



# Session 1

10 April 2024

11:45 - 1:00

**YOU HAVE 11 SESSIONS TO CHOOSE FROM THIS MORNING. PLEASE CHOOSE ONE SESSION TO ATTEND.**

## **WORKSHOPS (5 WORKSHOP SESSIONS ARE AVAILABLE)**

### **W1. Celebrating Young Carers: The Young Carers Festival by Little Dreamers**

**Emma Woodward**

Taking inspiration from the Young Carers Festivals that have been run in the UK since 2000, Little Dreamers has pioneered Young Carers Festivals in Australia. Running annually for the past eight years, Little Dreamers now facilitates Young Carers Festivals in three states - Victoria, New South Wales and Queensland, engaging over 600+ per year. Aligning with the conference theme of "Identify and Reach", the annual Young Carers Festivals have allowed Little Dreamers to reach not only new Young Carers and their families, but also build strong community engagement relationships, increasing connections between Young Carers, their families, and important support services that they can access, whilst also raising awareness among the general public and building strong local community connections for Young Carers.

### **W2. Occupational Therapy and It's Application in the Support of Young Carers and Their Families**

**Chris Hall**

As part of our "whole family" approach, we work alongside the University of Southampton to utilise occupational therapy students. They help in the support of young carers and their families giving a high level of informed support fitting the support for impact theme. I will highlight an innovative approach, utilising students from each level of the degree course to deliver interventions, research and plan activities and programs, enabling us to make real differences with support tailored to the individuals' needs and goals. The highlight of this is a funded ten-week placement where students case-hold young carers, family members or both after going through a referral process and assessment internally within our project. Supervision is jointly provided by qualified OTs at the University and project staff. This works towards our overall aim of reducing the caring impact for the young carer. By adopting a whole family approach we have the flexibility and funding needed to offer extended service. This subsequently opens doors to further partner support.

### **W3. Young Carers Futures: Partnering with Employers to Improve Employment Opportunities for Young Adult Carers**

**Daisy Falconer**

Launched in 2021, *Young Carers Futures* brings together young adult carers with some of the UK's leading brands and employers. It is the only UK-wide programme focused on raising awareness amongst employers of the impact caring has on the life chances of young adult carers. *Young Carers Futures (YCF)* seeks to level the playing field for young adult carers into employment. The aim of this workshop is to share learning from our pioneering *Young Carers Futures* programme and the impact we are achieving for young adult carers, employers and local carer organisations.

#### **W4. How to Spread Knowledge About What Works in Supporting Young Carers?**

**Tara Knegt**

It matters where you grow up in the Netherlands as a young carer. A total of 342 local governments are responsible for providing support to young carers. However they can individually decide what support to offer. That means that not every young carer has the same opportunities for support when needed, due to lack of transferrable knowledge and clear interventions for local government. Therefore, not only gaining knowledge on how to support young carers, but also distributing and enhancing knowledge is important. This workshop relates to 'support for impact'. In this workshop I will share information about what we know about what works in supporting young carers, and how Movisie disseminates this information throughout the Netherlands. We will explore how smart collaborations (between organisations, between professionals and with young carers) ensure knowledge distributing that enhances the support of young carers by local government. The target audience of this workshop is everyone who is interested in learning how to spread and enhance knowledge (scientific, practical and experience-based) about supporting young carers. The audience will gain insight into how to put knowledge in practice. Developing knowledge about support for young carers isn't enough to make a change. It's the combination of scientific, practical and experience-based knowledge, embedded in local context and collaborations between stakeholders that will make the difference. In other words: knowledge needs to flow.

#### **W5. Young Carers' Voices Influencing Changes to Carer Support Payments in Scotland**

**Nicola Bell**

In 2022, Carers Trust Scotland welcomed Scottish Government's plans to reform Carer's Allowance to Carer Support Payments. Proposed changes include allowing unpaid carers in full time education to be eligible. We have been calling for the removal of the full-time study restriction for many years as unpaid carers have told us the impact this has had on their life. The aims of this workshop are to share our consultation and research work with young carers and young adult carers, and how we used these experiences to influence this change. We will share our reflections from this work and our priorities for the future.

---

### **SHORT PRESENTATIONS (6 SESSIONS ARE AVAILABLE)**

#### **SP1. Different Care Situations (3 presentations in this session)**

##### **a. Age-Appropriate Videos to Deliver Key Messages to Young Carers in Palliative Care Situations: Good-Practice from Switzerland**

**Elena Guggari**

Severe illnesses and end-of-life care for a next of kin is a painful and life-shattering situation even for adults; Young carers who have to deal with such situations need help and support from their environment and practitioners (e.g., health professionals and school social workers). However, professionals often lack the tools to support young carers appropriately. A study in Switzerland aimed to understand the support needs of young carers in palliative care situations and what a professional requires to better support them. The results showed that awareness of young carers in those situations needs to be improved. Furthermore, young carers need more tailored and age-appropriate information and support. Through participatory workshops with professionals as well as with young carers in palliative care situations, two short videos have been developed to explain to young carers what 'palliative care' means and offer them tips to cope with the situation.

### **b. A Mixed-Methods Exploration of the Caregiving Experiences, Outcomes, and Unmet Needs of Young Carers in Oncology**

**Bailey A. Hendricks, Kevin Kupzyk, Katrina M. Poppert Cordts & Robin M. Lally**

Children of parents with cancer often assume a caregiving role without the same education, support, and acknowledgement that their adult caregiver counterparts receive. These young carers provide multifaceted, extended care without reduction of other home, school, or work-related responsibilities. Frequently acting beyond their capabilities, they experience a myriad of both positive and negative outcomes—spanning multiple domains of health and well-being. In the United States, few studies specifically investigate young carers in oncology and no interventions exist, severely limiting our ability to support this overlooked population. The purpose of this study was to explore the caregiving experiences, outcomes, and unmet needs of young carers who have a parent with cancer in the U.S. using an explanatory sequential mixed methods study design. Fifty-two adults who previously acted as young carers were recruited via social media and asked to complete an online survey. A subsample of 18 individuals were subsequently interviewed. We found that higher unmet needs and caregiving activity were both significantly associated with higher negative outcomes and parentification scores. The highest needs pertained to a) processing emotions, b) family communication, and c) tolerating uncertainty.

### **c. Support for Young Carers of Parents Living with Neurological Diseases or Injuries**

**Linda Gustafsson and Malin Björkquist**

According to the Swedish Health and Medical Care Act, Chapter 5, 7§, a child's need for information, advice and support shall be given special consideration if the child's parent or any other adult with whom the child permanently lives together has a serious physical illness or injury. **Methods:** We work primarily to inform parents how they can support their children. Some families are invited to meet a health care counsellor and a nurse. The idea of the meeting is to help the family start talking more openly about the disease. We also work with a preventive, manual-based method called Family Talk Intervention. This method involves the whole family and provides a deeper analysis of the situation.

### **d. Hard to Reach and Hidden: Improving Identification of Young Dementia Carers**

**Patricia Masterson-Algar, Kieren Egan, Greg Flynn, Gwenllian Hughes, Aimee Spector, Joshua Stott, and Gill Windle**

The number of children and adolescents who have caring responsibilities for a family member with dementia is rising. They need help to understand the illness and how it can affect their family member.

Drawing from the experiences of young dementia carers (n=6, mean age=13.5) and relevant professionals (n=5) we followed a co-design approach to adapt iSupport (an online training programme for adult dementia carers) to young people. The adaptation work resulted in the creation of iSupport for Young People which is the first e-health intervention of its kind and aims to support the mental health, knowledge, and skills of young dementia carers. It consists of 22 lessons distributed across five modules: Introduction to dementia; Being a carer; Caring for me; Providing everyday care and Dealing with behaviour changes. The lessons comprise relevant information, caregiving scenarios and interactive skills training exercises. We are currently working to extend the reach and significance of iSupport for Young People by exploring the experiences of these young people and proposing recommendations to raise their profile amongst relevant services and professionals in the UK. We have also, through working with international partners and relevant stakeholders in Spain and Brazil, translated iSupport for Young People to Portuguese and Spanish and we will be organizing showcase events to provide a platform for discussion on how to increase the awareness and support available for this group of young carers. By bringing a spotlight onto these young carers living in families affected by dementia we hope to start the conversation and build the foundations of evidence-based research to increase their identification, awareness and 'fit for purpose' support initiatives across UK, Spain and Brazil.

---

## **SP2. Young Carers' Support Needs & Services/Projects (4 presentations in this session)**

### **a. The First 16 Years of the US Caregiving Youth Project and Caregiving Youth Institute Amy Gordan & Elizabeth Olson**

The purpose of this presentation is to share the work and impact of the American Association of Caregiving Youth (AACY), a US Nonprofit corporation that was formed in 1998 to provide volunteers to people who were homebound and caregiving families. The program began direct work with young carers/caregiving youth in 2007 through the Caregiving Youth Project (CYP), and has expanded to support research, advocacy, and policy. In the State of Florida, the 2019 Youth Risk Behavior Survey revealed that more than 290,000 high school and middle school students in Florida provide some type of caregiving for family members.

### **b. In Their Own Words: The Support Needed and Valued by Young and Young Adult Carers Nicola Brimblecombe & Sara Gowen**

Children and young people provide a great deal of unpaid care in England and worldwide. Support is needed to prevent and reduce possible negative impacts of caregiving on education, employment, health, and social relationships. This support needs to be young carer-informed and responsive to carers' own expressed needs and goals. Our research sought the views and experiences of carers aged 9-25 of what support they found helpful, how it could be improved, what additional support was needed, and barriers to accessing support. Young carers were involved from the start through a Young Carers Research Advisory Group made up of representatives from the four study areas. Their input into the research methods, analysis and dissemination of the findings were a crucial element of this research. Methods were focus groups and in-depth interviews with 143 carers. We heard that support and services valued, needed but often lacking included (i) support to reduce or remove young people's need to

provide care and help improve the lives of the people they care for: a whole family approach; (ii) mitigation to address impacts of providing care on young carers' mental health, wellbeing, education, social participation and leisure activities, and (iii) assistance for the caring role, for example through information and advice or peer support. Much of this support is in current legislation. However, gaps in implementation remain. The recommendations for change were disseminated through an animation and through regional research and action events led by young carers – linking research into practice.

### **c. The Voice of Young Adults Making Sense of Their Caring Childhoods: Demonstrating Resilience Through Adversity**

**Angela MacDonald & Katrina McLaughlin**

The aim of the research was to give voice to young carers from Northern Ireland (NI) to gain a better understanding of the lived experience of childhood caring. Young carers in NI represent a marginalised and understudied group in comparison to their UK counterparts. Individual interviews were conducted with six females aged between 19 and 24 years old. Unstructured interviews asking only one question 'Please tell me what it was like for you having caring responsibilities during your childhood?' were transcribed verbatim, analysed using Interpretive Phenomenological Analysis (IPA), and had a participatory element. Analysis revealed four superordinate themes: Making sense of childhood experiences through adult eyes; An unpredictable and stressful childhood; Key people and their understanding; Onwards and upwards in transitioning forward. Participants reported difficulty understanding their caring experiences as children and how with age and comparison to others their knowledge increased. They detailed unpredictable, stressful childhoods involving juggling responsibilities in an attempt to cope. The quality of relationships appeared to influence resilience levels. Participants were not hidden but often felt ignored. Participants though, had a remarkable ability to spontaneously find benefit from their caring childhoods which seemed vital when deriving meaning and moving forward. The target audience are policy makers and professionals who are engaged in the support and service provision for young carers. Learning/key take away messages are 1) to emphasize the need for legislative changes in NI to be brought into line with UK young carer legislation 2) highlight the benefit of adopting a participatory, exploratory and open approach to enable young carers to recount their own lived experiences 3) going beyond the benefit finding to describing how their experiences shaped and enhanced their resilience and individual growth.

### **d. What More Can We Do? A lot. Challenges and Questions from a Young Carers Service**

**Andrew Deacon**

This presentation will explore the ongoing work of Sefton Carers Centre in identifying and supporting young carers in our borough, focusing on the challenges and questions we face as a service. Rather than highlighting the things that we do well, we want to share the difficulties we encounter in our daily efforts to be an effective and impactful service. Our presentation will communicate the journey we are on as a service to improve for our young carers above simply improving our administration. Delegates will realise from our presentation that, despite the very real challenges and questions we face, we young carers services can do more for more young carers.

---

### **SP3. Professional Perspectives on Young Carers (2 presentations in this session)**

### **a. Raising Awareness and Changing Practices: The French Healthcare Professionals' Viewpoint** **Pauline Justin, Géraldine Dorard, Valentyn Fournier, Aurélie Untas**

While awareness about young carers (YCs) is gradually growing in France, identifying and supporting them still faces significant challenges. Studies in the field of oncology have shown that healthcare professionals often struggle to recognize YCs within their patients' relative, because they are primarily focused on patient care. Nonetheless, professionals could be a valuable resource for this vulnerable population.

### **b. Teachers' Perspectives on Siblings as Young Carers** **Krister Fjermestad & Caitlin Prentice**

Studies of siblings of children with chronic disorders tend to mainly utilise parent and (sometimes) sibling self-ratings on measures of psychosocial well-being, which offers limited insight into the mental health and well-being of siblings within a school environment. Objectives. This presentation examines teacher perspectives on sibling mental health and how these compare with parent perspectives. Similarities and differences between these perspectives can provide a novel insight into the well-being of siblings and how their mental health may be enacted – and therefore supported, if necessary – in a school environment. We used paired sample t-tests to compare teacher and parent scores concerning sibling mental health, measured with the Strengths and Difficulties Questionnaire (SDQ). The scores were compared with population norms. Patterns of agreement/discrepancy between teacher and parent scores were explored using latent profile analysis.

---

## **SP4. International Perspectives (4 presentations in this session)**

### **a. Getting Young Carers on the Agenda in Norway** **Anita Vatland & Robin Kirknes Andreassen**

When we look at all the good job done in Europe by our colleagues, the Me-We project etc, Norway has failed to recognize and advocate for Young carers. It is estimated that in Norway about 150 000 children 0-18 years are living with parents and/or siblings suffering from physical and/or mental illness and addiction. A multicenter survey 2015 showed us a lot of the challenges they have. But what about the group that often falls between the chairs – not child but on their way to finish school and start their own lives? The group called young carers (young adult carers) age 16 to 25 are a group we know little about and lack data on in Norway. PÅA was the driver to advocate for the launch of the Norwegian Carers strategy 2020 – 2025. One of the action points was to perform yearly national surveys on important carers issues. In 2021 and 2022, 2 national surveys were performed – one on general situation and experiences that informal carers have and the next was on the carers and families of particular vulnerable groups. But the Carers strategy also stated: “No children should be caring for family members”. We know that is not the truth. Carers Day 2021 showed a lot of action in Norway among youth organizations when the theme was Young Carers. The politicians are concerned about all the young people falling out of school and not getting a job. This has worsened in and after the pandemic. The Government planned a “Youth warrant” from 2023 to help young people graduate school and get a job. We targeted and visited the politicians, talking about young carers/young adult carers and that we had no data on them, and that they are “a group in the group” of young people who need our attention. Especially young politicians could

see the need for this, also because of our population now exiting of 18 % with other ethnical and/or cultural background than Norwegian. Winter 2021/22 PÅA performed a small survey on young carers, to get background material and to convince the Directorate of Health of the need for data on this group. This convinced them that we needed more data about this group and what they need, in order to support them. In April 2023, we got the first National survey on Young Carers Norway. This showed us that 18 % of youth between 16- 25 say they are young carers according to the survey. They have worse mental health than the rest of the youth population.

## **b. What Do We Know About Young Carers in Finland?**

**Tiina Sihto**

In this presentation, the objective is to present the current state-of-art concerning research on young carers in Finland. This presentation will thus relate to the theme of identifying and reaching young carers and discuss the ways in which the Finnish results are similar and different to other, similar country contexts. Finland is usually classified as part of the Nordic welfare regime, which aims at providing comprehensive, good-quality, affordable and accessible social and healthcare services for all its citizens. However, due to the retrenchment of the welfare state and ageing of population, the expectations for family members, relatives and other kin are constantly growing. This development is likely to concern informal carers of all ages – including young carers. According to the 2019 Finnish School Health Promotion Study (SHPS), around 3% of eighth and ninth graders (aged 14–16) provide care on a daily or near-daily basis for family member or other kin. Thus, there are thousands of adolescents and young adults in Finland today for whom being a carer is part of everyday life. Despite this, the questions concerning young carers have only recently gained visibility, and Finland still lacks research, specific legislation, policies, and targeted services for young carers. In this presentation, I will discuss results from two waves (2019 and 2023) of SHPS, as well as qualitative research concerning the experiences of former young carers. The target audience is especially researchers, policymakers, NGOs and (former) young carers themselves.

## **c. How Many Young Carers Are There in France?**

**Éraldine Dorard, Jade Pilato, Basile Chevrier, Éléonore Jarrige, Christel Vioulac & Aurélie Untas**

In 2017, we launched the program JAID: Research on young carers in France. At that time, there were no scientific studies on young carers (YCs) and the situation of these young people was hardly known. It was therefore essential to identify the proportion and characteristics of YCs in order to contribute to raising awareness. We successively conducted three studies with large samples of middle school (ELIASS), high school (ADOCARE) and college (CAMPUS-CARE) students. The aim was to explore the prevalence and characteristics of YCs in France, using an identification method based on the extent of caring activities, including emotional support.

ELIASS included 1,983 middle school youth (Mage = 12.9; 56.2% female), ADOCARE included 4,037 high school youth (Mage = 16.1, 60.2% female) and CAMPUS-CARE included 6767 college students (Mage = 20.1; 77.3% female). They answered a self-report questionnaire assessing sociodemographic- academic characteristics, relative's illness/disability, caregiving activities.

## **d. Understanding the Everyday Geographies of Young Carers in the U.S.**

**Elizabeth Olson & Leiha Edmonds**

Progress towards recognizing the experiences and need of caregiving youth has been slower in the United States than in other countries. Moreover, the scarce research that does exist has tended to focus on advancing overall identification, or individualized conceptions of well-being that fail to connect youth caregivers with the broader political, social, and economic factors that shape their care. In this paper, we report on the findings from a multi-year, mixed-method qualitative research project conducted with young carers (“caregiving youth”). The study brings together maps (both GPS-enabled and sketch maps) with interviews and home visits to understand how fifty young carers experience care in diverse places, including their homes, schools, and streets. Objectives: We introduce a methodology created for this study that combined mapping data with audio and written diaries, and oral histories of care to understand how the intersections of disability, race/ethnicity, and class shape their experiences of providing care. We use grounded experiences to discuss the structures that delimit young carers opportunity to provide what they consider ‘good care’ for their family, friends, and communities.

---

## **SP5. Types of Caregiving Roles (4 presentations in this session)**

### **a. Better Understanding Emotional Support Provided by Young Adult Carers**

**Céline Lacombe, Christel Vioulac, Géraldine Dorard, Aurélie Untas**

The literature on young adult carers indicates that emotional support is one of the most common forms of support they provide. However, few studies investigated the manner in which this support is provided, nor its potential impact. Providing emotional support to an ill/disabled relative can be perceived as a challenging task because of the emotional and psychological investment it requires. Moreover, the tools measuring emotional support are limited and fail to provide comprehensive insight into this support. Therefore, a qualitative study was conducted among young adult carers to explore the characteristics of the emotional support they provide. Objectives: The primary aim of this session is to present the results of this study, which shows that emotional support may be provided through multiple actions: suggesting activities, being present, providing emotional protection, helping the relative to regulate his/her emotions, and being a preferred interlocutor. The findings also indicate that providing emotional support can have specific effects on young adult carers’ well-being as an emotional burden.

### **b. To Be the Bearer of Bad News**

**Emilia Öhberg**

In my role as Operations Development Officer at the Swedish Red Cross Treatment Center for persons affected by war and torture in Skövde, Sweden I provide support for children who are next of kin (CANOK) to our clients. Many of the children and young people I meet are young carers. Over the years we have discussed together many aspects of being a young carer. The task that many of the young people I have meet feel is especially difficult to bear is interpreting for their parents in a variety of different situations. This often leads to the young people experiencing stress, anxiety, self-doubt and feelings of pressure. According to the young people themselves it is especially difficult and stressful to interpret letters from authorities when these letters contain bad news. I will present one case that young carers have written that is based on lived experiences. In Sweden, who is and who isn’t considered to be CANOK is defined by the law. However, children and young people who interpret for their families can fall outside these categories. They may not have a significant other who suffers from mental or physical illness, but they are still providing care. I want to broaden the perspective of what a young carer is.



### **c. Young Adult Carers Pursuing Higher Education in London: Application and Transition into University; Reconciliation Between Caring and Student Life; and Perceptions of University Support Services**

**Camille Bou**

The study sought to explore how young adult carers and their households divide the division of labour, and the factors influencing their division of household labour. In this way, this study proposes a novel analysis of household labour division by focusing on families with young adult carers. To understand the division of household labour from the young adult carer perspective, the study answers the following questions: 'How do young adult carers divide household labour with their families? Why do they organise their household labour in this way? How do young adult carers experience their household division of labour, including their reconciliation between their caring responsibilities and their other responsibilities?'. I analysed data from semi-structured interviews that I personally conducted with 23 individuals living across England using a framework approach. Most participants in the sample were female, and most cared for their parents (specifically, their mother), with others caring for siblings. From the analysis of the interview transcripts, two models of decision-making and two models of implementation of household division of labour task emerged, influenced by several factors: 1) the illness of the care-recipient; 2) the care experience and specialisation of the young adult carer; 3) the agency and influence of the young adult carer in conversations about the division of household labour, and 4) the amount of support young adult carers and their households received, whether from formal or informal networks (e.g. health or social care system, or friends and family). Depending on the pattern of household labour in which they found themselves, and consequently how much care intensity they experienced, young adult carers were satisfied or dissatisfied. Nonetheless, most young adult carers saw themselves continuing to care in the future alongside the pursuit of their personal aspirations, although it was not always clear how they would achieve this. The division of household labour in homes with young adult carers is not something that had been studied before. This study provided insight into the daily lives of young adult carers and what happens within their home.

### **d. Collaboration and Co-creation Among Young Carers: Preliminary Experiences from a Photovoice Research Project**

**Deborah Ummel**

Young carers are often defined as individuals who are less than 25 years old and who support or help a parent who is sick or disabled are a hidden population. As caregiving is generally associated with older adults, society (e.g., parents, school) is struggling to recognize the existence of young carers, the care provided and the consequences of providing this care on their mental and physical health, their schooling and their social life. The study aims at 1) describing the adaptation of becoming a young carer and 2) better understanding what may influence the adaptation to that role, to elaborate, in collaboration with young carers, an action plan comprising means and strategies to support them. Anchored in participatory-action research, the study uses the Photovoice method as it allows participants to grow their critical awareness and engage them into action, as by taking pictures of elements they accord sense and value, they control the nature of collected data. In the present study, the sampling procedure allowed to recruit individuals who are 15 to 25 years old and are providing care to a parent, according to the score obtained at the MACA (multi-dimensional assessment of caring activities). Participants were then divided into 4 groups of about 8 participants. Each group met for five times. Transcribed data of the group interviews were analyzed according to thematic content analysis. Results: First, the adaptation of becoming a young

carer will be described, with an emphasis on how the collaborative nature of the research project played a role in that finding. Second, the several influences on the adaptation to that role will be presented. The strengths and challenges of using the Photovoice method with young carers will be discussed.

---

## **SP6. Co-Production with Young Carers (3 presentations in this session)**

### **a. Evaluating Young Carers' Experiences of Co-production and Co-delivery of Training and Awareness Raising, Providing Insight for Practitioners into Living with Familial Substance Misuse and/or Mental Ill Health**

**David Hambling**

Our 2021-2023 research explored ethical issues associated with the co-production and co-delivery of awareness raising events that young carers who care for someone with mental ill health and/or substance misuse have been involved in. These stigmatised areas of caring, are often hidden and unaddressed. Gloucestershire Young Carers and Sheffield Young Carers participated in the research, providing both a north-south and urban-rural perspective. The research was co-produced and co-delivered with former young carers. 16 young people participated in creative focus groups facilitated by a former young carer and a researcher. The aim was to improve understanding of the ethical issues associated with young carers sharing their lived experiences, in order to improve services and to build understanding about best practice.

### **b. An Exploration of the Experiences of Young Carers in Kandara Subcounty, Kenya**

**Frashia Ndungu**

Many children and adolescents care for ill family members, frequently performing substantial caring tasks and assuming levels of responsibility that are typically associated with adults. Although many young caregivers (YC) successfully juggle school and household responsibilities, some exceed what is expected locally. Most YCs are not acknowledged by institutions and receive limited support. This study explored the context of care in Kenya and the gaps in supporting or recognizing YCs in schools and other child welfare systems. This qualitative study conducted in Kenya included interviews with twenty young caregivers aged 10 and 22 years and seven key informants. The findings highlight the extent of caregiving responsibilities performed by the participants, including physical, emotional, and financial support, the difficulties they face (e.g., emotional burden, inability to comprehend the illness, stigma, and neglect), and the meanings they derive from the caregiving roles (e.g., seeking good karma and hoping to make the parent better). Schools were identified as safe spaces for YCs, where they could escape their caring responsibilities and concentrate on other aspects of their lives but could also be sources of additional distress due to stigma, lack of recognition and support. Caregiving was not considered problematic, but issues such as divorce, death and disrupted parent-child dynamics, exacerbated the experience. The study concludes that YCs require psychosocial support; and psychoeducation of their social networks to reduce stigmatization. Additionally, providing YCs with adequate and sustainable access to essential amenities, such as food and water, would ease their caregiving burden. These findings could benefit activists and policymakers in creating youth support. Researchers could also examine deeper how the highlighted issues influence experiences of young carers.

### **c & d. Community Nurses, Opportunities to Improve the Health and Wellbeing of Young Carers**

**Fiona Rogers**

Community nurses work from “cradle to grave” in a variety of roles and settings and are ideally placed to identify, support and signpost Young Carers (YC). YC voice is at the heart of many nurse-led initiatives from local service design to national policy work. Sharing “Tom’s Story” and Health for Young Carers Project evidence impactful positive outcomes empowering YC. Tom, 23 caring for 15 years supported a School Nurse leading YC Programme seeking to ensure YC’s voice embedded. Coincidentally wanting to support YC using his experience, knowledge and skills. Years of advising, supporting and coproducing followed including resources for campaign days, sharing lived experience at Board, starring on a billboard to attending the Houses of Parliament and speaking directly to politicians. Health for Young Carers Project led by two school nurses aimed to improve identification of YCs in Secondary Schools enabling access to timely health and social care support.

- Providing carer-friendly information and advice, support in the way which best supports YC.
  - Ensuring YC listened to in relation to their caring role having opportunities to influence services support through change.
  - Ensuring YC supported to establish their independence through signposting to appropriate health services.
  - A YC booklet, a whiteboard animation, film was coproduced, assemblies delivered. Shortlisted Nursing Times Awards 2023.
-