



# Unpaid Carers Report

July 2022

**healthwatch**

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# About Us

Healthwatch Thurrock is the independent Health and Social care services champion for the people of Thurrock. We gather and represent views of local residents in order to build up a picture of services that are doing well and where they can be improved.

Along with consultation work and gathering the voices of residents, Healthwatch Thurrock also provide an information, guidance and signposting service. Residents are invited to “speak out” via an online forum as well as through targeted surveys, conversations and face to face engagement within the community.

Healthwatch Thurrock presents the voices of Thurrock to aid in identifying the need for change, considerations before commissioning and to support best practice across services. Through conversation and engagement with people actually using the services, Healthwatch Thurrock highlight and promote improvements.

We know that services are better when people are treated as individuals and are actively involved with shaping support. To do this, services need to learn from examples of real experiences, how they can be adapted and fit around local needs.

# Background

## The Carers Strategy Refresh

Healthwatch Thurrock were commissioned by Thurrock Council to speak to unpaid carers of all ages in Thurrock. This work will help to shape Thurrock Council's Carers Strategy Refresh. The Carer's Strategy will set out a plan for how unpaid carers in Thurrock can be supported in the next few years.

Healthwatch Thurrock want to ensure the voices of real people feed into this strategy. One of the questions participants were asked was whether they would be interested in being part of a co-production group. This group could then feed into the Thurrock Carers Strategy so that it evolves with the needs of carers.

It is important to consider the context of caring in a post-pandemic world. Carers UK estimated that an additional 4.5 million people became unpaid carers in March 2020, translating to 1 in 4 adults in the UK providing care to an older, disabled or ill relative or friend in the height of the pandemic (Carers UK). Whilst pandemic restrictions have eased, unpaid carers are still facing challenges due to the changes in service provision caused by the pandemic.

Within this research Healthwatch Thurrock spoke to carers of all ages, including young carers.

Many took on more responsibility during the pandemic and many are worried about the staffing crisis in social care preventing them from accessing the support they need.

It is important to consider the support networks around carers, from workplaces, to school, to friends and family and the role these play in providing support.

Please note all names have been changed to protect the anonymity of participants.

# Methodology

## Surveys, focus groups and workshops

Healthwatch Thurrock created a survey for adult carers and a survey for young carers. The surveys were distributed to local groups and schools and put onto social media channels. Those adult carers known to Thurrock Council also received a hard copy of the survey via the post. The surveys were also taken to engagement meetings when Healthwatch staff went out to community engagement. From March to June 2022 Healthwatch Thurrock heard from 106 adult carers and 58 young carers. Young carers were engaged with in workshops in a school setting or in support groups facilitated by the Young Carers Service.

The health needs of those being cared for varied, some participants were caring for someone with dementia, some for a child on the autistic spectrum, some for individuals with addiction to drugs or alcohol, and others were caring for someone with a physical disability. Being an unpaid carer covers a broad spectrum of experiences. Someone does not have to be living with the person they are caring for to be considered a carer.

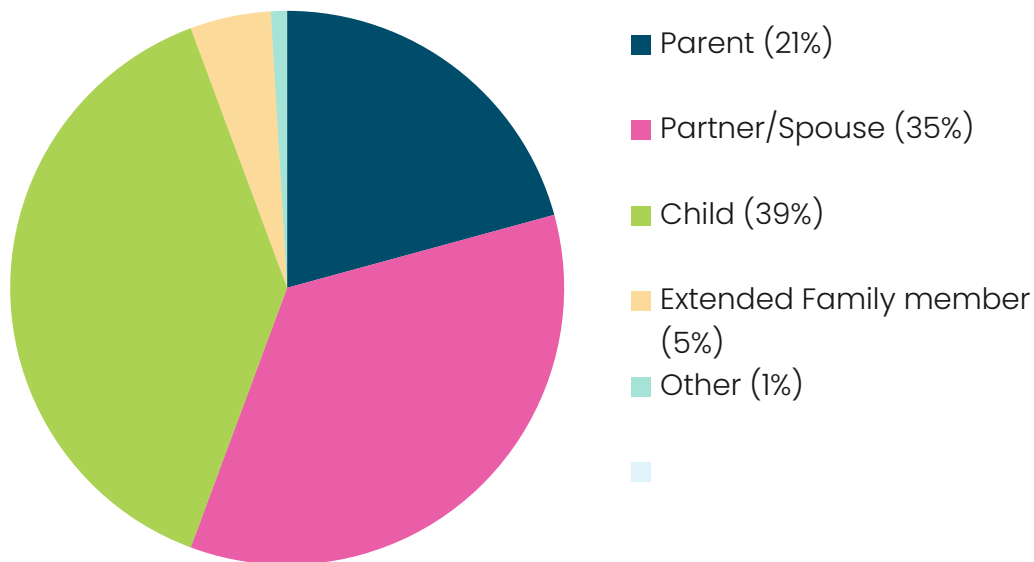
## Demographics of respondents

Ethnic Background	
White or White British	149 (91%)
Black or black British	7 (4%)
Asian or Asian British	6 (4%)
Did not wish to disclose	2 (1%)
Gender	
Female	117 (71%)
Male	46 (28%)
Did not wish to disclose	1 (<1%)
Age	
Under 18	58 (35%)
Aged 18-44	23 (14%)
Aged 45-64	39 (24%)
Aged 65+	44 (27%)

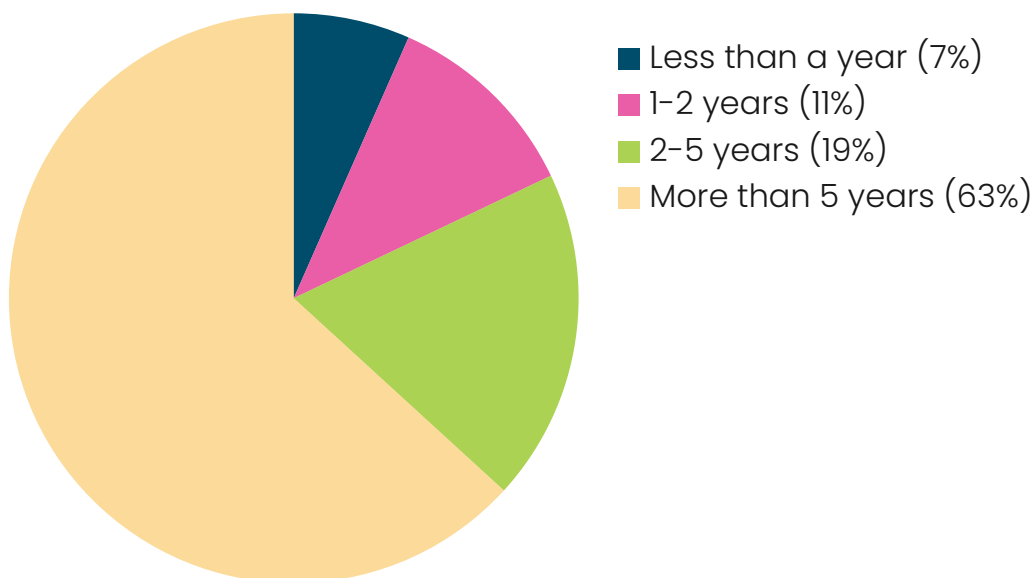
## Structure of this report

This report will begin by looking at the responses from adult carers, and the themes that emerged from those conversations. It will then go on to consider the themes that emerged from conversations with young carers. Finally recommendations will be made for how carers in Thurrock can be better supported.

## Relationship of the cared for (adult carers)



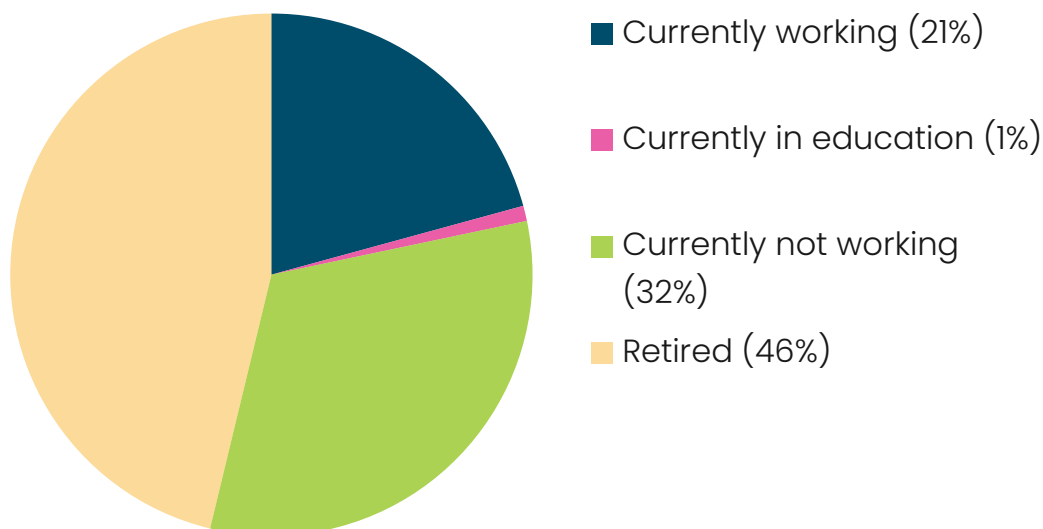
## Length of time support has been being provided



# Themes

## The challenges of working as a carer

Of those people we spoke to 38% were of working age, but even those who were retired were able to reflect on the challenges that caring presented to working part time or full time.



### Time constraints

Carers who were working full time or part time explained how it could be challenging to stay on top of the administration that accompanied caring. Many services are only available during working hours i.e. 9am-5pm. Therefore there are challenges of coordinating communication with them whilst holding down full time work.



“I have multiple people calling from various organisations that don't speak with one another and in 'helping' just keep emailing various links to



websites after I explain I don't have time to do all that is needed as I work full time. It isn't actually providing any help.” -Nadia- caring for her parent

**‘I work full time but my current employer are quite understanding and allow me to condense my hours into a four day week. They also allow me to manage my diary so I can work from home or pop home if necessary and I work locally. This is helpful because I worry about my husband when I am not home.’**

### **Trish – caring for her husband**

#### **Feasibility of working**

**“I happen to be retired but I know it would very challenging to balance looking after dad and making sure he is okay around doing a full time job.”**

**Diana – cares for her dad**

### **‘Preparing for the unprepared’**

There are also challenges in being contacted by services whilst at work. For example, within a focus group with parents of children with additional needs it was highlighted that they cannot predict when they will be contacted by their child’s school due to a crisis or emergency, and the difficulties this would pose if they needed to be at work or leave work at short notice.

There are some health conditions of the cared for which are more unpredictable than others, and carers spoke of the challenges of finding an employer willing to take on a carer who is ‘prepared for the unprepared’.

#### **Being called into school regularly**



**“I often get contacted by my daughter’s school because they are struggling to get her to take her medication or because she has had a meltdown. How would I balance this around work?”**



**Kayleigh – cares for her daughter**

### **Being able to trust who loved one is left with**

Within the subject of employment, some residents highlighted the challenges of leaving a loved one whilst attending work, due to the worry that they may not be okay, or they may not get along with whoever they are left with.



12% of adult carers mentioned how they did not feel there were enough care agencies with sufficient specialist training to provide care for their loved one.

Sarah who cares for her son spoke of how she would like more choice when it comes to deciding which care agency to go with, as she feels the current choice is quite limited. Her son is entitled to receive care hours but in the current circumstance she does not feel comfortable taking these.

It is not only around the carer trusting who they leave their loved one with, respondents also mentioned it is important that the cared for trust who they are left with as well.

## Trusting who you are leaving a loved one with



**“My son is not quick to trust people and I don’t feel able to leave him to go to work because he trusts me and relies on me for emotional support.”**



**Celeste – cares for her adult son with additional needs**

Nadine cares for her father who has mobility issues and early onset dementia and was not satisfied with the first care agency that provided his carers when he first became unwell. She described how there were issues around communication and the length of time spent attending to his needs. Nadine suggested that even if the council are partially paying for care there should be more choice of care agencies for the carer to choose from. She discussed how carers do not want to feel they have to compromise when it comes to meeting the needs of a loved one. Nadine also feels the process of the financial assessment should be more clearly explained.

In addition, during a workshop for parents caring for a child with additional needs it was highlighted that a lot of childcare options that are available are not suitable for children with additional needs. There are also the challenges of getting one-to-one support at after school clubs in mainstream schools.

## After school clubs

**“My son is eligible for one-to-one support at school, although it was a battle to get this, but he cannot get one-to-one support at after school clubs, I would have to pay for this. If he could attend these after school clubs then it would give me time to go to work. A lot of childcare options are not suitable for children with additional needs.”**

**Tina- cares for son**

## Communication between services

10% of residents highlighted the challenges of navigating access to different services and the requirement of repeating their story to different professionals. Particularly for those residents who felt their caring duties only give them a limited amount of time to organise appointments, this was highlighted as an issue. When there are time constraints on appointments, if a considerable

### Personal stories: Communication between services



“Communication to the support services is very challenging. It is very difficult to find contact numbers and very long waits for calls to be answered. The members of staff who have helped us from the service and social workers have been helpful and professional. We did not receive any written information from services that were finishing or terminated. We had a range of carers to support my wife with personal care but erratic times and different covers made it more difficult to adjust to. We feel there is a lack of continuity between administrations. We have had to constantly chase up services.”



**Steve – cares for his wife**

amount of time is spent explaining the needs of the cared for person then this is frustrating for carers.

This was particularly noted regarding patient records, both those of the carer and cared for. Carers felt that professionals should demonstrate that they have read through the patient records to allow for some continuity of care.

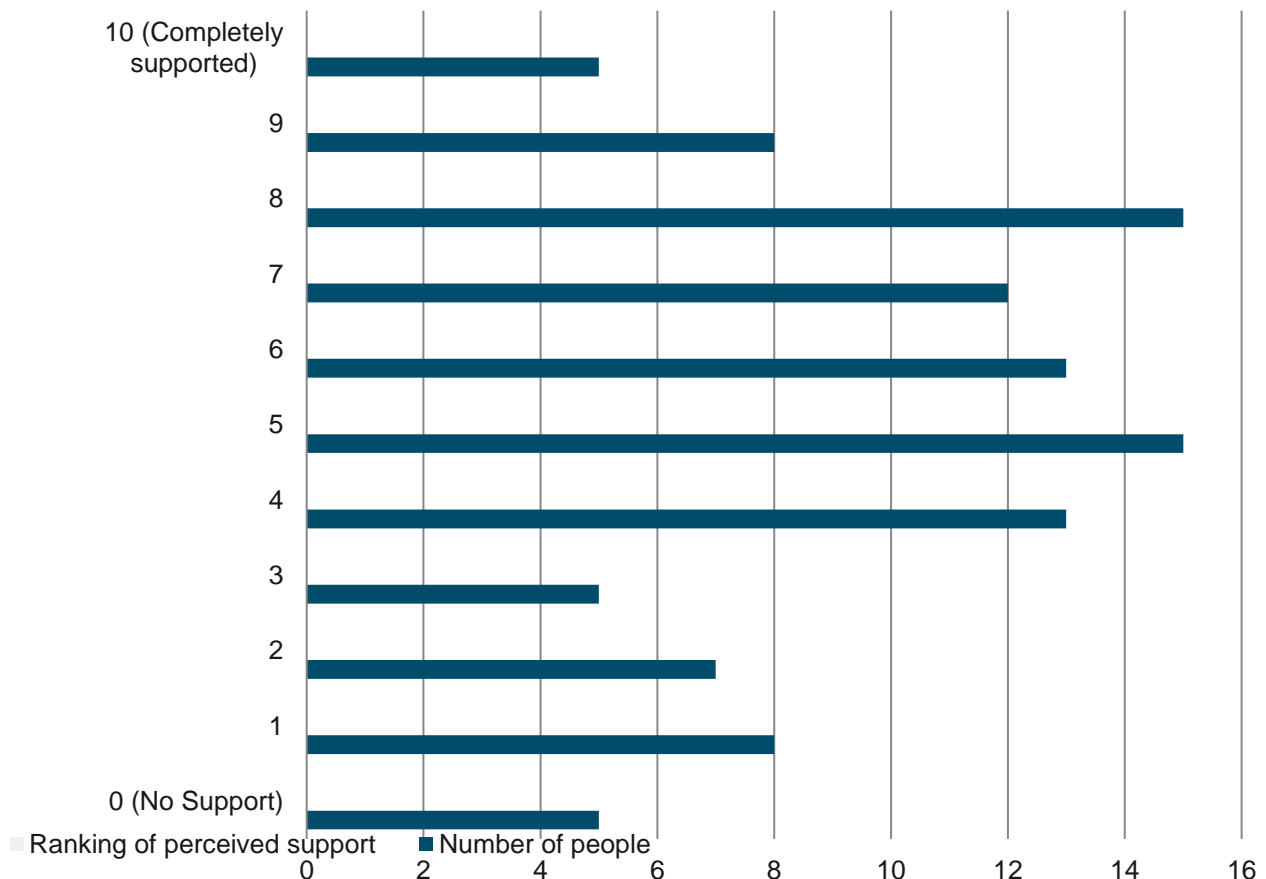
## Support from professionals

“I feel it would be helpful when health visitors or professional who can call you every now and then to find out about parents and children well-being when they have us in their record with additional needs. As parent, we want to show and prove that we are doing everything we can and usually we do not approach services until parents reach breaking point. So, it’s helpful to get well-being calls let’s say every 2 months.”

Julie - cares for daughter

## Levels of support

On a scale of 0-10 how supported do adult carers feel?



50% of carers rated the support they felt as 5 or less out of 10. Demonstrating that a significant number feel they are insufficiently supported.

## Accessing Support

Some residents were unsure if they had had a carer's assessment, which demonstrates a need for those undertaking the assessment to communicate what they are undertaking.

11% of residents spoke of not feeling comfortable sharing their financial details with the Council in order to access support. One resident said that she did not feel the financial assessment was explained in sufficient detail. Those respondents who had had a carers assessment also mentioned that they did not feel comfortable with the questions regarding financial eligibility for support. Respondents spoke of it feeling 'invasive' and 'irrelevant' to look at house ownership and savings.

For those who have been able to access respite or sit in service support, it is often not in the quantities which they require. For example, 10% of respondents mentioned having been assessed as being eligible for more support than staffing levels were able to accommodate. In addition, waiting times for support once assessed for it was considerable for some.

25% of carers said that they had found support harder to access since the pandemic, this was attributed by some carers as being linked with many services moving to digital and telephone consultations and assessments.

### Personal stories: Eligible for support but not getting it



"I have been assessed as being eligible for 6 hours a week sit-in service, but for months I have only been able to access 3 hours due to staffing shortages. I understand the pressures services are under but I provide constant care for my husband and I need that time to regroup and be myself again."

Brenda – cares for her husband



'A lot is put on me because I'm a willing carer'

Roy – caring for wife with multiple health issues.

## Wait times for support

"I care for my relative with dementia, she has been very changeable and aggressive, and when I was nearly at breaking point I still had to wait seven months for the sit in service to start. This was whilst I was balancing caring for her with caring for my young children. This is not acceptable."

Gemma- cares for elderly relative

## Personal stories: Accessing Support



"Feel that whoever shouts the loudest gets support, have to be in crisis to access a lot of support. Have to make yourself vulnerable and beg for support. You encounter the occasional professional who goes above and beyond but it is not the norm."

Laura – cares for her son with learning difficulties



## Accessing support



"You have to beg and make yourself vulnerable in order to access support."

Lisa – cares for two children with additional needs



## Accessing respite/sit in service – wait times for support

15% of the adult carers we spoke to mentioned that respite care had become harder to access in recent years. It was particularly noted that the waiting lists for the Sunshine Centre, a local facility that supports children with additional needs, now has particularly long waiting lists.

Respondents who have accessed respite in the past also mentioned the closure of more conveniently located respite centres and the difficulties this had caused, particularly for carers who are unable to drive.

**'I feel Thurrock Council have let carers down badly. The local respite centres were a godsend and if I needed to collect my husband urgently then because it was local it was easy for me. I think the people making these decisions have no knowledge of dealing with people who have dementia. Finding respite centres closer to home would help.'**

**Tammy – caring for her husband**

### Need for care and local services

I want Mum to have a structured week packed with few activities and someone else looking after her while I go to work or go on a short break.

Tracey- cares for elderly mum

### Respite to socialise and see friends



"I get three hours of respite twice a week from the council and a weekly sit in service from St Luke's Hospice. This means I can go and play golf with my friends and have a break which I appreciate, but given that I provide support 24/7 it really doesn't feel like enough."



Robin – cares for wife with dementia

## The pandemic – the challenges

The pandemic led to a change in how many services were delivered. During the lockdowns there was a move to telephone and online consultations for appointments in health and social care settings. It was also a time for online learning for students in school and college. For some carers this was a time for reduced anxiety because there was less pressure to go outside, for others it created additional challenges and was a lonely and isolating time.

Some carers said that the restricted access to GP services has made caring harder for them. The lack of specific appointment times when booking with the GP can make it difficult to navigate supporting their loved one and an appointment around other life commitments.

In addition the stress of having increased demands on time i.e. less time for headspace from their caring role, made the lockdowns difficult to navigate.



“I live yards from my local surgery but I do not trust them with my wife’s care, they are not supportive of our circumstance or her needs.”



Steve – cares for his wife



“Since my son has been diagnosed with autism all of his assessments have been done over the phone, how can you know a child’s needs from a phone call?”



Charlotte – cares for her son

## Being listened to as a carer

22% of respondents mentioned that they do not feel they are listened to by professionals in their role as carer. This was spoken of in terms of the frustration that it can cause. This is particularly in the context of medical appointments and discussing the health issues of the loved one they are supporting.

### Being listened to as a carer



“It rarely feels like you are listened to by medical professionals, either as a carer or a parent, despite the fact I provide complete support for my daughter, I know her needs better than anyone.”



Cara – cares for her daughter

### Being listened to as a carer

“I feel that Inclusion Vision Thurrock does not value or utilise the role of the carer, in fact I have felt that I am seen as a hindrance even when they have been given full consent from my son to have full transparency when communicating. On several occasions I have experienced a very hostile response from them which, when dealing with everyday challenges from my son’s addiction, can be very frustrating, debilitating and very worrying that if they can make me feel like that how do they treat their clients!”

Claire- cares for son

## Making information available to carers

44% of respondents said that they feel information regarding what support is available to them should be made more available, this includes assessments as well as emotional support via support groups.

In addition some carers mentioned they felt it would be useful to have more information about the nature of the health condition of the person to which they are providing support. For example, carers felt they would benefit from information sessions on how to support someone with dementia, or a child with learning difficulties. 39% of respondents said they would like information on LPA/guardianship to be made more available. The support service that advises



on it has a very long waiting list, a lot of people don't know about it until it is too late and will be difficult to put in place.

### Advice available to carers



"I am so unsure what to do with my daughter. I did research but I am not sure if I am taking the right approach with her. I need a professional to look at her and tell me if what I am doing is right. I need proper advice on her condition."



Angie – cares for her daughter

### Advice available to carers



"I would like for professionals to come to our support group meetings. I care for my son who has addiction issues and it would be good to get advice from a professional as to whether I am supporting him in the right way."



Mandy – cares for her son

### Advice available to carers



"I wanted information on getting an LPA in place but the wait times for the support service are 6-8 weeks. It would be good to be able to receive quicker support, the government website is overwhelming and difficult to navigate."



Gaynor – cares for her son husband

## Causes of stress

42% of carers when asked what the most significant cause of stress for them responded that they were most concerned for the health of their loved one and something happening to them. Within this was the unknown of how their loved one's health condition would progress as time went on.



10% of carers said having to navigate services and appointments and the time commitments this requires.

14% of carers mentioned that even with the financial support provided by the council they still found money challenging.

30% of carers were worried about what would happen to their loved one if something happened to them. An overall theme was the emotional stress that comes with providing care for someone.



Other issues that were mentioned were the challenges of arranging appointments, and arranging transport to appointments and lack of personal time for carers.

## Causes of stress

 I worry about cost of providing care, especially with the cost of living rising.” 

Louise – cares for her aunt

## Causes of stress

 “The most significant worry for me is finances, we have to rely on my wage and PIP as my husband does not get universal credit as he couldn’t cope with all the assessments. I also worry that something will happen to him and I won’t get back in time.” 

Carol – cares for her husband



“My husband has Alzheimer's. I feel sad at this times just watching him go through the illness how it has had an impact on him from the man he was and the man he is now.”



Karen – cares for her husband

‘The most significant cause of stress in my life is the loss of the husband and best friend that I used to have. Having read what dementia involves I worry where my life is going and how I am going to cope as dementia progresses. I worry when I leave him that he is going to worry where I am or have a fall.’

Lynn- Caring for husband with dementia

## What has worked well?

### Services and people that participants have reached out to for support

Below outlines a selection of the organisations and people that respondents listed as relying on for support:

- Asperger's Society
- Alzheimer's Society
- Friends and Family
- GP surgery
- Mental Health Team
- National Autistic Society
- PATT SENDIAS
- SNAP Thurrock
- Thurrock and Brentwood MIND
- Thurrock Carers Service
- Thurrock Council
- Thurrock Lifestyle Solutions
- School
- St Luke's Hospice

Residents who had received support from Thurrock Carers Service, provided by Thurrock and Brentwood MIND and commissioned by the Council, found that it was useful to speak to other carers who had similar situations to them in support groups and on the WhatsApp chats. Carers also highlighted the comfort from similar groups provided by St Luke's Hospice, PATT SENDIAS and NAS Thurrock.



"I appreciate the friendly voice at the end of the phone when I have my weekly phone calls with Thurrock Carers Service. I also feel better about my situation when I speak other carers about their experience looking after someone." Bob – cares for his wife



In addition, many carers who had managed to organise Direct Payments found that this provided them and their loved one with some additional independence and flexibility. Direct payments can be given to a carer as a one off to have some time to look after their personal wellbeing, or direct payments can be provided to the cared for are more commonly ongoing payments used to employ a care worker or personal assistant to help with their day-to-day needs or for a period of respite care (Carers UK, 2022).

'Thurrock Council have been able to give direct payments so our son can go to a wonderful placement 3 days a week. As our son gets older there will definitely be more help need as we get older our worry has always been what happens when we are no longer here. But at the moment we are grateful for the help we receive.'

– Jan and Tom – caring for their adult son

# Thurrock Voices

As part of this project Healthwatch Thurrock began a video series entitled Thurrock Voices. We took this as an opportunity to speak to people who had experience caring for a loved one, or those who had gone through a challenging health experience. This was a chance for people to share their stories and some of the challenges they had faced. These videos were well received.

Within Glenn's video he reflected on how being a young carer for his brother Barry had affected him growing up. Some of the things he reflected on came up when we speaking to young carers, including wishing to have some time with his parents. We appreciate that for those who shared their stories it was a challenging experience but we hope that it will help raise awareness about the issues people face.

## Personal stories: Glenn's video



"Hearing Glenn's story of caring for his brother and how it impacted him growing up made me look differently at how my daughter's health needs may impact my other daughter"

Susan – cares for her daughter



Karen reflected on how caring for her partner Ernie, who passed away in 2020, had completely altered her life. She also spoke about the impact it had on her mental health and how difficult it was to reach a point where she felt she could ask for help. Karen got support from Thurrock Carers Service which she found very beneficial, she now volunteers with Thurrock Carers Service providing support to other carers.

## Personal stories: Karen's story



"I never thought I would end up being a carer. I wanted to be there and not let Ernie down but then I got to a point where I couldn't do it anymore and needed help... St Luke's Hospice and Thurrock Carers Service were a big help."



## Recommendations for Adult Carers

Based upon the feedback from residents Healthwatch Thurrock would recommend the following

- Improve communication between different support services so as to avoid carers having to repeat themselves.
- Ensure timely follow up following referral into services.
- Better explanation of Carers Assessment process.
- Improve availability of information regarding support for carers. Having a central point of access, taking into consideration different digital abilities.
- Increase staff availability so that allowances agreed in assessments can be met.
- Work with employers to see how carers can be supported in the workplace and ensure flexible working that can meet the needs of carers that wish to work.
- Provide training workshops to carers to support an improved understanding of the health condition of their loved one.
- Working with healthcare settings to ensure that patient notes reflect carer status/ability to speak on loved one's behalf.
- Making sessions on LPA/Guardianship available to carers.
- Working with carers to ensure they have plans in place for if something were to happen to happen to them.

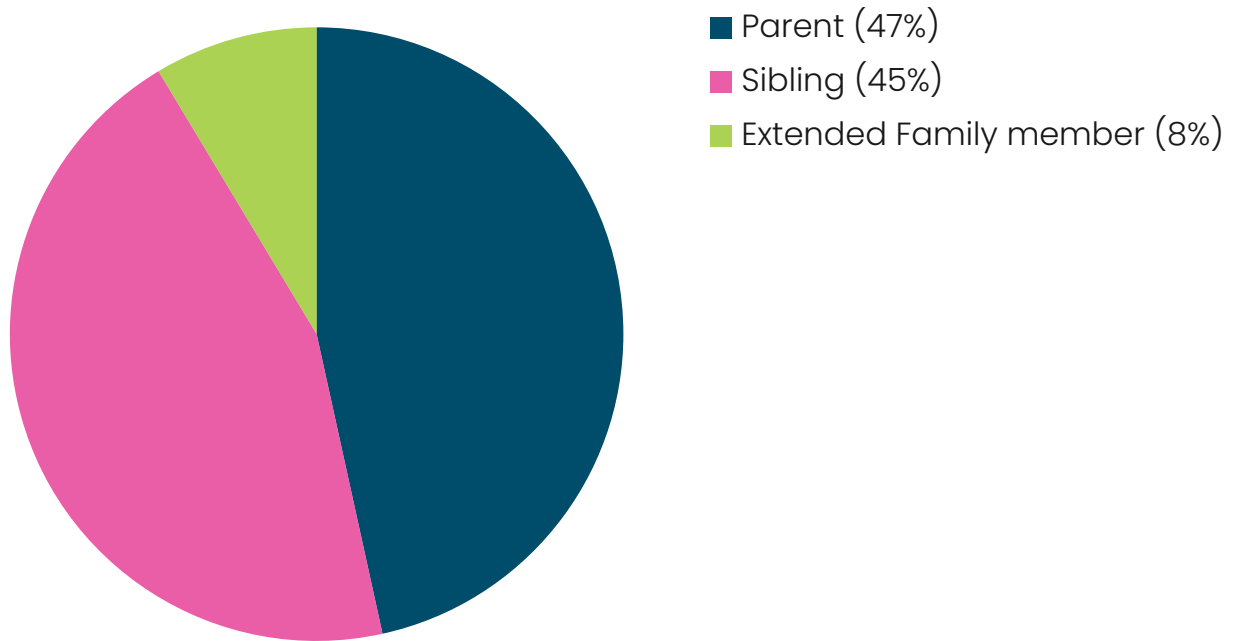
# Young Carers

The young carers we spoke to were providing support for relatives with a variety of health issues, from parents with addiction issues, mental health issues or long term health conditions or siblings with additional needs.

For some of the young carers the support they provided varied from looking after themselves e.g. making breakfast for themselves whilst parents look after the family member with additional health needs. Other young carers were more involved in the family member's care e.g. helping them get dressed or helping parents prepare dinner or clean. There were also some young carers who assisted their loved ones at appointments or communicating with services if they had communication needs.

It should be noted that if a young person spoke to us about anything we found concerning then this was raised with the relevant member of staff or safeguarding lead to look into.

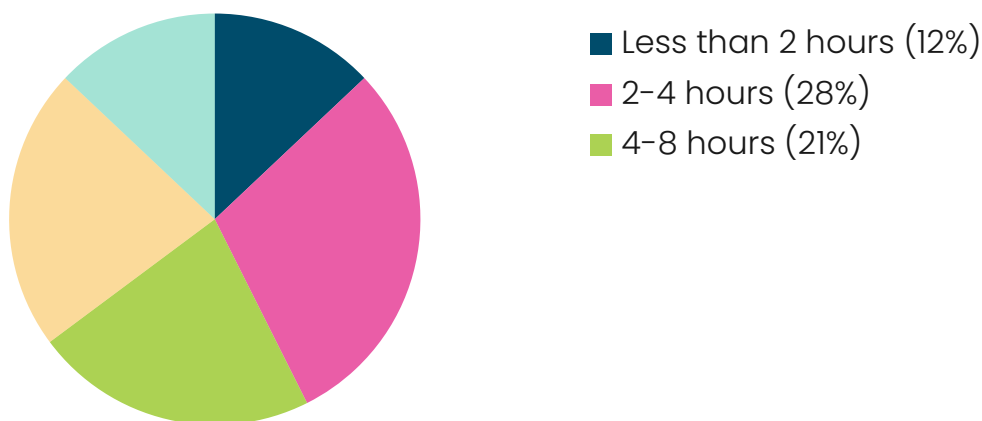
## Relationship of person being cared for (young carers)



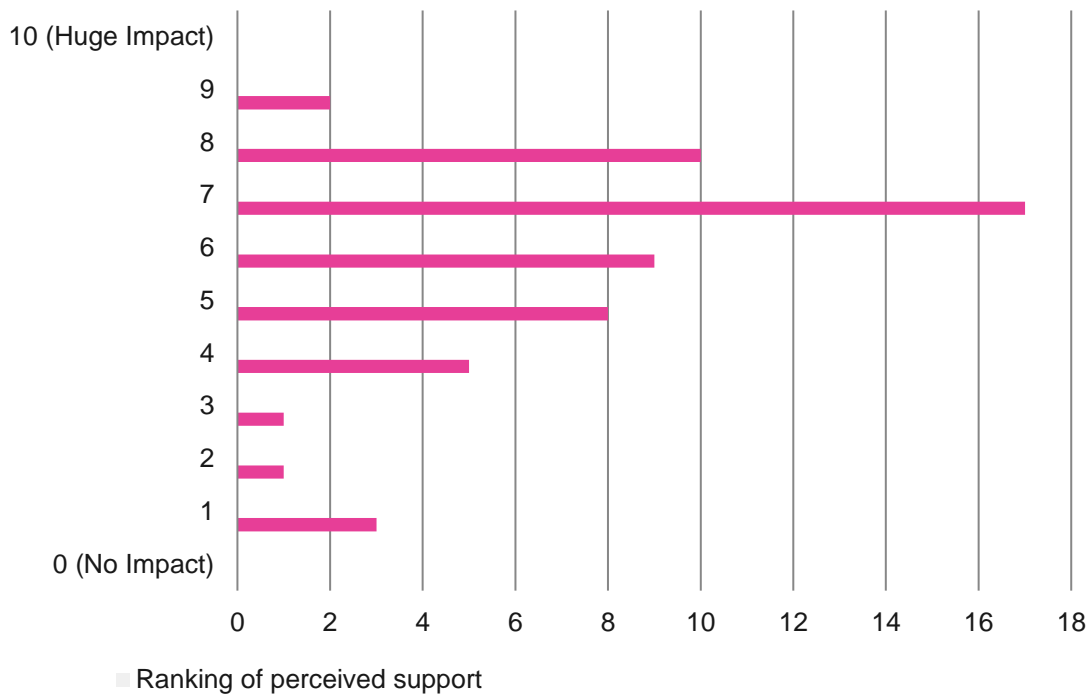
Most (92%) of the young carers we spoke to were caring for a parent or sibling. Of those who were caring for an extended family member it was generally a grandparent, aunt or uncle or cousin.

## How many hours a week support do you provide?

The amount of support young carers provided to their loved one varied, with most (88%) providing more than 2 hours support a week. Older carers (i.e. those in secondary school) wanted to highlight how every day is different, they might provide more support one day if their loved one is having a particularly bad day, then not need to the next day. Sometimes the unpredictability of the situation can be challenging.



## On a scale of 1-10 how much do you feel being a carer has impacted your life?



When asked how much being a carer had impacted their life. Most of the young carers we spoke to rated it as being a 6 and above.

This included aspects such as not being able to go out with friends as much as they would like, or balancing being a carer with school work.

### Personal stories: Caring for my mum



“I care for my mum, there's no one else, my nan and aunt do help but at the end of the day I have to take care of my mum. It's like I am the mum and my mum is the child. I don't like to leave her alone. My school's zero tolerance policy to mobile phones causes me a lot of stress because I need to check whether my mum has taken her medication. There is one member of staff at school who I would feel comfortable speaking to and no one else at school. I don't know what activities I would want for young carers because I wouldn't want to leave my mum alone for too long to do them.”



**Keeley – Age 15**



## Support in school

41% of young carers said that they would like more support for young carers at their school. This included from staff and a designated space for carers.

Within a workshop with young carers they spoke about how there is a lack of understanding among teachers and other students in school and college about young carers. They had all experienced bullying or intolerance at one time or another whilst being in school or college, either about themselves or the family member they were caring for.

Students who had additional support found this helpful, e.g. having a mentor or assigned member of staff that felt comfortable speaking to.

### Personal stories: Ella's story



Ella (11) helps her nan care for her younger sister. She plays with her sister and makes sure she is okay if her nan is busy. Ella has a social worker and a therapist she feels comfortable speaking to. Ella gets very anxious but finds it useful to attend her school's Anxiety Support Group. Ella feels it is important that young carers get enough time to themselves to feel less stressed and overwhelmed.



Some of the older students particularly did not feel comfortable speaking to any member of staff in school about their concerns, they did not know who pastoral care was and did not feel supported by the school.

Those in junior schools were more likely to have a favourite teacher or member of staff they felt comfortable speaking to whilst in school.

Some schools had provided support groups for carers in school, e.g. a quiet space for them to go if feeling overwhelmed. This had been well received but due to staffing changes had largely stopped.

## Support Groups in School



"I used to enjoy the sessions we had with Mrs S to go and have time with other young carers in the canteen and have some space and a chance to de-stress but this has stopped now she has cut down her hours."

- Sarah (13) – cares for her dad



Gina (17) helps care for her brother who has a rare chromosomal condition, she finds it stressful to navigate college because of the time constraints of being a young carer and getting all of her college work done. She also feels there is not much awareness or understanding amongst staff and students of the different health challenges people can face. She would like more support from her college. Gina has also had to chase up medication issues with her GP surgery for her brother, and finds it challenging to find the time to communicate with them whilst balancing college commitments. Gina would like more time to do the things she enjoys like jewellery making.

## Support for carers in schools



"I feel let down by my school and the lack of support there is for young carers. I am very open about being a young carer and I have had younger students come to me because they don't know who else to speak to."

Debbie (15) cares for her brother



## Support for carers in colleges



"I don't feel my college have any support for carers. The teachers never listen when I talk about how it is hard to concentrate at home and how it makes it difficult to get work in on time."

Seb (17) cares for his mum



## Support for carers in colleges



“When I’m in school I worry about whether my brother is okay and the school’s zero tolerance policy to phones makes this really difficult. If they see you with it they’ll take it away immediately. Some teachers are easier to talk to about what’s going on at home than others but no one really understands. I would like a quiet place to go and sit when I get overwhelmed.”



Dana (14) cares for her brother

## Support for carers in school



Mandy (10) spoke about the support she receives from her mentor at school. Mandy helps her nan to look after her baby cousin. She does not want to worry her nan about how she is feeling when she is overwhelmed so it is nice to know she can speak to her mentor if she is worried. Her mentor has also given her a journal to record her feelings and she finds this helpful.



This links with the theme explored below surrounding awareness of carers in school, both amongst staff and other students, and how this affects how supported young carers feel.

## Bullying and stigma in schools and colleges

30% of young carers felt that stigma was an issue with young carers in their school or college. They felt there was a lack of awareness among students and teachers. This affected whether they felt comfortable to talk about being a carer.

Those young carers who were looking after a parent with mental health or addiction issues often did not feel comfortable talking about the health issues of

their loved one, particularly in a workshop setting. This could also be indicative of perceived stigma.

Respondents also mentioned about feeling that there was judgement in school or college about the health need of their loved one and that there should be more awareness raised about the different health challenges people face.

The method by which any awareness raising is done is important. When asked, young carers felt that assemblies may not be the most engaging way to approach important topics such as the challenges young carers and their families face. Therefore when looking to address this issue it is important to work with young people to ensure they are engaged and support which ever method is chosen.

### Personal stories: Kayla's story



"I care for my mum who has mental health issues. I don't feel comfortable speaking to my friends or teachers about being a carer because I know they won't understand. People can be really judgemental."



Kayla – Aged 13

### Personal stories: Stigma in college



"College is really difficult, other students can be really mean about my mum's health and it is really hard to focus."



Dave – Aged 16



### Personal stories: Stigma in school



Reese (11) supports his mum who has mental health issues and also helps look after his little sister. He feels that there isn't any support at school, he wouldn't know who to speak to at school if he felt there was a problem. He would like to see more awareness of mental health issues among young people and more awareness about young carers.




## Personal stories: Stigma in college

 Kieran (17) goes to college and does not feel they are supportive of young carers, he did not feel his previous school were supportive. Has been bullied about his mum's health issues many times since being in education. Makes it difficult to go to college. He  feels that some staff are very intolerant towards it. "They don't seem to get that I don't have the same home life as other people in my class"

## The pandemic



53% of young carers said that the pandemic was stressful because it exacerbated concerns over their loved one and it was difficult to concentrate at home.

### Personal stories: The pandemic

 "I helped look after my nan a lot more in the lockdown. She needed me more. This was hard."


Daniel – Aged 8 

### Personal stories: The pandemic

 **"The lockdown was hard. My sister has epilepsy and autism and she comes into my room a lot because she wants to play. This was hard with online lessons. Teachers don't get that this makes it hard to do homework."** 

**Simeon – Aged 12**

### Personal stories: The pandemic

 "I found the lockdown hard. My sister has autism and she would have meltdowns and it was very loud at home."

Ruby – Aged 9 

## Personal stories: The pandemic



**“My brother has learning difficulties. He used to go to respite but this stopped because of the pandemic and this has been hard for my parents.”**

**Graham – Aged 13**



20% of young carers found the pandemic less stressful because it meant they did not have to be away from their loved one and they could know they were okay.

## Personal stories: The pandemic



**“I found the lockdown better in some ways because I find it difficult to be away from mum because I worry about her.”**

**Keeley – Aged 15**



## Worrying about family members

81% of the young carers said that their most significant cause of stress was their loved one's health condition and the wellbeing of their loved one.

It is also important to note the effect having a loved one with a health condition can have on the younger members of the family. Some of the young carers, particularly those who had a sibling with a health condition spoke of wanting to do more with their parents but being unable to due to the constraints on their time.

## Personal stories: Spending time with family



**“My sister has autism and my parents care for her. I would like it if they had more support so that they could spend more time with me and be less stressed.”**

**Mary – Aged 11**



## Personal stories: Worrying



“My sister has mental health issues. I worry about her when she goes away to hospital or in to respite and I don’t know if she’ll be okay.”

Priya – Aged 10



## Personal stories: Worrying about money



**“I help my mum care for my nan who has mobility issues. I worry about my mum not having enough money to pay for nan’s care and keep paying for everything else.”**

**Jesse – Aged 8**



## Personal stories: Spending time with family



“I help my mum and my nan look after my baby sister. I really like baking and like doing this with my mum or my nan but they are very busy looking after my sister so it would be nice to do this more.”

Nancy – Aged 5



## Young Carers Service

Those young carers who had accessed the Young Carers service found it to be useful and they enjoyed the day trips and activities that were offered.

## Personal stories: Young carers service



“Young Carers Service gives me time to do things a normal teenager would do at my age, and I’ve made some great friends there who understand what I’m going through.”

Debbie – Aged 15



There were some young carers who said they were waiting on their school to get them into the Young Carers Service. Some Young Carers said that they would be interested in attending, this information was passed on to the schools. It is worth considering the awareness schools have of the Young Carers Service and whether all young carers are being referred in order to access the service.

There are a variety of activities that young carers would like to see offered, either by the Young Carers Service or through support at school:

- Ice skating
- Go karting
- Adventure Island
- Play football
- Harry Potter world
- Jewellery making
- Going out for food

## Recommendations for Young Carers

Based upon the feedback from young carers Healthwatch Thurrock would recommend the following

- For the Council to work with schools to ensure that Young Carers can be identified by members of staff to ensure they can get the proper support
- Timely referrals into the Young Carers Service
- Expand the referral pathway into the Young Carers Service i.e. self-referral or referral by other services.
- Clearer signposting to pastoral care in schools and colleges.
- Reasonable adjustments made for young carers that take into account challenges at home e.g. adjusted detention times, warning systems for phone removal, quiet space in school
- Carers support groups either teacher led or peer led in all schools in Thurrock
- Raising awareness of carers amongst student population to help young carer identification and reduce bullying
- Raising awareness of different health conditions amongst student population to reduce bullying
- More days out and activities for young carers, giving them time and space to embrace their hobbies



## References

Carersuk.org. 2022. *Direct Payments - Carers UK*. [online] Available at: <<https://www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/direct-payments#:~:text=What%20is%20a%20direct%20payment%3F%20Generally%2C%20direct%20payments,pa y%20for%20driving%20lessons%20or%20a%20break%20away.>> [Accessed 4 July 2022].




# healthwatch

Healthwatch Thurrock  
The Beehive Resource Centre  
West Street  
Grays  
Essex  
RM17 6XP

[www.healthwatchthurrock.org](http://www.healthwatchthurrock.org)

t: 01375 389883

e: [admin@healthwatchthurrock.org](mailto:admin@healthwatchthurrock.org)

 [@HealthwatchThrk](https://twitter.com/HealthwatchThrk)

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