

Behind the Care:
Exploring the lived experience of carers

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A heartfelt thank you is extended to all the carers who contributed to this report, your voices have been heard and your courage and experiences acknowledged by Healthwatch Herefordshire.

Your valuable perspectives and insights have greatly contributed to our understanding of the impact of being a carer in Herefordshire.

Finally, your selflessness and dedication in caring for others is deeply appreciated.



Who is a Carer?

A Carer (also known as a caregiver) is an individual who provides unpaid or paid assistance to someone who is unable to manage daily tasks independently due to age, illness, disability or other health conditions. Carers may offer support with activities such as personal hygiene, medication management, mobility, household chores, emotional support and co-ordination medical or social services.

Carers can be family members including children, friends or professional workers, and their role is essential for the well-being and quality of life of the person receiving the care. Unpaid carers, such as family members, often take on this role out of necessity and duty, while professional carers are typically employed by healthcare or social settings.

State of Caring...

Across the UK, millions of people provide care (paid and unpaid) for an ill, older or disabled family member or friend. The number of unpaid carers has been increasing as the population ages and healthcare continues to improve.

It was estimated from the last census in 2021 that the total number of carers in the UK today is around 10.6 million, which means that 1 in 5 adults are providing care. Nationally carers' support was valued at £162 billion a year that's £22.40 per hour and in perspective that means unpaid carers across England & Wales are now worth the equivalent of the NHS in England.

In November 2023 Carers UK published their findings on The Impact of caring: health, which highlighted a widespread lack of support and recognition from health and care services is severely damaging unpaid carers' mental health.

In Herefordshire in 2021 it was estimated that just under 1 in 10 people aged 5 and over provided unpaid care in Herefordshire. This represented around 9% of our population. (for reference this is the same percentage as England & Wales).



Executive Summary

Background & Objectives

An increase in feedback to Healthwatch Herefordshire about the realities of being a carer in Herefordshire has led to the undertaking of this piece of research.

In our study, we used qualitative research to explore the lived experience of carers, focusing on the personal, emotional and social aspects of caregiving. Through semi-structured interviews, we gathered rich, detailed narratives that allowed us to understand the complexities of caregiving.

We have analysed the interviews using thematic analysis, identifying key themes that represent the carers' challenges, coping strategies and support they need, this approach gave us deep insights into their day-to-day realities and highlighted areas for improvement in caregiving support system.

Each interview lasted between 45 mins to 3 hours, using guiding questions in a semi-structured manner, but allowing flexibility to follow up on any unexpected or interesting themes. All interviews were noted with consent, and later transcribed for analysis.

In doing this we aimed to ascertain information to lead to the following outcomes.

- Identify carers' needs and challenges by gaining a deeper understanding of the physical, emotional, social and financial challenges carers face.
- To advocate for improved support systems, such as better policies, services and resources to support carers.
- Increase public and institutional awareness about the significant role carers play and their unmet needs.
- Inform policy development, offering recommendations for policy change at local, regional or national levels.
- Empower carers through representation, providing carers with a sense of validation and empowerment through making their voices heard using Healthwatch as that platform.
- To understand the reasons and barriers which prevent carers from not accessing help and support for themselves.

Key Findings

Every experience that we captured was unique and each had complexities of their own such as managing the physical or mental health needs of the cared

for person or family dynamics for example, but all had commonalities that were experienced at some point in their journey.

What were the common themes we heard?

- Emotional and psychological stress caused by the stresses and anxieties of caring but also having to witness the decline in a loved one's health or wellbeing.
- Physical strain and health issues – the role of a carer is often physically demanding which can lead to chronic health problems and injuries.
- Financial burden.
- Social isolation often created from the demands of caregiving limiting their time to maintain social connections, leading to loneliness.
- Role conflict/identity shift – caregivers struggle balancing their caregiving roles with other roles such as being a spouse, parent or employee. Often leading to stress.
- Difficulty navigating healthcare systems – having to '**wear many hats**' or '**tell their story more than once**' to navigate the different healthcare organisations involved, this can become overwhelming and time consuming.
- Not having their views or opinions considered or valued by professionals.
- Limited access to respite care – Herefordshire doesn't have adequate respite services to provide temporary relief for caregiving duties.

"I didn't have time to do both, so I had to give up work, I would like to still be in work"

"If their health drops, so does yours – especially your mental health"



Several carers reported "emotional blackmail" from their loved ones at times "not realising how hurtful they are being"

Most carers explained that their caring role had a negative impact on their health – this varied from physical illness to the impacts that caring has on your mental health. Several carers told us that they had experienced depression and anxiety because of their caring role, some had needed prescription medication to help this.

“When going to the doctors, it would be useful if the appointment could be jointly done, allowing an opportunity for carers to speak about their own health – or even just to check you are ok”

Some carers had been caring for a loved one for a few months whereas others had been caring for a loved one for twenty plus years. It was the consensus that caring was a 24/7 role, but in terms of length of time spent caring each day this varied considerably – many caregivers expressed that even when they are not physically carrying out a caring act that they can't switch off from the role as they are thinking and worrying about loved ones and living from time frame to time frame before having to carry out the next task.

What would make a positive difference?

- A need for improved/availability/access to training -related to medical conditions & needs, general care tasks and health & safety.
- Carers would like access to talk to someone/or online access to support locally (not always big groups) but one-to-one, to help feel less isolated.
- Improved availability to respite care and respite care services
- Free support for carers to increase their digital skills to support the amount of admin that must be navigated and completed online.
- Carers are given the choice of having advocates to speak up for them and help them navigate the system.
- Allowing both parents to register as a Parent Carer would be beneficial.
- Ensuring carers are listened to and their value recognised and appreciated.

Main Report

Context

Recognising that carers often feel unseen and unheard, this report reflects our commitment to listening with empathy and care. The in-depth engagement we conducted where carers were given the space to express their thoughts, feelings and needs in their own words. The qualitative approach allowed us to capture the nuances of their experiences, ensuring their unique challenges were fully understood and respected.

Through this process, we not only aimed to document their experience but also to create a foundation for meaningful action. By shedding light on the issues, they face from emotional and financial strain to social isolation and burnout – we hope to inform policy makers, healthcare providers and support services about the changes needed to improve the lives of carers.

During our engagement, caregivers shared their experiences of disclosing their caregiving responsibilities. Most comments reflected a lack of empathy or willingness to help, underscoring the need to provide a platform for them to express their thoughts, feelings, and needs.



Approach

This qualitative listening project identified key themes within the population, focusing on insight rather than prevalence. Our goal was to encourage reflection and inform strategy. Findings were developed through thematic analysis.

We listened to 24 individuals in face-to-face interviews lasting between 45 minutes to 3 hours.

The interviews were semi-structured, allowing participants to share their stories with minimal prompting for clarity. More targeted questioning focused on their expectations, the barriers they face in seeking support, existing gaps, and ways to improve support for caregivers.

Alongside this research project, we ran an online survey asking very specific questions around carers assessments and hours caregivers provide. This information was used to influence Herefordshire's Carers Strategy review that was undertaken between September 2023 to March 2024. More information about the strategy can be found [here](#).

*We had a total of 69 responses to the online survey – please refer to the appendix at the end of this report for the full results. *Appendix A**

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Herefordshire

Carers Project

Share your experiences of being a carer in Herefordshire

We are eager to listen to lived experiences of carers of any age, to identify what is working well and what areas need improvement.

These experiences will help influence Herefordshire's Carers Strategy review.

Please complete our online survey:
www.smartsurvey.co.uk/s/ABZ2BH

Alternatively, we welcome 1:1 conversations.

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Talk to us...

Who we listened to

- Recruitment was undertaken through;
- using existing connections, we had within organisations who work alongside carers,
- social media advertising (pictured opposite)
- and through conversations that we were having when active engaging with the public around the county.

While we are confident our respondents represent a broad spectrum of

experiences, we want to acknowledge the unique challenges they face and specific

nature of their roles which prohibits caregivers in participating in this kind of research. A highlight of these challenges are;

- Time constraints
- Emotional & mental load
- Unpredictable nature of providing care
- Guilt of reluctance to speak about challenges

Main Findings

The Impacts

Every story is unique, but the most apparent impacts can be themed as follows.

- **The Impact of caring on – Stress and Mental Health** – the widespread lack of support and recognition from health and social care services is severely damaging carers' mental health.

The conversations we had highlight how people caring around the clock do not have adequate support from statutory services that are in place to help them – leaving many with feelings and thoughts of fear, dread and hopelessness.

All the caregivers we spoke to talked about their overwhelming feelings of tiredness, fatigue and lack of sleep which drives up stress levels and leaves many living with low level mental health issues.

“Often we are left to cope with any situation either with little or no practical support – unless we use more time and energy fighting for this support”

- **The impact of caring on – Finances** – all the carers we engaged with talked about how as carers they are struggling to make ends meet/experiencing financial hardship, which over the last two years has worsened with the cost-of-living pressures.

A lot of the unseen expenses were talked about such as, petrol for appointments, car parking at hospital and specific dietary requirements. The financial implications to many, mean that they then cut back on seeing friends and family as a way of saving money.

Loss of employment or reduced work hours had led to a direct loss of income but

also career progression and job security – long term financial stability becomes a risk.

“I no longer have the time or energy to do both, so I had to give up work, it was almost expected of me. I would still like to be in work in some way”

- **The Impact of caring on – Physical Health** – it is evident the caring role has a negative impact on the caregiver's physical health. Some expressed how they felt they were more 'regularly' feeling generally unwell and seem to be susceptible to more seasonal illness (which in turn become a huge worry for their cared for person). They didn't really have the time to make an appointment with a doctor, as a result, symptoms seemed to persist and ultimately get left.

A lot of the physical health conditions come from the strain and injury often being caused by physically demanding care activities – resulting in many chronic back, joint and muscle strain injuries.

- **The Impact of Caring on – Relationships & Social Contact** – caregiving responsibilities can significantly impact the caregivers' relationships, affecting family dynamics, friendships, and romantic partnerships. It was clear that the emotional, physical and time demands of caregiving often create tension and stress in relationships, leading to isolation, strained communication, and role changes.

We heard how caregiving can create complex emotional responses, including resentment towards the person being cared for or even the other family members who are not contributing equally.

We also heard how caregivers feel a loss of independence and personal identity. The feeling they are no longer able to pursue their own hobbies, interests, or professional goals, which can lead to frustration and dissatisfaction, impacting their relationships with others.

“We went into the consultation appointment as husband and wife and come out with a person now living with dementia and a carer”

“My life feels like a distant memory now, it's all over the place, we used to go out and get asked out all the time, but this doesn't happen anymore – probably as we always had to cancel”

- **The Impact of Caring on – Support, Training & Guidance** – the carers we spoke to talked about many situations where it would be useful to have been given training and support on their cared for persons condition and outcomes over time.

Many felt that topics such as medical information, manual handling and conditions such as dementia, strokes and neurodiverse conditions would be beneficial. This would help provide some sense of what is 'normal' and what is not for the person they cared for – in turn reducing some of the caregivers' anxieties and need to speak with professional services all the time.

“Professionals rely on us as carers, we have to be resilient and persistent to know everything – but we are not the experts, we aren't even given the opportunity to learn”

- **Impact of Caring on – Isolation & Loneliness** – carers seem to gradually withdraw from social activities, either because they feel too exhausted to participate or because their responsibilities prevent them from leaving the person they care for. It appears over time this withdrawal can create deep feelings of isolation from family, friends and communities. The caregivers expressed that this often stems from the lack of understanding from others, that they don't understand the challenges they are facing and the time restrictions they live their lives by.

Carers feel they cannot express their struggles or that others won't appreciate the depth of their experience. The other side of this demonstrates also a strong sense of duty towards the person they care for, and often feelings of guilt if they spend time on their own needs, including socialising, which reinforces the isolation.

All the caregivers we talked to said to a certain degree they felt forgotten by society and they feel very undervalued and underappreciated – which again widens the feelings of isolation and loneliness – as the sense of being forgotten makes it much harder to reach out and stay connected.

“Caring is isolating and all consuming, its 24/7, you rely on people coming to see you, sometimes it's like being a prisoner in your own home”

- **The Impacts of Caring on – needing to take a break** – caregivers we talked to had mixed perception of what a 'break' could be. Some felt this was about having a few hours to themselves where others felt it was more of a definite amount of

time away – like 2 or 3 days.

What was universal in the conversations was that the key to any break would be to have an opportunity to forget about caring and do something which was purely for them, however many felt this was almost impossible to achieve.

Some carers felt that it was hard to identify and admit you need a break and asking for help can be uneasy and may look like they aren't coping, risking reaching crisis point before getting a break. The other side of this is about the affordability and accessibility of respite care if you don't have someone else in the family who can support this.

“Having a break is important, I work longer hours now than people in employment, but the opportunity of a holiday doesn't exist and if it did, we couldn't afford too”

- **The Impacts of Caring on – experience of grief**– some of the carers we spoke with expressed that following the end of their carers' journey, when their cared for person passes away, they struggle and as a result feel more isolated as they have been cut off from their social support, maybe losing touch with family or friends while caring.

These connections then become important as a part of dealing with grief and adjust to bereavement and not caring as a role. Some of carers also expressed that dealing with closure tasks, such as funeral arrangements and financial paperwork had been very difficult.

It was acknowledged also that grief can start much earlier in a person's caregiving journey – often at the point of diagnosis when a realisation that a person you love and care for has now completely changed, many of the caregivers looking after someone with a form of dementia expressed this.

“The biggest cause of upset and stress for me is the loss of my husband that I used to have – we were best friends too and that has gone now – I feel sad at times just watching him go through this illness and the impact it has had on him and how we no longer recognise each other”

Main Findings continued...

Communication, Inclusion and understanding

In almost all our interactions with caregivers, there were some other common resounding themes that ran through all their experiences, they were about communication, inclusion and understanding of their roles.

There were often strong emotions of anger and upset that these feelings arise, they feel as though they are not heard or recognised due to the invisible nature of their work and the often-apparent under-valuing of their work by healthcare systems and professionals.



Lack of Acknowledgement – a lot of the work carers do is ‘behind the scenes’ involving tasks like personal care, emotional support and household management – this makes many feel like their contributions are not recognised as ‘real work’ compared to professional roles.



Societal Expectations – many caregivers felt that there is often an assumption from society, professionals and family members it is a simple a duty or responsibility that should be carried out without the need for external acknowledgement or praise – as a result leaving caregivers feeling taken for granted.



Insufficient support from Healthcare Systems – the caregivers we spoke to expressed that often they felt excluded from key decisions made by health and social care providers about the person they are caring for – not being consulted about treatment plans, care schedules or challenges they face at home – a sense of being done to and not with, was articulated. This leads to a feeling of being unheard and undervalued by the medical and social care community.



Communication – linked to the inadequate support form Healthcare systems, caregivers also expressed their frustrations and exasperations of the constant need to be the ‘coordinator’ of the services.

The Herefordshire caregivers we spoke to all talked about the challenges of navigating and communicating with the different services needed and the constant requirement of **repeating their story** to different professionals. Many caregivers recognise that different organisations have different systems that possibly don’t ‘talk’ to each other – but the constant nature of having to re-tell a story or re-highlight issues with the same organisations is waring and massively time consuming.

Linked to this is the issue of many appointments that are eventually made, have time constraints in terms of how long the professional must spend with someone and then much of the appointment time is taken up with relaying the 'story so far' and in some cases providing the medical history for the person as this isn't recorded properly. Carers felt that professionals should demonstrate that they have read through patient records to allow for some **continuity of care**.

"We have to constantly chase up services, it is hard to find the right contact numbers the council's website isn't sufficient and not easy to navigate and not always up to date, we feel there is a lack of continuity between services"



Non- Existent or Inadequate Training – it was clear that many of the caregivers we talked to had been expected to deal with complex medical conditions and manage them often on their own – yet any necessary training or knowledge for dealing with these things weren't offered or in many cases aren't provided. Some had expressed that they felt like an afterthought or almost like an extension of the patient, rather than individuals who are dealing with all these complexities daily.

"If systems and professionals recognised the needs of my partner more, then possibly my partner wouldn't have as many struggles as they do now, because we would've been able to identify what was needed and put it in place sooner"

"We don't really want to see another carers strategy when nothing actually changes... we are overwhelmed, tired of fighting and tired of not being listened to"



Understanding – a large majority of the carers we spoke with expressed frustration and upset about general misconceptions of being a carer and how this devalues what they are doing. Caregivers explained they are often viewed as almost 'super-human' and are 'strong' or 'built' for the role – just because they are doing it, often not seeing that just like others they are only human and struggle too.

Another element of this was the '**myth of choice**' with many caregivers feeling like others assume that carers are always willing participants and chose the role freely – when many feel obligated and like they have no other option. This was highlighted a lot especially when carers talked about professionals (doctors, consultants and social care) assuming they will take the role on for their partner etc – often without out any asking or even explaining.

"I didn't choose this role, I am doing it because I love the person I am caring for and in reality, no one else will do this – I am not a saint, I am just doing what needs to be done, but it's hard and I could use more understanding"

Coping Strategies

Through our conversations it became apparent that caregivers use coping strategies to help better manage their caring responsibilities. These were varied and it's evident that different strategies suit different people, and that 'one blanket' approach or method wouldn't work.

Here are some of the things that carers are doing to help them cope;



Exercise (this is anything from walking a dog through to arranged exercise classes)



Space and time away from their cared for person. This is in varying amounts – depending on the individual circumstance and support available)



Meditation and breathwork – this was a popular one as it can be done without others or having to leave the cared for person & there are lots of free apps that can support ways to do this.



Time spent outdoors/in nature – This was popular amongst those we spoke to, as this can often be done with the cared for person and doesn't require support from others as much.



Taking time for simple hobbies such as reading, enjoying art, creative outlets that bring joy and fulfilment and gardening.

"At some of my lowest times, an hour or so doing painting or gardening has really brought calm back to me and helped me relax a little"

Some of the caregivers we engaged with whose caring journey had come to an end, talked reflectively about methods of coping that are now more obvious and they wished they had been given the information about using these during their time as a

caregiver as it would have positively impacted them and their cared for person. Some of the carers said that this is where peer support groups run by carers with lived experience could really help. The methods we talked about can be summarised as follows;



Sharing how you feel – sharing your feelings with someone you can trust. This may even be a neighbour or talking to others on Carers forums.



Try to be realistic and recognise that you don't have to take everything on otherwise you feel like you're never achieving anything. Accepting things that you can't change or do alone will help you feel more able to cope.



Finding positives in your relationship with the cared for person – trying to remember that first and foremost you are their partner, family member or friend.



Understanding the link between 'food & mood' and the importance of looking after yourself as a caregiver through nutrition. Simple things like maintaining blood sugar levels and regularly eating and drinking food that release energy slowly for example.



Advocating for carers rights – learning about your rights as a caregiver and feeling empowered to advocate for your needs and the needs of the cared for person.

Carers Assessments & Entitlements

Many of the caregivers we spoke to were unsure if they had had a carers assessment – this quickly highlighted that there is a greater need for those conducting the assessment to communicate what they are undertaking and ensuring it was explained in enough detail, but also outlining the next steps following the outcomes of this assessment.

"Herefordshire Social Services never followed up the outcomes and suggestions made from the assessment – I have never heard back"

Another theme emerged from our engagements on the carers assessments and entitlements that highlighted that many caregivers felt uncomfortable with so many questions regarding financial eligibility for support – several described this as ‘invasive and irrelevant.’

For those who had been assessed as able to access a care support service (respite or sit-in service) the quantity of what they were offered wasn’t sufficient – making it pointless to a certain degree as the caregivers still had to be there as staffing levels of care staff are so low and often the care staff can’t carry out the support on their own. It was noted also that waiting times for support once assessed seemed to be considerable for some.

“ I care for a relative who has dementia and a cardio-vascular long term condition, increasingly their dementia has made them more challenging to support, it was virtually at the point of breaking as I had to wait 8 months for the ‘sit in’ service to start after the assessment – the needs of my relative had changed by then, as they had worsened so the hours we received weren’t suitable when they started- I had to manage all of this while looking after my young children and this significantly impacted their lives during this time”

“You have to be in crisis and beg for support now – unless you are vulnerable you won’t get access to what you should”

Concern for the number of assessments that are now carried out over the phone was also something we heard frequently in our engagements. Some felt this was a fallout from the Covid-19 pandemic that has become more convenient for services and therefore they have continued to do things this way. Caregivers felt that this was almost impossible to fully express what their cared for person is like as an individual and what their personal requirements are for care over the phone.

“Since my son had been diagnosed with autism every single one of his assessments has been completed over the phone – how can anyone assess what a child’s needs are from a phone call?”

It is apparent throughout conversations that respite care in Herefordshire is extremely limited and not always evenly located geographically around such a rural county – meaning that for some it’s impossible to get them to and from respite care without additional costs.

The biggest barrier in arranging a carer's assessment included the lack of response from Adult Social Care or just being denied an assessment on initial request. Many also expressed that a barrier has occurred as they had a lack of clarity between what a carer's assessment was and what a need's assessment for the person, they care for was – as often no explanation was provided.

Carers Services and Support

Herefordshire has a range of free support services available for carers. Some of these services do reach out to the market towns and more rural areas of the county – but many are focused on Hereford City.

Many of the groups that exist in the market towns are peer-support groups – many of the caregivers expressed that while these offer a great opportunity to pop along and, in many cases, take your cared for person with you – it becomes more of a day care drop-in rather than something that is specifically for the caregiver themselves.

Caregivers wanted to highlight in their conversations with us that while they are hugely grateful for these groups, it often does not allow them a place to 'safely talk' to others or decompress away from their cared for person or just allow them to be themselves. The biggest and most positive benefit of these groups for many appeared to be the opportunity to find out contacts for further support or information about carers in general through conversations with others.

The caregivers we met on a one-to-one basis all expressed how they felt the opportunity to talk to someone on a one-to-one basis provided them with a sense of decompression in a different way to what a group setting would allow. It meant they could speak freely without guilt of the cared for person listening. Some suggested that a service that provided this or even individual phone calls or online conversations would be a great way to support caregivers and build a relationship with someone you can trust and regularly see.

Caregivers said they would also like to see hyper local opportunities for training, education and participation in the following areas.

- First aid, moving & handling and medication administration.
- Free or reduced rates for physical activity classes that would support the carers health and wellbeing.
- Digital courses – using computers, emails and social media.

- Courses to build your confidence in caring and making that transition into the role (preventative).
- Personal care (the basics).
- Understanding how the different social & health care teams work together in Herefordshire.



TALK COMMUNITY

DIRECTORY

Community Support

From our conversations and engagement, it is clear that communities play a crucial role in supporting carers by offering practical, emotional, and social assistance. Caregivers that live in strong and well-connected communities felt a difference, they expressed they felt less isolated and better equipped to manage their responsibilities.

Communities can help through;

- **Raising awareness and reducing stigma** – organising local carer appreciation days or similar events, sharing facts and experiences to respond to misconceptions or negative comments.
- **Offering practical help and assistance** – helping with errands, meal preparation or grocery shopping.
- **Create social opportunities for carers** – organising hyper local social events or activities where the carer and cared for person can attend.
- **Check ins** – having a system locally where neighbours check-in with carers to make sure they are ok and provide reassurance they are not alone.

Support in the Workplace

Our representative group consisted of some individuals that had retired already when becoming a carer, some that were in work, some that had to give up work and some that were in education.

All the caregivers talked about workplace support as an important factor in carers managing financially and as part of keeping their identity and career. Many felt that there may be a point in time when they will want to return to their employment and continue with their chosen career.

Many of the caregivers recognised that it is not always possible for employers to make specific allowances around productivity when they have demands to meet themselves. But many expressed that conversations around flexible workload and adjusted expectations would be beneficial. Some also discussed the options of doing a different role within the same organisations that carried less responsibility but allowed them to remain with that employer.

A key theme to the conversations around working whilst caring was the importance of communication about caregiving. If employers can provide an open and inclusive culture around caring, it will reduce shame and embarrassment when it comes to communicating their additional responsibilities.

Summary

From our engagement it is important that we support the voice of carers in being heard and recognised in Herefordshire, often they report feelings of isolation, stress and burnout due to the demands of balancing caregiving with their own personal lives. The voice is often not heard.

Many struggle with insufficient support, both in terms of respite care and professional services, which leaves them feeling overwhelmed. Carers express a desire for increased recognition of their role, more accessible financial assistance, better mental health support and flexible working arrangements. They also advocate for improved training and resources to enhance their caregiving skills and improve the quality of care for their cared of person.

It is apparent from our conversations that carers often hold the solutions that are tangible to their needs but lack the support to make these happen.

Young Carers

In Herefordshire it is estimated that there are up to four thousand Young Carers and that in a recent survey 39% of Young Carers said no one at their school was aware of their caring role. (data from - Herefordshire Young and Young Adult Carers).

Nationally the average age of a young carer is 12, and in the last census over 45% reported a mental health problem because of being a young carer. 29% of young adult carers have dropped out of college or university also.

The young carers we engaged with during this project, through group sessions, were providing care for relatives with a variety of health issues, from addiction issues, mental health issues, long term conditions or siblings with additional needs.

The support they provided was varied, from looking after themselves (such as making breakfast or dinner etc.) through to helping the cared for person get dressed or clean. Some young carers were also acting in an advocacy capacity supporting with appointments or communicating with services if the cared for person struggled with this.

Many of the young carers in the groups we spoke with, talked about the impact of caring for them, including aspects such as not being able to go out with friends as much, not being able to join in with additional activities or groups or having to balance schoolwork with being a carer.

We also heard that within school, young carers would like more support and recognition of being a carer and how this impacts their time and life outside of school. Some felt that there was a lack of understanding from some teachers and other students in school/college about young carers, some had even experienced intolerance/bullying at one time either about themselves or the person they cared for.

Young carers face challenges in planning for their future and this was apparent in the conversations we had with young carers. Due to their caregiving duties making plans for starting in a chosen career path or further education planning is difficult. It was identified that schools and colleges can do more to support young carers. Some of the ideas discussed were around;

- **Provide college or vocational education pathways** compatible with caregiving responsibilities like online or part-time programs.
- **Help young carers explore scholarships** or financial programs that support students with caregiving roles. Looking at student loans and other forms of financial aid and helping young carers to understand what is best for them.
- **Partnerships with local businesses** and organisations to offer flexible apprenticeships or work experience placements that can be designed for young carers.

- **Support carers to build employability skills** through workshops on things such as CV writing, interview techniques and time management to help prepare them.

Students who had been in school environments where additional support was available – such as dedicated space for carers to work or support from teaching/support assistants or dedicated person they could talk to found this helpful during their time in education.

“I don't feel like the college has support for carers, the teachers don't seem to want to listen when I have tried to talk about my additional responsibilities, and I am trying to explain, it's hard for me to concentrate at home or find the time so makes it difficult to get work done on time.”

Themes

The themes that we heard from young carers echo those we heard from adult carers, about the additional responsibilities not fitting in with education times, the stigma and lack of understanding from teachers and other students can feel very isolating and frustrating and affects how supported the young carers feel.

Also just like the adult caregivers we spoke with, almost all the young carers said that their most significant cause of stress and anxiety was the concern about their loved one's health condition and the overall wellbeing of them. However, the other challenges they faced can be themed as follows;

- Feelings of guilt and isolation
- Depression (from long term caregiving leading to emotional exhaustion and depression)
- Pressure and responsibility
- Exhaustion and fatigue
- Neglect of their own health
- Lack of recognition and support
- Invisibility of their role



Services for Young Carers

In Herefordshire the Young Carers we engaged with all interacted and used support services provided by [Herefordshire Young and Young Adult CIC](#).

The young carers using this service spoke very positively about what the group provides and the connection to other young carers that it has facilitated. Enabling them to meet, access opportunities and have a break from their caring role.



Recommendations for Young Carers

- Council to work with schools and colleges to ensure that Young Carers can be identified by staff to ensure they get the proper support needed.
- Carers support groups in schools and colleges – they can be teacher or peer led.
- Raise awareness of the different types of health conditions that young carers are giving support for, to reduce bullying.
- Raise awareness of Young Carers amongst student population to help reduce stigma and bullying.
- Make reasonable adjustments in education for young carers which consider the challenges at home (adjusted deadlines, quiet space in school, permission to have phones with them).

Summary & Recommendations

By gathering the lived experiences of carers in Herefordshire, we've highlighted key insights and given carers a platform to be heard. It's evident that carers often feel

misunderstood and lack sufficient support from both the community and formal systems, intensifying their challenges.

Despite these difficulties, our conversations revealed the remarkable resilience and creativity carers show in managing their responsibilities. This report underscores recurring themes such as emotional strain, social isolation, financial concerns, and the impact on mental and physical health. Through these in-depth discussions, we've also identified actionable recommendations to improve the lives of carers in Herefordshire.

Recommendations

- **Use existing networks setup within the county** – such as Herefordshire Carer Links, Herefordshire Carers Talk Community Hubs etc. to provide specific training, guidance and learning opportunities. Working with local businesses/organisations who can provide this training and in turn raise the profile of carers and support available.
- **Set up information hubs specifically for caregivers**, using existing assets such as GP surgeries, libraries and community hubs – where carers can access up to date information on services and support available locally to them (e.g. respite, financial support, mental health support etc)
- **Improve access to health and social care services for carers**. Looking at reduction in delays in getting through to services, ensuring professionals are identifying carers in their conversations and work to reduce the number of times a carer must re-tell their 'story' to each professional.
- **Support grassroot services through financially supporting peer support groups that provide practical support for carers** – these groups aren't always identifiable in communities as carer specific groups and it is important to recognise this as the support they offer is just as valuable, and as a result feelings of isolation are reduced.
- **Better signposting for Carers** (this could be offered by GP -referred social prescribing) as often these are the initial point of contact.
- **Education and training for key stakeholders**, this could be education workshops for community leaders, local employers and healthcare providers – to be taught to recognise and support caregivers in their respective roles.
- **School & youth programs to support awareness raising** in schools and colleges – through offering talks and assemblies about young carers and about long-term conditions/life limiting illnesses.
- **Collaboration with local business**, an opportunity for local business especially in the market towns to host carer friendly cafes or events and shops could offer discounts for carers during certain times.

- **Carers Charter for businesses** – working alongside local HR providers for business to create a charter or mechanism that allows discussion and support within the workplace.
- **Engage with local faith groups and neighbourhood organisations** to raise awareness of carers in their local communities to support the **reduction of loneliness and isolation**.
- **Use of creative storytelling** – using the work that Healthwatch Herefordshire has started to do with collecting lived experiences of carers, with consent from caregivers or support groups creating short films/documentaries that can be shared through community events or online platforms, which can be a powerful way in raising awareness and reducing stigma.
- **Introduce the Cares Passport** – there is an opportunity to introduce a carers passport system in the county, as done in other area. So they don't have to repeat their story over and over. Like that used within the Learning Disability community.
- **Local websites** – utilise the Talk community Website service to identify carer support groups more readily and enable easier searching through clearer coding and tagging in their system. Also ensure that Herefordshire County website information and signposting for carers is reviewed and kept up to date on a very regular basis – and ask carers to test its accessibility.
- **Clear Service Remit** – raise awareness with organisations providing support and services to carers to ensure they are clear who is responsible for providing what to carers – using Carers Links to manage/co-ordinate this with service providers.

Next steps

- Engage with stakeholders to present the findings of our research.
- Create round table discussions – open community forums where carers and others can discuss the report, share more experiences and explore solutions together which are carer led.
- Continue to provide a platform for carers to have their voice heard and experiences valued.

Behind The Care Appendix

Appendix A – Survey Results & details

Appendix B – Carina’s Story

Appendix C – Stuarts Story

Appendix D – Anna’s Story

Appendix E – Sue’s Story

Please refer to the attached Appendix for these.




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