

The background of the cover is a photograph of an elderly couple walking away from the camera on a path through a wooded area. The man is on the right, wearing a green and white striped sweater, and the woman is on the left, wearing a dark sweater. The path is paved, and the trees are in the background with some green foliage. A large blue diagonal graphic element is overlaid on the right side of the image.

# **CARING IN NORTHUMBERLAND REPORT**

**MARCH 2024**

CARERS NORTHUMBERLAND ANNUAL SURVEY



# INTRODUCTION

Over the past year, there have been several reports published regarding the state of unpaid care in the UK. These reports, from Carers UK and Carers Trust, highlight the issues and concerns of many unpaid carers across the country. Carers Northumberland wanted to find out what the local picture for unpaid carers in Northumberland looked like and whether it reflected what was being reported nationally. 214 unpaid adult carers completed the survey throughout January 2024, Carers Northumberland would like to thank them for their responses and for their very candid experiences of what it is like being a carer in Northumberland right now.

The survey was focused on finances, access to health and social care and carer wellbeing, with some additional questions for carers who were supporting someone with a dementia diagnosis.

Carers Trust, in their 'Pushed to the Edge: Life for Unpaid Carers in the UK' stated that the top three things that unpaid carers said would make a real difference to their lives were more money, better support for the person they care for, and a break from providing care. The results from our survey, combined with the comments from carers, reinforces these findings in Northumberland.

Two-thirds of unpaid carers told us that they worry about money. 65% of unpaid carers have used their own money to pay for care, and items for the person they care for. 61% of unpaid carers are providing over 60 hours of care a week, which seriously impacts their ability to work full-time and as a result impacts on the household finances.

50% of unpaid carers feel there are not enough care and support services available in Northumberland, and as a result of their caring role, their own wellbeing, and their family relationships were affected.

Carers Northumberland aim to support unpaid carers of all ages. Further information on the practical and emotional support that is available can be found on the Carers Northumberland website [www.carersnorthumberland.org.uk](http://www.carersnorthumberland.org.uk)

**7180**

**CARERS**



Registered with Carers  
Northumberland (Feb  
2024)

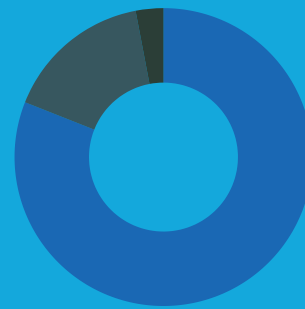
# DEMOGRAPHICS

In section 1 carers were asked about their age, the age of the person they care for, the hours they spend caring each week and the condition of the person they care for.

## AGE OF CARERS



## CARED FOR



81% care for an adult, 16% care for a child, 3% no longer care

## TIME SPENT CARING



61% are caring for more than 60 hours each week

## CARED FOR CONDITION



***"I just feel I have no time for myself."***

***"I feel stressed as there is not enough support out there for the people I care for. They rely on me to be the one constantly offering care and I am starting to feel burnt out."***

# DEMENTIA CARERS

Carers who told us they look after someone with dementia were asked some additional questions about their experiences of dementia services in the county.

**57 carers of  
someone with  
dementia  
answered the  
survey**

**26% have not  
accessed any  
dementia  
services**

**Nearly 50%  
would be  
interested in a  
dementia day  
centre**

It is estimated that there are over 5000\* people in Northumberland living with dementia. The total cost of care for people with dementia in Northumberland currently stands at £203 million pounds\*, and set to increase to £359 million\* by 2030.

Carers report that there is a lack of provision for people with dementia in Northumberland, that waiting lists are long and that there is little consistency across the county. Those who have accessed memory groups or other voluntary sector led services have reported them to be very useful.

***“My mum seems to keep being signed off or dropped between the cracks [due to lack of consistent staff]. Currently its just the GP and me, with no other specialist support.”***

***“I don’t know a lot about what services are out there.”***

***“No support available for the practicalities of day to day [living] when the person still has capacity.”***

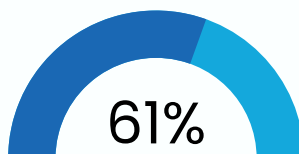
***“All the services we have used have been good, the memory group was really helpful.”***

\*Data provided by Northumberland County Council, JSNAA dementia document.

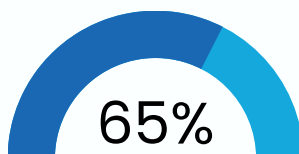
# FINANCE

## CARERS ALLOWANCE

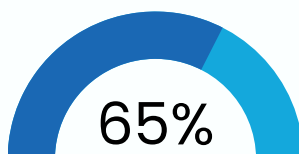
Carers Allowance is a benefit paid to people who look after someone for 35+ hours per week. This benefit is the lowest of its kind and is paid at £76.75 per week (23/24). This benefit is only available to people of working age who earn less than £139 per week. You cannot claim if you are over state pension age, if the person you care for does not claim a disability benefit or if you are in full time education.



told us they do not claim Carers Allowance



said that Carers Allowance was not enough to meet their needs



told us they have used their own money to pay for care or items for the person they look after

***"I work full time and financially I am really struggling which upsets and worries me. I don't know how people manage."***



2/3 told us they worry about money



1/4 said they worry about money right now



1/3 said they worry about money if something was to happen



1/2 said they worry about money in the future

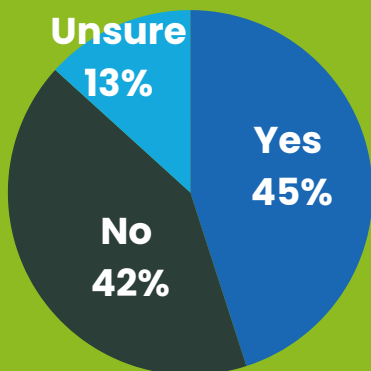


1/3 said they worry about savings running out

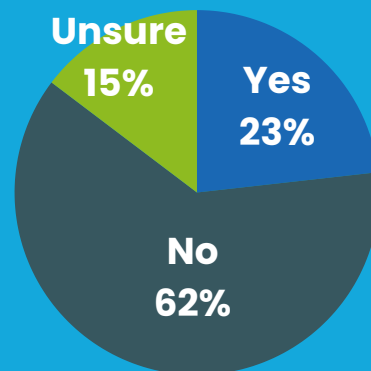
# HEALTH AND SOCIAL CARE

Around half of the carers who have accessed a Carers Assessment told us that it was useful to them. 59% of carers responded that they and/or the person they care for do not access any care services. Of those who do access services around 3 in 5 were supported by the local authority to arrange them.

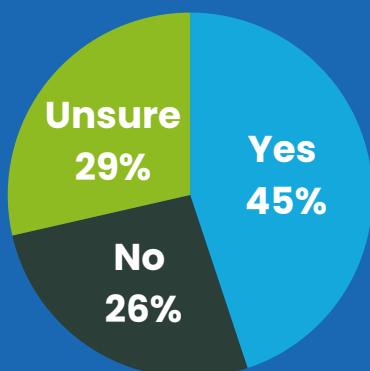
## CARE NEEDS ASSESSMENT COMPLETED



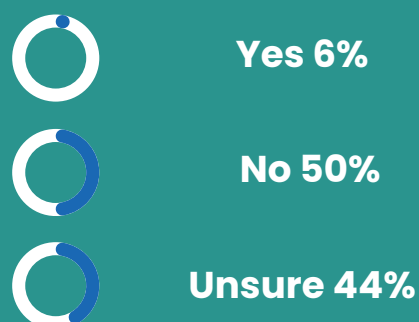
## CARERS ASSESSMENT COMPLETED



## WAS CARERS ASSESSMENT USEFUL



## ARE THERE ENOUGH CARE SERVICES IN NORTHUMBERLAND



***“Social services support has been generally excellent”***

***“[It is] hard and unsupported, on summary. Because we were not using services care manager was withdrawn and we were abandoned.”***

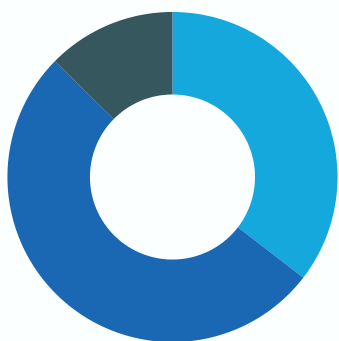
# WELLBEING

Has your caring role caused you to feel more:



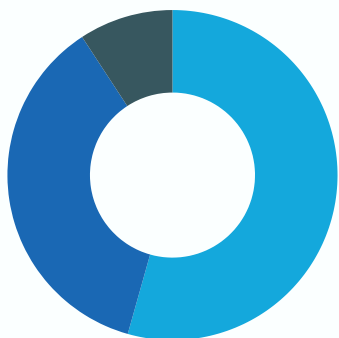
**Only 8%  
responded  
they felt none  
of these things**

***"Its really hard at times, with no support for the carer"***



Had a break in the last 12 months:  
Yes 35%  
No 52%  
No, but I did not want one 13%

***"It is very stressful being a carer, very draining. There are so many emotions to go through. It helps to talk"***



Relationships negatively affected by caring role:  
Yes 55%  
No 36%  
Unsure 9%

23% of carers told us that they have left their job or reduced hours at work in the last 12 months due to their caring role. Carers also told us that they have taken sick leave to care, have used annual leave to care and feel they are unable to seek promotions.

***"It is a struggle to look after your own mental health as well as caring for a family member."***

***"Frustrating and lonely."***

# SUMMARY

While the report highlights many of the negative feelings and experiences of unpaid carers in Northumberland, Carers Northumberland is committed to supporting carers, responding to their needs, and sharing the voice of carers with service providers and decision makers in the county.

Carers Northumberland are already in a partnership with North Tyneside Carers' Centre and Newcastle Carers, funded by the North of Tyne Combined Authority to support unpaid carers into sustainable employment, volunteering opportunities, education, training, and support carers who are in work to maintain their employment.

Carers Northumberland are also supporting the distribution of the Household Support Fund to carers who are in need of additional financial support with household essentials.

Carers Northumberland are working with Northumberland County Council's Adult Social Care, Children's Social Care, and other health and social care providers to improve services for adult carers of adults, parent carers and young carers and find innovative ways to support carers to access respite and breaks from their caring responsibilities. This report will be shared with all key stakeholders in the county with a responsibility for carer support services.



107 & 109 Station Road  
Ashington  
Northumberland  
NE63 8RS

Tel: 01670 320025

Email: [info@carersnorthumberland.org.uk](mailto:info@carersnorthumberland.org.uk)

Web: [www.carersnorthumberland.org.uk](http://www.carersnorthumberland.org.uk)

Registered Charity: 1122972 Registered Company: 6266972

***Attached appendices show original survey questions sent to carers and their individual responses to questions 7 and 29***



# APPENDIX 1

## Annual survey questions

If you would like any support to complete this survey or would prefer to answer over the telephone our friendly team are happy to help, call us on 01670 320025.

Our annual survey helps us to plan new services, ensure that we continue to support carers the way they want to be supported and help us to understand what is important to you.

By taking part in our survey you have the opportunity to be entered into a prize draw, please complete your personal details at the end of the survey if you want to be entered.\*

Thank you to everyone who takes part, your answers really do make a difference and help us to continue our work supporting all carers in Northumberland.

*\*Anonymous surveys will not be entered into the draw. Only one survey per carer will be entered into the draw. Winners will be notified once the survey closes.*

### About your caring role

#### 1 - Your age

☐ 18 - 65

☐ 66+

#### 2 - Who do you look after

☐ Someone over 18

☐ Someone under 18

☐ I am a former carer

#### 3 - How many hours do you spend caring each week?

☐ 0 - 20

☐ 20 - 35

☐ 35 - 60

☐ 60+

#### 4 - Does the person you look after have:

☐ A physical disability / health condition

☐ A mental health condition

☐ A learning disability / sensory needs

☐ Dementia\*

*\*If you answered "Dementia" on this question, please continue to answer the next section. If not, please skip to the Finance section, question 8.*

## Dementia Carers

5 - What dementia services have you / the person you look after accessed?

- |  |   |   |
|--|---|---|
| <input type="checkbox"/> Support through GP                                  | <input type="checkbox"/> Memory groups          | <input type="checkbox"/> Specialist advice services |
| <input type="checkbox"/> We have not accessed any dementia specific services | <input type="checkbox"/> Other (please specify) |   |

6 - If there was a specialist dementia day centre in Northumberland, would you make use of this?

- ☐ Definitely
- ☐ Likely
- ☐ Unsure
- ☐ Unlikely
- ☐ Definitely Not

7 - Would you like to tell us anything else about your experiences of dementia services in Northumberland?

## Finance

8 - Do you claim carers allowance?

- |   |                                       |  |
|---|---------------------------------------|--|
| <input type="checkbox"/> Yes *Go to #11 | <input type="checkbox"/> No *Go to #9 | <input type="checkbox"/> Unsure *Go to #11 |
|---|---------------------------------------|--|

9 - If no, why not?

- ☐ I am not entitled because I am over retirement age / claim state pension
- ☐ I am not entitled because my income is too high
- ☐ Someone else claims carers allowance for the person I look after
- ☐ Unsure / have not checked if I am entitled
- ☐ Other \_\_\_\_\_

10 - Is the amount of carers allowance enough to meet your needs?

- ☐ Yes ☐ No

11 - Do you claim any means tested benefits? *Means tested benefits are based on your income and include things like pension credit, housing benefit, council tax support, universal credit and working tax credits.*

- ☐ Yes ☐ No ☐ Unsure

12 - Have you accessed a grant in the last 12 months? *This could be a grant from Carers Northumberland or any other source to help pay for household goods, groceries, respite / taking a break, energy costs, travel or anything else.*

- ☐ Yes ☐ No ☐ Unsure

13 - Have you ever had to use your own money to pay for things to support the person you care for? *This could be using your own money to cover additional care costs, paying theirs bills / debts or other costs, buying disability aids or adapting the home.*

- ☐ Yes ☐ No

14 - Do you worry about money? *This could be now or in the future*

- ☐ Yes \*Go to #15 ☐ No \*Go to #16

15 - If yes, do you worry

- ☐ About money right now (low income and struggling to pay bills)
- ☐ About money if something was to happen (home repairs / replacing broken items etc)
- ☐ About money in the future (future care costs, rising bills etc)
- ☐ About savings running out

## Health and Social Care

16 - Has the person you look after had a care needs assessment completed by the local authority?

☐ Yes

☐ No

☐ Unsure

17 - Have you had a carers assessment?

☐ Yes \*Go to #18

☐ No \*Go to #20

☐ Unsure \*Go to #20

18 - If yes, was this done separately from the person you care for?

☐ Yes

☐ No

19 - Was it useful to you?

☐ Yes

☐ No

☐ Unsure

20 - Do you / the person you care for access any care services?

☐ Care Home / Residential Care

☐ Home Care Services (care providers coming into your own home)

☐ Day Centre

☐ Respite Care

☐ Direct Payments

☐ No we do not access services \*Go to #23

☐ Other \_\_\_\_\_

21 - Do you / the person you care for pay for these services?

☐ Yes \*Go to 22

☐ Partly \*Go to 23

☐ No \*Go to 23

22 - If yes, did you have help from the Local Authority to arrange these services?

☐ Yes

☐ No

23 - Are there enough care services in Northumberland? *By care services we mean home care providers, day centres, respite services and care home spaces.*



☐ Yes

☐ No

☐ Unsure

## Health and Social Care

24 - Have you had a break from your caring role in the last 12 months? *This could be officially arrange respite, or a break organised with the help of family / friends*

☐ Yes

☐ No

☐ No, but I did not want one

25 - In the last 12 months has your caring role caused you to feel more:

☐ Stressed

☐ Worried

☐ Tired

☐ Lonely

☐ None of these

26 - Have your relationships been negatively affected by your caring role in the last 12 months? *This could be relationships with a partner, family or friends.*

☐ Yes

☐ No

☐ Unsure

27 - Has your caring role had an impact on your employment or education in the last 12 months?

☐ No / Not applicable

☐ I have left my job due to my caring role

☐ I have reduced my hours at work due to my caring role

☐ My studies have been affected by my caring role

☐ Other \_\_\_\_\_

28 - Would you like some additional support with employment, education or training?

☐ Yes

☐ No

*If yes, please provide a contact name and telephone number / email at the end of the form*

29 - Can you tell us what it is like to be a carer in Northumberland right now?

*This is your opportunity to provide us with a snapshot of what life is like for you right now, we will use these answers to demonstrate the current state of caring in the county and to help us to communicate with the local services that carers may access.*

### Your Details

*All carers who complete this section will be entered into a prize draw. Winners will be drawn at random and will receive a shopping voucher.*

*Please ensure you complete this section if you are happy for a staff member to contact you to discuss your answers or would like further information on any of the topics covered.*

Full Name

Address including Post Code

Telephone number / Email

If you have any further questions or comments please include them here

Completed forms should be posted to (no stamp required):

FREPOST RTRU-UKLY-CSAR, 107 &109 Station Road, Ashington, Northumberland, NE63 8RS

# APPENDIX 2

## Annual survey all quotes

### **Would you like to tell us anything else about your experiences of dementia services in Northumberland?**

- Mum is now in residential care, but I will still keep taking her to signing for the brain where possible.
- No support available for the practicalities of day to day when person still has capacity. For example where to buy a watch that is digital with no other features. How to help with reading. What activities to do when they don't want to colour in, do jigsaws, craft which is all that gets suggested. No follow ups or monitoring, just left to own devices after diagnosis. No info on when to increase dosages, change meds etc
- It currently feels there is not a lot of services out there
- All the services we have used have been good. The 7 week memory group was really helpful
- Living in Rothbury is not easy to attend memory groups, it all depends where the day care will be in Northumberland
- Memory services were very helpful
- I don't know a lot about what services are out there.
- Mum doesn't need them at the moment but there may come a day when we will.
- don't know any
- I have found them very helpful
- Just a sad time
- I would like more meeting to be held in Cramlington
- Mum has the dementia – refuses to go to these groups. Ho Hum.
- My mum seems to keep being signed off or dropped between the cracks of temporary people at the Fairnington Centre. Currently it's just the GP and me with no other specialist involvement.
- Not a lot in the west
- Haven't had to access any services yet but I think that the time is near when I'm going to need advice and help.
- No practical information available. Want advice on what watch to buy, what activities to do when they are male and don't like suggestions offered (jigsaws, colouring in, crafts etc), but only get advice on respite or personal care which is not needed yet.
- My hubby has passed away but the support I got was good lots of support from social care and carers of Northumberland
- Have a great key worker who gives me support. Haven't had to access outside help yet but think that I will need some respite care for my husband this year.

### **Can you tell us what it is like to be a carer in Northumberland right now?**

- Like entering hades Unless you meet someone else also in the same position, they don't understand
- Hard work, tiring, stressful, lonely but necessary to keep my mother alive and with the best life she can have without her worrying.

- Stressful
- Often feels unsupported when I have things like medical appointments and no provision for care so I can attend
- It is very stressful being a carer, very draining. There are so many emotions to go through. My whole relationship with my mum changed with her dementia. I attend a local carer group in Blyth and it really does help to speak to other people in a similar situation. It helps to talk.
- Hard
- We haven't had any council supported respite care for our son for over 10 years. In the summer he had a breakdown and we asked for an emergency placement...we're still waiting, we were granted 4 weeks respite but no help or support finding or securing a placement!
- I have no family help, I am exhausted and miserable most of the time. I never expected to become a carer for my husband and I don't feel qualified to do it.
- It is really hard at times with no support for the carer
- No one cares. No follow through since diagnosis few years ago
- Too hard no help
- I don't feel like I am a carer, I am a wife looking after my husband.
- Rubbish, the only support we get with 2 children with disabilities is from community groups/charities!
- Scary. The threat of money being further and further restricted by this inhumane government is always on my mind. We care for 3 disabled children, my husband does not work as he needs to be at home with the kids while I'm studying. Even if he could get a job he would lose the pitiful carer's allowance so there's no point. It's exhausting and we're terrified for our kids futures.
- I work full time for the NHS. My son has ASD and attends mainstream school. Transport was not granted for him so myself, my husband and 2x private drivers transport my son to and from school. Very hard – transport should be provided by LA. We love our son but it is hard to look after a child with additional needs 7days/ week. More services and respite is needed for working parents.
- Hard
- Without begging for it help is virtually non existent
- Tiring, isolating, limiting, tense, mediator, advocate, parent carer, no real time to self on a weekly basis. Worry about future and how role would be fulfilled if anything happened to me as there is no service which supports access to my child to develop a trusting relationship with anyone else.
- Tiring trying to find the support needed
- Hell. NCC do not assess you correctly using the parent carer assessment. Provide minimal direct payment that don't cover needs or costs. Unqualified lack of understanding professionals who speak out of their remit don't know the law and think they're above it. As a registered carer then say your not and that as a disabled adult and children that you don't have needs and go as far as to say your not autistic.
- Both child and family assessment parent carer assessment stand alone and two DCT assessment unlawfully conducted and what at the moment in time have been subjected to alleged do a rumination harassment and victimisation. To be told after 11 years of battling we have been under the wrong team and been assessment by those that are not qualified in the area of expertise needed verbatim.
- The trauma inflicted by these so called teams and services and continued to so of what was unbiased conscious is not biased and having three children with complex need and a caring for them 24.7 as not in education with my own needs is hard and feeling of being trapped lonely and in a survival mode situation. The panel who determine needs and decision makers who deliberately don't look at all Facts when making decision has caused and ensured significant damage to my family.



- I don't have any faith trust in services who have failed us on an epic scale or hold them with any integrity until they abide by the legal law and provide adequate support
- Being a parent carer is not recognised in Northumberland, specifically the parent part. The activities, clubs, groups etc I have seen are targeted at carers of adults, not children. They are also not accessible to those who cannot get someone to look after the person they care for whilst they attend.
- It's very hard to get time to self care.
- I worry that, if needed, there won't be help in the house or a place in a care home. I have friends who help out but often feel everything is a bit precarious
- Frustrating and lonely
- Difficult at times but it has to be done
- It is isolating being a carer in Northumberland. Services like CYPS and children's services are an absolute waste of space. They are understaffed and so slow they are more of a hindrance than anything else and children's services cause additional stress and trauma to the children. Neither services listen to parent who know the children the best
- It is a struggle to look after your own mental health as well as caring for a family member
- Hard and unsupported, on summary. We had a care manager at NCC social services, because we were not using services and trying to be independent, the care manager was withdrawn and we were abandoned, which means if there is an emergency we need to go through the whole assessment process again.
- Services are sometimes hard to find and if you don't live near them they can be difficult to access. Especially if you have mental health issues/anxiety getting on public transport can be very daunting.
- There are a lot of thing we didn't know but CN really helped us know what is out there.
- Living in a remote area (Rothbury) if I were to attend any meetings it is a very long journey to our nearest destination. We used to have a day care in the village but it has ceased to exist, I don't know why.
- I am almost 89 (January) therefore I do find I get very tired by evenings. We did have carers for 30 mins each morning rather unnecessary as their of my ages experience! Therefore I pace myself and use a lot of common sense
- Very demanding and tiring, but the private help me get help enormously relieves the burden
- Life at the moment is ok sometimes things get on top of you and you worry your doing the right thing
- Could do with more help to find a PA with direct payments as have been waiting months, also more respite available
- I'm a parent carer, so just go with the flow and take it in my stride. My daughter needs me and she has nobody else to meet her needs like I do.
- It is a lonely experience with support
- largely only offered by charities.
- I get tired and having health problems myself, it is a lot when I look after more than 1 person
- It's extremely hard. I rely on friends and family to support me. Having the Facebook page Carers in Northumberland is a great means of getting information. Unfortunately I am unable to attend any of the support groups as they are often a distance away from where I live
- Being a carer is hard and do not think nationally as a whole the government does not accommodate enough support and funding
- Money is tight and costs are going up it's an added worry on top of already having a pretty stressful time

- It's hard to be a carer, but I just don't trust anyone else to care for my hubby as they just don't see the everyday problems. It's stressful and affects my mental health and physical health. I look after him and forget to look after myself! I can't trust my hubby to make or attend appointments as his memory isn't good and he is partially deaf which makes things difficult if he is alone at appointments. I work full time but my hours are extremely early till just after lunch so I can work it around my hubby. Without my job, my mental health would be so much worse!!
- Not enough urgent accessible services
- It is okay
- It is a lonely, hard life. My husband is taken out by a support worker from Blyth Star Enterprises 3 times per week for 2 hour periods. It's a great help but not long enough for me to go out for very long.
- I don't get much information on what's occurring in area. A book with groups and grants available would be useful
- I care for my husband full time which I have done for years now. I haven't asked for help because I manage. Sometimes I find myself overcome with tiredness because he doesn't always sleep that which impacts on me.
- My past 13 years plans were shattered by the change of government withdrawing grants to allow me to set up my joinery business to accommodate young adult with special needs. It also resulted in reducing my special needs sons college days, which in turn reduced my working hours. Finally they could not provide a day centre and 1 to 1 care for him despite his care plan stating this is required. I was therefore forced into part time work and then to give up work to provide full time care for him myself. He does receive a personal budget which he has to contribute towards himself. Each time his benefits increase (still below inflation) the amount he pays towards his personal budget increases resulting in his assessed needs are less and less met in financial terms each time, as the cost of these increase his payments to access these reduce.
- Hard
- Its hard work being a carer for someone who has autism
- I live to be able to help people
- Getting people to work via direct payments is problematic- rural area and need to drive raises costs for people to apply for the job when advertised
- I am lucky as my mother and I are both financially secure but we live in a rural location so transport for her to access social events etc is non existent. For us, transport is the main problem.
- Difficult and lonely. I have to work full time to support myself, my husband and two student sons. Because I work, I am not able to access support from the likes of Carers Northumberland. I have two full-time roles - my career and my caring role, which is difficult and exhausting, and there is very little support for people in my position. I have not met anyone else in my position, yet I know I cannot be the only one!
- I don't have my own life and am currently getting a divorce, due in part to my caring role
- Feel that I am not considered worthy of consultation in certain processes and as if I don't really matter

- Hard work. I've been caring for my wife for 16 years, 14½ of those in Northumberland. We moved from terraced housing in the industrial town of Burnley, Lancashire, to the countryside 4 miles outside Wooler. This was to give my wife a better quality of life, as I was working 4 on 4 off 12 hour days, 48 hours, so while I was working my wife was stuck at home. On my 4 days off, however, we had quality time together and I was able to do shopping and take my wife out of the house. We had discussed moving to Northumberland previously, as we had holidayed in the county for 18 years. My wife had planned to retire early from the NHS at age 55. But ill health forced her to retire at 49, so I decided I would give up full-time employment. I knew I could apply for Carers Allowance and top my income up with part-time work, which is exactly what I did. Moving to Northumberland has literally been a life saver for my wife because of the scenery and wildlife around our cottage. An unintended outcome of our move North is that our medical care has drastically improved. We have a fantastic GP, who provides excellent support and medical care for us both. Indeed, medical facilities in general are much better than in Burnley, and a GP slot is 10 minutes, compared to only 5 in Burnley. The only fly in the ointment is Cramlington A&E, where waiting times are absurd! Unfortunately, recent developments in NHS services, and the aftermath of the Covid pandemic, has meant that many of the procedures have gone backwards as Northumberland has moved to working methods "enjoyed" further South.
- Had a lot of input in beginning from memory team going to groups etc but they all finished.
- I feel like there is no support for the person I care for who has both physical difficulties, autism and mental health issues. I feel defeated because I can't get any support to help her. You get an autism diagnosis and then there is no help out there to help her which makes me feel annoyed and alone.
- I work full time and financially I am really struggling which upsets and worries me. I don't know how people manage.
- My experience. Care and support services provided by a care agency is generally very good, although occasionally gaps appear. Mental health services (CNTW) can be patchy, continuity of care is not always maintained. Social services support has been generally excellent. Support from carers Northumberland is very good along with support from escape family support based in Ashington. Obtaining funding for my wife's care was initially far too difficult and a massive challenge. But once in place funding has been maintained and increased.
- My husband is 91 on January 29th 2024, he is registered blind, has the card to endorse this, I was told by RNIB that because of this disability we would qualify for a council tax benefit i.e. - we are in band B and would now be band A. Well, I phoned NCC up. They said did I have a shower downstairs? I said no. Tough, you don't qualify. Well this is one loaded question which for the councils a win win. I know no one living in a house who have a shower downstairs - people in bungalows, someone in a downstairs flat, but for the other 99% a shower is located upstairs, is it not enough that my husband of 66 years is registered blind that he does now qualify unless I shower him in the pantry. Give the man who thought of this a star, wait till he gets old. I live two lives now - meals - making sure food is cut up at times - placing cup to make sure my husband can lift it carefully - sometimes he is lost throughout the night and I have to see him to the toilet then back into bed.
- My husband had a stroke when he was 57, he is 80 now. I have only had help these last 2 years. Also I have just had respite, now it's getting harder.
- Life is very hard at the moment, my partner can not be left for any length of time, but I do manage to see friends and get shopping because my partner has two sons, both help and sometimes it becomes hard to manage with chores etc
- I know if I needed help I could ring my brother's care manager to increase care if I needed a break, Usually friends and family step in to help me

- Disappointed with total each of respite care available and government
- Very stressful. One call 24hrs a day in case emergency call button is pressed, lack of quality respite care and what is available is expensive.
- all the staff friendly and very helpful. If I need help they give me advice and information. Thank you very much for help.
- I just feel I have no time for myself. I do my shopping early morning before my husband gets up otherwise I have to ask someone to sit with him, his mobility and eye sight is really bad.
- I enjoy caring for my husband even though at times it can be very frustrating and tiring. He has been very caring husband so now it is my turn to care for him
- I know there's help out there if I need it. I have phone numbers I can ring and I know carers Northumberland would help me if needed
- We appreciate our care worker who comes every morning to shower my husband. But I worry about their working conditions as they rush from person to person and get no travelling time allowed. It worries me as much as looking after my husband.
- I provide care for my father in law and mother in law as they both have caring needs. My father in law has Alzheimer's and my mother in law was struggling to cope with his needs as well as her own health needs. I provide emotional care and arrange appointments, lifts, help with organising/cleaning, shopping, gardening, days out with my husband too.
- I am the main carer for my husband who has numerous health conditions, including heart failure, prostate cancer and diabetes. This has changed our husband/wife relationship as he can no longer do things we used to do together, like travelling, walking etc. I am now more of a care giver than a wife. This can make me feel lonely at times and sometimes a little envious of friends who do not have these issues.
- Carer for husband who is a very private person, so we manage fine 24/7
- Life is more tiring because I have to do all the household chores, gardening, shopping, driving and finances as well as assist my husband with practical things and sort out and administer his medication and drive him to medical appointments
- I seem to have more things to do for my wife but I don't mind but life seems to get just that little bit harder for us both as we are 80 years old. I think there is help out there if you look for it.
- I have met some really lovely kind people because of my husbands dementia. I never thought I would be sat in a group of people with dementia and their carers talking, laughing, singing. How my life has changed, but its not all bad its different then my previous life but there are good bits
- Very stressful at moment. But my husbands brother is very supportive and our son has moved nearer to help.
- I feel that there are not enough specific services for dementia because of the number of older people and the increase in dementia. And I cant see a light at the end of the tunnel because pf the demands on all health care and social care services
- well winter is the hardest time of year for me my dads in bed a lot more
- I try to get out as much as possible but I cant get fishing that's the only time I get a break
- All a sad time
- I feel it is something we have to get on with atm. I am more busy now having to do all the driving, shopping, organising the house etc etc. But isn't this all part of married life - take each day at a time. Trying hard to deal with events as normally as possible.
- I feel on my own a lot, I have to be home 3 days a week as I have to let the nurse in so that they can see to my partner. They cannot say what time they will call, so I have to be in all day for them
- It is stressful at times so my wife I try to get away for breaks and my daughter takes over the care
- The person I care for is my wife, so I am prepared to give all the help and support she needs for the present



- finance, tired, stress
- life can be hard once you come 65 you cannot get any benefits to look after someone
- I care for my wife – married for 69 years, a privilege for me. Help is always available through you, my daughters
- I enjoy carers meeting, it gives us all a chance to chat. Also was a great help to me when I lost my husband.
- Difficult – we moved over here, 100+ miles away from our jobs and friends and life to help mum as it's too expensive to buy in all the help and support she feels she wants and it's not always available anyway. So we now commute & hotel back over to work (which adds a lot of cost and time), we still need to work full time and on top of this support mum. We struggled to access advice before moving over on progression of Dementia, what support is available and whether we actually needed to move at all (i.e. was the help she needs available, would she need it and for us what would their personal cost be of moving over – turns out very high) Now we're here mum has given up trying to do anything for herself, and expects us to be there at the drop of a hat which isn't easy when you're tired all the time and have no time for yourselves as it is.
- I am going to spend more time with my daughter who is 16 and my son is 20 as due to my caring role I feel we don't do so much together like going out for the day early as walks around lakes etc
- Always trying to get hold of social workers. Social workers always changing leaving messages
- two people's lives have been drastically effected here. I am unable to go out alone without paying for a companion to come in as he is unsafe to be left alone. i.e., hairdressers, hobbies, shopping. A safe and secure drop in centre in Hexham would I'm sure be well used
- It is very tiring
- Life is ok at the moment, I have plenty of telephone numbers to contact if there is any problem
- Carers Northumberland have been my own personal saviour. As my care role is a lot of support mentally, over the phone help is greatly appreciated
- We are coping for the moment, my wife can not walk unaided. She has a walker. I still drive, her wheelchair lives in the front of the car, she is a blue badge holder so that helps
- I was never able to access any help or support whilst I cared for my son who has mental health issues. I have cared for my son since the age of 17 when his illness became worse. He would not see anyone and did not believe he was ill. His paranoia and phimosia continued to get worse. Because he was an adult I was not able to get any health care or in fact any help at all. For eight years I was the only person he would see so I did everything. Sadly his psychosis became very bad and he made an attempt on his life. He was sectioned and still currently at St George's hospital. It has only been due to this terrible incident that my son and I have been given the support needed.
- Difficult as unfortunately income is too much therefore have to pay for majority of care. Also not sufficient carers available in north Northumberland or respite placements, it is so stressful to fulfil my mother's wishes, to stay at home
- I am 82 years old and suffer from multiple sclerosis. We have 2 carers 3 times a day and lots of equipment to make life easy – hospital bed, steady stand, commode, ceiling hoists in bedroom and lounge, I manage during the days but because of MS become very exhausted by night
- My life is ok at the moment apart from knowing what entails with Parkinson's carers from burn brae are second to none
- The provision of items to assist my husband and respite has been excellent. As he is now house bound the district nurses are wonderful. I care as a wife but the addition of all the jobs my husband used to do around the house as well as coming for his needs

- There are times I feel very lonely and tired, as my immediate family are unable to help very much. And I don't think they totally understand caring for a person with dementia. They appear to have more sympathy for their dad other than with me. I run our house and finances, keep my husband clean. The treats I take for myself is going to the hairdressers twice a week as I am only gone for 45 mins and he is able to be left for that length of time
- when looking after my husband for nearly 7 years, felt completely alone. When he first collapsed and ended up in hospital I was strongly advised to put him in a home by hospital staff, doctors, nurses, social services. I said if he went in a home it would be my say, not anyone else's
- We have only just moved in last 3 months. We're in process of transferring a care package that was a direct payment from Co. Durham & waiting for decision from senior management in social care. Unfortunately there's not a lot of facilities that meet daughter's needs i.e. special needs theatre group etc. However our appointed social worker is helpful & had found 1 that maybe suitable 25 mins away for 1 day a week.
- Hard work which will get worse when dementia takes over completely
- Feel stressed as not enough support out there for people I care for. Rely on me to be the one constantly offering care and starting to feel burnt out.
- Hard work
- My husband is a double amputee and wheelchair bound. he is reluctant to accept outside carers.
- We have Valley alarm and a lady who cleans two hours a week.
- Tied to the house. Only able to go out for a limited time. Always click watching. Disturbed nights. Having to answer endless questions and not believed.
- Help & support is difficult to access when living in very rural areas, most services are based in towns.
- I care for my husband who is 81, I am 76. I receive good pensions from my late husband. So presume I cannot claim anything. My husband is totally blind, has an implanted defibrillator/pacemaker and is on the waiting list for a prostate operation, so he has a catheter. He is mobile but we are limited as to walking far at the moment by the catheter. I have recently lost a lot of my sight in one eye due to MD. Though still legal to drive, I think I will have to give up my licence this year. I have arthritis in my neck and shoulders so have an Age UK domestic helper for an hour a week to do my ironing, vacuuming and cleaning.
- Apart from Carers Northumberland I have had to find support by myself. there are lots of classes but think struggling with funding so unsure what future will be like. doctors once was the person you could go to but now it difficult and getting to see them even waiting to get through to Dr r a joke
- Always tired but will continue
- Being a carer is extremely difficult. Limited access to services with long waiting lists make it very difficult to get professional advice and intervention. It makes the road seem very long with no sign of a light at the end of the tunnel. It worries me for the future and what caring services will look like as he reaches adulthood
- I love calmer therapy services and team they are always very friendly and helpful. Having that on our door step is brilliant and online help too thru social media of fb pages like calmer therapy and carers Northumberland. I'm not sure what other help there is available in my immediate area Morpeth and beyond in Northumberland.
- My son requires bespoke provision for weekend residential respite, however we have been told that only group living is available. This does not meet my son's needs.
- Difficult, tiring, sometimes feel alone and desperate.

- The caring role that I provide to my children is such that I would be completely unable to return to work in the next few years. There are insufficient wrap around and holiday care options for disabled children in this area. One of my children is on a reduced timetable from school as he is unable to access full time school. There are vastly insufficient school facilities in the West of Northumberland to cater for the children with SEND that live here and it is unacceptable that a child with needs should have to sit in a taxi for 1.5 hours a day to get to a school that is able to cater to their needs. As such, I'm unable to work and cannot see this changing in the near future.
- Lonely and unappreciated
- There isn't enough support
- Rewarding but hard work
- I look after my husband 24/7. We have no support, but manage. I take care of everything, his meds, ordering it and making sure he takes it. I have to wash and clean his legs, he has no feelings so doesn't know when he needs to go to toilet.
- Being a carer is new to me but I was lucky as carers Northumberland use the community centre I run in Blyth as a carer meeting place. This means I can pop in when the group is running whilst at work. They supported me especially at first with info I wasn't aware of, thank you for all the support
- as a carer I seem to be always tired and stressed. I also have a few things wrong with me such as diabetes, irregular heartbeat, anaemia
- I don't feel I can fill this in now as my husband passed away
- No one expects to be a carer and for years I was just a mam. But then things change and everyday things get harder
- It's fantastic. We moved here 3 years ago because I hoped it would give both of us a better quality of life but it's better than I thought it would be. Lots of beautiful places to visit, friendly locals and plenty to do that is free. My son has thrived and I feel very lucky.
- I just get on and do it no day is the same life has to go on
- Lonely and stressed
- I have done it for so long now, it is just a way of life!
- Hard, tiring stressful and very lonely. No me time
- Not enough time for myself not eating or sleeping properly
- Hideous
- Very isolating compared to ten years ago when I cared for my father, less involvement from health and social care, and fewer charitable organisations around to help, e.g. handyman, gardening services, volunteering services for sitting with cared for person
- Sometimes I get very tired because of my age. We do get respite but this is only in Blyth which is a 3 hour round trip. It would be good if we had this closer to home. My caring role is full time, she does go to a day centre which helps giving some time through the day
- We get no support from the County Council, if it wasn't for Council Tax they wouldn't know we exist. The Environmental Health has visited our rented property twice to look at damp and mould problems, but our landlord has done nothing to rectify any of the causes. In the New Year I will contact my union to see if they can help, and if I can claim compensation or a rent reduction.
- Some days can be stressful. Wait times to access services needs to be looked at, also activities for adults with autism needs to be improved.
- It's ok but I worry about the future
- Sometimes worry as to whether home care will stop short notice as this happened at the start of mams care
- I look after my husband who has mixed dementia, we no longer go away he does not like being away from home in the evening or overnight. However he always wants to go out somewhere through the day we have found lots of different groups to attend which help greatly for wellbeing

- My wife hates going to the doctors and will not go. She suffers from anxiety. She had a trip a few years ago and refused to seek help. Sue now spends most of her time in bed. Her mobility is shockingly poor, she gets attendance allowance, I myself have cancer at the moment. I struggle somewhat with daily chores and worry about the future
- I was caring for my 99yro mum until she sadly passed away in September 2023. She had been living with us for 3 1/2 years – since just start of covid pandemic. It was very difficult at times to navigate the social care.
- Find it hard to get a good carer as my husband even though on 24 hour care he's very active and repetitive.
- I feel overwhelmed and isolated in my caring role. Respite care is impossible to find when it is needed. I work full time and holidays are booked in advance. I can't plan breaks away as the respite may not be available.
- Mentally and physically draining. No support for dementia, once diagnosed you are discharged and no after care. Such hard work and constant, get angry at everything, grieving then the guilt.
- Honestly, I would rather talk to someone about it.
- With two children with additional needs it's extremely difficult! Other than school, I don't get any respite at all, even when they are at school I have to balance work, cleaning, cooking, meets and form filing, appointments etc because once they are home from school, none of the above can be done
- The more difficult the need the less care or help you get and we are left alone to care with very little support
- There are miles between everything. Anything I need to access is miles away, which makes it harder to access as it's time away from home, travel time, and finding places.
- Difficult
- It's hard and lonely at times you try to support the young adult out and about and people look and judge them as a lot of disabilities are non visible . I am lucky to be able to provide the funding for carers but know of people who get nothing and its awful it shouldn't be like that this day and age
- I am fortunate in that I am much younger than my husband , and in good health , therefore I am able to care for him myself at the moment. He has not been able to obtain a diagnosis of his condition other than it is mild cognitive impairment. His abilities vary day by day , therefore unless a medical practitioner was able to visit in the moment or I was able to take him somewhere for an immediate assessment it will be extremely difficult for any of the support services to understand his needs. He enjoys attending various clubs so it would be great if there was a local dementia day centre he could go to.
- We have moved from DCC to NCC in last 5months & the facilities for adults with LD are far fewer than Durham unfortunately.
- It's hard work juggling. My daughter is here 24 hours a day. Her big sister is living at home at the minute and that's the only reason I can do my job.
- I am currently on sick leave from work due to stress, in part from my caring role. I struggle to access support as it is at times when I have responsibilities. My son does not access support due to his autism. It's tough to find things for him that suit as he seems to 'sit in the middle' , meaning his disability is not 'severe enough' or 'mild enough'. This tends to mean that he relies on me completely for any form of social interaction and recreation and interests. I worry about his quality of life. This all leads to me feeling like I don't fit into carer groups to my sons disability 'level'.
- Caring is hard work emotionally, mentally as well as physically. There is a lot of stigma around caring and not many employers understand, as well as not enough support and facilities within communities to access

- I have struggled to find respite care for my adult son, since he was 18. If it wasn't for family then my husband and me would not of had any time to ourselves. Support from social services is almost non existent. We live in a rural area nowhere near Morpeth/Blyth which seems to be where the main focus of adult social care is based.
- Very lonely as I don't have relatives living locally and unable to get out without clock watching. Unable to get out at all when it is dark.
- Sorry I'm too exhausted
- Less outings/ sleep patterns/work in home harder to do ,to get going ! Jobs get left !
- It's hard however Northumberland carers help as I know I'm able to contact the and apply to carers fund to have time to myself
- Hard due to the stress on relationships & family life and costly due to limited funds vs expenses
- Awful
- As we don't access services I cannot comment.
- when you have no support life can be very difficult and tiring. no one seems to care about mental health, this seems to come bottom of the pile regarding care and support
- can be hard at times but just get on with it