



Young Carers Takeover Project

March 2020





Contents

Summary.....	3
Recommendations.....	4
Response from Northamptonshire Young Carers	4
Response from Healthwatch Northamptonshire CEO	4
Recruitment to Young Healthwatch Northamptonshire.....	5
Patient stories	6
Young Carers emotional wellbeing survey	8
Introduction	8
Key findings	9
Method	10
What people told us.....	11
Conclusion	16
Acknowledgements	16
About Young Healthwatch Northamptonshire.....	17
About Healthwatch Northamptonshire	18
About Connected Together	19
Appendix -survey questions.....	20
Contact us.....	22





Summary

By gaining a Takeover Challenge grant from NHS England, Young Healthwatch Northamptonshire was able to carry out a joint project with Northamptonshire Young Carers Service¹. The Takeover Challenge² was designed to connect young people with the NHS. By taking part in this project we wanted to achieve goals set out by NHS England, these included:

- Having a positive impact on how young people are involved in local and/or national health and care priority setting supported by cross-sector action.
- Demonstrating the value and impact of involving young people - at an individual, organisational and end user level.
- Highlighting good practice, for example through case studies.
- Sharing learning and developing networks to support further youth participation and volunteering opportunities.
- Helping to reduce health inequalities and support equalities.
- Demonstrating the value of working in partnership with the Voluntary, Community and Social Enterprise (VCSE) sector and others.
- Producing a report of key messages and recommendations.

Given there is a specific commitment to young carers in the NHS Long Term Plan³, Young Healthwatch wanted to work together with young carers to explore the needs and experiences of young people under the age of 20 who care for someone. We worked in partnership with the local Young Carers Service, with the aim of using this project as an opportunity to drive positive change.

Our project had three specific aims that we wanted to achieve:

1. To recruit young carers to Young Healthwatch Northamptonshire. This would ensure that local young carers who were interested in volunteering would have the opportunity to do so and that the voice of young carers would be heard by local service commissioners and providers.
2. To ensure that there was clear communication between the Children and Young People's workstream of the Northamptonshire Health and Care Partnership (NHCP)⁴ and young carers.
3. To explore the emotional wellbeing of young carers as a continuation of the previous Healthwatch Northamptonshire project exploring young people's wellbeing.⁵

To do this we invited young carers to our Young Healthwatch Northamptonshire meetings, gathered patient stories and completed a survey looking at the emotional wellbeing needs of young carers in Northamptonshire.

We found that including and listening to young carers can add valuable insight to groups such as Young Healthwatch and that their experiences are valuable in helping ensure services are accessible to everyone. Whilst many young carers and non-carers experience mental health and

¹ www.northamptonshire-carers.org/young-carers

² www.childrenscommissioner.gov.uk/takeover-challenge

³ www.england.nhs.uk/blog/our-long-term-commitment-to-carers

⁴ www.northamptonshirehcp.co.uk/about-the-partnership

⁵ www.healthwatchnorthamptonshire.co.uk/YHWemotionalwellbeingreport2018



emotional wellbeing difficulties, being a young carer can have an additional impact on mental health, which requires understanding from professionals and support services. Many young carers are far more resilient due to being carers from a young age and naturally developing coping strategies beyond their years.

The collaboration with Northamptonshire Young Carers Service has ensured that this project has been successful and will continue so that future work is more sustainable. Northamptonshire Young Carers Service helped with the identification of young carers, transport, venues, refreshments and staffing, and supported this project at all stages. This enabled us to better communicate with young carers and make involvement even more accessible to young carers in Northamptonshire. Working together has enabled us to forge relationships with staff, young people and our services. This will ultimately mean that the voice of young carers will continue to be heard in future projects and across the healthcare systems in Northamptonshire.

Recommendations

1. Listen to young carers about where and how they need support - it is important services are made aware of the pressures faced by young carers and how their support needs may differ.
2. Design emotional wellbeing and mental health services that provide extra support for young carers - they are more likely to value support groups and being listened to.
3. Use young carers' experiences and insight to help design services and support their involvement in youth groups such as Young Healthwatch.
4. Put in place ways to identify young carers as the caring responsibilities of young people can often be missed by healthcare professionals.

Response from Northamptonshire Young Carers

We would like to thank Young Healthwatch for the opportunities the Takeover Project has given young carers to share their views. It was both powerful and meaningful and will hopefully support young carers in the future to get their voices heard. I think we can draw a conclusion that more emphasis on young carer specific wellbeing and counselling support is needed locally. This feels like the beginning of improving access to the support that we are seeing and hearing is needed first-hand. We really hope that young carers can continue to be a part of conversations locally to help to improve and develop support available for young people (including carers) and drive appropriate change. Thank you Esther and the team.

Jo Johnson, Young Carers Service Manager

Response from Healthwatch Northamptonshire CEO

This has been a great piece of work between Young Healthwatch Northamptonshire and Northamptonshire Young Carers Service. It has helped highlight some of the issues young carers face in Northamptonshire and given them a chance to participate in a project to get the views of other young carers. It has helped bring a different perspective and dynamic to Young Healthwatch too and been a great learning exercise for everyone involved.

Kate Holt, CEO



Recruitment to Young Healthwatch

Northamptonshire

NHS England set out its long term commitment to carers in January 2019. As part of that there was a commitment to help young carers use their life experiences to extend their skills in volunteering: “We will also help young carers who so wish to use their life experience to extend their skills in volunteering, apprenticeships and NHS employment.”⁶

Young Healthwatch enlisted the support of Northamptonshire Young Carers Service⁷, who have over 1,000 young carers and young adult carers registered with them for their support. We wanted to ensure that the meetings were accessible to young people who are in a caring role. Young carers are already deemed a hard to reach group and in Northamptonshire are made up of various ethnicities, sexual orientations and different abilities. We wanted to support them by ensuring the workload of the group was manageable, that the meetings were not too long (so they did not interfere with caring responsibilities) and that they were offered the same opportunities as our other volunteers.



We gained four new members who were all registered with the Northamptonshire Young Carers Service. We changed our meetings from once every six weeks to once a month to give people more opportunity to attend.

“It has been so important for the Northamptonshire Young Carers Service to work in collaboration with Young Healthwatch Northamptonshire. Young carers often come into contact with many health and social care services, for themselves and for the people they care for. Their unique experiences are invaluable in helping to guide services and making sure that they accessible and appropriate for everyone. The opportunity to be part of Young Healthwatch has also positively impacted the young carers’ confidence and given them the chance to develop new skills and take part in new experiences.”

Philp Mayes, Senior Young Carer Worker, Northamptonshire Young Carers Service

Having young carers as part of our group has brought a new dimension to the meetings. It has made everyone who interacts with the group consider how services could work better for young carers and their families. The young carers that we have worked with have also grown in confidence and gained new skills such as increasing their self-esteem and made them feel part of a group, giving them a sense of identity and able to give back to their community.

“Having young carers as part of Young Healthwatch means that we have a variety of different people with different experiences that can share their views too. Young carers see a different side of health care to most young people because of their extra responsibilities.”

Young Healthwatch Northamptonshire Member, aged 12

⁶ www.england.nhs.uk/blog/our-long-term-commitment-to-carers/

⁷ www.northamptonshire-carers.org/about-young-carers



Patient stories

To help the health and care system hear more about the issues faced by young carers we gathered some stories from young carers about their experiences of local services. These were shared with service providers through the NHCP Board and fed down through each organisation.

Here is one of the patient stories.

“It all started three years ago, I was somewhat an ordinary child before I got sick the week of the bank holiday weekend. It was May 2016 when I was rushed into emergency surgery for a burst and infected cyst/abscess on my lower back area after going to my local GP surgery.

After going into my appointment, I was sent to Northampton General Hospital (NGH) for my first of four surgeries. When I first arrived at NGH, I made it very known to the nurses and doctors that were going to be treating me that I was petrified of what was about to come and that my mum, who suffers with mental health must be with me every step of the way so she knew I was okay and I knew she was, but I didn't feel very supported in NGH for being a young carer and for my own issues and things I was feeling after the life changing thing that was going on right now.

Being a young carer and in hospital for your own problem is a very self-conflicting time, I wanted to make sure my mum was okay and getting the support she definitely needed whilst also making sure I was getting the care and support that I needed, as well as worrying about my siblings. I went for my surgery and when I came back around, I couldn't walk or move without help. It took me about a week to regain my balance properly and be able to walk unassisted. From then on I was having daily dressing changes at the GP surgery and other than infections, I didn't suffer from any illness or other issues in the meantime, apart from the pain I was in.

In May 2018, I had my second surgery at Kettering General Hospital, we decided to go to Kettering the second time in the hope that I'd be able to get better support there and I did. Before my surgery, I had an MRI and a fistula was found. A fistula is a tunnel that connects two organs or an organ to an opening on the skin, with a fistula, it's very, very hard to heal wounds that the fistula connects to so this was very bad news and although this had been found, the hospital decided they would wait to do anything about it. After my surgery and relearning to walk for a second time, I was put on a new antibiotic for a severe infection that I'd got, and it turned out I was allergic to the antibiotics they'd put me on but we didn't find this out until I got home. Once I was home I was vomiting really badly, fainted three times and hit my head against the wall and the corner of my bed and knocked myself out for two minutes. My step mum called the paramedics and they came out to me four times before taking me into hospital, after running tests they found that my oxygen levels were dropping and my heart rate had slowed significantly so I was put on oxygen and had monitors connected to me to make sure my heart rate and oxygen levels were raising as they should've been.

In November 2018, I had my third operation at Kettering again, the nurses and doctors in Kettering are much nicer in my opinion and Kettering will probably always be my first choice. Before the third surgery I had another MRI and my fistula was seen again, in the same place but a tad bit bigger so during my surgery they investigated but no fistula was found, a lot of confusion came up then because they aren't typically things that heal by themselves but again, nothing else happened. After relearning to walk for the third time, I got a Vac Dressing put on. A vac dressing is a machine and tube that connects to the outer dressing of a wound to help pull the skin closed and get rid of the bad skin tissue and massively reduce the risk of infection. I was told that without this machine my body would never heal. Two weeks later the nurse at my local GP took the machine away with no known reason to do so. I'd never felt so defeated and run down in my whole life. A short time after this I saw the plastic surgeons at Nene Park



Outpatients Clinic in Irthlingborough. After explaining everything that'd been happening to me he made a few comments regarding my weight, this really knocked my self-confidence and my self-image and it took me a long time to find my confidence again afterwards. The plastic surgeon referred me to Leicester Hospital to see a specialist about my suspected fistula. This made me feel really anxious because meeting new people and having to start my story all over again is always a challenge for me. My last surgery was In July 2019. I had this surgery also at Kettering General Hospital again. This time, it felt much different afterwards. I didn't have trouble walking again and it only took me about two days to regain my balance fully. After a lot of fighting for what I wanted and knew I needed, I got my vac dressing back. This was one of the best feelings I've felt in a long time and the big weight I felt had finally been lifted off of my shoulders. But this time was also the hardest time I'd been through since my very first operation. I felt the most amount of pressure this time round in terms of being a young carer for my mum. My mum experienced a lot of mental challenges to help me get my machine back and this is the one time in my whole recovery process that I was really struggling to hold myself together in order to make sure my mum was okay. After a while of having my vac dressing machine, I got a smaller one, a PICO Negative Pressure Wound Therapy machine. This was a massive deal for me because those machines are only given to patients who have a wound that is 1cm deep or less. I had the PICO machine for two weeks and was announced officially healed. I felt so many emotions all at once and I finally felt complete. I went on to have an MRI at Leicester to rule out the fistula and I'm still waiting for the result from that. It's safe to say that I'm definitely in a much better place physically, emotionally, mentally and even spiritually than I have been for the past three years."





Young carers emotional wellbeing survey

Introduction

In 2018, Young Healthwatch Northamptonshire gathered the views and experiences from young people across the county on mental health and wellbeing services⁸. They heard from 749 young people between the ages of 11-19 and 71 of them (9%) told us that they looked after someone with a long term illness or disability (i.e. that they were a young carer).

As a continuation of that work we wanted to look at specifically at young carers and their emotional wellbeing. We wanted to find out where young carers would like to receive support for their emotional wellbeing and how much they felt their caring role affected their emotional wellbeing or mental health.

We received responses from 85 young people that identified as young carers between December 2019 and February 2020. The young people that we spoke to were between the ages of 11 and 19 and lived in Northamptonshire. Nearly 75% of everyone who responded told us that they were registered with their local Young Carers Service.

The findings of this survey and feedback from young people will be shared with commissioners and service providers across Northamptonshire as well as NHS England, The Carers Trust and Healthwatch England so they can help improve wellbeing services for young carers living in Northamptonshire and beyond.



⁸ www.healthwatchnorthamptonshire.co.uk/YHWemotionalwellbeingreport2018



Key findings

- 85 young carers between the ages of 11 and 19 responded to the survey.
- On average young carers rated their emotional wellbeing as 5.7 out of 10 on the day that they took the survey. The average score given by males (7.2) was higher than the score given by females (5.1).
- 64% of young carers said that they felt their caring role affected their emotional wellbeing or mental health.
- 65% of young carers said they knew where to go to access support for their emotional wellbeing or mental health and 45% said they had used a support service for this.
- The support received from these services was rated as 3.5 out of 5 on average, with 91% rating the support as 'ok' or better, and 52% as 'good' or 'very good'.
- Over half had experienced the challenge of long waiting times when accessing a service and around a third felt they had not been given enough support or that the services did not know about their issues.
- Basic counselling (43%), self-help or coping strategies (42%), support groups (40%) and one to one listening support (39%) were the services young carers would most like to see available or use.
- Over half the young carers would prefer to access support for their emotional wellbeing at school (57%) or at a youth club (54%).
- 50 who identify as young carers (59%) also have a long term illness or disability themselves.





Method

Survey development

Young Healthwatch Northamptonshire and Northamptonshire Young Carers Service worked together to adapt the survey that was used previously in the Emotional Wellbeing of Young People in Northamptonshire project in 2018. At the Young Healthwatch Northamptonshire meeting in the autumn of 2019 the survey was drafted with young people adapting the questions and making them more relevant to young people in a caring role. In the winter of 2019 Young Healthwatch Northamptonshire piloted the survey in a Young Healthwatch Northamptonshire meeting.

Survey distribution

The survey was shared on social media, with local contacts and partners and a press release was sent out to all local news agencies. Northamptonshire Young Carers Service also completed surveys at the groups they attended across Northamptonshire. Due to the time of the year there were no public events that we attended apart from the Young Carers awareness day that was hosted by Northamptonshire Young Carers Service.

Example social media image:





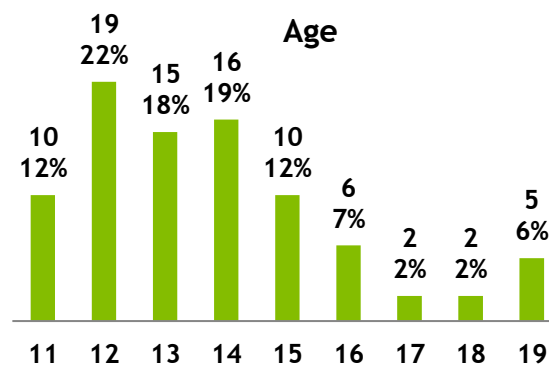
What people told us

- 85 young people responded to the survey between December 2019 and February 2020.
- All figures given are percentages of the answers received for each question, unless otherwise specified.

Demographics

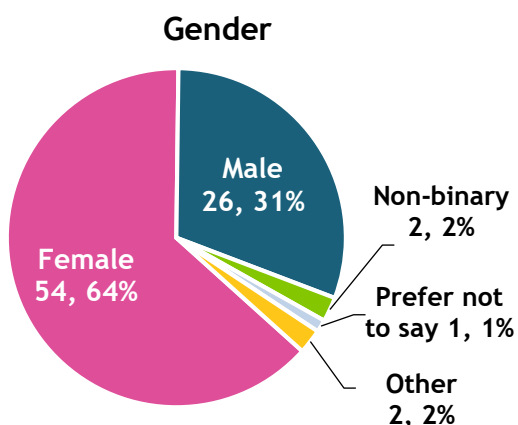
Age

Most of the young carers that completed the survey were under 15 years old (71%, 60 of 85).



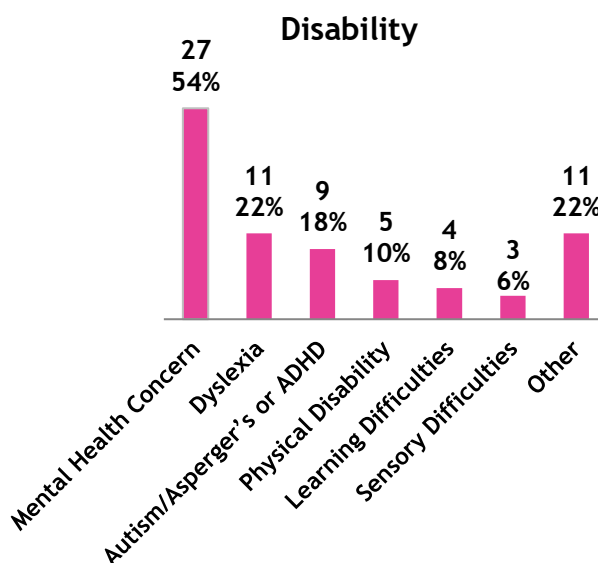
Gender

Almost two-thirds of young carers who responded identified as female (64%, 54 of 85). Two people identified as non-binary, one as trans and one as pansexual.



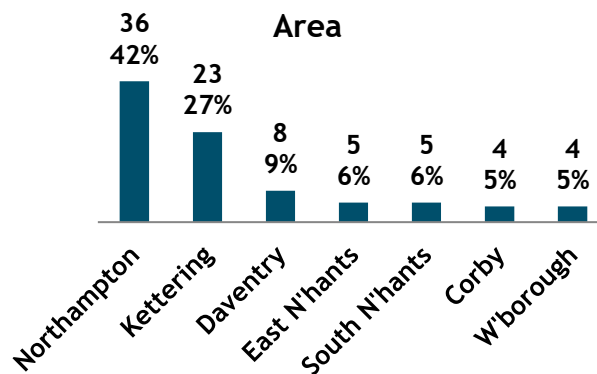
Disability

50 (59%) young carers told us that they had a disability, with 15 selecting more than one of the options. Half of those with a disability told us they had a mental health concern (27 of 50 people, 54%). Two of those who told us they had another disability mentioned anxiety, two OCD and two dyspraxia. One said they had anphantasia and one said they were deaf in one ear. Another had a heart condition but pointed out that it does not 'disable' them.



Area of Northamptonshire

Nearly 70% of all young carers that completed the survey said that they lived in Northampton or Kettering (69%, 59 of 85). The remaining 31% were spread across the other districts in Northamptonshire.

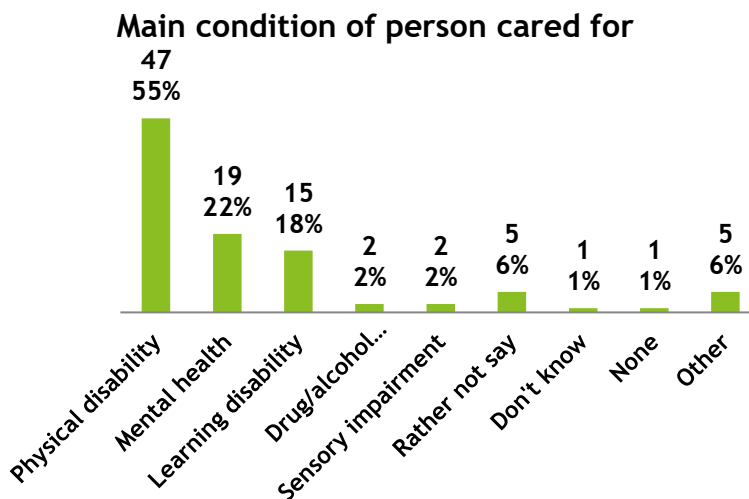




The people they care for

We asked young carers about the main illness or disability of the person that they cared for. Over half said they cared for someone with a physical disability

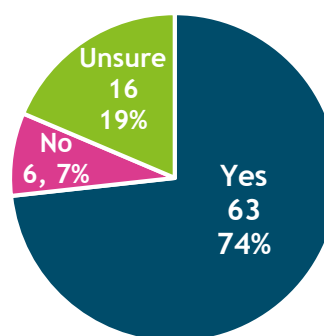
The majority of young carers (55%, 47 of 85) said that they cared for someone with a physical disability. 22% (19 of 85) said the person they cared for had a mental health concern or need and 18% (15 of 85) said that a learning disability was the main reason for their caring role. Ten people cared for people with more than one type of condition or more than one person. Four of the 'other' condition mentioned were autism or ADHD and two were cancer. One person said the person they cared for did not have a disability or health conditions.



Registered with a carers service

Three quarters (74%, 63 of 85) of young carers told us that they were registered with a young carers service and 19% were unsure whether or not they were registered.

Registered with local young carers service

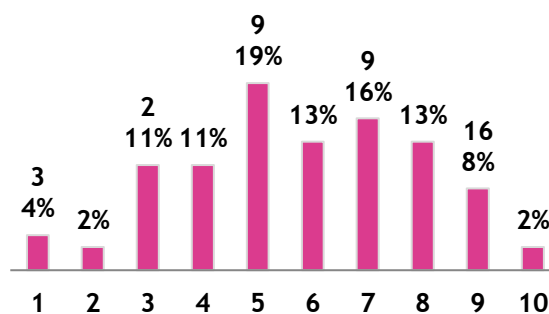


Emotional Wellbeing

Emotional wellbeing score

We asked young carers to rate their emotional wellbeing out of 10 on the day of taking the survey, with 1 being the lowest and 10 being the highest. The average rating was 5.8 out of 10 and the answers were spread. The most common answer was 5, followed by 7.

Emotional wellbeing / mental health score

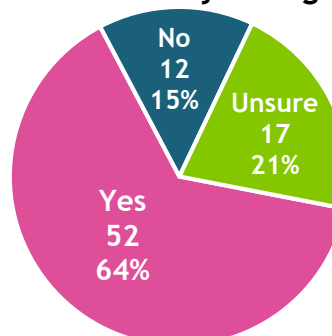


The average rating for females was significantly lower⁹ (5.1) than for males (7.2).

How a caring responsibility affects wellbeing

The majority of young carers (64%, 52 out of 81 who answered) felt that their emotional wellbeing or mental health had been affected by their caring role. Females were more likely to feel this way with 70% (38 of 54) answering yes, compared to 45% (10 of 22) of males, although this difference was not statistically significant.

Emotional wellbeing / mental health affected by caring role?



⁹ t-test P<0.001



Support services

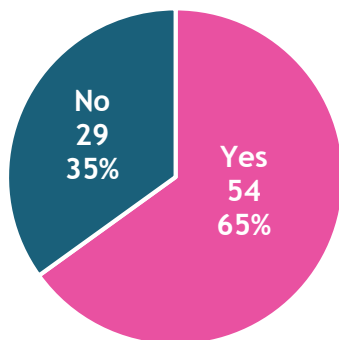
Knowing where or how to access support

Overall 65% (54 of 83) of young carers said they knew where to access support for their emotional wellbeing and mental health.

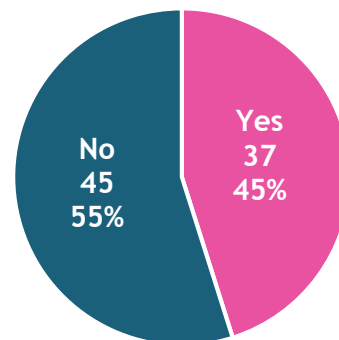
A higher percentage of males (73%) than females (58%) said they knew where to access support, but this difference was not statistically significant.

Just under half of young carers (45%, 37 of 82) said they had accessed a support service for their emotional wellbeing or mental health and the figures were similar for males (46%) and females (43%). Half (51%) of young carers that were registered with a young carers service had used a support service for their emotional wellbeing or mental health, compare to only 29% of young carers that were not registered with a young carers service (but due to the small number of unregistered carers this difference is not statistically significant).

Knowing where or how to access emotional wellbeing / mental health support



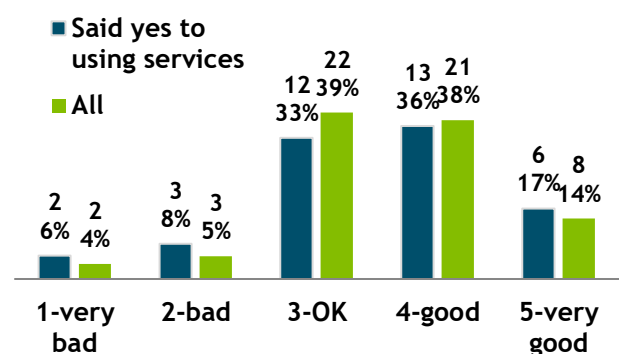
Have used a support service for emotional wellbeing / mental health



Use of support services

Those that had used a support service for their emotional wellbeing or mental health were asked to rate it. 56 people gave a rating even though only 37 people said they had used a service. The average rating for all 56 was 3.5, with 91% rating the support as 'ok' or better, and 52% as 'good' or 'very good'. The average for the 36 who said they had used a service (and answered) was also 3.5, with 86% rating the support ok or better, and 53% as good or very good.

Rating of support service



Challenges accessing support

When asked about challenges they had experienced when accessing support, 37 young carers selected one or more challenge from the list they were given, 26 of whom had said they had used a support service in the earlier question. Some people experienced more than one challenge, with 16 selecting more than one challenge and 11 selecting three or more.

Long waiting times was the challenge experienced by the most young carers (62% of those who had used a service and 45% of those who had not) and was also the biggest challenge for males and females. Around one third of those who had used services felt there was not enough support given in general (35%) or that the services did not know enough about their issues (31%). Not



being able to attend an appointment because of the appointment time or transport issues were also challenges for almost one-quarter of young carers who had used services (23%).

Challenge	Responses			Percentage of those who answered		
	All (37)	Those who had used a service (26)	Those who had not used a service (11)	All (37)	Those who had used a service (26)	Those who had not used a service (11)
Long waiting time	21	16	5	57%	62%	45%
Not enough support given in general	12	9	3	32%	35%	27%
Services did not know about my issues	11	8	3	30%	31%	27%
Wasn't able to attend appointment due to lack of transport	8	6	2	22%	23%	18%
Wasn't able to attend appointment due to time of appointment	6	6	0	16%	23%	0%
No follow-up after referring myself	4	4	0	11%	15%	0%
The right service was not available	4	3	1	11%	12%	9%
Slow follow-up after referring myself	3	3	0	8%	12%	0%
My case was closed due to me not attending one appointment	3	3	0	8%	12%	0%

There were three 'other' answers - one wasn't able to get a follow up "because of hard school times", one said their "concerns were ignored" and one said they hadn't tried to access service because they "talk to their key worker at school".

What support would you like to see?

We asked young carers what support services they would like to see more of, or use, to help their emotional wellbeing and mental health. They were able to pick more than one from eight options given. The most popular options were basic counselling (43%), self-help or coping strategies (42%), support groups (40%) and one to one listening support (39%), all chosen by over one-third. No other suggestions were given and 43 people selected more than one, 16 of whom selected four or more.

Support type	Responses			Percentage of those who answered		
	All (67)	Females (48)	Males (14)	All (67)	Females (48)	Males (14)
Basic counselling	29	25	2	43%	52%	13%
Self-help or coping strategies	28	20	5	42%	42%	33%
Support groups	27	18	8	40%	38%	53%
One to one listening support	26	23	3	39%	48%	20%
Resilience building (ways to help you cope with life's difficulties)	20	17	2	30%	35%	13%
Stress busters	20	15	4	30%	31%	27%
Peer to peer support (People using their own experiences to help other people)	16	10	4	24%	21%	27%
Information about CBT (Cognitive Behavioural Therapy)	13	12	0	19%	25%	0%

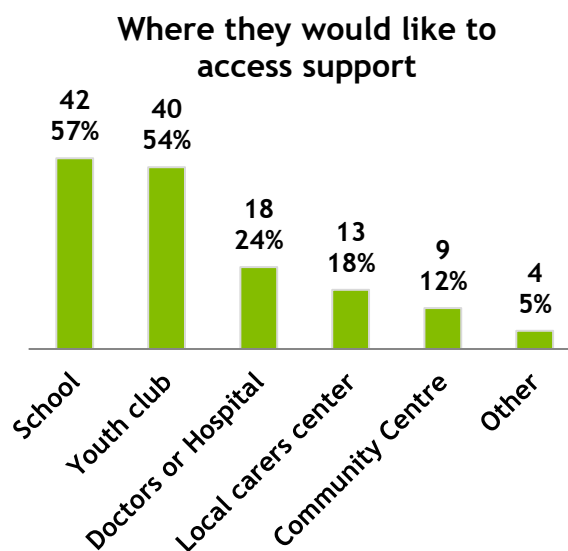


Basic counselling¹⁰, one to one listening, resilience building and information about CBT were more popular with females than males, and support groups were more popular with males.

Where would you like to access support?

Over half the young carers would like to access support for their emotional wellbeing or mental health at school (57%, 42 of 74) or at a youth club (54%, 40 of 74) - 40 young carers said one or the other and 21 said both. 31 young carers selected more than one location and 12 selected three or more. Males and females gave similar answers.

In Northamptonshire the young carers support groups are set up as youth groups so it is possible that the young carers that responded to this question would view the young carers groups that they attended as youth clubs. Two young carers suggested young carers groups for ‘other’, one said “social services” and one said “home”.



Other comments

Eight young carers commented when asked if they wanted to share anything else about their experience. Two were positive comment, presumably about their young carers groups:

“It is a very nice experience which has helped me a lot.”

“I always love to come out to talk to new people and I feel comfortable with my surroundings.”

Two young carers commented on their group sessions:

“Only get set number of sessions as limited space.”

“It was short. I would like counselling please. Please may I go out with young carers more?”

One young carer said they were “tired” and one felt people confused the pressures of caring with having a mental health issue:

“Just it is hard, people use the fact you’re a carer as an excuse to mental health issues when sometimes it’s not.”

One young carer gave more details about the struggles they face getting mental health support:

“Support for my mental health as a young carer has been really hard. Not only do I struggle to admit when I’m struggling as I have to be the strong one at home because I care for all three family members so no time for me to be poorly but being a young carer is also really isolating and means I have no one to turn to - I’m the one holding everyone else up with no one to turn to myself - apart from Northants Young Carers, they’re amazing, but they can’t manage our mental health long term, but because of all our responsibility we often don’t have anyone to offload to - but because we’re so good at being strong on the outside no one ever asks if we’re okay either when just knowing someone cares would make a massive difference. I think earlier identification is really important too - in caring for my mum with leukaemia, it should be told to professionals that that’s a lot to deal with for a young person let alone all the anxiety and worry that comes

¹⁰ Chi-square test, P<0.05



with it. When I have had support from young carers to access mental health support (which has been a massive step) I've found it really hard as even then professionals don't get what it's like to be a carer let alone a young carer so it's frustrating to not feel understood - I think all mental health professionals should have young carer training. It's not easy to put ourselves first because naturally we're bottom of the pile in priorities and often we physically don't have time either - if I'm not at school/work I'm caring, I don't have any time for me or friends. Also recognise that carrying a lot from such a young age is tough - it is our normal and we just crack on with it but it doesn't mean it's easy."

Conclusion

The findings of this survey highlight that being a carer giver has an impact on the mental health of young carers, as illustrated by the comments above. They are comparable with the finding from our previous survey of young people¹¹, with the average score for emotional wellbeing being the same for young carers and the wider group of young people. A similar proportion of young carers and young people knew where to go to access support and slightly more young carers said they had needed to access support for their emotional wellbeing or mental health (45% compared to 38%). Long waiting times were a barrier for both groups and both would like to receive support for their emotional wellbeing and mental health at school. More young carers would like support groups than the wider group of young people.

Acknowledgements

We are very grateful to all those who took the time to share their views and experiences with us. We would especially like to thank all who shared our survey, including:

- Northamptonshire Young Carers Service
- All the organisations and people who shared the survey on social media.

¹¹ www.healthwatchnorthamptonshire.co.uk/YHWemotionalwellbeingreport2018



About Young Healthwatch Northamptonshire

Young Healthwatch Northamptonshire are a group of young people between the ages of 11 to 24 who are health and social care champions.

What we do:

- Look at local health and social care issues
- Give young people a voice for all aspects of health and social care locally.
- Work with professionals on the health and wellbeing of young people locally and nationally
- Set our own work plan
- Learn new skills
- Report back to the Healthwatch Northamptonshire Board

WE ARE ALWAYS LOOKING FOR MORE YOUNG PEOPLE TO JOIN US. PLEASE GET IN CONTACT



[Facebook.com/younghealthwatchnorthamptonshire](https://www.facebook.com/younghealthwatchnorthamptonshire)



[Twitter.com/YHWNorth1](https://twitter.com/YHWNorth1)



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If you are a professional that wants to work with us please contact us by email:
younghealthwatch@healthwatchnorthamptonshire.co.uk

Young
healthwatch
Northamptonshire



About Healthwatch Northamptonshire

Healthwatch Northamptonshire is the local independent consumer champion for health and social care. We are part of a national network of local Healthwatch organisations. Our central role is to be a voice for local people to influence better health and wellbeing and improve the quality of services to meet people's needs. This involves us visiting local services and talking to people about their views and experiences. We share our reports with the NHS and social care, and the Care Quality Commission (CQC) (the inspector and regulator for health and social care), with recommendations for improvement, where required.

Our rights and responsibilities include:

- We have the power to monitor (known as “Enter and View”) health and social care services (with one or two exceptions). Our primary purpose is to find out what patients, service users, carers and the wider public think of health and social care.
- We report our findings of local views and experiences to health and social care decision makers and make the case for improved services where we find there is a need for improvement
- We strive to be a strong and powerful voice for local people, to influence how services are planned, organised and delivered.
- We aim to be an effective voice rooted in the community. To be that voice, we find out what local people think about health and social care. We research patient, user and carer opinions using lots of different ways of finding out views and experiences. We do this to give local people a voice. We provide information and advice about health and social care services.

Where we feel that the views and voices of Healthwatch Northamptonshire and the people who we strive to speak on behalf of are not being heard, we have the option to escalate our concerns and report our evidence to national organisations including Healthwatch England, NHS England and the Care Quality Commission.

Find out more at www.healthwatchnorthamptonshire.co.uk

healthwatch
Northamptonshire





About Connected Together

Connected Together Community Interest Company (CIC) is the legal entity and governing body for Healthwatch Northamptonshire.

The remit of the Connected Together CIC includes:

- Contract compliance
- Legal requirements
- Financial and risk management
- Sustainability and growth
- Agreeing strategy and operations
- Agreeing policies and procedures



Connected Together CIC is a social enterprise and a partnership between the University of Northampton and Voluntary Impact Northamptonshire. It aims to be first for community engagement across the county of Northamptonshire and beyond.

By using our expertise and experience, we can help you in delivering community engagement programmes including workshops, research, surveys, training and more. Contact us to find out how we can help your community.

We welcome ideas and suggestions for projects that benefit Northamptonshire and its community.

Find out more at www.connectedtogether.co.uk





Appendix -survey questions

This survey is for people between the ages of 11 and 19 living in Northamptonshire who are young carers. A young carer is a child or young person who provides ongoing care and emotional support to a family member who is physically or mentally ill, disabled or misuses substances.

Emotional wellbeing can affect the way you think, feel and behave. The emotional wellbeing of young people is just as important as their physical health, it allows children and young people to develop ways to cope with whatever life throws at them and grow into well-rounded, healthy adults.

Good emotional wellbeing includes: being happy and confident and not anxious or depressed, the ability to problem-solve and manage emotions and having good relationships with others.



1. What is your age?

- 11
- 12
- 13
- 14
- 15

2. What is your gender?

- 16
- 17
- 18
- 19
- Female
- Male
- Other (please specify)
- Non-binary
- Prefer not to say

3. What area do you live in?

- Wellingborough
- Kettering
- Corby
- South Northamptonshire
- Other (please specify)
- East Northamptonshire
- Northampton
- Daventry

4. What is the main disability/health condition of the person / people that you help to look after?

- Drug and alcohol dependency
- Physical disability
- Mental health concern / need
- Other (please specify)
- Learning disability
- Sensory imperment
- Rather not say

5. Are you registered with your local young carers service

- Yes
- No
- Unsure

6. On a scale of 1 to 10 with 1 being the lowest and 10 being highest, how would you rate your emotional wellbeing / mental health today?

1 - Lowest	2	3	4	5	6	7	8	9	10 - Highest
☆	☆	☆	☆	☆	☆	☆	☆	☆	☆

7. Do you know where or how to access support for your emotional wellbeing / mental health?

- Yes
- No

8. Have you ever used a support service for your emotional wellbeing / mental health?

- Yes
- No



9. If you have used a support service for your emotional wellbeing or mental health, how would you rate that support out of 5?

1-very bad	2-bad	3-OK	4-good	5-very good
☆	☆	☆	☆	☆

10. If any, what challenges did you come across when trying to access the support services?

- | | |
|--|---|
| <input type="checkbox"/> Long waiting time | <input type="checkbox"/> The right service was not available |
| <input type="checkbox"/> Services did not know about my issues | <input type="checkbox"/> Wasn't able to attend appointment due to time of appointment |
| <input type="checkbox"/> No follow-up after referring myself | <input type="checkbox"/> Wasn't able to attend appointment due to lack of transport |
| <input type="checkbox"/> Slow follow-up after referring myself | <input type="checkbox"/> My case was closed due to me not attending one appointment |
| <input type="checkbox"/> Not enough support given in general | <input type="checkbox"/> I have not tried to access a service |
| <input type="checkbox"/> Other - please tell us | |

11. What services would you like to see more of or use to help with your emotional wellbeing/mental health?

- | | |
|--|---|
| <input type="checkbox"/> Support groups | <input type="checkbox"/> Self-help or coping strategies |
| <input type="checkbox"/> Basic counselling | <input type="checkbox"/> Resilience building (ways to help you cope with life's difficulties) |
| <input type="checkbox"/> Peer to peer support (People using their own experiences to help other people) | <input type="checkbox"/> Stress busters |
| <input type="checkbox"/> Information about CBT (Cognitive Behavioural Therapy is a talking therapy that helps treat a wide range of emotional health conditions in young people) | <input type="checkbox"/> One to one listening support |
| <input type="checkbox"/> Other- Please tell us | |

12. Do you feel that your emotional wellbeing / mental health has ever been affected by your caring role?

- Yes
 No
 Unsure

13. As a young carer where would you like to access support for your emotional wellbeing / mental health?

- | | |
|---|--|
| <input type="checkbox"/> School | <input type="checkbox"/> Youth club |
| <input type="checkbox"/> Doctors or Hospital | <input type="checkbox"/> Local carers center |
| <input type="checkbox"/> Community Centre | |
| <input type="checkbox"/> Other - please tell us | |

14. Do you have a disability?

- | | |
|---|--|
| <input type="checkbox"/> Physical Disability | <input type="checkbox"/> Autism/Asperger's or ADHD |
| <input type="checkbox"/> Mental Health Concern | <input type="checkbox"/> Learning Difficulties |
| <input type="checkbox"/> Dyslexia | <input type="checkbox"/> Sensory Difficulties |
| <input type="checkbox"/> Other (please specify) | |

15. Is there anything else that you would like to tell us about your experience?



Contact us

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