

CARERS RIGHTS DAY 2023



THE CHALLENGES FACED BY CARERS IN
BRADFORD, HARROGATE, CRAVEN AND SELBY
- IN THEIR OWN WORDS





INTRODUCTION

On Carers Rights Day in November 2023, Carers' Resource invited unpaid carers to share their stories, challenges, and hopes for the future, at events in Bradford, Harrogate, Craven and Selby.

People who look after their relatives or friends were asked: "What are the biggest challenges for you as a carer?" and "What would make your life as a carer easier?"

Carers' Resource held events at its offices in Skipton, Harrogate and Bradford, and at the Selby Carers Coffee Morning, as part of the national Carers Rights Day.

North Yorkshire Council and Bradford Council are currently developing new strategies for unpaid carers, and Carers' Resource wants to ensure that the voices of people looking after relatives and friends are heard.

This report collects together the comments received from carers during the events, along with comments from carers who contributed to the conversation by filling in an online form, if they were unable to attend any of the meetings.

The challenges that were shared will not be hugely surprising to those who work closely with unpaid carers, but they do give an insight into the issues faced by many today.

This is an opportunity to hear from carers, in their own words, about how their lives are affected by looking after relatives or friends.



WHAT ARE THE BIGGEST CHALLENGES FOR YOU AS A CARER?

Key challenges identified by carers included:

Health, education and social care

- Accessing health services
- Waiting lists for mental health services
- Accessing the right support for the cared-for person
- Accessing educational support
- Services not linking together

Respite and breaks

- Accessing affordable respite/breaks
- Accessing suitable paid-for care

The carer's own emotional and physical wellbeing

- Feeling overwhelmed
- Struggling with mental and physical health issues
- Dealing with challenging behaviour
- Lack of time to themselves

Financial and employment issues

- Carer's Allowance too low
- Difficulties balancing work and caring
- Expenses of being a carer

THE BIGGEST CHALLENGES FOR BRADFORD CARERS - IN THEIR OWN WORDS

HEALTH, EDUCATION & SOCIAL CARE SERVICES

Mental Health statutory services are limited, even in crisis situations. Intensive Home Treatment team have increased their threshold for support, First Response takes over an hour for a call handler to answer, My Wellbeing College (now Talking Therapies) have a long waiting time of over 6 months plus which results in cared for needing more intensive support under the Mental Health psychologists which also have a **long waiting list** (cared for still waiting two years on).

Long waiting times in A&E for a **mental health assessment** in crisis situations

I found that the biggest challenge was around receiving **joined-up care** from the carers and the nurses from the GP practice. It was frustrating that they did not communicate with one another.

Loss of **transport facilities** to attend groups.

Health **waiting lists**.

It's a **broken system**.

Getting **support for cared-for** person who has poor mobility and Alzheimer's.

The biggest challenge is getting the **right school** for your child.



THE BIGGEST CHALLENGES FOR BRADFORD CARERS - IN THEIR OWN WORDS

RESPIRE AND BREAKS

Not getting preplanned breaks / holidays. Have been told by Social Services to contact them "when desperate".

How desperate do I have to be after 45 years?

I wouldn't / shouldn't be expected to do a 24/7, 365 days a year job for an employer without proper time off.

I can get direct payments, but I **can't find a carer.**

There's no facility to **vet carers.**

Making **time** for groups is a barrier.

I need support to have a **break.**



THE BIGGEST CHALLENGES FOR BRADFORD CARERS - IN THEIR OWN WORDS

THE CARER'S OWN EMOTIONAL AND PHYSICAL WELLBEING

I believe my current situation will only be helped **when I have a mental, emotional or physical breakdown** or injury or one of us dies.

Little time for supporting myself in the highly physically and **emotionally demanding** role. As an older person, caring for two older people, my own strength and health is becoming severely depleted.

Isolation, for carers without family.

As an unpaid carer, full time, **I go hungry** every lunch time. I care for my mum 24 hours a day, 7 days a week.

No time for carer to self-care – that impacts your mental health and physical health, **it wears you out.**

What will happen **when I'm no longer here?**

Feelings of **overwhelm.**

Having to adapt to a new lifestyle, **not being able to do things** we had planned for our future, or having to change plans at the last minute.

Other family **not supporting.**

There's **no time limit** on when it's going to end.

When carers face their **own health difficulties**, and caring can make it harder for carers to look after their own health.



THE BIGGEST CHALLENGES FOR BRADFORD CARERS - IN THEIR OWN WORDS

FINANCIAL & EMPLOYMENT ISSUES

Working full time allows me to be me, and perform the role I trained for, however **it can be difficult when you are really tired**. I also juggle with a long-term health condition characterised by fatigue. The person I care for has been stuck in all week and likes to get out at the weekend, however this is my recovery time.

The **benefits system** - various aspects including applying, assessment process, lack of resources to help forms be filled in.

The biggest challenge is trying to stay well and **meet all the demands** of work and caring.

A lot of us have **given up good jobs to be carers** and when you look at the amount you get in Carer's Allowance, **it's insulting**.



THE BIGGEST CHALLENGES FOR NORTH YORKSHIRE CARERS - IN THEIR OWN WORDS

HEALTH, EDUCATION & SOCIAL CARE SERVICES

Managing **all the aspects of being a carer** and all the people now involved in our lives i.e. social services, health appointments, paid carers, benefits system etc.

Getting help from **social services**.

Voluntary **carers are treated as 'nothing'** by NHS staff/council/GP surgery staff.

EHCP process not working.

Fighting for everything.

Council staff are **incompetent & inefficient**. I've had to follow up / do the leg work / do the admin, resend forms etc. so much so, it's felt like a part-time job.

Waiting times to speak to a receptionist at a GP surgery is often in excess of half an hour to 45 minutes which seems unacceptable. There is **little understanding** of the surgery about carers and their issues.

Lack of services.

Communications with North Yorkshire care systems - the **system is broken**.

Dealing with all the hospital/doctor/therapist appointments for our son. That's sometimes like a **full-time job** in itself.

CAMHS service **underfunded** - no support until you are in crisis - need more early intervention.



THE BIGGEST CHALLENGES FOR NORTH YORKSHIRE CARERS - IN THEIR OWN WORDS

RESPIRE AND BREAKS

Never being able to plan anything with any certainty.
Support workers don't always turn up, meaning that my husband and I have to step in at the last minute, whatever else we have planned.

Not having time for yourself.

Being tied to the house.

Places for respite care are **too few and too short**

Not being able to get **respite care.**

Not being able to leave my daughter, who I care for alone. No services to help her are available. Not knowing who to turn to in different situations for support.



THE BIGGEST CHALLENGES FOR NORTH YORKSHIRE CARERS - IN THEIR OWN WORDS

THE CARER'S OWN EMOTIONAL AND PHYSICAL WELLBEING

Always feeling as if I'm **constantly on high alert**, managing my daughter's needs. Never being able to switch off.

One of the biggest realisations is that **this is it for ever** and seeing no way out, it is all consuming and leaves no energy, motivation or head space for anything else, it is **truly relentless**.

Feeling **lonely**.

Worrying about the future - what will happen when we're no longer fit to care for our son, or no longer here?

Coping with **behavioural challenges** - at-home stealing, mood shifts, attachment insecurity, past trauma

Feeling **stressed and overwhelmed**, with no help from family.

Rushing from one situation to another.

Having too many people to care for at present and **not having the time to look after myself**.

I live my life in a **constant state of anxiety**.

Never put myself first. Put things off as too overwhelmed.

Getting people to understand that my wife of 44 years will not get better. Understanding is very important.



THE BIGGEST CHALLENGES FOR NORTH YORKSHIRE CARERS - IN THEIR OWN WORDS

FINANCIAL & EMPLOYMENT ISSUES

The threshold to receive care support from the council is very low: if you have approx. £26,000 savings then you can't receive free/discounted care. This is incredibly low; **unless you are broke, you won't receive support.** Even if you are eligible council care support is priced at £25-£30/hour approx, which is the same as private care costs?!

Carer's Allowance works out at **just over £2 an hour**, it should be minimum wage – it doesn't cover lost earning.

Money management, when there **isn't enough** to start with.

Worrying about **having to pay for long term care** when I am not capable of looking after her.

Balancing the household budget taking into account the significant extra costs of disabilities plus the **reduced ability to work** due to caring responsibilities.





WHAT WOULD MAKE YOUR LIFE AS A CARER EASIER?

Key factors identified by carers included:

More support from Government, health and local authorities

- More recognition for carers
- More information and resources
- Reduction of waiting lists/times
- More personalised, joined up support
- Improved health and social care services
- Better SEND provision

More respite and breaks

- Affordable access to pre-planned and emergency respite care
- More groups catering for carers and cared-for people

More emotional support

- More groups for carers
- More holistic therapy/wellbeing activities
- More counselling support
- More peer support groups

More financial support

- An increase in Carer's Allowance
- Statutory sick pay for carers
- A benefits system that is easier to navigate

WHAT WOULD MAKE LIFE EASIER FOR BRADFORD CARERS - IN THEIR OWN WORDS

MORE SUPPORT FROM GOVERNMENT, HEALTH AND LOCAL AUTHORITIES

I would like to feel heard and validated. **Understanding** about the many unpaid carers' role in society needs to be raised at local & governmental level, & **appropriate funding** to provide appropriate resources put in place.

Getting help from **social services**.

More **recognition** of the positive impact of being a carer, personally and in society.

More information and **resources**.

Sympathetic and proactive GPs and Social Services.

Statutory waiting times in Mental Health reduced. **Carers' views are taken seriously** about cared-for's decline in mental health.

To have a key worker who would keep in regular touch with me and **help me navigate the system** and spot when I am getting overloaded and need intervention.

Reduction of waiting lists at CAMHS

Being able to access club **SEND programmes** without formal diagnosis.

Better **understanding of additional needs/behaviours**, in professional staff

Compulsory training in suicide awareness, mental health and unpaid carers for NHS and social care staff

Being able to discuss medical worries when they crop up with the **same local GP** who knows the patient's medical history



WHAT WOULD MAKE LIFE EASIER FOR BRADFORD CARERS - IN THEIR OWN WORDS

MORE EMOTIONAL SUPPORT

I feel there should be some sort of regular provision for **offloading about the stresses and strains** of this role.

More **local groups/satellite groups**.

More **peer support groups**.

Support with **negotiating the difficult & demanding**.

Social contact makes carers feel more positive and more able to cope – battery recharge.

Programmes that support **self care & wellbeing** cannot be underestimated. The carer's role is demanding both physically and emotionally. It takes an immense toll.

Holistic days.

Specific workshops and **groups with caring themes** e.g. groups for carers of Parkinson's/cancer/learning difficulties

I wished that there was more support to carers, not financial but somewhere that could advise on things, like what to expect when the time came at the end or **talk to others in the same boat**.



WHAT WOULD MAKE LIFE EASIER FOR BRADFORD CARERS - IN THEIR OWN WORDS

MORE RESPITE AND BREAKS

A national Care Service similar to the NHS which facilitates **preplanned care** for husband so that I can have breaks, plus **emergency care** when I'm unwell. I've had to manage caring with, for example, broken foot, sprained ankle, wrist injury (in a sling), catheterised at home with kidney infection, pneumonia.

Social/drop-in provision for cared for people.

Knowing that it's ok to **take a break** from caring.

MORE FINANCIAL SUPPORT

More funding - an **increase in Carer's Allowance**

My life would be easier if the Carer's Allowance was increased as we spend a large portion of our income on energy. **I care for my wife over 70 hours per week and my Carer's Allowance is £76 per week.** My wife needs care through the night as she is often confused in the evening and overnight and cannot find the bathroom or understand that our house is also her home. I took early retirement from work and I have to live on a small works pension and Carer's Allowance.

WHAT WOULD MAKE LIFE EASIER FOR NORTH YORKSHIRE CARERS - IN THEIR OWN WORDS

MORE SUPPORT FROM GOVERNMENT, HEALTH AND LOCAL AUTHORITIES

Access to real **day to day support**, such as help locating/introductions to resources, particularly in relation to my partner who has complex mental disabilities and other co-morbidities.

To have more places **disabled-friendly**, accessible.

Named person (as well as [**Carers' Resource locality worker**], who has been fantastic) to call who can take relevant actions.

A **mentor** to turn to in times of need, especially out of working hours.

Better **communication between services** with joined up thinking and working.

If the local **council were more efficient** and competent. I have numerous examples of them providing a poor service.

Better **cross boundary support** - education is NYC, Health BDCT - don't always work together

Access to **earlier mental health support** for me and my child.

To not have to constantly **wait for medication**, from neurologist, to specialist, to GP.

Support to get my daughter **back into school** as education are not doing anything.

More **support for children** between mainstream and special school would help me.



WHAT WOULD MAKE LIFE EASIER FOR NORTH YORKSHIRE CARERS - IN THEIR OWN WORDS

MORE EMOTIONAL SUPPORT

Dignity and respect for unpaid carers and our true value being recognised for the skills we have.

The help I receive from [Carers' Resource locality worker] in Skipton is amazing. **I know that she's there for me** should I need help and or support.

Local carers group providing **realistic support and contact**, a regular casual drop in session (coffee & chat with the opportunity to get some quick advice) especially in rural areas where isolation is an issue.

More groups like the **cognitive therapy** group in Skipton.

More group meetings so that we can meet like-minded people and **talk through troubles and share**.



WHAT WOULD MAKE LIFE EASIER FOR NORTH YORKSHIRE CARERS - IN THEIR OWN WORDS

MORE RESPITE AND BREAKS

Someone to look after my wife for **half a day a week** free.

Having **time off.**

A meeting for **both carer and cared-for to attend**, where they can participate.

Access to a **sitting service.**

MORE FINANCIAL SUPPORT

Better pay!

Carer's Allowance to be paid in line with a **living wage.**

Many benefits are not claimed now. **A carer should be helped to understand the benefit system** as such as lot lies unclaimed.

A proper Carer's Allowance that actually reflected the amount of work carers do and the huge amount they save the budget compared to providing paid carers (even could those carers be found). Quite honestly **Carer's Allowance in its current amount is an insult.**

Statutory sick pay for all carers - I can't afford to be ill/off work.



NEXT STEPS

Carers' Resource will share this report with Bradford Council and North Yorkshire Council, who are currently drawing up new carers strategies.

We will also use the findings in this report to develop our own services for the future. Many carers raised the need for more respite and breaks, more wellbeing and emotional support, and these are areas we are exploring in our plans moving forward.

Carers also expressed the need for more support from Government and statutory services, and more recognition of carers in society, and Carers' Resource will continue to campaign on this and many other issues affecting carers in the districts of Bradford, Craven, Selby and Harrogate.

A huge thank you to all the carers who took the time to contribute to this report. We know how valuable your time is and we appreciate everything you do.

Thank you also to the professionals from Bradford Council and North Yorkshire Council who came to our events to listen to what carers had to say in person.

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