support to children and young adults who have or had a loved one battling Amyotrophic Lateral Sclerosis (ALS) or Lou Gehrig's disease."

### **Kesem**

[Youth who are caring for someone with cancer](#) | "Kesem is a leading national nonprofit organization that supports children affected by a parent's cancer. Kesem provides year-round programs and services to support children ages 6-18 at no cost to families."

### **Hidden Helpers**

[Youth who are caring for a Wounded Warrior or Veteran](#) | The Elizabeth Dole Foundation | Hidden helpers are the children, youth, and young adults (up to age 18) who are impacted or involved in the mental, emotional, or physical care of a wounded, ill, or aging service member or veteran.

### **Lorenzo's House**

[Youth who are caring for someone with Younger-Onset Dementia](#) | "We are a nonprofit social impact organization designed to empower youth and families living with younger-onset dementia."

### **PSYCH/ARMOR**

[Supporting Youth Who Support Veterans](#) | Caregiving Youth often make sacrifices to provide care for family members who are ill, injured, elderly, or disabled. This course acknowledges the contributions of these youth caregivers, goes into the scope of the problem, and offers some solutions.

### **The Caregiver Foundation**

[Support for Caregiving Youth in Hawaii](#) | The Caregiver Foundation is committed to providing practical, financial, and emotional support to Hawaii's Caregiving Youth through a variety of programs supported by community partnerships and grants.

### **YCare**

[Youth who are caring for someone with ALS + Young Caregivers](#) | "YCare is a modular training skills and support program for children, youth and young adults who provide care to someone with an injury, diagnosis or illness."



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# Resources for Caregiving Youth

## Publications

### **Book - I Am a Teen Caregiver. Now What?**

Teen Life 411

Many teens enjoy a carefree time of school, some light household responsibilities to help their family, and good times with their friends. According to a National Alliance of Caregiving report in 2005, at least 1.3 million children between the ages of eight and eighteen are shouldering the heavy responsibilities of caring for family members who cannot care for themselves without help. Readers will get a frank description of the work faced by many teen caregivers. Teens who are immersed in this life already can find resources and organizations for support, as well as sound advice for coping in tough times.

- Print: <https://rosenpublishing.com/title/I-Am-a-Teen-Caregiver-Now-What>
- [E-Book](#)

### **Caregiving.com**

Youth Caregiving | Caregiving.com has an entire section on "Youth Caregiving," including an email template to help parents initiate a dialogue with teachers, explaining their caregiving situation, its potential impact on their child's academic journey, and strategies for supporting their child's wellbeing.

### **U.S. Department of Health and Human Services - .PDF**

**National Institutes of Health | National Cancer Institute | When Your Parent Has Cancer – A Guide for Teens**

<https://www.cancer.gov/publications/patient-education/when-your-parent-has-cancer.pdf>

### **Report on Caregiving Youth in the U.S. | Progress and Opportunity | December 2023**

Report on Caregiving Youth in the U.S. | [Executive Summary](#)

Report on Caregiving Youth in the U.S. | [White Paper](#)

Report on Caregiving Youth in the U.S. | [Recommendations](#)

### **Social Policy Report | July 2021**

[The United States should recognize and support caregiving youth](#)

Emma Armstrong-Carter, Catherine Johnson, Julia Belkowitz, Connie Siskowski, Elizabeth Olson