

Carers Rights Day 2022



**Young Carers
Alliance**

Young Carers and Health

We will be starting at 10am

@YcAlliance

#CarersRightsDay

Welcome and housekeeping

- 🌸 Ensure microphones are on mute
- 🌸 We will be recording the session
- 🌸 Introduce yourself and make use of the chat
- 🌸 Any questions will be followed up after the event
- 🌸 Join in the conversation on Twitter - @YcAlliance #CarersRightsDay



The mental and physical health of young carers: what do we know from quantitative studies?

Rebecca Lacey, Baowen Xue and Anne McMunn

Institute of Epidemiology & Health Care, University College London

Systematic review – what is it?

- Comprehensive summary of all evidence on a specific topic
- One of the strongest forms of evidence
 - Review is conducted following a series of pre-defined steps that aim to minimise bias and maximise the thoroughness of the review
 - Provides a thorough summary of evidence on a topic
 - Assesses the bias present in existing evidence
- Provides a reliable source of evidence for policy and practice

Background

Previous reviews of health of adult carers:

- Mental health (Bom et al, 2019; Del-Pino-Casado et al 2021; Pinquart & Sorenson, 2003)
- Physical health (Bom et al, 2019; Pinquart & Sorenson, 2003)
- Carers of people with specific conditions (Masefield et al, 2020; Pousada et al, 2013)

No review of the health of young carers

- Cannot assume the health consequences of caring in childhood or adolescence are the same as in adult

Methods

Systematic search of peer-reviewed (academic) and grey literature

Searched six databases:

- Applied Social Sciences Index and Abstracts (ASSIA), Cumulative Index to Nursing and Allied Health Literature (CINAHL), MEDLINE, PsychINFO, Scopus and Google Scholar

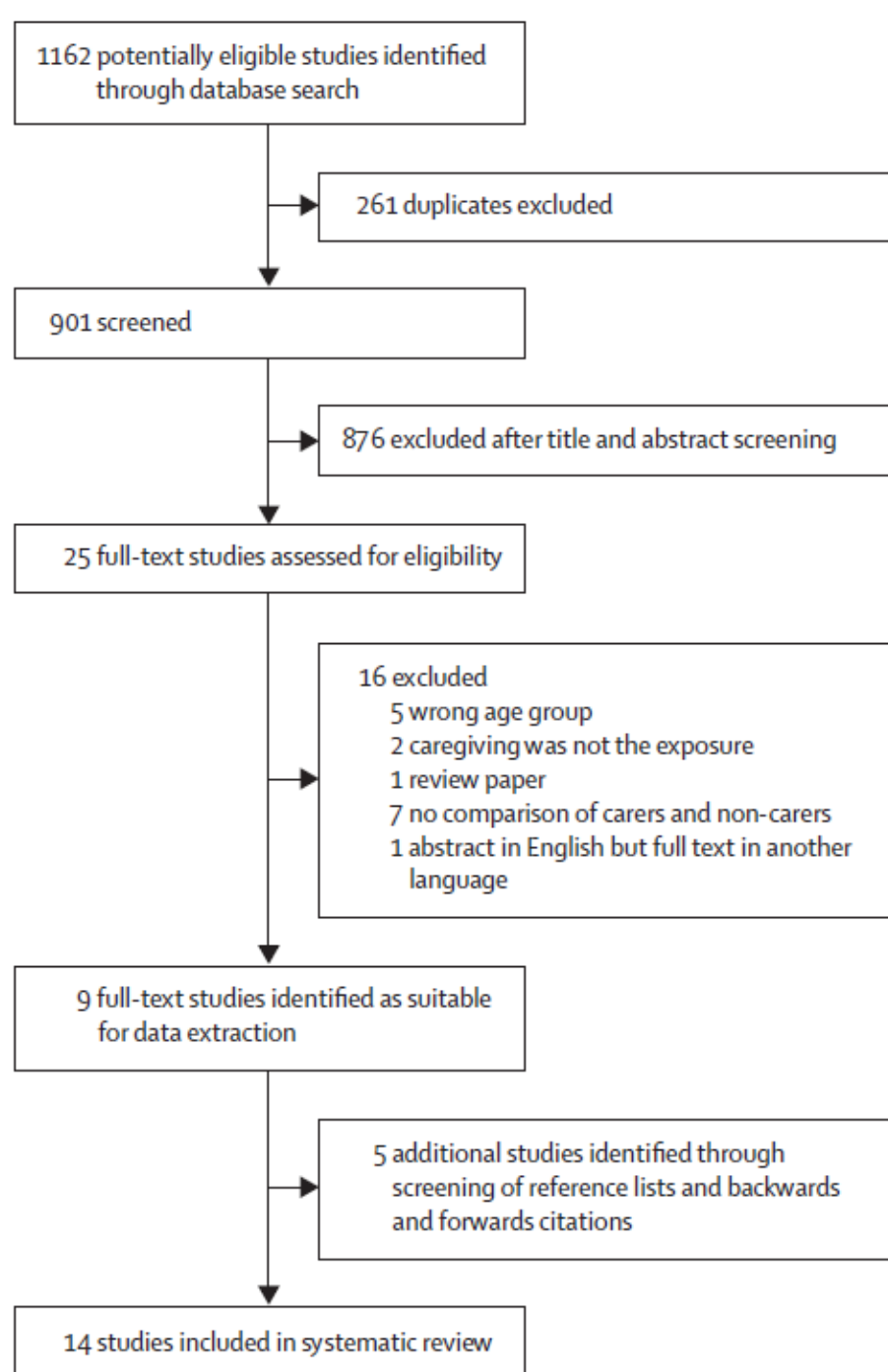
Search terms

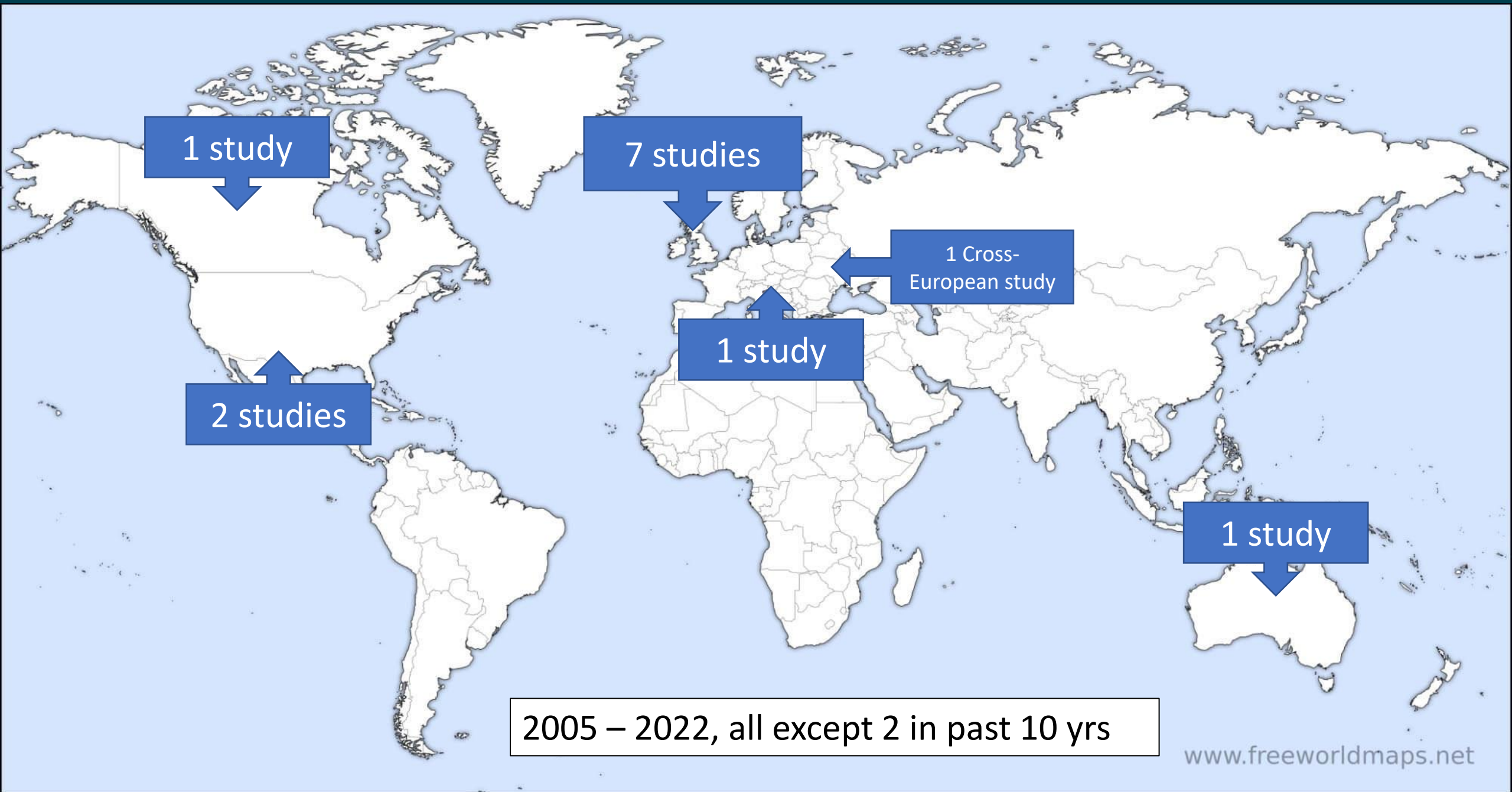


“Young carer*” OR “Young caregiv*” OR
“teen* carer*” OR “teen* caregiv*” OR “teen* caring” OR
“child carer*” OR “child caregiv*” OR
“adolesc* carer*” OR “adolesc* caregiv*” OR
“carer* under 18” OR “caregiv* under 18” OR “caring under 18” OR
“caregiv* in childhood” OR “caregiv* in adolesc*” OR
“carer* in childhood” OR “carer* in adolescence” OR
“caring in childhood” OR “caring in adolescence”

Eligibility criteria

- Published in English
- Quantitative studies
- Define young carers as those aged <18 years
- Include a comparison group of non-carers
- Quantify at least one association between young caring and any measure of physical or mental health





Results

12 studies were cross-sectional, only one longitudinal

Samples from 40 – 773,422 people

5 studies physical & mental health outcomes, 7 studies only mental health, and 1 study only physical health

Most studies rated as “high quality”

e.g. most had representative samples of young people, sufficiently documented their methods

Mental health findings

-All except one study found that young carers had poorer mental health, on average, compared to their non-caregiving peers

- More symptoms of anxiety and depression
- Lower self-esteem
- Poorer health-related quality of life
- More antisocial behaviours
- Higher total scores on Strengths and Difficulties Questionnaire
- More likely to report chronic mental health condition

-Little evidence of gender differences

-Care intensity was important

Physical health findings

-All studies showed that young carers had poorer physical health, on average, compared to their non-caregiving peers

- Poorer self-rated health
- More likely to report a physical health condition or disability
- More likely to report physical health symptoms
- Worse sleep
- More mobility problems

-Again, care intensity important – although only one study examined this

Conclusions and recommendations

- On average, young carers had poorer mental and physical health than their peers, especially those providing the most intense levels of care
- Relatively new area of quantitative research
- We need studies in low and middle-income studies
- We need longitudinal studies
- How does being a young carer lead to worse health?
- Nuance in what care involves e.g. activities, intensity, who, level of support
- Positive outcomes, not just negative

The mental and physical health of young carers: a systematic review



Rebecca E Lacey, Baowen Xue, Anne McMunn



The health of those who care for someone with a health condition or advanced age is poorer, on average, than non-carers. However, the health of young carers (<18 years of age) has been under-researched, especially in quantitative studies. This systematic review aimed to summarise studies assessing the mental and physical health of young carers. 1162 unique studies were screened and 14 associations between being a young carer and health were identified (two studies were treated as a single unit of analysis as they had information from the same sample). Most of the included studies were done in the UK, with the remaining studies done in the USA, Canada, Australia, and Austria. A cross-European study of 21 countries was also included. Five of the included studies investigated both mental and physical health outcomes, seven studies investigated only mental health outcomes, and one study investigated only physical health outcomes of being a young carer. All of the included studies, except one, were cross-sectional in design. Most studies found that young carers had poorer physical and mental health, on average, than their non-caregiving peers. However, the evidence is relatively weak and more quantitative research is needed, particularly research that is longitudinal in design and assesses physical health outcomes.

Lancet Public Health 2022;
7: e787–96

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Introduction

The General concept of a carer is defined as the person who provides care and support to someone with a health condition or advanced age (caregivers providing intense care).⁸ Furthermore, there

More info

- Full paper:
 - Lacey, R, Xue, B and McMunn, A (2022) 'The mental and physical health of young carers: a systematic review' *Lancet Public Health*, 7, e787-96
[https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667\(22\)00161-X/fulltext](https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667(22)00161-X/fulltext)
- Email:
rebecca.lacey@ucl.ac.uk

**Believe in
children**



Barnardo's

Young Carers and Hospital Discharge

New legal rights

Becky Rice

Senior Policy Advisor for mental health and wellbeing



Young Carers Intro

800,000 CYP possible
young carers

Predicted 180,000 are
missing out on support

On average young carers
are caring for 3 years
before they are identified

1 in 3 young carers has a
mental health issue

Hospital admission and young carers

The admission of a family member may result in:

A child or young person becoming a carer for the first time

The identification of a child or young person who has been providing informal care without support

A change in condition resulting in a temporary or permanent change in the level of support provided by a young carer



Hospital admission of a family member

Distressing for children and young people

Often overlooked during admission and on discharge planning

Needs a whole family approach

Health and Care Act

Health and Care Bill proposed removing “discharge to assess” requirements for NHS to consult with carers before discharge (Clause 80)

Amendment 113 places a duty on NHS providers to consult carers, understand their capacity and willingness to provide care

Now part of the Health and Care Act

Discharge Planning

Should start from the moment of admission or elective or emergency care and should involve carers from the beginning

Should involve temporary or long term arrangements for rehabilitation and recovery

Should involve a multidisciplinary team, and children and young people should be at the centre



What does this mean for young carers?

Should expect to have their needs and wishes taken into account as part of discharge planning

Should be given information and support that makes involvement accessible

Should be provided with appropriate support according to their needs as a carer

Case Study

In November 2021, following a short hospital stay after a stroke, a mother and her 13-year-old son were sent home with little information upon discharge beyond being told she would be referred to a stroke clinic.

Becoming a young carer led to her son being worried about his mother's safety and reluctant to go to school in case she needed him. There was no sign posting by the hospital for a young carer needs assessment or wider support.



What does this mean for ICSs?

Amendment 59 requires NHSE to assess how well ICBs are meeting the needs of 0-25s

Also now in Health and Care Act

There is also a legal duty for ICBs to consult with carers (including young carers) in the planning and delivery of commissioning services (as well as decisions which relate to the prevention, diagnosis or care/treatment of person they care for)

Means children and young people are not an afterthought and must be considered in forward planning.

Means there must be leadership and accountability



Implementing the Act

Young carers need to be identified, engaged with and supported

Organisations need to understand young carers rights

Young carers and their families need to know their rights

Commitment to Carers Programme NHS England

Paula Cruise

How can we identify & support Young Carers

Numbers of Young Carers

800,000 young carers aged 5-17 care for an adult or family member in the UK

Estimated as **20%** of the school population

39% reported that no one in their school was aware of their caring responsibilities

27% of young carers aged 11-15 miss or have difficulties at school due to their caring responsibilities

Reflects that we still have so many **hidden young carers**

'It's harder than anyone understands' 2022 - Carers Trust

Carers Trust surveyed over 500 young carers/young adult carers in Spring 2022 showing:

- ❖ More than half (53%) said the number of hours they spent caring had increased in the past year
 - ❖ 42% said they 'always' or 'usually' feel stressed
 - ❖ More than 1 in 3 (36%) 'always' or 'usually' feel worried because of being a young carer/young adult carer and 1 in 3 'always' or 'usually' feel lonely
 - ❖ Nearly 1 in 4 'never' or 'do not often' have someone to talk to about their feelings.
-
- ❖ **National GP Survey:** carer health worse than peers.
 - ❖ **Making Caring Visible** (YouGov) June 2020: 1 in 4 people currently have a caring role = 4.5 million extra unpaid carers



NHS commitment to all carers

- To secure better outcomes of care for patients, and for the millions of people who care, unpaid.
- To build a carer-friendly NHS to a greater extent than ever before.
- To start to build an NHS where no carer feels left alone and that the NHS is there to support them in their caring journey
- To change things so that carers are better able to look after their own health and wellbeing, manage the care of the person being cared for and are less likely to go into crisis.

Long Term Plan Commitment to Carers deliverables 2020-2024

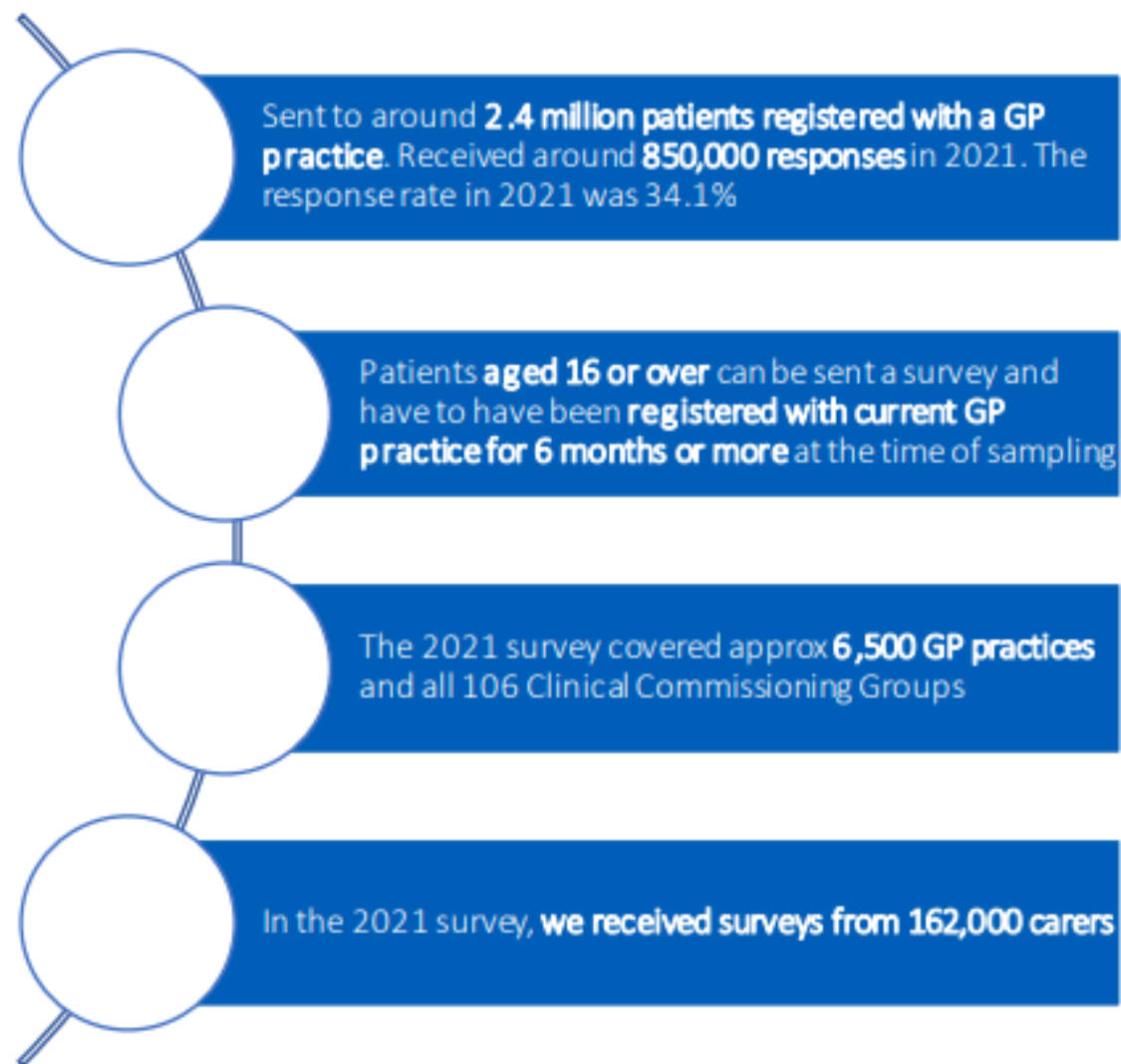


1. Identifying and supporting carers, particularly those from vulnerable communities
2. Introduction of Quality Markers in Secondary Care, including increasing Carer Passports
3. Ability to share caring status with healthcare professionals wherever they present via electronic health record
4. Carers understand the out-of-hours options that are available to them and have appropriate back-up support in place for when they need it
5. Young Carer “top tips” for general practice to include preventative health approaches, social prescribing and timely referral to local support service
6. Introducing best practice quality markers for primary care

Evidence Base:

- ❖ To increase recognition of carers as a vulnerable community and caring as a social determinant of health <https://www.gov.uk/government/publications/caring-as-a-social-determinant-of-health-review-of-evidence>
- ❖ Alignment with population health approaches (Health Inequalities, Vulnerable Communities, Prevention, Proactive Inclusion Health) <https://www.inclusion-health.org/pcn/audit-results/?print=pdf>
- ❖ Linked to NICE Guidance NG150 – Supporting Adult Carer. Published Jan. 2021 <https://www.nice.org.uk/guidance/ng150/resources>
- ❖ Examples of CQC outstanding practice can be found here: [Involving people and caring for carers.](#)
- ❖ Integration & innovation: White Paper: <https://www.bing.com/search?q=integration+and+innovation+2021&src=IE-SearchBox&FORM=IESR3A>
- ❖ [NHS England » Supporting carers in general practice: a framework of quality markers](#)
- ❖ [National Commitment to Carers NHS Futures platform](#) for up to date information, best practice
- ❖ [GP mythbuster 44: Caring for carers | Care Quality Commission \(cqc.org.uk\)](#)
- ❖ <https://www.england.nhs.uk/commitment-to-carers/>
- ❖ <https://www.longtermplan.nhs.uk/blog/our-long-term-commitment-to-carers/>

GP Patient Survey background



Q59 Do you look after, or give any help or support to family members, friends, neighbours or others because of either:

- long-term physical or mental ill health / disability, or
- problems related to old age?

Don't count anything you do as part of your paid employment.

☐ No

☐ Yes, 1 to 9 hours a week

☐ Yes, 10 to 19 hours a week

☐ Yes, 20 to 34 hours a week

☐ Yes, 35 to 49 hours a week

☐ Yes, 50 or more hours a week

'Non carers' are those who answered 'No' to Q59 and **'Carers'** are those who answered one of the following to Q59:

- 'Yes, 1-9 hours a week'
- 'Yes, 10-19 hours a week'
- 'Yes, 20-34 hours a week'
- 'Yes, 35-49 hours a week'
- 'Yes, 50+ hours a week'

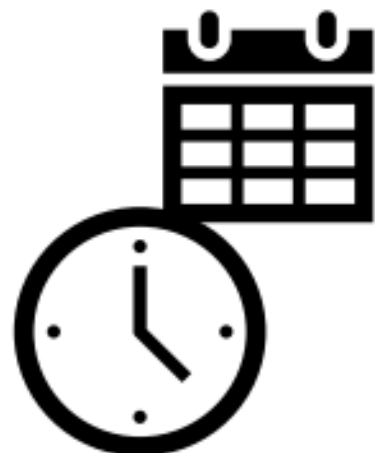
Making an appointment (1)



Less than two in three carers (64%) were offered any choice when they last tried to making an appointment



Compared with 69% of non carers. Any choice could refer to time/day, location, type of appointment, and healthcare professional



Around a third of carers (34%) were offered a choice of time or day

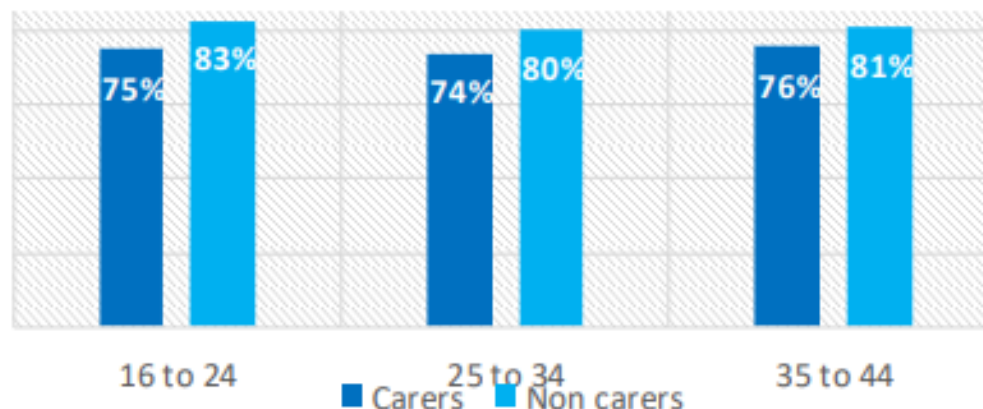
Compared with 41% of non carers. This choice demonstrated the largest difference between carers and non carers



78% of carers were satisfied with the appointment offered

Compared with 82% of non carers

The difference in satisfaction between carers and non carers is greatest for younger patients



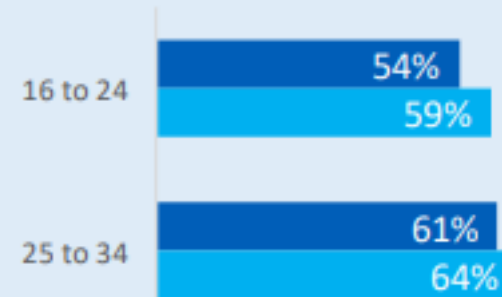
Overall experience questions (2)

Disparities were demonstrated between carers and non carers most prominently across younger patients aged between 16 to 24 and 25 to 34

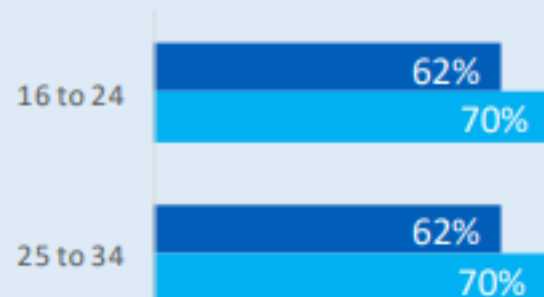
Good overall experience of their GP practice



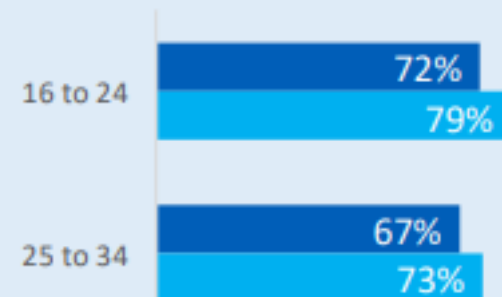
Good overall experience of NHS services when GP practice was closed



Good overall experience of making an appointment



Good overall experience of NHS dental services



Mental health need – Last appointment experience

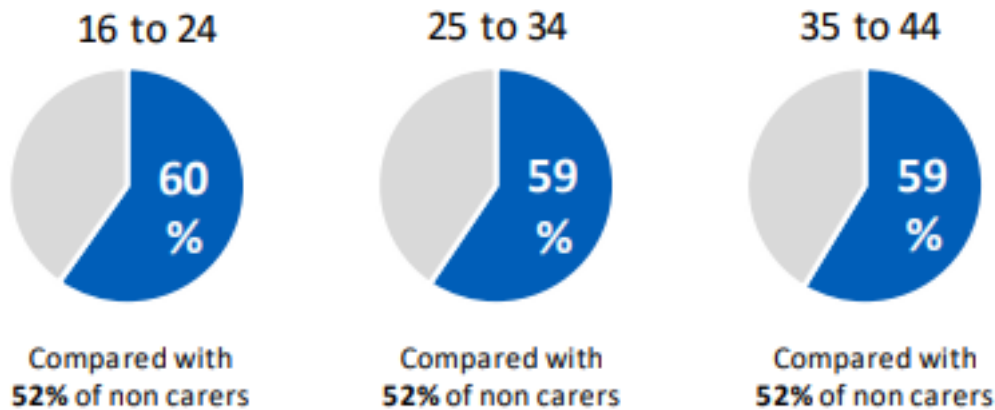


Half of carers (50%)
had a mental health
need at their last
general practice
appointment

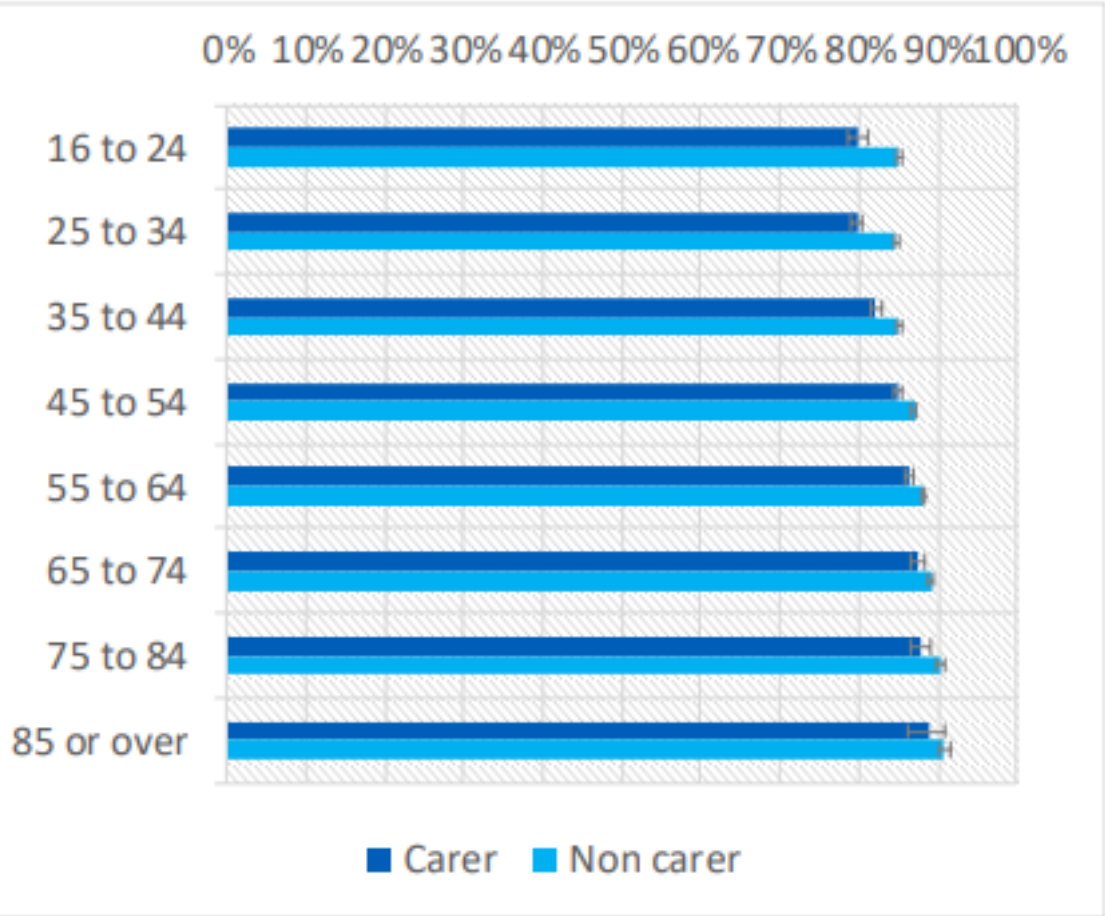
Compared with 47% of non carers



This rose to around three in five carers
aged 16 to 44



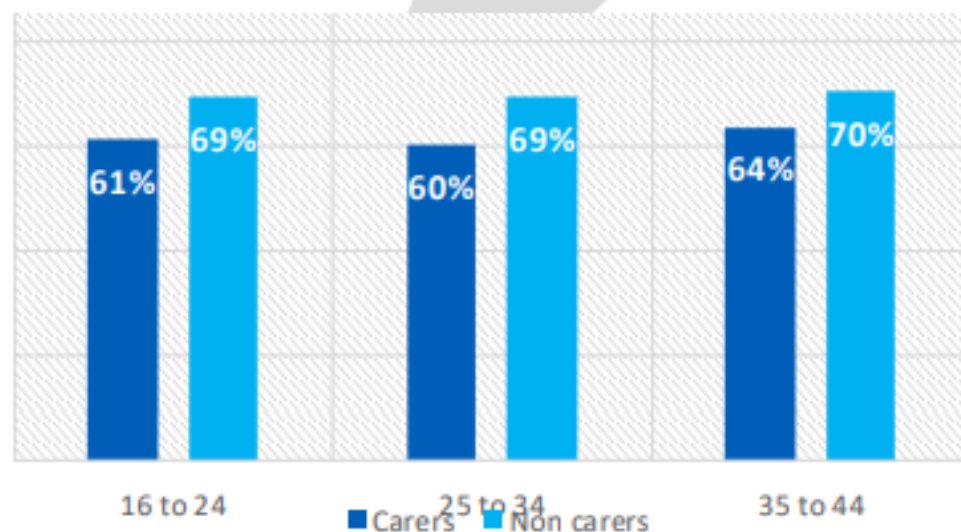
Carers aged 16 to 34 in particular were less
likely to say their mental health needs were
recognised or understood



Support for long-term conditions and care planning

71% of carers felt supported by local services to manage their long-term conditions or disabilities

Compared with 74% of non carers



Younger carers in particular were less likely to feel supported

Around two in five (41%) carers have talked about what's important to them when managing their conditions with a health care professional

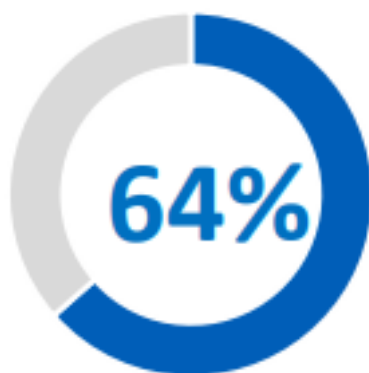


Around one in five (22%) of carers have agreed a plan with a healthcare professional to help manage their conditions



Long-term conditions, disabilities and illnesses (2)

Around two in three carers felt their day-to-day activity was affected by their conditions



Compared with 58% of non carers



On average this was 12 percentage points higher for carers aged 16 to 44 compared with non carers of the same age

Example: 78% of carers aged 16 to 24 said their day-to-day activity was affected, compared with 66% of non carers the same age



Carers aged 16 to 55 were more likely to report a long-term mental health condition compared with non carers



Carers across almost all ages were more likely to report arthritis or ongoing problems with back or joints compared with non carers

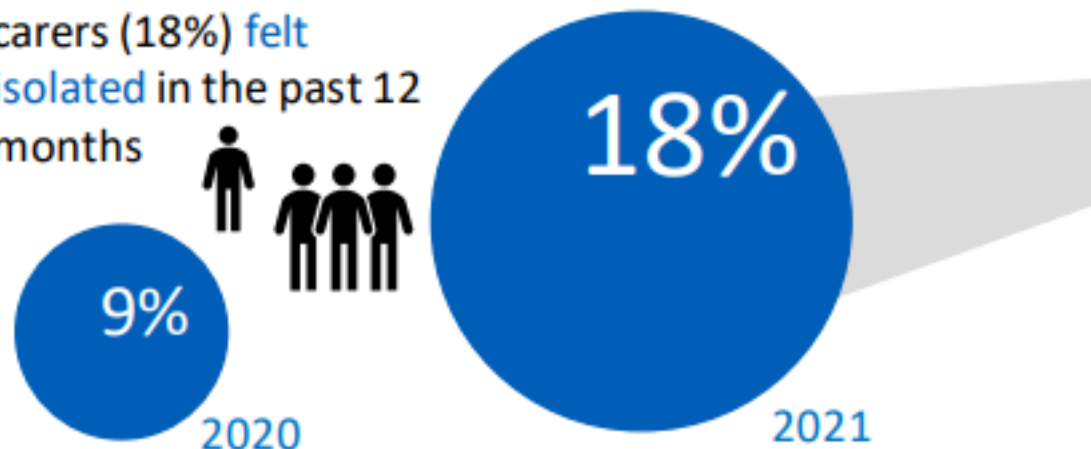


Carers aged 16 to 45 were more likely to report a breathing condition compared with non carers

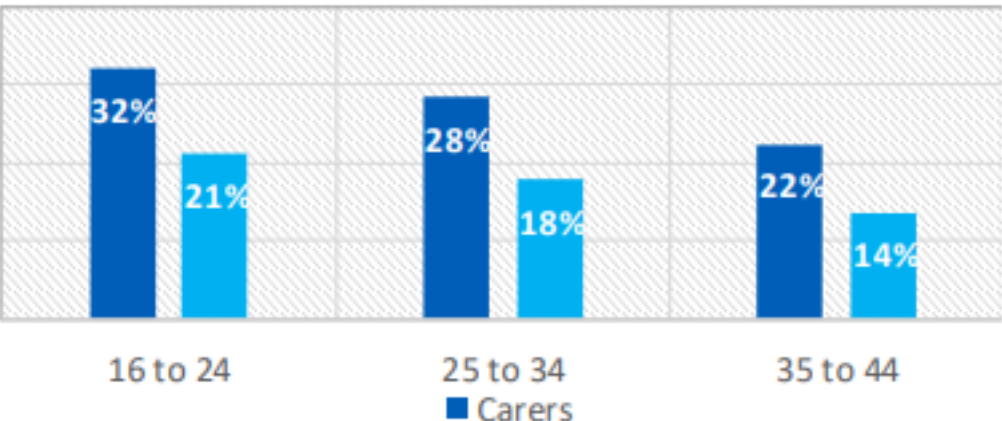
Feeling isolated from others and shielding



Around one in six carers (18%) felt isolated in the past 12 months



Carers aged 16 to 34 were most likely to feel isolated

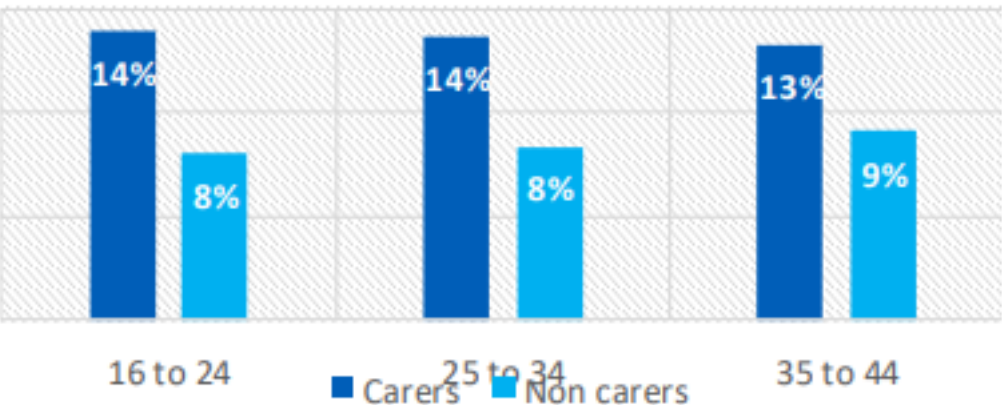


This magnitude of increase is seen for non carers too: 2020 (7%) and 2021 (14%)

18% of carers shielded for themselves over the past 12 months...

Compared with 16% of non carers

The difference between carers and non carers is greatest for younger patients



2.35 The NHS will roll out **'top tips' for general practice which have been developed by Young Carers**, which includes access to preventative health and social prescribing, timely referral to local support services. Up to 20,000 Young Carers will benefit from this more proactive approach by 23/24

TOP TIPS for general practice

1. Recognise that they have individual needs, and shouldn't be all treated the same
2. Think about the support and understanding a young person may need
3. Listen and actually hear what young people are saying
4. Avoid relying on young carers interpreting for the person they care for
5. Think about how you can make appointments more accessible; after school or double appointments

Young Carers Wish List



What can professionals do to support Young Carers?



- Ask the question 'do you help to look after someone at home?'
- Try and establish the level of care and what could help that person
- Offer flexible appointments (after school, virtual, separate to cared for person)
- Check in with a Young Carer on their mental health
- Encourage Young Carers to register within Primary Care
- Flag/code young carers on shared health records
- Signpost young person to local carers voluntary organisation for carers assessment & further support.
- Refer to a Social Prescribing Link Worker if possible.
- Establish a carer/young carer lead within your system

What support do local Carer's organisations give YC's?

Carers Trust

<https://carers.org/help-and-info/carer-services-near-you>

Children's Society

<https://www.childrensociety.org.uk/information/young-people/young-carers/local-service-finder>

Both can signpost to local services for
Young Carers

Do I look
like I care?
#NHSThinkCarer

paula.cruise@nhs.net

Stay connected to the NHS England Commitment to Carers programme

- **Sign up to the NHS Future Collaborations Platform** (Commitment to Carers group) to access, publications, funded project reports, webinar recordings, blogs, case studies, future events, workstream updates etc.
- **Bi-monthly lunch and learn**
- Please request access by emailing england.nhsthinkcarer@nhs.net
- Visit the NHS England website <https://www.england.nhs.uk/commitment-to-carers/>

Supporting young carers' health through football (& other sports)



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Football and Community

Many football clubs are a key part of their local community and offer support to local groups in their catchment area.

This can include support for young carers; most commonly provided through a partnership involving a local young carers service (and sometimes also the local council or health service). For professional clubs, work is normally undertaken through a charitable trust or foundation attached to the football club.





Football and Young Carers Report

A Young Carers Alliance report (June 2022) details lots of examples about how football clubs are helping to identify and offer support to young carers. This helps promote their health and wellbeing through providing opportunities to be physically active and to promote their social inclusion.

A wide range of initiatives

We have already seen a wide range of initiatives happening. These tend to be for boys and girls together; including for example:

Football coaching and taster sessions in community settings and in schools

Young carer mascots

Stadium tours



**Young Carers
Alliance**

Raising the Profile

There has been considerable success in awareness raising through football about a wide range of social issues including mental health and fighting both racism and homophobia. There clearly is potential to do something similar for young carers and carers.





Carers Active

In a project funded by the National Lottery and Carers UK have developed a carers active hub to help carers increase activity levels and improve their health and wellbeing.

<https://www.carersuk.org/help-and-advice/activity-hub/how-to-use>


The Young Carers Alliance wants to help ensure that young carers have opportunities to be physically activity and have fun playing sports. It makes sense for us to make common cause.



Carers Active April

The Young Carers Alliance is planning to work together with Carers Active to promote “Active April” in 2023.


This will be the second year for this month long event but this time expanded to much more clearly include a focus on young carers.







Carers and other Sports



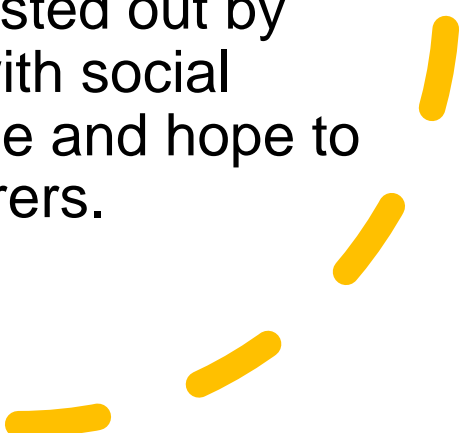
We are now seeing exciting signs of similar developments in other sports; so far including Rugby Union, Rugby League and Netball. The approach taken for promoting young carers health and wellbeing seems to be entirely transferable from sport to sport.



Social Prescribing

Social prescribing has been extended to include children and young people through out the country. Statistically, young carers form a significant portion of the cohort of “vulnerable children” that social prescribing is targeted at. There is a national sports work-stream for “Social Prescribing” and that includes a specific focus on football.

Social prescribing schemes should refer to services for carers and young carers, including football and other sporting initiatives. This is being tested out by Watford FC who are undertaking work with social prescribing for children and young people and hope to test out how this might benefit young carers.





**Young Carers
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A new tranche of Services

The work of the Young Carers Alliance and Carers Active could potential create a whole new tranche of services to refer to, including through social prescribing. We need to make sure that local social prescribing services are carer and young carer aware.



Opportunities for Development

We can see a range of highly effective, low cost, high impact initiatives that promote young carers' emotional and physical wellbeing and also help raise awareness in the community.

Many of the activities being delivered help enhance young carers fitness and also promote their social inclusion.





Opportunities for Development

Some of the opportunities for development include:

- Advice to support sports organisations in becoming “young carer friendly”
- National sporting bodies asked to take up young carers issues
- Promote research related to the needs of young carers and young adult carers to access sports and opportunities for physical activities
- Ensure that funding organisations such as Sports England and the Football Foundation have young carers and young adult carers on their agenda

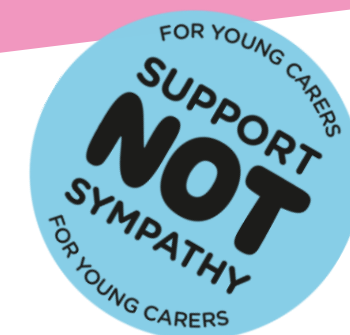




For More Information or Discussion

Contact:

- John Bangs,
- Independent Carers Policy Adviser
- at: jbangsuk@icloud.com
- or @JohnBangs15 (Twitter).



Kelly Hockaday
Young Carers Coordinator

Manchester Young Carers Partnership
Manchester City Council



Dear Healthcare
Professional.

An open letter
from Manchester
Young Carers.



I am a Young Carer. I know your main focus is on my loved one and I appreciate your care for them. You understand their medical needs and the healthcare they require.

As a Carer, I spend a lot of time with my loved one. I know them very well and I am there through all of the ups and downs. This can be hard as I don't always know all of the medical terms or how things work in the medical world. When we see you, I have some questions but the appointment isn't for me so I don't always have the confidence to ask.

I want to be included. If you speak to me, I can tell you a lot about them. I can tell you how they have been sleeping, how much they have eaten or if they have had a fall lately. I am a good advocate for them. I can also notice signs that may mean their health is a worry.

If I am contacting you, or have been referred to you for my own health I may not tell you right away that I am a Carer. Sometimes my caring role causes me stress and worry, and sometimes it is other aspects of my life. It's helpful if you know about my caring responsibilities as you can understand me better but it doesn't automatically mean something is wrong. I am proud to be a Young Carer and look after my loved one. They trust me and I know exactly what they like and dislike. I will just need your help to make sure it doesn't get too much and that I get the help I need to keep caring.

Please ask about my caring role if I come to appointments with my loved one or if I am at home when you visit. My role is important to me. Please point me in the direction of any help I can get for my caring role or even just for me. Remember I am a young person too and will put others first so checking in with me helps when I find it difficult to reach out to others.

I want to stay well so I can do the best caring I can. We will make a great team working together!

Improving Young Carer Experiences

Early identification is the crucial first step to support which means a young carer and their family can receive appropriate help before a child becomes vulnerable.

‘Young carers rarely make themselves known to their GP and often avoid seeking help although caring can impact significantly on their lives.’ [3]

Steps to support young carers: Identification & Support

- A named Lead for Young Carers in the surgery – Linked to Young Carers Coordinator. (Champion)
- A Young Carers briefing for all staff members .
- Awareness posters and promotion of support.
- Whole practice agreements – Passport, Ring Fenced Appointments, Signposting, Private spaces to talk.
- Sensitive conversations – the cared for, including the young carer.
- GP Websites update and reflect current practice offer for Young Carers.
- Named lead on Help and Support Manchester
- Routine health screening – Eating, Sleeping, Wellbeing & Social Prescribing.
- Early Help Hubs / School Nurse – connected Health Lead.

Source [3]Royal College of General Practitioners (2013) *RCGP supporting carers in general practice Summary report on GP practice journeys towards improved carer identification and support*, https://www.rcgp.org.uk/clinical-and-research/resources/a-to-z-clinical-resources/~/_media/EFE191B727514B66909FEED20FF23E1F.ashx

#SupportNotSympathy



MANCHESTER

Select Language

Powered by Google Translate

Accessibility

Register / My Account

Health & Wellbeing

Keyword(s)

Place name or postcode

Search

My Shortlist

Home / Help & Support Manchester / Adults Care & Support / Carers / Support for young carers / Health & Wellbeing / Search Results / The Arch Medical Practice - Young Carer Aware

The Arch Medical Practice - Young Carer Aware

Actions

Print

Add to My Shortlist

Back to results

Is this information correct?

Disclaimer

Share

SMS

Social

Mobile number

Send SMS

We are a young carer aware practice.

We have a designated Young Carer Champion at our surgery - Rukaya Ashley

We will have promotional materials to help identify and raise public awareness of who young carers are and how they can access support.

At our surgery all our staff have had young carer training

We will listen to young carers and their families and are committed to connecting them to the support they may need and want.

We can make arrangements for young carers so that their visits to our surgery are at a time that works around their caring responsibilities

We have private spaces so young carers and their families can talk openly about any worries or needs they may have

We are dedicated to supporting families overcome any barriers to accessing services, this includes overcoming barriers that might prevent families from seeking help and support.

We will work closely with the Young Carers Lead to keep up to date of all the latest offers and opportunities available to young carers in our city.

We will continue to raise awareness to all our staff so that we can be confident in identifying and supporting young carers.

We will ask young carers and support young carers about their own health needs and want young carers to know that we care about them, the challenges they and their families face and can be someone to turn to for advice and signposting.

Where to Go

Name of venue	The arch Medical Practice
Venue address	175 Royce Road Hulme Manchester
Postcode	M15 5TJ



Resources

[Help and Support Manchester – Young Carers](#)

[Young Carers: Information for healthcare professionals](#)

[Young Carers In families affected by parental mental illness.](#)

[How can you help a young carer in just 5 minutes?](#)

[Young Carers NHS](#)

[Carers Trust and the National Centre for Social Research \(NatCen\)](#)

[The Children Society – Young Carers](#)

Young Carers # Support Not Sympathy

Young Carers and Health



**Young Carers
Alliance**

Comfort Break

@YcAlliance

#CarersRightsDay

Young Carers Alliance Presentation by Family Action Young Carers Healthcare Team



Building
stronger
families

Nov 2022

3 year project, funded by The National Lottery Community Fund
(Apr 2022 – Mar 2025)



What we have done, so far



We began by researching a number of Government papers and acts that support young carers, referenced as follows:

- Children and Family Act 2014
- Carers Act 2014
- Young Carers Needs Assessment Regulations 2015.
- Carers (Scotland) Act 2016.

- Care Act – The Whole Family Approach
2015 (Department of Health)
- Supporting Carers in General Practice: a framework of Quality Markers.



We have also met with other Young Carers Services:

- Gloucester Young Carers
- Buckinghamshire Carers
- Caring Together and the Carer Friendly Tick.
- Carers Trust



...and linked in with established forums:

- National Young Carers Alliance Healthcare Forum
- Health and Well-being Forum, and
- Disability Inclusion Forum

...as well as working towards establishing our own client and professional forums:

- Parent/Carers' Forum
- Young Carer Ambassadors
- Healthcare Roundtable Forum



Barriers identified to engaging with primary care services:



- Time, for professionals to explore the wider family support
- Invisibility
- Lack of confidence or willingness to self-identify
- Lack of awareness of the role of young carer by professionals
- Stigma and shame, and fear of implications of caring role being publicly acknowledges
- Language and terminology used by professionals
- Staff turnover



Potential solutions and actions implemented, to date:



TIME and INVISIBILITY

- Ensure targeted, direct question(s) on Healthcare professionals' assessment forms ask if there is a child in the household.
- Improved use of electronic databases, e.g. use of YC code as 'Child Carer' on EMIS, the G.P.'s database.
- Parental consent requested for GP letter to be sent to use icon for YC identification on database.
- Improved, efficient referral pathways.
- Training at induction and CPD sessions for Healthcare Professionals



Potential solutions and actions implemented, to date:



INVISIBILITY and LACK OF CONFIDENCE

- FAYC Healthcare Team engaging in Regional and National Forums, e.g. Roundtable and Young Carers Alliance
- Promoting the benefits and positive aspects of being a Young Carer whilst supporting Young Carers to equip them to be more vocal and independent, etc. through direct and group work with Young Carers:
 - 1:2:1 sessions with Young Carers
 - Group Work – Level-Up wellbeing group
 - Accessing external support services, e.g. Esteem Youth Groups
 - Putting Young Carers in touch with a Young Carers Champion and training and recruiting more YC'S Champions



Potential solutions and actions implemented, to date:



LACK OF AWARENESS, STAFF TURNOVER and LANGUAGE

- To provide opportunity for discussions with families and partners to improve understanding and communication across the community.
- Targeted use of communication resources and distribution of promotional marketing material including using a standard GP letter to notify GP's of identified YC's.
- Continuous, on-going training and CPD sessions within professional departments from induction, including Young Carers Champions Program (Train the Trainer) and regular reflective sessions.
- FAYC Annual Celebration Event



Potential solutions and actions implemented, to date:



STIGMA and FEAR OF IMPLICATIONS

- To provide education, training and information through:
 1. facilitating reviews of practise, tailored training sessions with professionals, e.g. GP's, lunch and learn sessions, etc.
 2. establishing forums for discussion and inviting public participation to influence the community positively.
 3. training of Young Carer Champions to disseminate learning to pupils in assemblies and PSHE lessons to break down stigma and offer suitable support.



So, what is next for the RBWM Healthcare Team over the next 4 – 6 month period...



- Liaising with hospital discharge teams; Govt guidance states to include voice of YC in discharge plans
- Presenting a GP roadshow, and standard letter sent notifying GP's of Young Carers attending their surgeries.
- Presenting at both Windsor and Maidenhead's Health and Wellbeing Forum, and the Disability Inclusion Forum
- Continuing to assess and provide direct support with YCs and their families
- Delivering minimum of 2 x YC Level-Up wellbeing groups, per annum
- Development of YAC's Level-Up wellbeing program and exploration of program for younger carers, aged 5 to 6 years of age.
- Co-production of project with Young Carers Ambassador annual program and Parent/Carer Forum
- Young Carers Champions, minimum of 2 x Train the Trainer Sessions per annum
- Creation and distribution of marketing resources
- Sourcing media space in various local newspapers and magazine distributions and on-line.





Building
stronger
families

For enquiries

rbwm.yc@family-action.org.uk

kate.anderson@family-action.org.uk

scott.biddle@family-action.org.uk




Belinda Jones

Awareness and Voice Team Manager

Improving Awareness in Health Settings

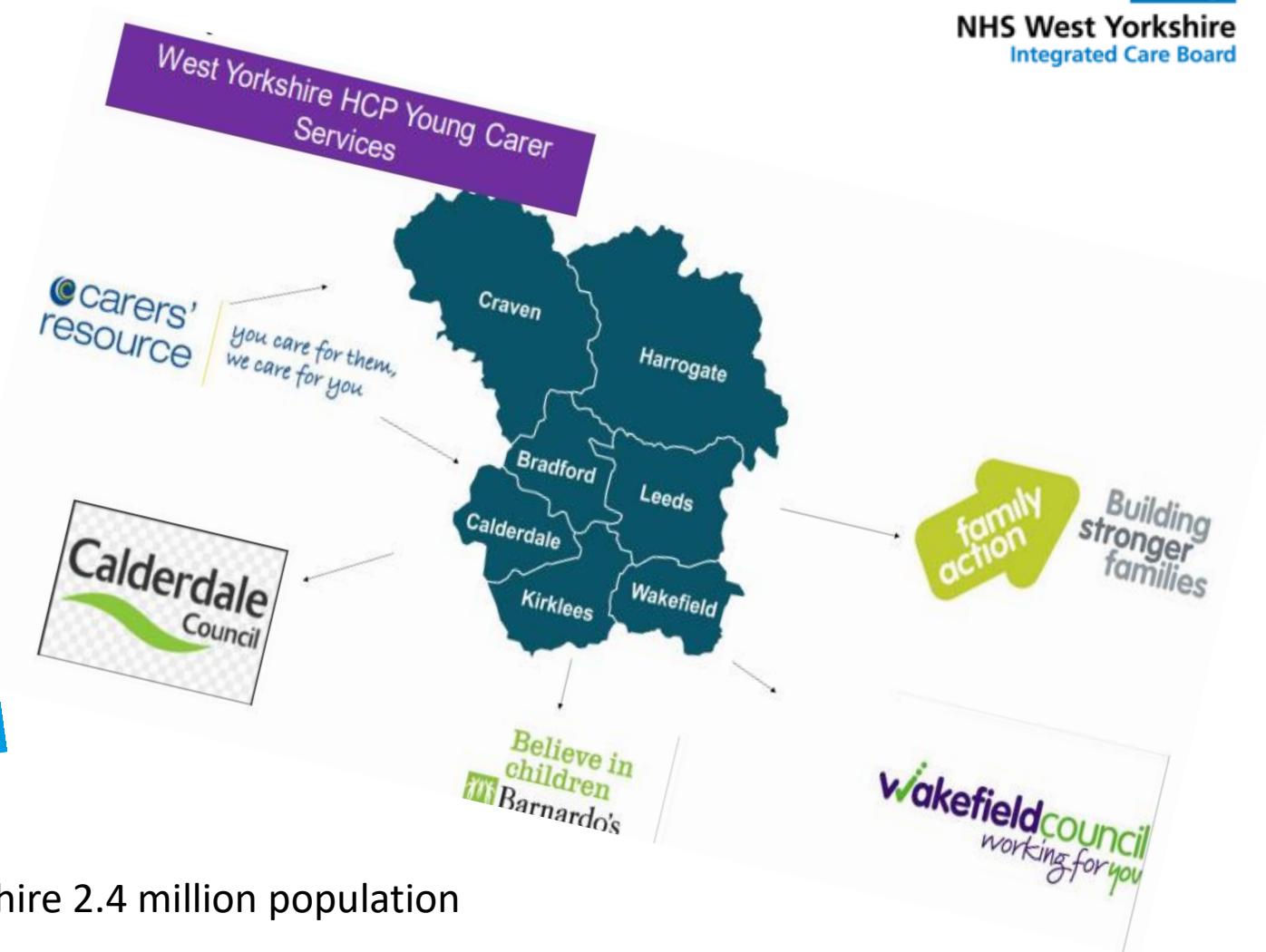


- 
- 🌸 Hospital engagement
 - 🌸 GP surgeries
 - 🌸 East of England Ambulance Service- Directory of Services
 - 🌸 IC24 (111 Service)
 - 🌸 Student Social Workers/Occupational Therapists/Nurses
 - 🌸 0-19 Healthy Child Programme
 - 🌸 Carer Friendly Health settings
 - 🌸 Norfolk Young Carers Forum
 - 🌸 ICS Roundtable
 - 🌸 [James Story –NNUH](#)

Young Carers Health Update November 2022

Fiona Rogers Programme Manager
LTC and Personalisation Function

Background

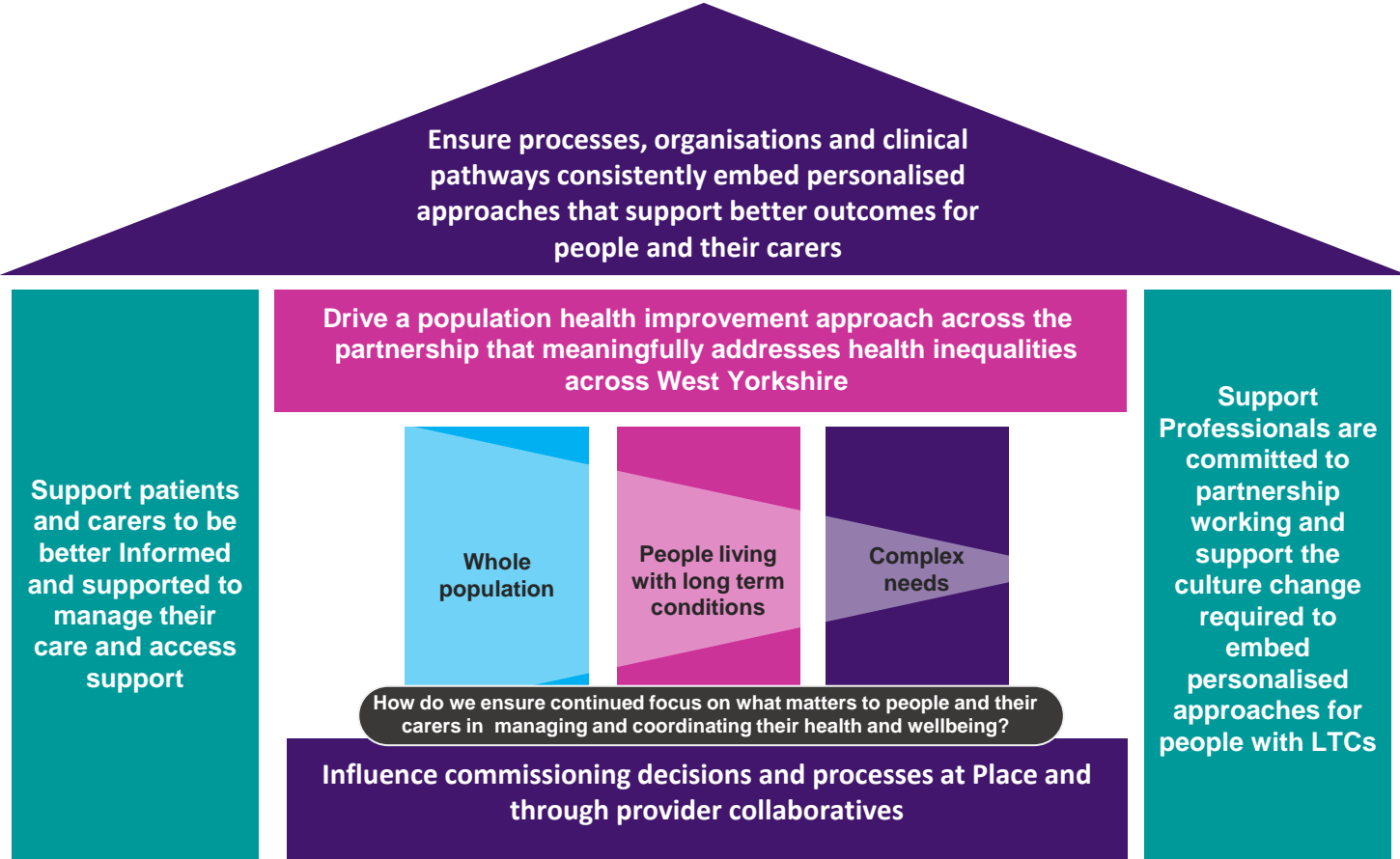


West Yorkshire 2.4 million population

Children account for 23% (570,000) of the total West Yorkshire and Harrogate population - 2020

1574 Young Carers Registered
Young Carer Services - 2021

Long Term Conditions and Personalisation Function



Unpaid Carers System Aspirations 2022- 2025

Increase better recognition and support for carers across West Yorkshire

Increasing awareness & support for young carers

01

- Establish digital app ambassador role via Youth Collective
- Development of bitesize resources and promotion to education sector including staff training and awareness sessions
- Develop champions in schools
- Targeted comms resource and promotion to diverse communities and schools
- Identification of young carers through 111/YAS
- Focus on Supporting transition into adulthood

Indicators

- No. of people trained
- Case studies eg video/lived experience
- No. of Carer champions in schools
- Young carers collective established
- No of digital app downloads/reach

Improving the lives of working Carers

02

- Trusts to sign up to Carers Accreditation
- Increase number of passports across health and care and monitoring of monthly data passport numbers from HR
- Launch of managers guidance to support local policy
- Promotion of health and wellbeing of working carers including those from diverse backgrounds
- Continued communication and resources to increase reach and identify working carers
- Evaluate impact and reach of the working carer passport

Indicators:

- All health & care organisations to have adopted the passport by 2022
- Case studies eg video/lived experience
- 300 working carers passports by 2023
- All Trusts to have signed up to carer accreditation

Better recognition and support in primary & Community Care

03

- Develop primary care resource pack to increase identification and support for carers including consistent clinical coding and network of carer champions
- Consistent recording of registered carers across PCNs and numbers of contingency plans on a quarterly basis
- Ensure carers maintain priority status for vaccinations/flu jabs
- Access to PPE/covid testing across all local places

Indicators:

- Adoption of primary care resource and carer champions by all 5 places by 2023
- Case studies eg video/lived experience
- No of practices who've adopted the template /coding protocols
- Access to PPE/covid testing across all 5 places by 2023

Working With Our Hospitals

04

- Development of message in a bottle campaign to support better planning for carers in the event of unplanned situations
- Development of offline and digital contingency plan via YHCR and recording of plans across WY.
- Carers toolkit shared with health care organisations
- Strengthen good practice including carers charter across Trusts
- Carers passport across Trusts
- Consistent policy for carers supporting a loved one in hospital/patient journey from point of admission to discharge

Indicators:

- No of orgs who've adopted a charter
- Case studies eg video/lived experience
- Discharge pathway that support carer involvement across health and care
- No of Development of offline and digital contingency plans

Recognising carers as experts in care

05

- Workforce to recognise expertise of carers via training/case studies
- Launch of ACP resources to support better conversations with carers and their loved ones.
- Support better access to carer assessments including carer breaks and financial support, warmer homes discount schemes and access to digital apps including toolkit relaunch

Indicators:

- No of carers trained
- Case studies eg video/lived experience
- Launch of ACP resources
- Relaunch of toolkit
- Number of carer assessments
- of Self Management courses

Supporting the mental health/wellbeing of carers

06

- Supporting our Mental health Trusts and VCS organisations with a suite of resources focusing on wellbeing to support carers including a charter
- Engagement with communities to better understand the impact of caring on mental health with a focus on leaning disabilities and ethnic minorities to improve outcomes for carers and their loved ones.
- Work with commissioner leads in to ensure carers receive the support they need such as access to carer budgets and carer assessments.

Indicators:

- All 5 places have a charter and mental health action plan informed by the peer review
- Delivery of engagement sessions
- Number of carers accessing carer budgets and assessments

Young Carers Film Project

Project Aims

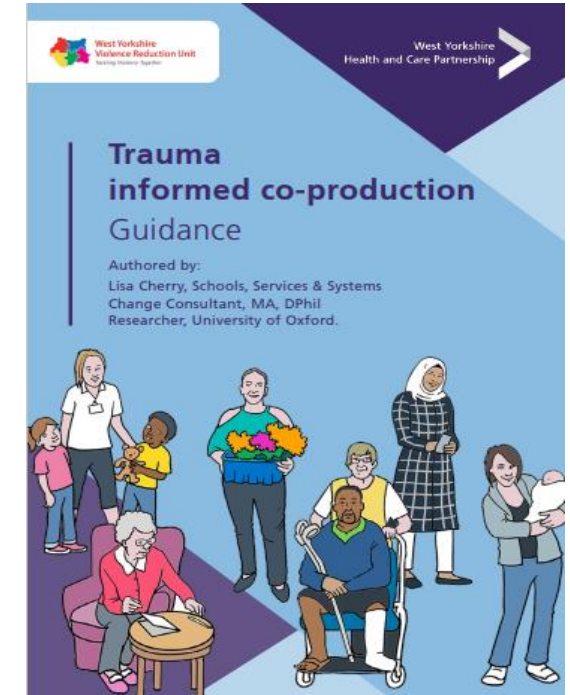


Young Carers report feeling unrecognised and unidentified

Coproduce with a group of young carers a series of short films that could be used across the system including health setting to raise awareness of young carers.

West Yorkshire is aiming to be a Trauma Informed System by 2030

Pilot Trauma Informed Guidance for Coproduction



Doing With
Considering the environment / Designing together
Being transparent what is happening
Offering compensation
Cultural humility

Feedback from Young Carers

- Set up was cool. Place is awesome. Amazing experience.
- Entirely different to other coproduction – they tell you what to say, you let the story tell itself. Felt comfortable with questions
- Was ok to step away from the brief. Felt safe highlighting parts of being a young carer aware going on social media YouTube, had choice how much to say.
- People involved seemed genuinely interested Cool being around people who wanted to know, not pushing it on them
- People had gentle voices, calming voices, not bossy. Welcoming, honest and kind.
- It made me feel special. I feel important. Other young carers can relate. I feel like a celebrity.
- You and producer offered young carers opportunity to pull out at any stage and just do an audio if preferred or nothing at all – that was fine too



Feedback from Project Team

“thank you for championing these young people and helping them to have a voice and be heard. It means a great deal to many people and I know Dan and his mum were so proud and welcomed the opportunity.”

Young Carer Lead



[Dan's story: My life as a young carer - YouTube](#)



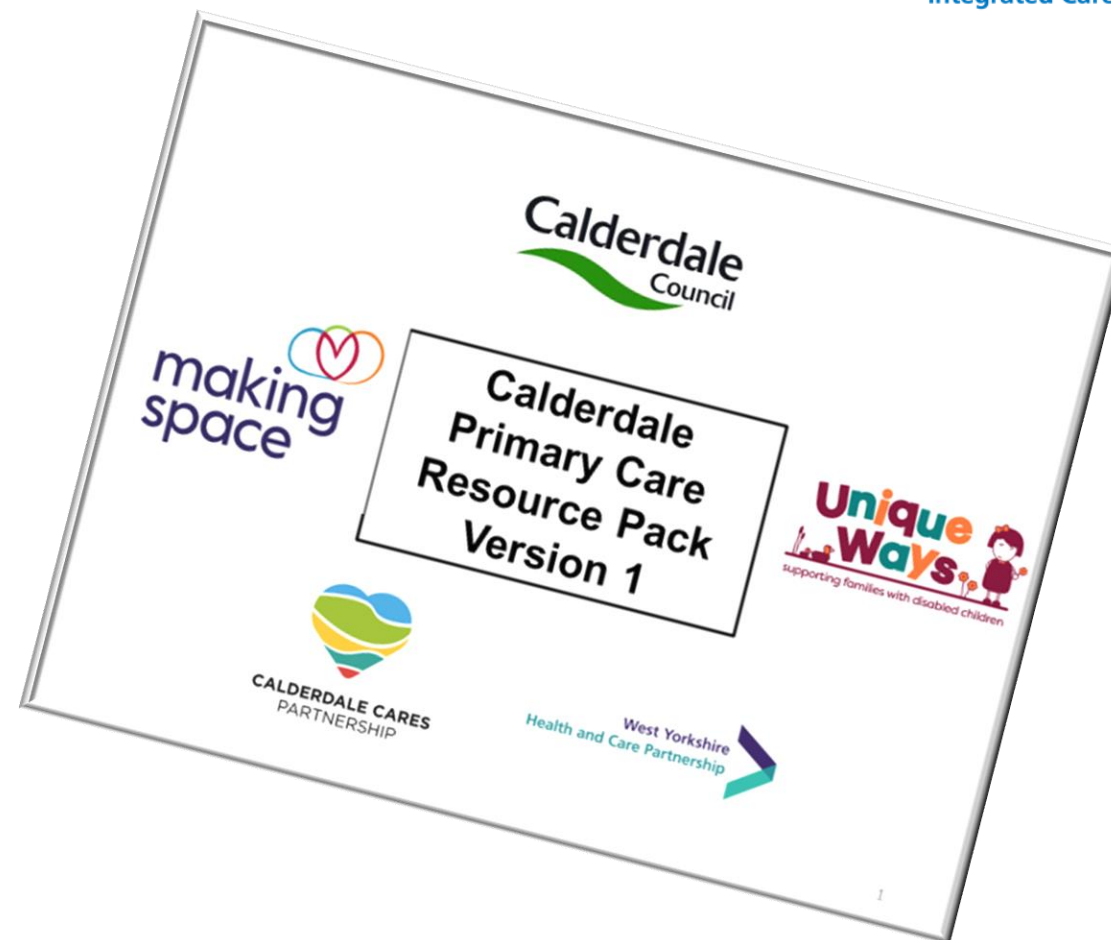
“..had to be more flexible and responsive....turned production process on its head....young people have ownership...”

Production Company

Primary Care Resource Pack

The Ask....

Co produce a bespoke resource pack of information in each Place (using the North Tyneside pack as a guide if required) to support professionals working in primary care to **Identify Signpost Support** unpaid carers including young carers.



What is a young carer? [here](#)

- All patients who identify as a young carer and with consent should be referred to the [Young Carers Service | Calderdale Council](#)
 - Support is available on how to refer young carers: [Young Carers Service | Calderdale Council](#)
 - Young Carers can download the free Young Carers Support App : [Young Carers Support App : West Yorkshire Health & Care Partnership](#)
 - The Partnership's [Bitesize Website](#) also provides resources for those who work with children and young people enabling them to be able to identify, support and sign post young carers
 - Further information about young carers is available from [the Children's Society website](#)
-
- Safeguarding - Should there be safeguarding concerns with regards the carer or the person being cared for the named safeguarding lead in the practice should be made aware and contact made with Gateway to Care for adults on 01422 393000 or MAST for children on 01422 393336 during working hours and 01422 288000 out of hours. More details are available here: [Report concerns – Safeguarding Calderdale](#) 999 should be called if there are concerns with regards immediate safety.



**The
Children's
Society**

Quality Markers	Identification and registration / holistic support
NICE NG150 / QS200	Quality Statement 1 Identify Carers / Quality Statement 2: Working with Carers / Quality Statement 3 – Carers Needs (please note that NICE guideline and Quality Statements refer to Adult Carers Only)

Young Carer's Top Tips for GP's

Recognise that young carers have individual needs and shouldn't all be treated the same.

Think about the support and understanding a young carer may need.

Listen and hear what young carers are saying.

<https://youtu.be/ZzK6OY9mvBo>

Avoid relying on young carers interpreting for the person they care for.

Think about how you can make appointments more accessible; after school, double appointments etc.

Young Carer Assessment of Needs

Think about the support and understanding a young carer may need, consider a referral for care act assessment The **Care Act** 2014 and the Children and Families Act 2014 strengthen the rights and recognition of carers in the **social care** system, and came into affect in 2015. New rights entitle carers and the people they care for to a clear right to an **assessment** of their needs regardless of their income and finances or their level of need and can offer additional support for young carers when considering extra educative or work demands.

Quality Markers	Identification and registration / holistic support
NICE NG150 / QS200	Quality Statement 1 Identify Carers / Quality Statement 2: Working with Carers / Quality Statement 3 – Carers Needs

Personalised Care Approach to Discharge Planning

- Unpaid Carers lived experience demonstrates there can be positive experiences but also experiences where there was room for improvement
- Young Carers lived experience noted they are often not included in discharge planning even when they are the primary or sole carer



The Benefits

There are many potential benefits to adopting a Personalised Care Approach to Discharge Planning including benefits to:

- Young Carer
- Loved One
- Hospital Services
- Community Services
- Preventing additional use of **A**mbulances for readmission
- Preventing additional use of services when there is a **B**acklog of over 7 million
- Preventing additional requirement for social **C**are and hospital beds
- Preventing additional use of **D**octor appointments and time



Best Practice to inform

Extracts from Hospital Discharge and Community Support Guidance

DHSC updated July 2022:

- Determine “what matters to you” after discharge
- Plan, commission and deliver appropriate care and support that meet local population needs
- Understand the quality, cost and effectiveness of local treatment, care and support to inform people of their options
- Understand organizational roles and have appropriate safeguarding policies and procedures in place.
- Take joint responsibility for individual and young carer including young carers welfare when decision making
- Transfer seamlessly and safely with joined up care, via clear evidence based assessments representing medical, psychological need and social preferences
- Identify young carers and determine if willing and able to provide care and if so what support they may need – including young carers’ needs assessments

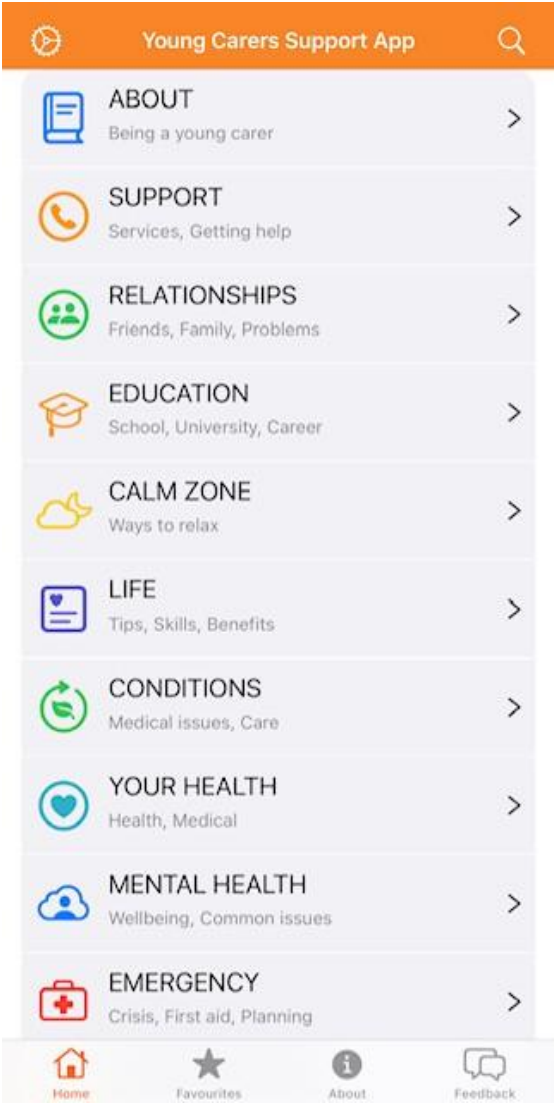
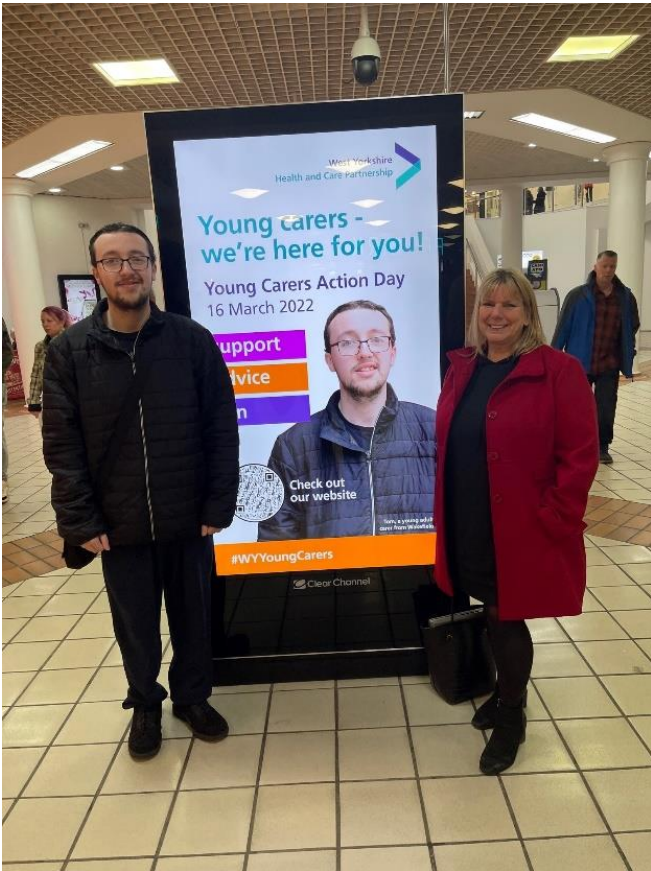


Actions in progress

- Scoping local and national Practice
- Research Project North East
- Work with Young Carers Steering Group / Unpaid Carers Steering Group / VSCE network, Unpaid Carers Clinical Leads
- Seek lived experience through networks
- Seek involvement Stakeholders: Acute Trusts, Community Services, Primary Care
- Coproduce set of Principles



Young Carers Health and Wellbeing Projects



[Young Carers Support App - YouTube](#)

Tom's Slide - "What I've Learned From Being Involved"

"While working with the WYHCP team on projects, I have gained a lot of skills and improved on some I already had learned throughout my life, Some of the key ones include....."

- Teamworking
- Communication skills
- Building confidence
- Time management
- Researching and IT skills
- Problem solving
- Building presenting skills
- Building creativity and design skills
- Focus





Some initiatives for young carers in South Ayrshire

Claire Flanagan

Young Carers Strategy Lead Officer

24th November 2022

**CARERS
TRUST
SCOTLAND**



**2020 VISION: HEAR ME, SEE ME, SUPPORT ME
AND DON'T FORGET ME.**

**The impact of Coronavirus on young and young adult
carers in Scotland, and what they want you to do next.**

July 2020



**The Scottish
Government**

UWS-Oxfam Partnership: Collaborative Research Reports Series
Series Editors: Hartwig Pautz, Kelley Temple and Chloe Maclean

Report No. 9

Young, caring, and struggling to make ends meet

**The worsening economic circumstances of Scotland's
young carers during Covid-19**

**"We don't have any money
left to do or have nice
things"**

Chris, 17 years old

**"Sometimes you look in
the cupboard and you're
like 'oh, there's not much
food in today'"**

Danielle, 16 years old

Chloe Maclean and Nicola Hay

June 2021

UNIVERSITY OF THE
WEST OF SCOTLAND
UWS

**UWS-OXFAM
PARTNERSHIP**

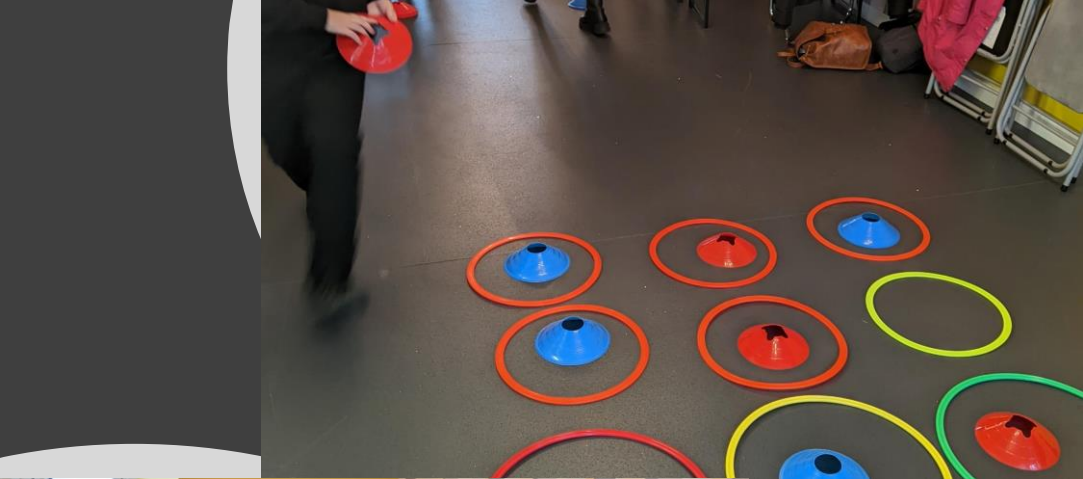


Data & evidence



Physical fun
& activities





Self-Care Club



Awareness





School stress



YCare South Africa: Developing Young Carer Education and Support Programs in South Africa

YOUTH CAREGIVING: TRAINING, SKILLS, & SUPPORT

**Young Carers Research, Policy and Practice Forum – Young Carers
and health**

Thursday 24th November 2022



Melinda S. Kavanaugh PhD, MSW, LCSW

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





Thank you to the
most amazing
collaborators



Children and youth caregivers in ALS: Data from a U.S. study

ARTICLE

US data on children and youth caregivers in amyotrophic lateral sclerosis

Melinda S. Kavanaugh, PhD, Chi C. Cho, MA, Megan Howard, MA, Dominic Fee, MD, and Paul E. Barkhaus, MD
Neurology® 2020;94:1-8. doi:10.1212/WNL.00000000000009217

Correspondence
Dr. Kavanaugh
kavanaugh@uwm.edu

- Almost 50% were younger than 12 years old
- The majority were female, but many males participate in care
- Care occurs weekly – often daily - for many hours per day
- Young caregivers often provide care alongside another adult in the home or family
- All youth felt they had *some* responsibility for care, while 24 (44%) felt they had *a lot* of responsibility for care.

South Africa Data

VULNERABLE CHILDREN AND YOUTH STUDIES
<https://doi.org/10.1080/17450128.2020.1837409>



Taylor & Francis
Taylor & Francis Group



Young carers and ALS/MND: exploratory data from families in South Africa

Melinda S. Kavanaugh^a, Franco Henning^b and Andre Mochan^c

^aSocial Work, Helen Bader School of Social Welfare, University of Wisconsin-Milwaukee, Milwaukee, WI, USA;

^bConsultant Neurologist and Lecturer, Division of Neurology, Department of Medicine, Faculty of Medicine and Health Sciences, Stellenbosch University, Cape Town, South Africa; ^cNeurosciences, University of the Witwatersrand, Johannesburg, South Africa

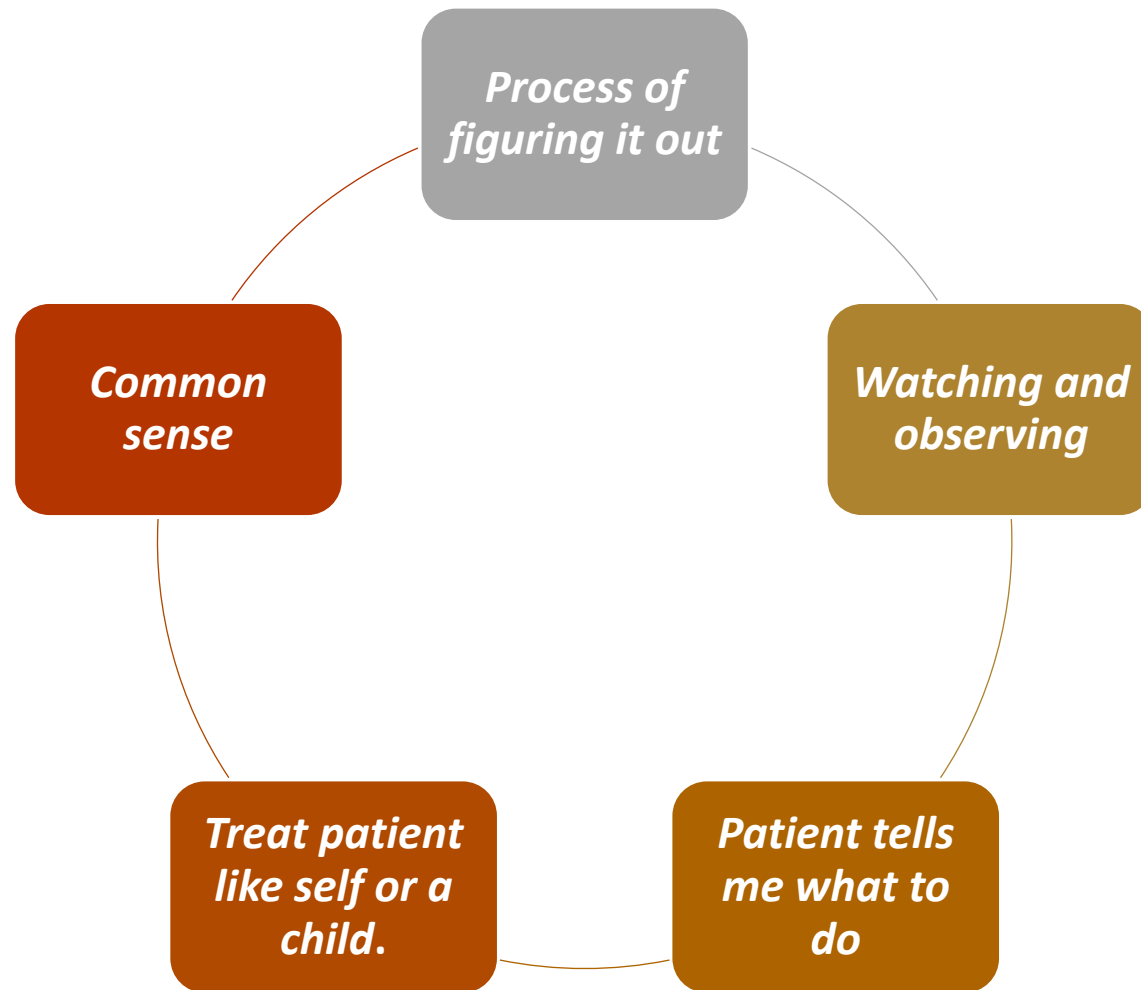
- Youth spend an average of 24 hours per week providing care
- Feel overwhelmed – ***majority requested assistance with hands on care***
- Both adults and youth stated a need for more assistance from the association and others.
- Equipment
 - transportation assistance
 - financial help
- Patients acknowledge intensity of youth caregiving, yet had no other choice due to isolation, financial limitations and few supports.
- Youth felt a ***strong sense of responsibility for care***, even when it impacted school and their own well being.

65% of youth never received any training or guidance about caregiving – reflected in data from the U.S.

How young carers know what to do?

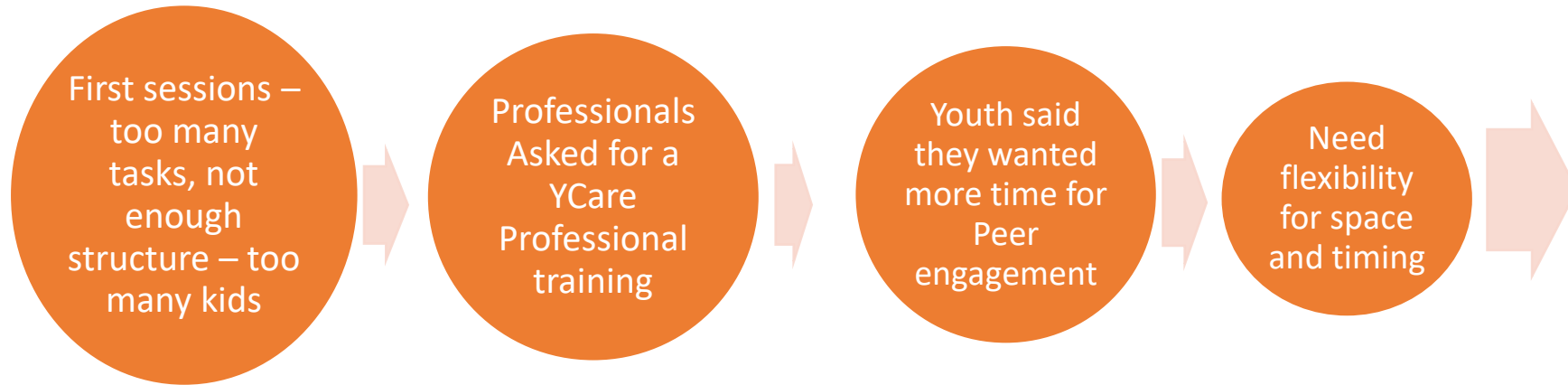
Results from U.S. data

(Kavanaugh, Howard and Cho, 2018)



Creating education and skills programs for young carers

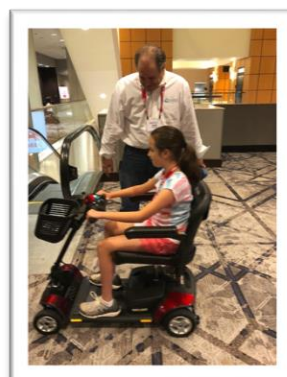
(Kavanaugh et al, 2018; Kavanaugh et al, 2020)



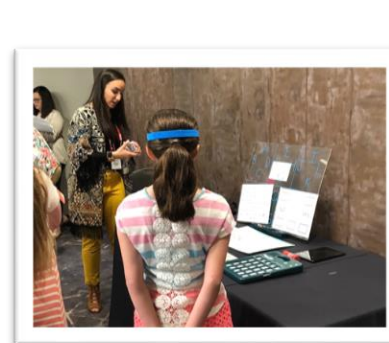
Respiratory equipment



Power chairs



Eye gaze equipment



Food prep and feeding



Child & Youth Care Forum (2019) 48:479–492
<https://doi.org/10.1007/s10566-019-09490-z>

ORIGINAL PAPER



"I Just Learned by Observation and Trial and Error": Exploration of Young Caregiver Training and Knowledge in Families Living with Rare Neurological Disorders

Melinda S. Kavanaugh^{1,2} · Chi C. Cho² · Megan Howard¹



YOUTH CAREGIVING: TRAINING, SKILLS, & SUPPORT

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

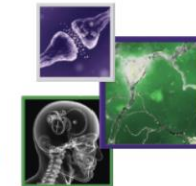
Melinda S. Kavanaugh, Megan Howard & Lori Banker-Horner

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

Neurodegenerative
Disease Management



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

Melinda S Kavanaugh^{*}, Young Cho², Dominic Fee³ & Paul E Barkhaus³

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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

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How to adapt YCare to the South African Context?

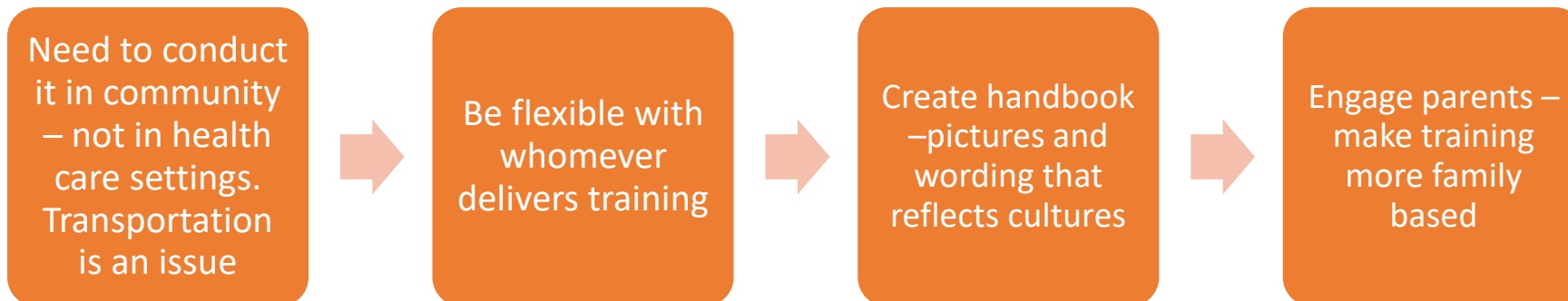


Program assumptions based on U.S. context

- Access to a variety of allied health professionals
- DME equipment available to all living with ALS

What do we need to know to adapt to South African context...

- Availability of Allied Health professionals?
 - Lack of DME available for those living with ALS/MND
 - Culture is everything – as is spirituality
-
- Received funding from the ALS Association to build on previous data
 - Held meetings in 2019 to begin adaption process and discussions
 - Bring donated equipment from ALS Wisconsin



Youth manual



YOUTH CAREGIVING: TRAINING, SKILLS, & SUPPORT

YOUTH MANUAL – SOUTH AFRICA

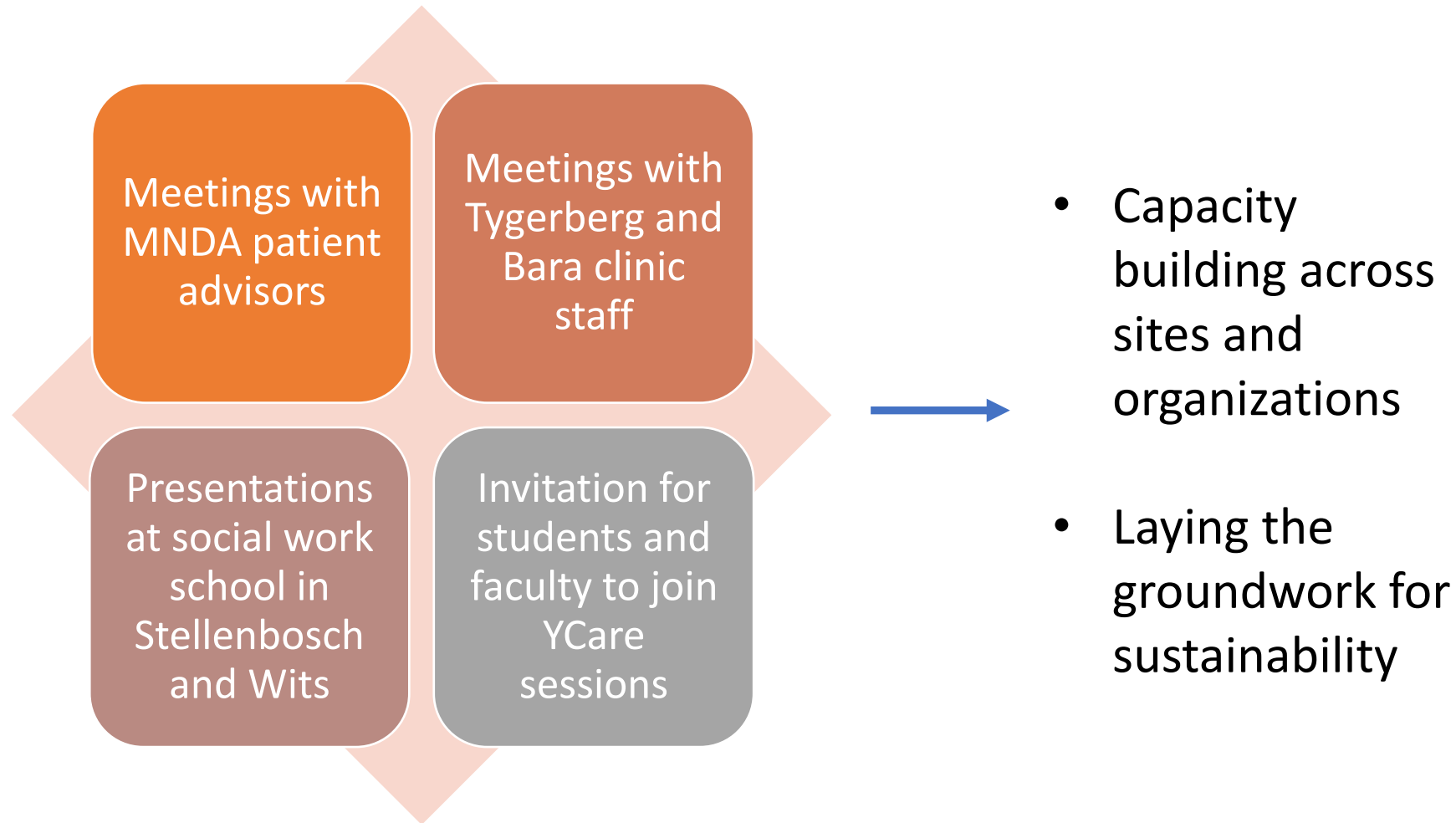


Full collaborative effort

- MNDA
- Social work faculty
- Neurologists
- Patient advocates
- Physiotherapists
- Social workers

Focused on what was available and how to adapt care needs to home situation

Covid restrictions lifted, sessions planned for both Cape Town and Johannesburg



Meetings with MNDA and clinic staff

- Focus on capacity building – what programs exist, how can the clinics and association engage with families and integrate in “treatment as usual”
- What do they need to know to conduct YCare?
- What do we add? Remove? Alter?
- Who needs to be involved, or conduct the training?



Implementing YCare

Two sessions in Cape Town

One in Johannesburg

Cape Town session held in large room in church

Joburg in education center at hospital – in several rooms



“I was amazed at the specific questions the kids asked, they wanted to know more”

- **Youth**
 - favorite session was the basic care. Felt more hands on, and for the attendees, this is exactly what they needed.
 - The low-tech communication boards were what they needed – not all have smart phones or other adaptive equipment
 - After the session one family reported back they were excited to use the tools they learned
 - Took LOTS AND LOTS of notes
 - Peg and pressure sores discussion were critical
- **Therapists**
 - Wanted the MND discussion with Dr earlier
 - Add another bed for transferring
- **Patient advisors**
 - Combine some of the tasks
 - They know the families, so could be more involved in the training
 - Want to make sure they are all cross trained across all the sessions



Towards sustainability

Importance of including MNDA patient advisors

- They do home visits and know the families and communities

Arranging for transportation was critical – was included in the grant

- Future administration can be done in the community or at home

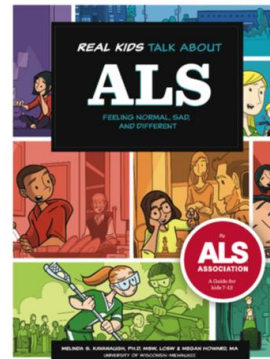
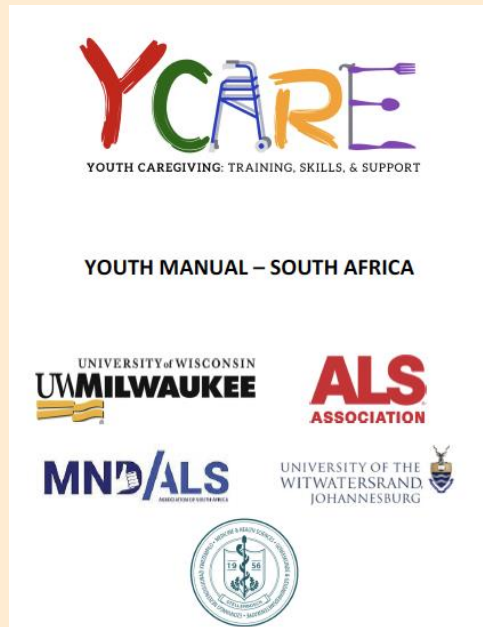
Difficulty getting therapists

- At both sites, we did not have all allied health present, despite critical nature of each in MND
- Clear with public professionals it is difficult to arrange for time off or work on a Saturday

Change handbook to “Family” book – to include all members of the family

Detail about what is MND is, is so important. Youth and their parents DO NOT know enough about the disease (how to get it, being cursed, what to say to family)

Next steps – translation of materials



- Recognize the criticality of language
- Working with Wits social work to translate the handbook into isiZulu
- Also translate the youth graphic novel to isiZulu

THANK YOU!!!!

Families across South Africa who have participated in our project

And to the amazing research and development partners:

- Witwatersrand Neurology/Bara
 - Prof Mochan, Hayley, Samira, Taryn, Wasifah, Shelissa
- Stellenbosch Neurology Tygerberg
 - Prof Henning, Helen, Ashley
- MNDA
 - Sheila, Wendy, Esme, Chantalle, Elizabeth, Daleen, Carina, Wilma
- Witwatersrand Social Work
 - Thobeka Nkomo
 - Busisiwe Nkala-Dlamini
 - Motlalepule Nathane-Taulela



*Please reach out – happy
to answer any questions!!*

YCare website:

<https://uwm.edu/ycare/>

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YOUTH CAREGIVING: TRAINING, SKILLS, & SUPPORT

Will you pledge your support for young carers and young adult carers?

- 🌸 Young carers and young adult carers have acquired a series of legal rights and policy provisions over the past decade (more than 10 different sources)
- 🌸 Evidence suggests these rights are not consistently being implemented
- 🌸 We are asking for organisations and individuals to pledge their support to help ensure these existing rights are a reality for all young carers
- 🌸 The Young Carers and Young Adult Carers pledge focuses on 8 principles, consolidating what should be in place based on existing legislation and policy
- 🌸 www.caringtogether.org/youngcarerspledge



Young Carers and Young Adult Carers pledge principles

1. Every young carer should know and understand that they have legal rights and know how to access their rights

2. No child or young person should be required to provide inappropriate or excessive levels of care which impacts on their health, wellbeing, education or development or childhood.

3. Every local area should take proactive steps to identify the number of young carers in their area and ensure they get the support they need.

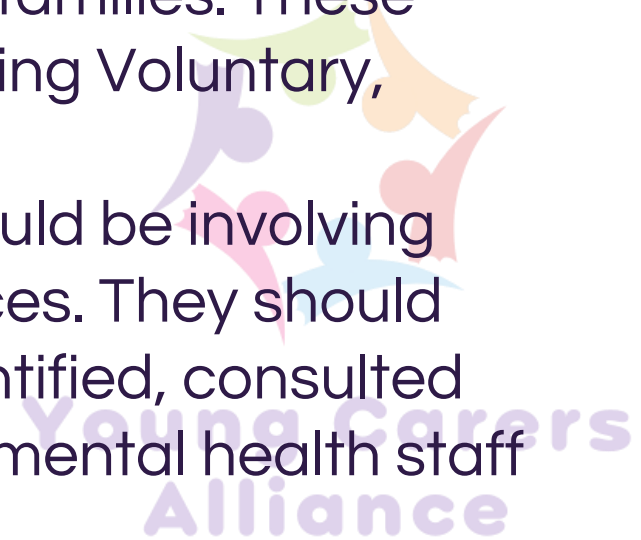
4. Every young adult carer should be supported to ensure they can make a successful transition into adult life.



Young Carers
Alliance

Young Carers and Young Adult Carers pledge

5. Every young carer should have someone within school, college or university who they can talk to about their caring situation or if they are in need of extra help.
6. All schools should proactively seek to identify who their young carers are and whether they are in need of additional support.
7. Every local authority should have an active Memorandum of Understanding to ensure children and adult social care services are working together to provide a whole-family approach to support for young carers and their families. These should also include health and other key stakeholders, including Voluntary, Community and Social enterprise (VCSE) organisations.
8. Integrated health and social care boards/partnerships should be involving young carers and young adult carers in the planning of services. They should also make sure young carers and young adult carers are identified, consulted and linked into support by health professionals such as GPs, mental health staff and those involved in hospital discharge.



Thank you for attending

Upcoming Young Carers Alliance webinars

Thursday 1 December, 1:30-3pm – Improving health and wellbeing of young carers through sport

www.caringtogether.org/youngcarerspledge

To find out more about the Young Carers Alliance or become a member/subscribe to updates

www.youngcarersalliance.org

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