



EVERYBODY'S BUSINESS

Gateshead Adult Carers Survey Report 2020

Gateshead Adult Unpaid Carer Survey 2020

Background

In 2011 this organisation introduced the first of a series of three yearly surveys of people aged 18 and over who provide unpaid care to a family member or friend in Gateshead. The surveys have been repeated in 2014, 2017 and now in 2020. The aim of each survey is to;

- Provide the most comprehensive and detailed knowledge of the lives of unpaid carers in Gateshead
- Gain an understanding of their experience of the health and social care system in Gateshead
- Raise awareness of their contribution to the lives of those they care for
- Explore their contribution to and the sustainability of health and social care services in Gateshead
- Identify emerging trends, challenges and improvements in the lives of people who provide unpaid care in Gateshead

Why these surveys are important

- Without the support and care of family members and friends thousands of people in Gateshead (21,000 at 2011 census now estimated at 25,000) because of their disability, health condition or frailty, would not be able to manage their daily lives, stay safe, reach their potential and live the life they want to live and are entitled to.
- Without the willingness of people to provide unpaid care and support to people with a disability or health condition the burden of care would legally fall on the already stretched resources of Gateshead Council and the NHS.
- The provision of unpaid care to a family member or friend is something which the majority of the population of Gateshead will do at some point in their lives.

The survey was distributed both electronically and by post to all carers on our database and to members of the Carers Partnership, made up of stakeholders across the Voluntary and Community Sector and health and social care services for Gateshead, for wider distribution between September 2020 and October 2020 (closing date 31/10/2020). It was also accessible online through Gateshead Carers Association's website and social media platforms.

The survey took between 30 and 45 minutes for carers to complete and **a total of 247 were returned.** This compares to the 284 carers who completed the GCA Carer Survey in 2017. Our thanks go to all those unpaid carers in Gateshead who, somehow, found the time to complete this survey.

Respondents were eligible to enter a prize draw on completion and return of the survey with 4 winners each receiving a £25 shopping voucher. A total of 184 respondents entered the free prize draw.

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Key Findings

Which agency or organisation did you receive this survey from?

245 responded to this question with 238 stating Gateshead Carers Association.

Postcode of Carers 213 respondents provided their postcode

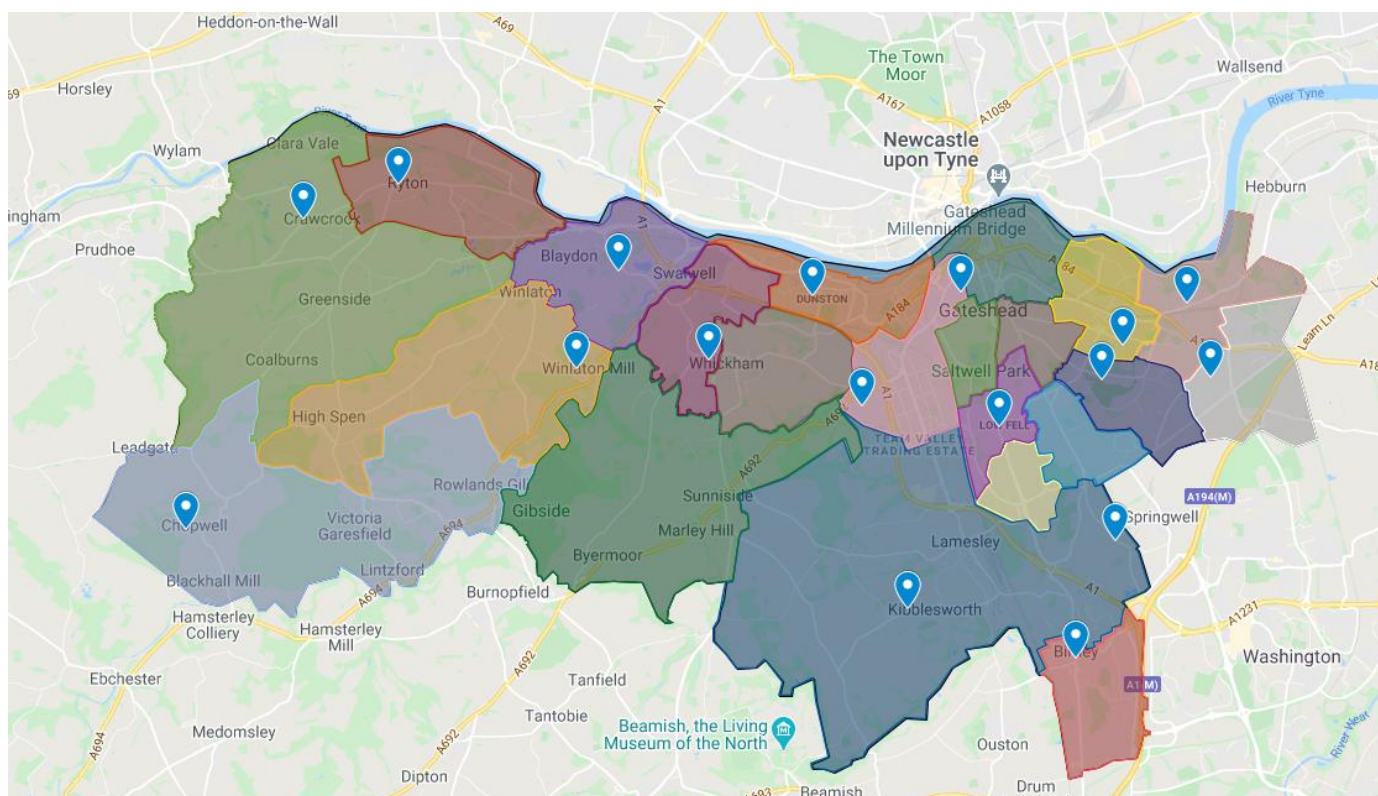
In 2020, the majority of respondents live in **NE10 (47), NE9 (39) and NE8 (34).**

In our 2017 survey, the majority of respondents lived in NE8 (53), NE9 (48), NE21 (24) and DH3 (24).

Rowlands Gill Harlow Green Wrekenton Swalwell Ryton
 Windy nook Whickham Teams low fell wardley
 bensham winlaton Felling greenside
 Leam Lane Deckham Dunston Sunnyside
 blaydon Eighton Banks Birtley sheriff hill Gateshead Lobley Hill

Areas within Gateshead

Respondents live across the borough of Gateshead with over half of respondents living in the following areas: Felling, Low Fell, Bensham, Leam Lane, Blaydon, Dunston, Whickham, Birtley and Ryton.



About Carers

Gender

The majority of respondents are Female at 66% and 34% Male. Nationally, the breakdown by gender is Female 58% and Male 42% (Census 2011).

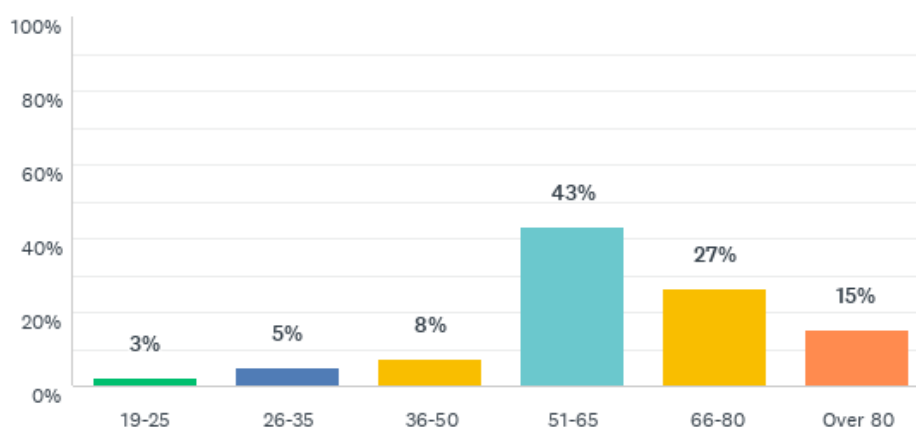
Age of Carers

Carers involved in the survey ranged from age 18 to over 80.

The age profile has continued to rise with **83% of respondents aged over 51 in 2020.** In 2014, 71% of respondents were aged over 51, increasing to 80% in 2017.

Interestingly, males aged 80+ are twice as likely to be providing unpaid care than females aged 80+ with 15% of males and 8% of females being in this position.

Q7 How old are you:



Ethnicity of Carers

The vast majority (92%) of respondents describe their ethnicity as white British. This has decreased slightly from 2017 (95%).

8% of respondents were from other ethnic groupings including white European (1%), white Other (2%), Asian or Asian British (3%) and other ethnic groups (2%) stated as Arabic (3 respondents) and Latino Mexican (1 respondent).

Religion of Carers

A high percentage (59%) of respondents describe their religion as Christian / Protestant/ Methodist/ Lutheran/ Baptist. 21% of respondents are Catholic, 2% Jewish, 1% Sikh and 9% Atheist or Agnostic. Other religions detailed are Jehovah's Witness, Pagan and Humanist.

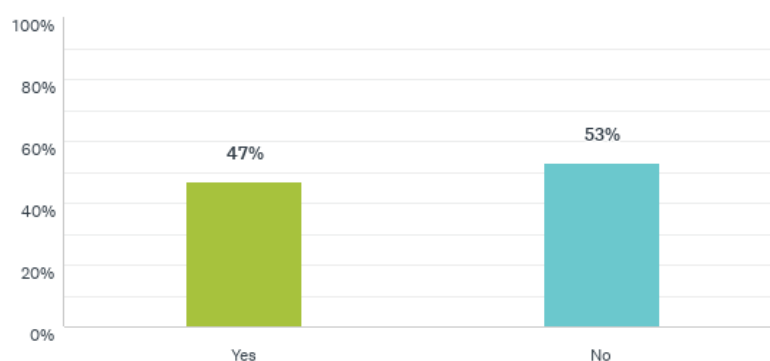
Armed Forces

5% of respondents have previously served in the Armed Forces. There are gender differences with 13% of unpaid male carers having served in the armed forces compared with 4% of female unpaid carers.

Disability of Carers

Survey respondents were asked whether they considered themselves to have a disability or long term illness. For the purpose of the survey disability is defined as '*a physical or mental impairment that has a substantial and long term adverse effect on your ability to perform day to day activities*'. Long standing means anything that '*has troubled you over a period of time or that is likely to affect you over a period of time*'.

Q11 Do you consider yourself to have a disability or long-standing illness/condition?

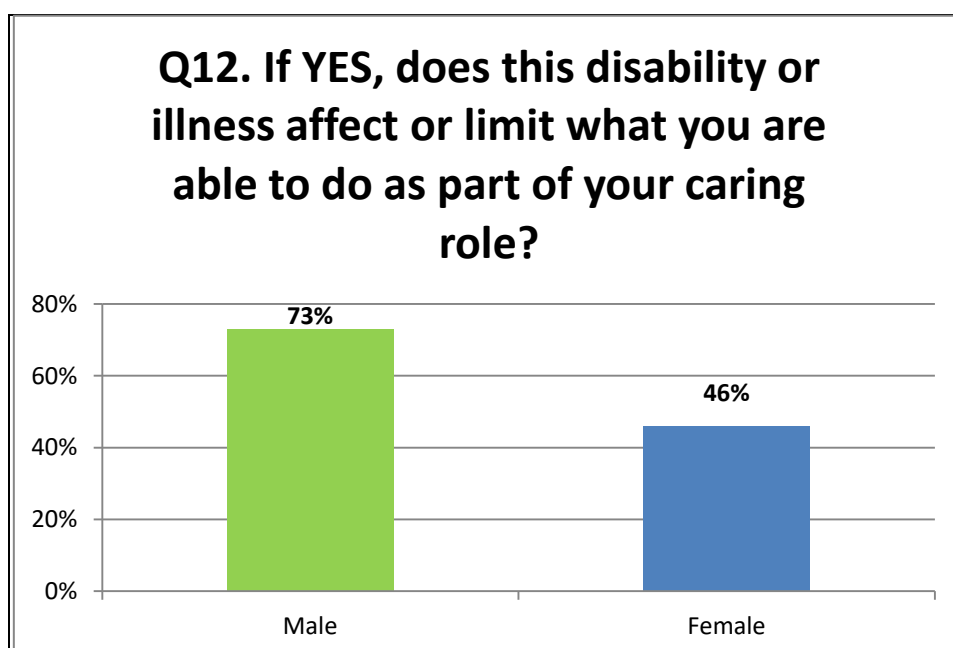


In 2020 almost half of all carers, 47% report having a disability or long standing illness themselves.

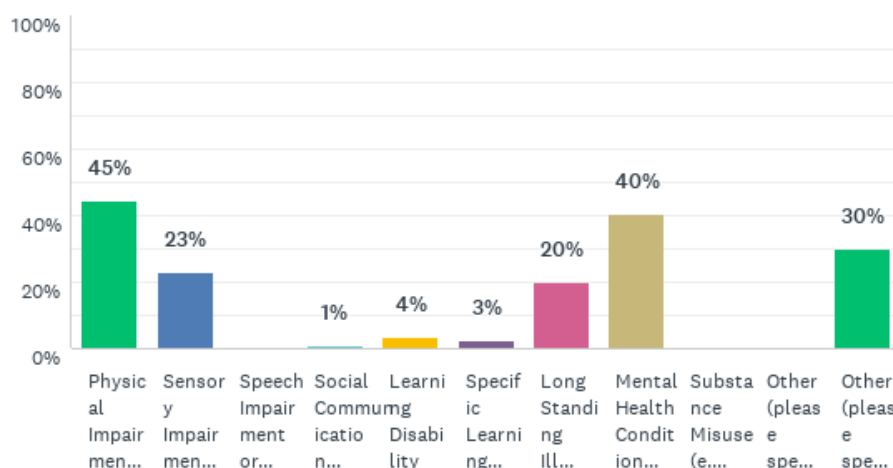
In 2014, 41% of respondents described themselves as having a disability or long standing illness and this increased to 52% in 2017. Significantly more male unpaid carers (53%) report having a disability or long standing illness than females (45%).

55% (compared to 57% in 2017) **of respondents stated that this disability or illness affects or limits what they are able to do** as part of their caring role.

This impacted differently by gender:



Q13 Please describe your disability or illness. (Please tick ALL that apply).



Changes noted from 2017 survey:

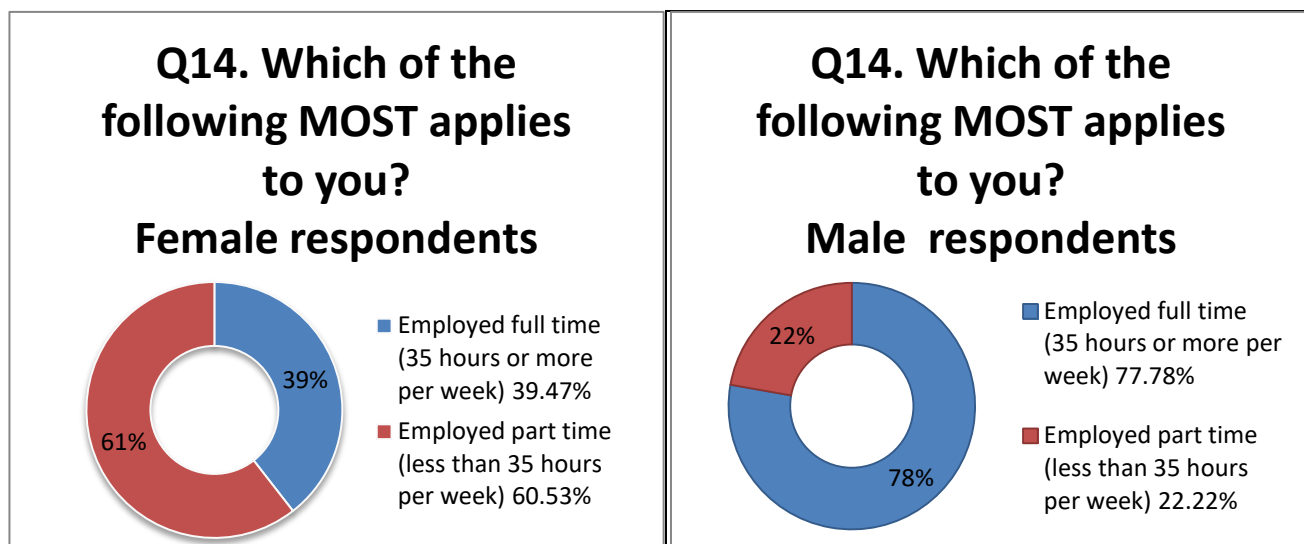
- Physical impairment/mobility issues has **increased from 31% to 45%**
- Mental health condition has **doubled from 20% to 40%**
- Sensory impairment (e.g. blind, deaf, hearing, vision impairment) is 23%
- Long standing illness has **increased from 9% to 20%**
- Other including COPD, Diabetes, Learning disability, arthritis and heart condition has increased from 29% to 30%
- Of male carers 55% report a physical disability compared to 40% of females.
- Of male carers 38% report a mental health condition compared to 42% of females.

Employment Status

A total of 33 respondents said that they currently work in Gateshead with 8 stating that they have now retired.

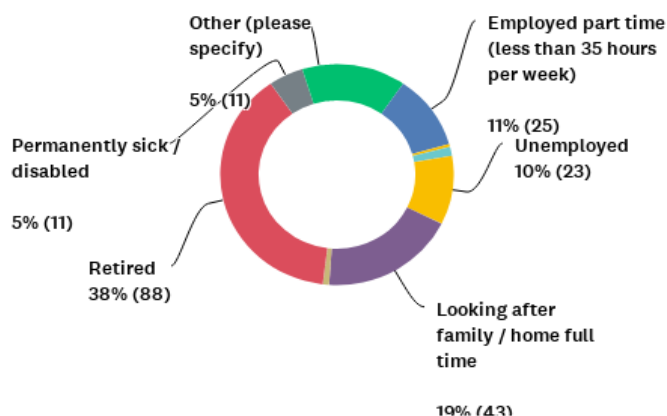
- The number of respondents describing themselves as unemployed has **increased slightly** from 8% in 2017 to **10% in 2020**.
- The unemployment rate for Gateshead is 5.1% (June 2020). **You are twice as likely to be unemployed if you are an unpaid carer in Gateshead.**
- The percentage of respondents describing themselves as working full time or part time has decreased slightly from 23% (2017) to 21%.
- 42% of females reported that they are in full time or part time employment compared to only 9% of males.
- The majority of respondents described themselves as retired 38%, which is an increase on 35% in 2017.

The split between full time and part time employment by gender:



- Although the employment rate (21%) amongst unpaid carers is exceptionally low, of those in employment, women (61%) are almost three times as likely to be in Part Time employment than men (22%).
- The converse applies in that male unpaid carers are significantly more likely to be in Full Time work (78%) than unpaid female carers (39%).

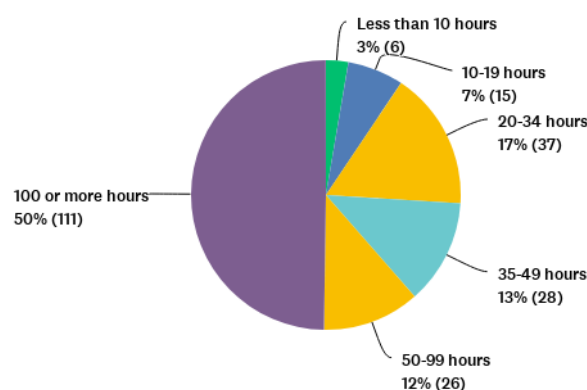
Q14 Which of the following MOST applies to you? (Please tick ONE only):



The Caring Role

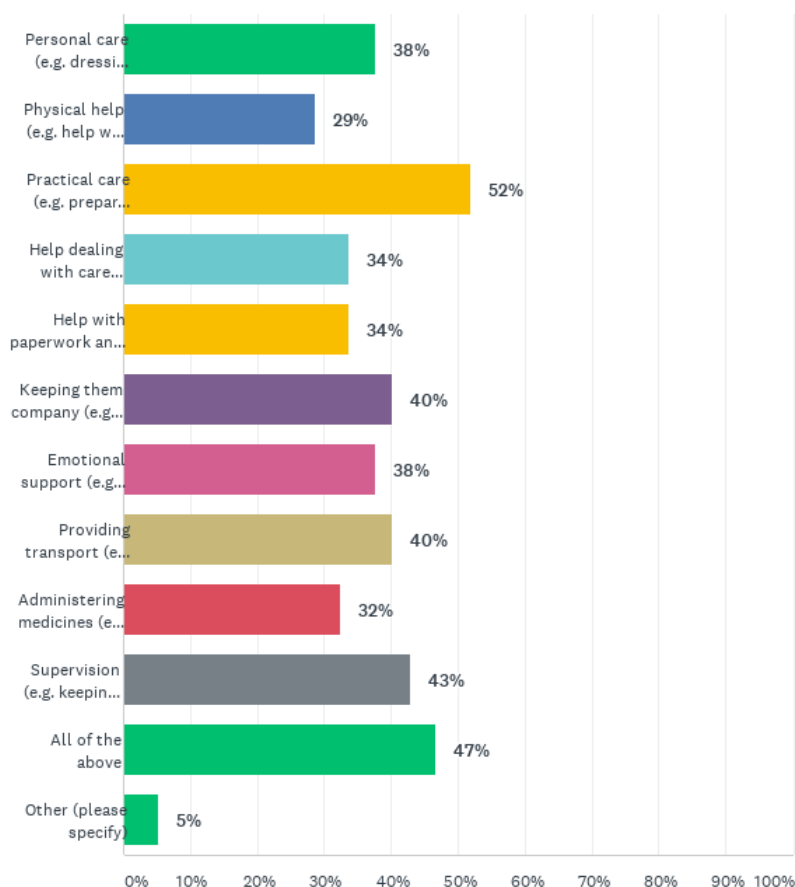
- The majority of respondents **84% care for one person**, a slight increase on 2017 of 81%.
- 69% of respondents care for 1 person who lives with them.
- 16% care for 2 or more people, a reduction from 19% in 2017.
- The vast majority of respondents, **75%, are providing care for over 35 hours per week** (80% in 2017).
- **50% of respondents are providing 100 or more hours per week**, an increase of 7% on 2017.
- 23% of respondents said that they have responsibility for another dependant in addition to the person they care for.

Q18 How many hours a week do you care for this person? If you care for more than one person, please answer only in relation to the person you spend the MOST time helping. If you spend an equal amount of time caring for two or more people, please choose one person to answer the following questions about.



- 27% of respondents have been caring for this person for over 5 years but less than 10 years (23% in 2017).
- **42% have been caring for this person for 10 years or more with 20% having been caring for 20 years or more.**
- A staggering **84% of respondents had been caring for over 1 year before contacting Gateshead Council or a voluntary organisation for support.** Of these 42% had been caring for over 5 years before seeking support.

Q21 Over the last 12 months, what type of caring duties have you undertaken on behalf of the person you care for? (Please tick ALL that apply)



Respondents identified a variety of different duties.

- 62% provide practical care (prepared meals, shopping)
- 54% provide supervision (62% in 2017) (e.g. keeping an eye on the individual)
- 51% help with paperwork and financial matters
- 51% provide help dealing with care services and benefits
- 50% keep them company
- 50% provide emotional support
- 44% providing transport.
- The least frequently reported help was physical help (e.g. help with walking, get up/down) which was identified by 26% of respondents (35% in 2017).

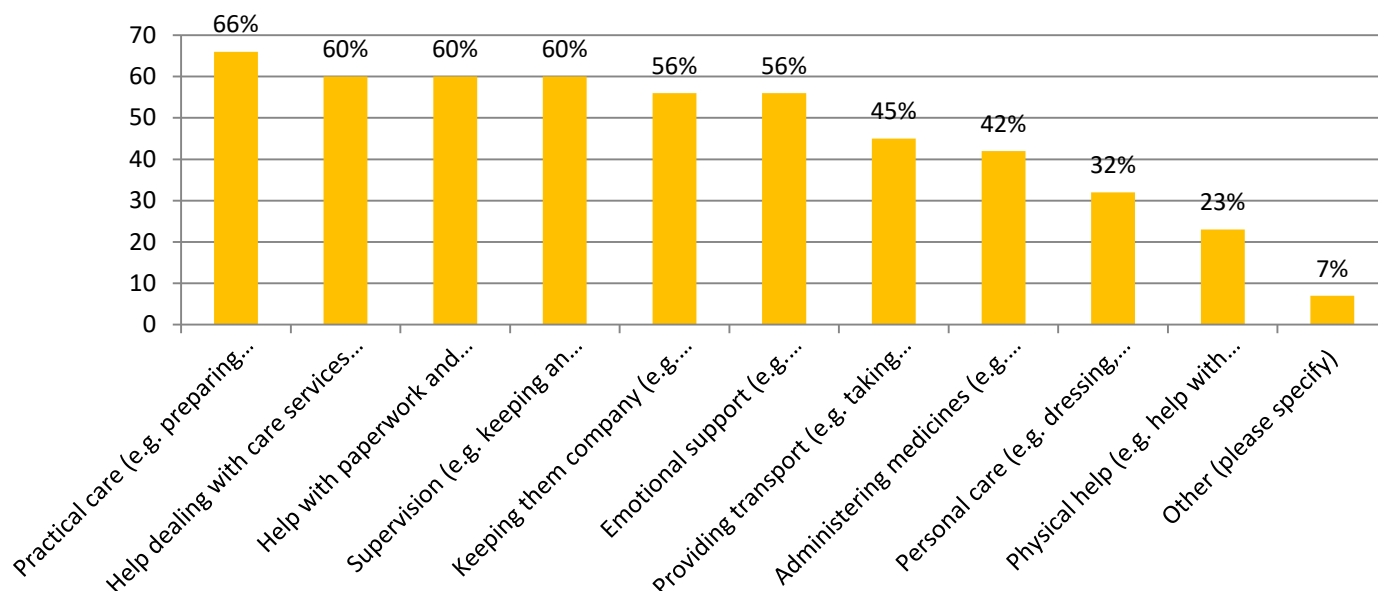
Results show a significant fall across a number of identified areas including:

- **Administering of medicines** has fallen from 45% in 2017 to 39% in 2020.
- **Help dealing with care services and benefits** down from 57% in 2017 to 51% in 2020.

There are significant gender differences with females providing more care across all areas.

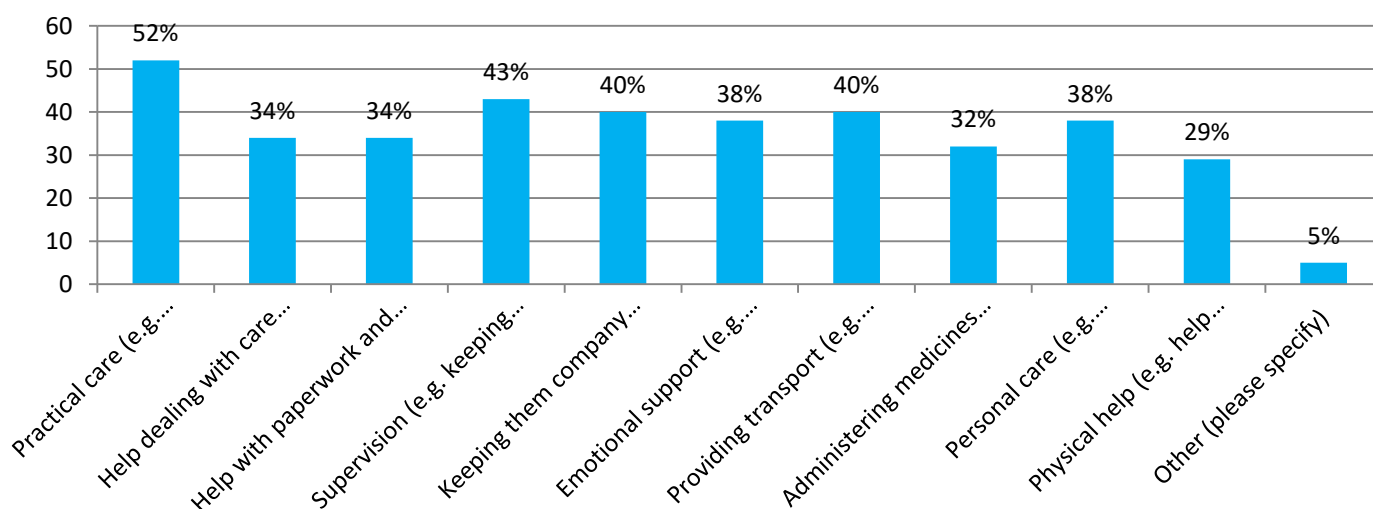
Q21. Over the last 12 months, what type of caring duties have you undertaken on behalf of the person you care for? (Please tick ALL that apply)

Female Response only

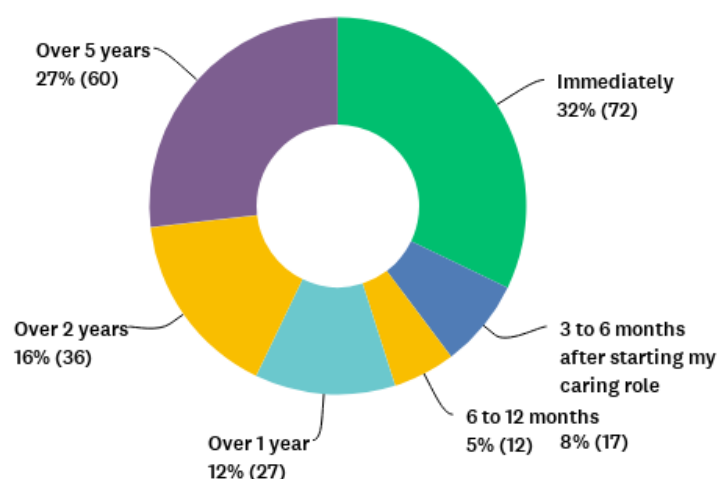


Q21. Over the last 12 months, what type of caring duties have you undertaken on behalf of the person you care for? (Please tick ALL that apply)

Male Response only



Q22 When did you first see yourself as an unpaid carer?



- The majority of respondents, **55%, stated that it took them over 1 year before they first saw themselves as an unpaid carer**, with 27% stating over 5 years.
- 31% saw themselves immediately as an unpaid carer.
- When asked how they came to recognise themselves as an unpaid carer, 40% said they had received information from a family member or friend and 22% stated hearing or reading about unpaid carers on TV, Radio, newspapers, publications.
- Other reasons given included: Hospital, Therapist, Family Services, Social Services, OT, Crisis Team, GP surgery, Citizens Advice, Housing Association, GCA Information Stand, Parkinson's adviser, Memory hub.

What do you think of the word 'carer'?

62% of respondents responded negatively to the word 'Carer' with 19% saying they don't like seeing themselves as a carer and 18% thought the word meant a paid care worker.

30% of respondents said it helped them to see that they are a carer and 8% stated it meant that they were able to access support earlier.

On average women provide more years of unpaid care and more hours of unpaid care per week than men. Respondents expressed their views through the following statements:

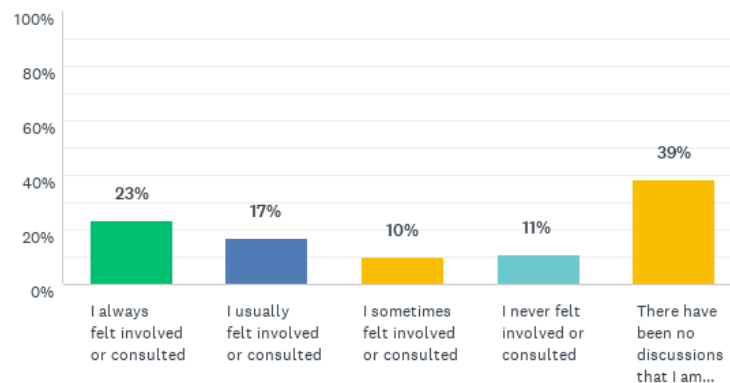
35% agreed there is always the assumption that it's women who will provide unpaid care. Of these 43% of female unpaid carers felt that there was an assumption women would provide unpaid care compared to 15% of men with an unpaid caring role.

Some responses detailed:

- *It's around balancing care ...and as long as it's shared it's fair.*
- *Societal perceptions have been changing, enabling a breakdown of the stereotypical viewpoints which have been seen as 'Women work' so we can live in fairer and equal society.*
- *In this world of equality rights any adult can be a carer.*
- *It often happens that the woman falls into the carer's role naturally, not necessarily that it was specifically decided it would be the woman who became the carer. In my case it is my partner who I am carer for, so there was no choice or decision*

- *I know men who do an amazing job caring for family members. Both sexes can carry out this role equally as well.*
- *I didn't and still don't refer to myself as a carer, I look after my mum so to me it's helping her in her time of need the way she looked after me in my time of need in my younger years, I prefer to think I am showing love and respect to her as my parent, previous to my dad's death I looked after them both out of love*
- *It should be more equal*

Q72 In the last 12 months, do you feel you have been involved or consulted as much as you wanted to be, in discussions about the support or services provided to the person you care for? (Please tick ONE only)

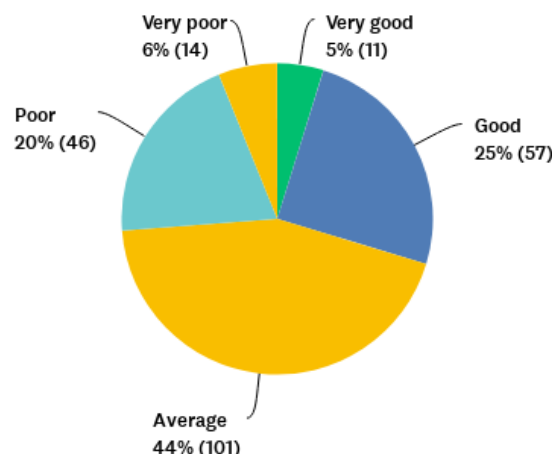


50% of carers said they have never felt involved or had any discussions about the support or services provided to the person cared for over the last 12 months.

Impact of Caring on Health

Overall 70% of carers described their current general health as 'average, poor or very poor'. This compares to 75% in 2017. The proportion of carers reporting their health as 'average, poor or very poor' is the same as in 2014.

Q26 How would you currently describe your general health?



'In the last 12 months, has your caring role affected your health?'

73% stated Yes, my health is a little worse or a lot worse.

Of those that stated Yes their health has been affected;

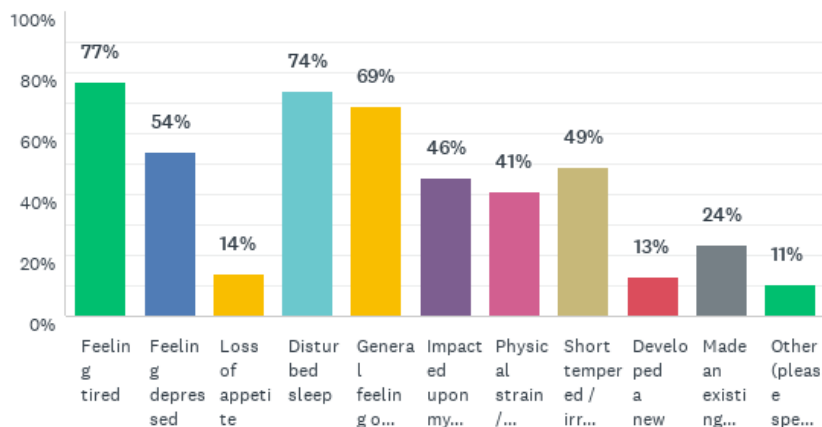
- 77% said they are **feeling tired** (up from 82% in 2017).
- 74% said they have **disturbed sleep** (up from 66% in 2017).
- 69% have a general feeling of **stress** (72% in 2017).
- 54% stated feeling **depressed** (52% in 2017).
- 49% stated short tempered / irritable

Other responses included;

having no time to myself
overwhelmed
prevented me from living my life
sometimes gets me down
I put my own needs after those of the person I am caring for. It can be stressful at times.

24% said their caring role has not affected their health at all with 2% stating that their health is actually better as a result of caring role.

Q28 If YES, how has caring affected your health? (Please tick ALL that apply)



For respondents with health problems;

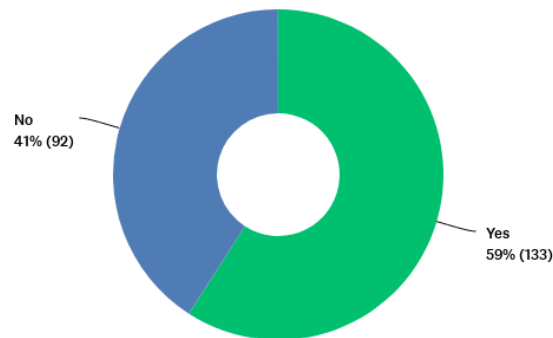
- 50% stated that these have not affected their ability to adequately care
- 38% stated that yes it is a little more difficult to provide care (down from 45% in 2017).
- 12% stated that it is a lot more difficult to provide care

For 1 in every 2 carers their health has been affected by their caring role.

Accessing Healthcare Services

There has been a **dramatic fall** in the number of carers reporting that they have time to visit their GP when necessary from 78% in 2017 **to 59% in 2020**.

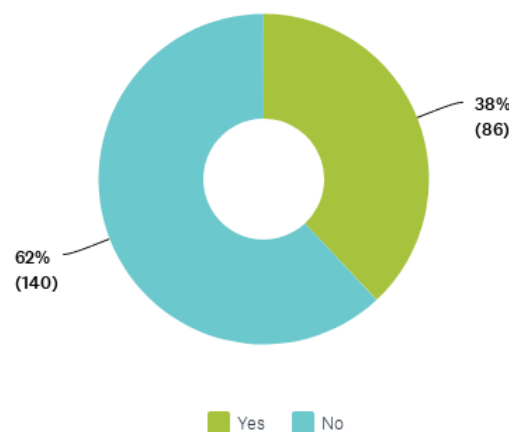
Q30 Do you feel that your caring commitments enable you to have time to visit your GP when necessary?



Registering as a Carer with your GP

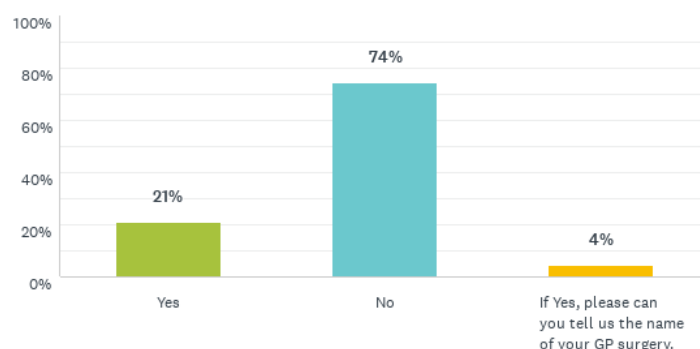
- There has been a **sizeable decrease** in the number of carers who are aware that they can register as a carer with their GP. This is down from 46% in 2017 to **38% in 2020**.

Q31 Are you aware that you can register as a carer with your GP?

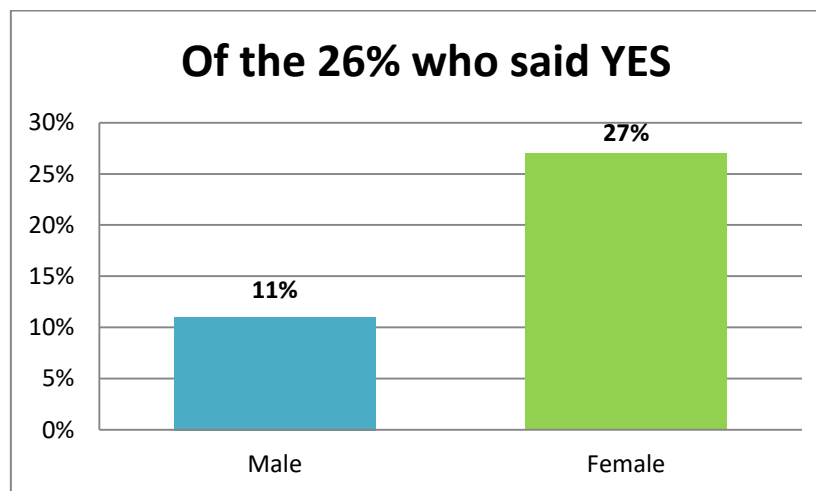


- 74% stated that they have never been asked by their GP or other staff at their surgery** if they are a carer (71% in 2017).

Q32 Have you ever been asked by your GP or other staff at your surgery if you are a carer?



- Of the 26% who had been asked there is a stark difference between males and females. **A female (27%) is 2.5 times more likely to be asked if they are caring for someone than a male (11%).**



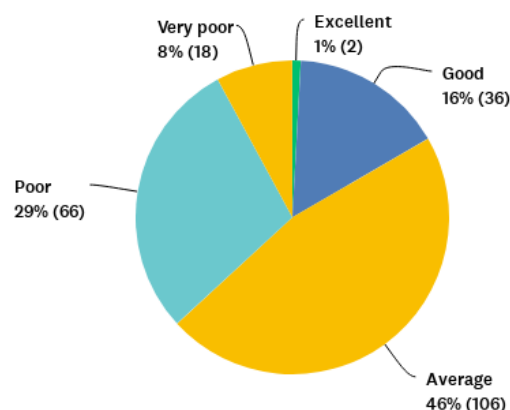
- Of those who are aware that they can register only 24% have done so. This is a further decrease from 2017 when 30% had done so.

Impact of Caring on Quality of Life

Carers were asked to rate their quality of life which was defined as *'your ability to enjoy normal life activities.'*

- 83% of carers described their quality of life as 'average', 'poor' or 'very poor'** which is an increase from the 2017 figure of 79%.
- 17% of carers described their quality of life as 'excellent' or very good' which is a drop from 2017 when 21% described their quality of life in this way. Again there are gender differences with 82% of females describing their quality of life as average to poor compared to 89% of males.

Q34 How would you rate your overall quality of life at the moment?(Quality of life is your ability to enjoy normal life activities).



We then asked carers if they have had to give up some aspects of their life since becoming a Carer (**e.g. time socialising, training, education, hobbies, and work**).

- 78% of carers said Yes**, almost the same as the 2017 figure of 79%

Carers were then asked to give more detail about their quality of life.

In summary, carers reported in 2020 feeling less appreciated and valued as a carer than in 2017 with a majority of respondents less able to;

- Spend time as they want to
- Have the space and time needed to be themselves
- Have as much control over their daily life as they want
- Have as much social contact as they want with people they like
- Enjoy opportunities in the local community e.g. volunteering

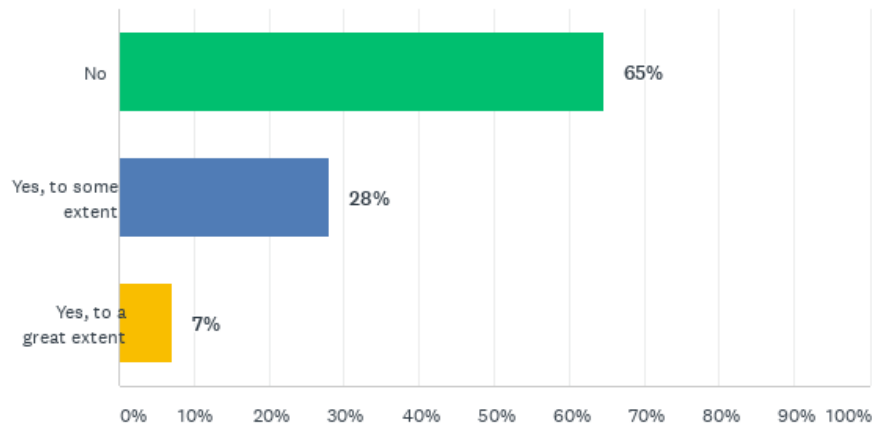
40% feel isolated or lonely, 44% feel they have lost their independence and freedom and 57% do not have sufficient time or energy to participate in training or education. 58% feel their caring role does not allow them to continue with the paid work they would like to do. A staggering 87% worry about what would happen to the person they care for if they were not there.

- **I feel appreciated and valued as a carer.**
50% (down from 57% in 2017) agreed or strongly agreed with this statement.
- **I am able to spend my time as I want, doing things I value or enjoy.**
57% disagreed or strongly disagreed with this statement.
- **I have the space and time I need to be myself.**
54% disagree or strongly disagree with this statement.
- **I have as much control over my daily life as I want.**
58% disagree or strongly disagree with this statement.
- **I have the time I need to look after myself (in terms of getting enough sleep, eating well etc.).**
35% agree with this statement.
- **I have as much social contact as I want with people I like.**
58% disagree or strongly disagree with this statement (up from 48% in 2017).
- **I am able to enjoy opportunities in the local community e.g. volunteering.**
63% disagree or strongly disagree with this statement (up from 52% in 2017).
- **I feel I get sufficient breaks from caring.**
49% disagree or strongly disagree with this statement.
- **I have a life of my own outside of my caring role.**
51% disagree or strongly disagree with this statement (up from 45% in 2017).
- **I often feel isolated or lonely.**
40% agree or strongly agree with this statement.
- **I feel I have lost my independence / freedom.**
44% agree or strongly agree with this statement.
- **I feel I have sufficient time / energy to participate in training and education.**
57% disagree or strongly disagree with this statement.
- **My caring role allows me to continue with the paid work that I'd like to do.**
58% disagree or strongly disagree with this statement.
- **I worry about what would happen to the person I care for if I was not there.**
87% of respondents strongly agree with this statement.
- **I worry what would happen to me/what I'd do if / when my role as a carer ends.**
47% agree or strongly agree with this statement.

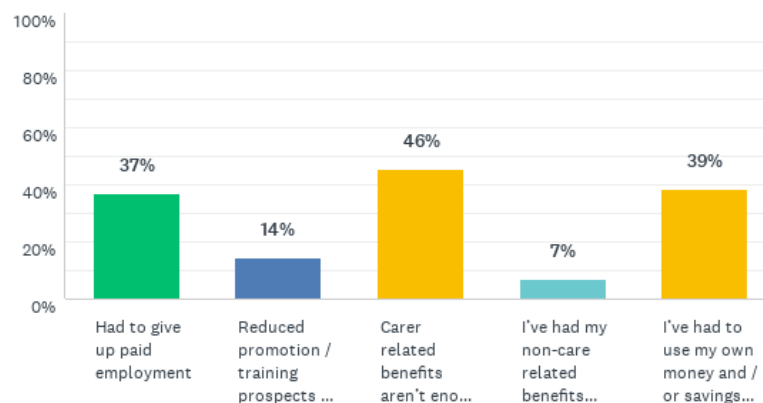
Impact of Caring on Personal Finances

- Indications are that in the last 12 months the impact of caring on personal finances has been less than in 2017, with 35% saying it has caused difficulties in 2020 compared to a higher number of 46% in 2017.

Q37 In the last 12 months, has caring caused you any financial difficulties?



Q38 If YES, what are these difficulties? (Please tick ALL that apply)



- 37% stated that they had to give up paid employment** compared to 20% in 2014 and 29% in 2017.

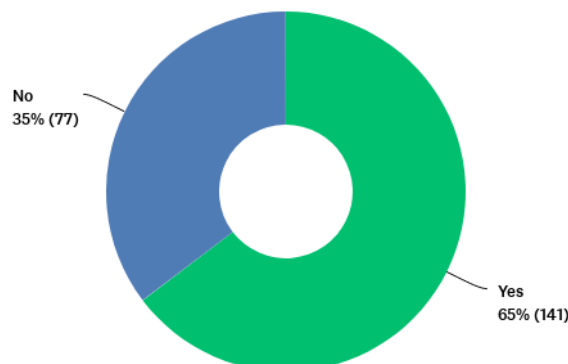
There are marked gender differences in relation to giving up paid work to provide unpaid care.

43% of females have had to give up work compared to 31% of males. These are apparent again with females (20%) reporting 'reduced promotion and training opportunities' compared to males (7%). Females with a caring role are three times more likely to have reduced promotion / training opportunities than male unpaid carers.

- 39% stated that they have had to use their own money and / or savings to pay for equipment and services for the person they care for compared to 47% in 2017.
- 46% stated that carer related benefits aren't enough to live on**, compared to 36% in 2017.
- 14% felt that they had reduced promotion / training prospects as work compared to 11% in 2017.

Work commitments have to be juggled around my caring role Covid has caused greater mental health problems for my daughter

Q39 Are you aware of the benefits available to support carers in their caring role?



We have seen an increase in the number of respondents 65% that are aware of the benefits available to support carers in their caring role (up from 61% in 2017) and of those that are aware, an increase in claiming some benefits to support them in their caring role 60% (up from 51% in 2017).

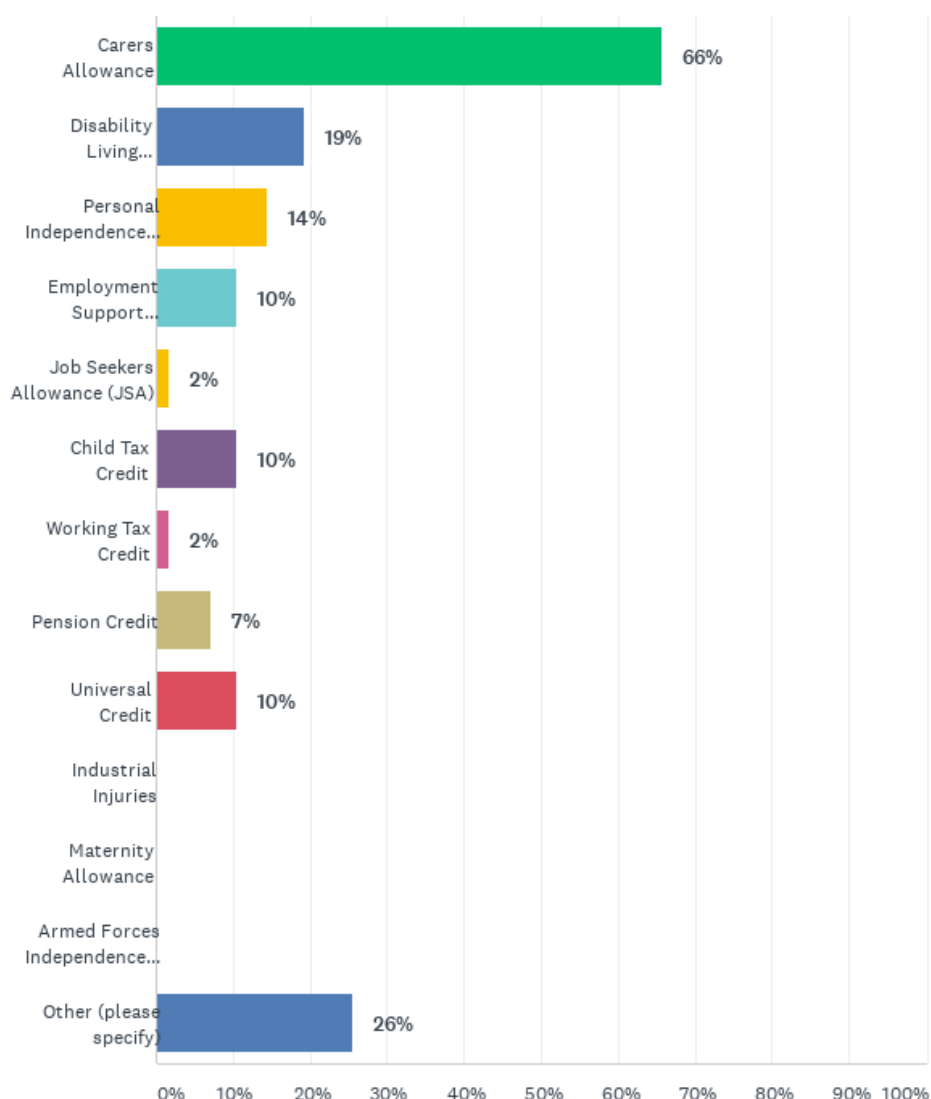
Benefits claimed

Of the benefits claimed;

- **Carers Allowance is claimed by the most respondents at 66%**
- Disability Living Allowance (DLA) is claimed by 19%
- Personal Independence Payment (PIP) is claimed by 14%
- Employment Support Allowance (ESA) by 10%
- Child Tax Credit by 10%
- Universal Credit by 10% of claimants.
- Other benefits detailed in responses include Asylum seeker support and housing benefits.

carers allowance income work help money due
benefits receive reduced bills pay left caring

Q41 If YES, which benefits do you claim? (Please tick ALL that apply)



When asked if you do not claim benefits to support you in your caring role, why not?

- 51% said they are not entitled to any carer related benefits (49% in 2017)
- 18% said it is too complicated to understand or apply for (16% in 2017)
- 18% said 'If I did claim any, I worry it might affect the benefits of the person I care for'

Other responses included;

- *I was told pension credit would affect my money*
- *I was told because I get a state pension I am not entitled to anything.*
- *The people I care for will not allow me to claim*
- *I receive retirement pension not allowed to claim another benefit.*
- *Because I am 90 years old they would just take it off my pension.*
- *Not sure what I am entitled to*

Carer's Assessment

NOTE: The government imposed easements, due to the Covid 19 pandemic, around the council's obligation to carry out this statutory duty under the Care Act.

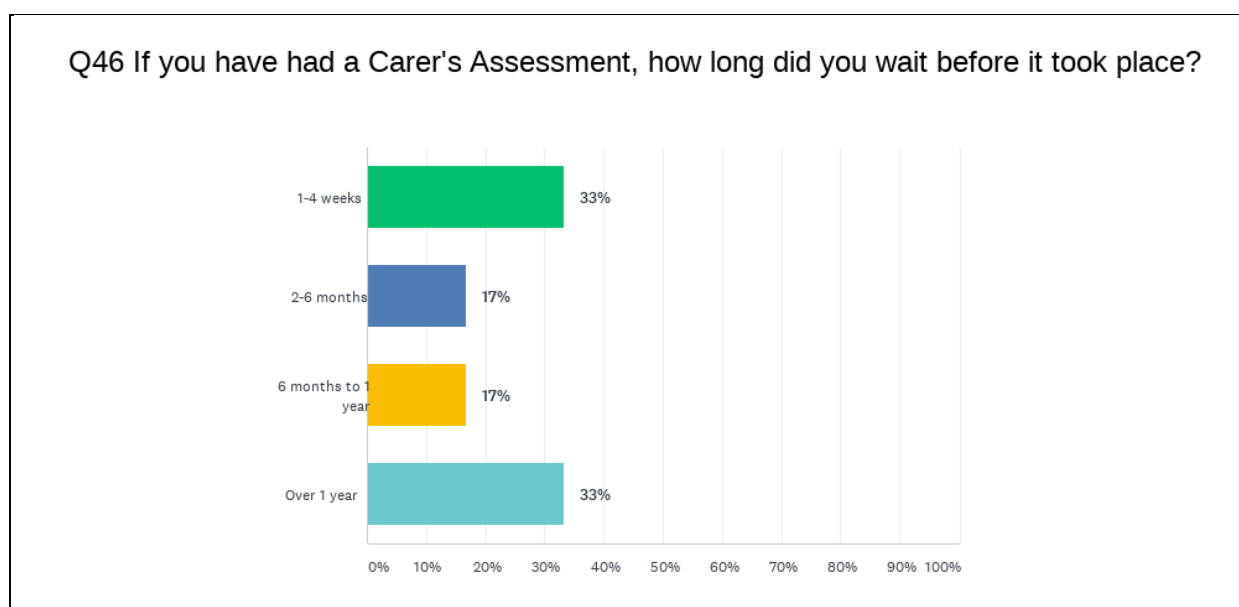
If you have become a carer in the last 12 months have you:

Been offered a Carer's Assessment?	90% said No (up from 82% in 2017)
Asked for a Carer's Assessment?	95% said No (up from 93% in 2017)
Had a Carer's Assessment?	93% said No (up from 89% in 2017)

If you have been a carer for more than 12 months have you:

Been offered a Carer's Assessment?	80% said No (up from 77% in 2017)
Asked for a Carer's Assessment?	87% said No (same as in 2017)
Had a Carer's Assessment?	83% said No (up from 82% in 2017)

When respondents were asked if they had been told by social services of their right to have a separate Carer's Assessment, 90% said No (up from 82% in 2017).



Whilst 33% of respondents only waited 1-4 weeks for a Carer's Assessment a further 33% waited for over 1 year.

The experiences of male unpaid carers and female unpaid carers was broadly similar with one exception. Male unpaid carers (55%) were more likely to get a Carers Assessment within 6 months than female unpaid carers (46%).

- **Only 15% of the small minority who had a Carers Assessment received a copy of their support plan** (down from 20% in 2017) and of these respondents only 13% said that their support plan included their Personal Budget (down from 2% in 2017) with 85% of them choosing to take their Personal Budget as a Direct Payment (down from 92% in 2017).

- When asked 'Have you had a Carer's Assessment as part of a joint assessment with the person you care for?' 62% said No, with a further 29% saying don't know.

Other responses included;

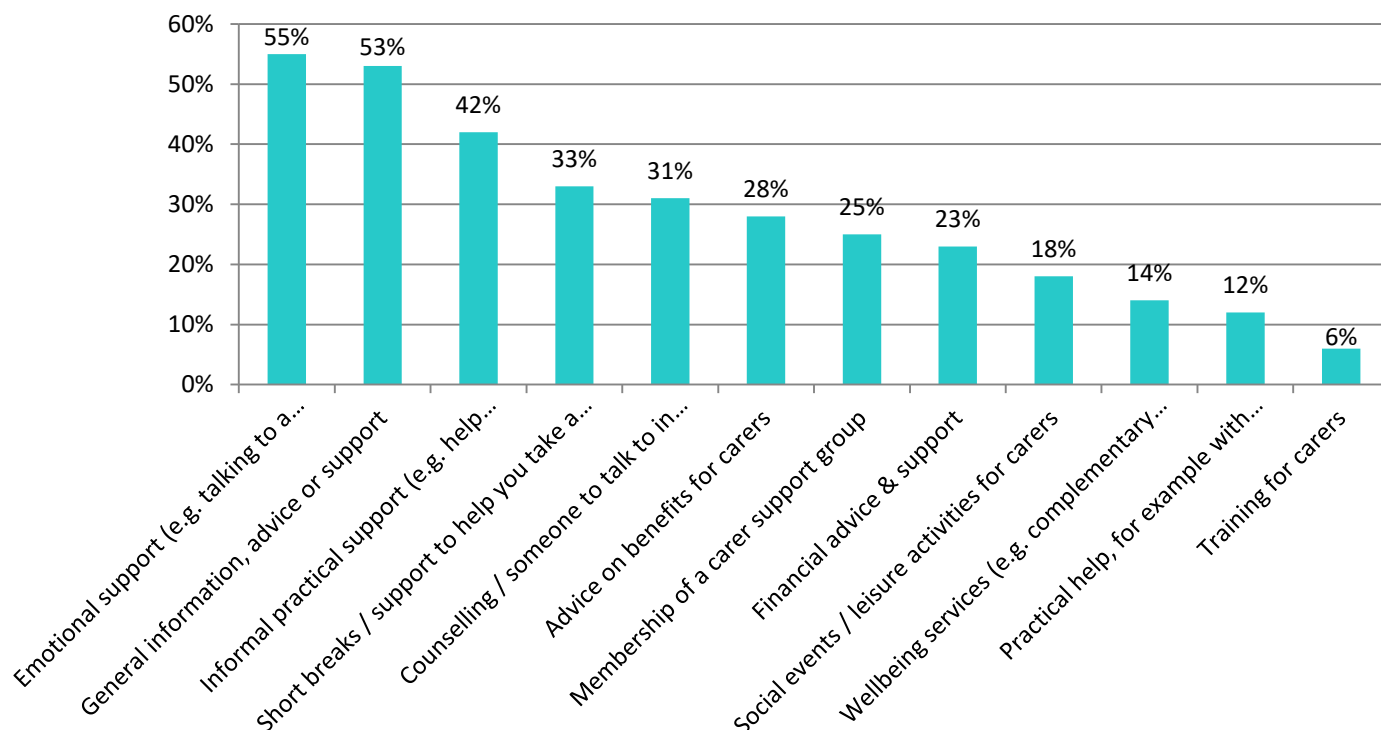
- *I requested a carer's assessment and submitted an application report but progress has been suspended due to Covid lockdown.*
- *Not sure what all this involves*
- *I have never had an assessment as my daughter would not allow anyone near her due to her unpredictable personality disorder*

Support Services

Respondents were asked 'Have you accessed any of the following types of support in the last 12 months, to support or help you in your caring role?' The following responses record the percentage of carers who have accessed these types of support regularly, occasionally or once.

- 55% Emotional support (e.g. talking to a friend or neighbour)
- 53% General information, advice or support
- 42% Informal practical support (e.g. help from a family member with hospital visits)
- 33% Short breaks / support to help you take a break from caring
- 31% Counselling / someone to talk to in confidence
- 28% Advice on benefits for carers
- 25% Membership of a carer support group
- 23% Financial advice & support
- 18% Social events / leisure activities for carers
- 14% Wellbeing services (e.g. complementary therapies, relaxation)
- 12% Practical help, for example with household tasks
- 6% Training for carers

Q52. Have you accessed any of the following types of support in the last 12 months, to support or help you in your caring role? % of respondents who access Regularly, Occasionally or Once



When asked where they have received this support from in the last 12 months, **53% of respondents said they regularly or occasionally receive support from Gateshead Carers.**

9% stated regularly from their GP Practice Staff (down from 18% in 2017) and 9% from Other Health Services.

Other sources of support detailed by respondents; memory protection service, Parkinson's charity, care navigator, your voice counts, sight services, citizens advice, Facebook support groups, local counsellor, Crossroads, Dale Care Services, Bensham Hospital, Stroke Association, G.A.T.E.S., housing support worker.

Cultural barriers

96% of respondents (of 186 replies) said that they have NOT faced any cultural barriers or difficulties when accessing support services to help them in their caring role. Of those who said Yes, 24% said they encountered these barriers or difficulties with their Local Council/Social Services (40% in 2017), 24% stated GP or Practice Staff.

When asked which categories did these issues fall into;

- 36% said Lack of awareness on the part of the service users (same as in 2017)
- 24% said Lack of confidentiality (18% in 2017)
- 20% said Lack of women-only services (12% in 2017)
- 16% Lack of understanding of cultural / religious beliefs, Language barriers

Emergency Support Service

71% of carers are not aware of the Emergency Support Service (up from 68% in 2017).

61% do not have plans in place for the person they care for if they should fall ill or are unable to continue to provide care (64% in 2017).

Of the 29% who are aware of the scheme there is a significant difference in awareness with 37% of males aware of it compared to 22% females.

Equipment

- 38% of carers reported that the person they care for needed special equipment (e.g. mobility/walking aids/stair lift) down from 44% in 2017.
- 83% of these carers said they were able to access / receive the appropriate equipment (74% in 2017).
- 49% said they have not been able to receive financial support to help them access this equipment (55% in 2017).

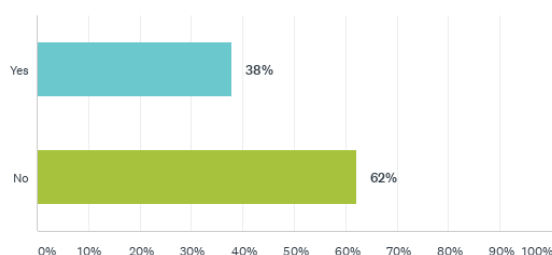
I am an asylum seeker and do not get support credit enough

Please use this space if you would like to tell us more about any equipment that you use as part of your caring role:

Wheelchair, specialist home seating toilet seat & frame, wet room, shower chair, hoist, walking sticks, commode, ramp, stair lift, special mattress, bed, stair rail, bathing aids, step climber, bed positioning sheets, incontinence sheets, Zimmer frame, perching stool, elbow crutch, lazy Susan, support stockings, electric motor scooter, lifeline, riser chair.

Taking a Break from Caring

Q64 Are you aware of where to go to access support or services to help you take a break from caring? Please DO NOT include unpaid help from family and friends.



The majority of respondents **62% stated they are not aware of where to go** to access support or services to take a break from caring.

When asked if during the last 12 months they had used any support or services to help them take a break from caring (excluding help from family or friends) a staggering 85% said No (81% in 2017).

Of those accessing breaks;

There is clear **downward trend from 2014 to 2020 for those carers taking a break on their own** and a rise in carers taking a break with the person they care for: 55% took a break on their own (away from the person they care for compared to 66% in 2017 and 72% in 2014).

Of those not accessing a break;

- The main reason (46%) was that unpaid carers don't want to leave the person they care for with someone else
- 35% did not know how or where to access this support
- 28% said they do not need to take a break from caring
- 20% said they cannot meet the costs associated with taking a break

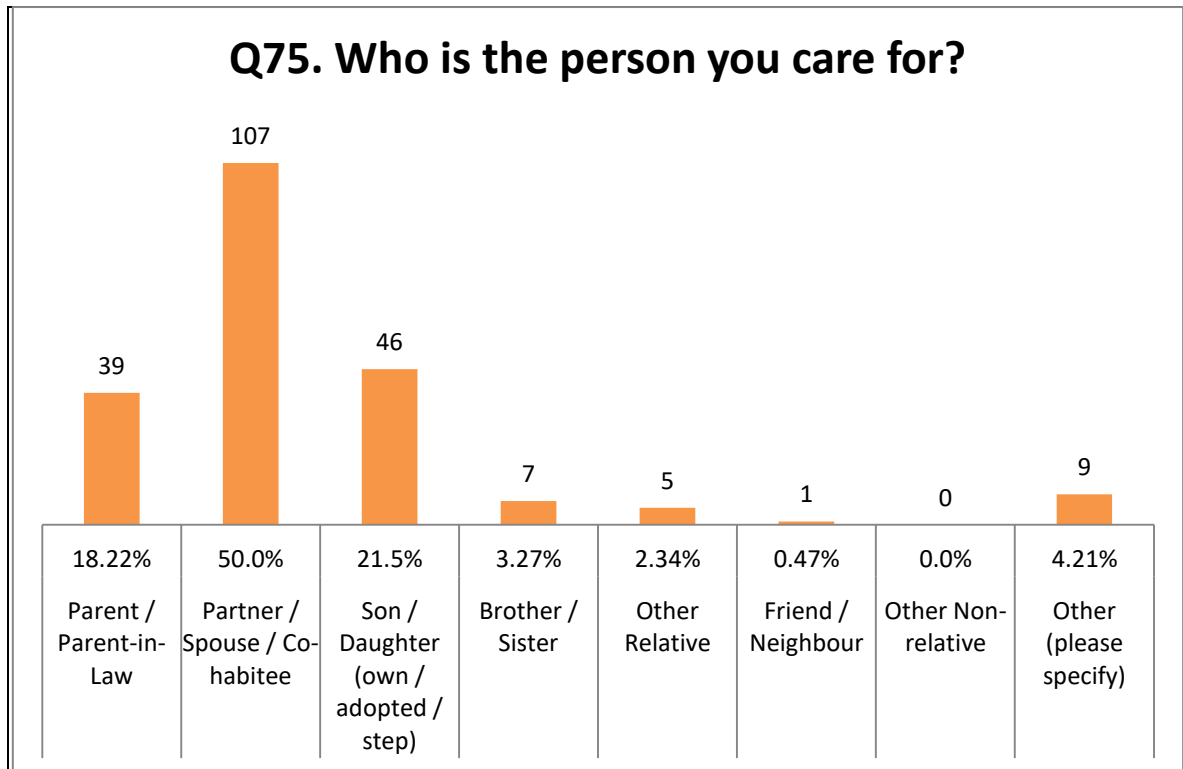
Carers tell us more about their experiences of taking a break:

It was funded by Gateshead Carers and was amazing!!

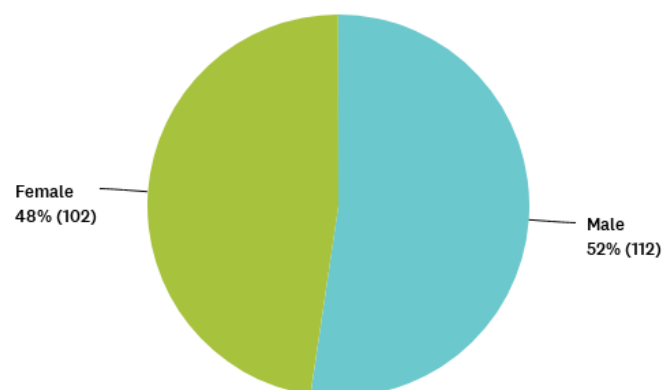
- *The only break I ever had was when I had a nervous breakdown and spent a lovely week on a psychiatric ward.*
- *I usually take a break and my brother watches mum.*
- *Years ago I had a holiday paid for by charity and it was really good*
- *Should be allowed at least 3 breaks per year, it is very stressful.*
- *If I take a break there is so much organisation needed to ensure that the people I carer for are sorted and know what to do*
- *Only able to take short break, COVID allowing, as Mum and Dad become Anxious when I'm away*
- *I got funding for a shed to do my crafting away from my caring duties, but still be at hand if I'm needed.*
- *Went fishing for a week*
- *Really beneficial to me for my mental health*
- *I usually go on holiday abroad to have a total break*
- *I went to the theatre so I took a break for 4 hours including travelling*

About the Person Cared For

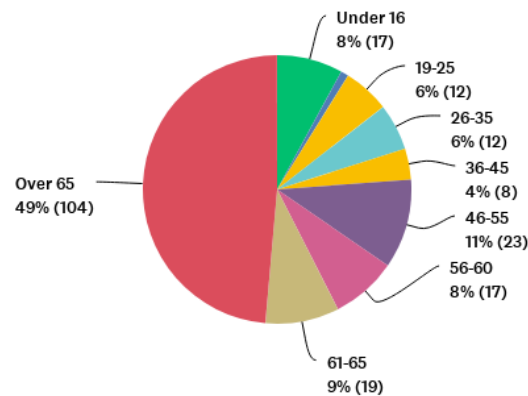
- **50% of respondents care for their Partner / Spouse / Co-habitee**, compared to 43% in 2017
- 21% care for their Son / Daughter (own / adopted / step) compared to 28% in 2017
- 18% care for their Parent / Parent-in-Law



Q76 What is the sex registered to them at birth?



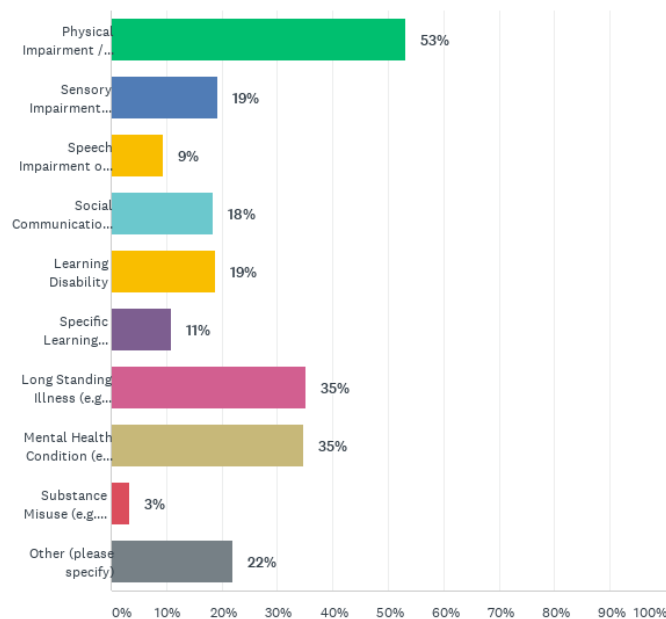
Q78 How old is the person you care for?



49% of respondents care for someone over the age of 65 years, up from 44% in 2017.

When asked if the cared for person has previously served in the Armed Forces, 10% said yes (22 respondents).

Q80 Which of the following best describes the condition of the person you spend most of your time caring for? (Please tick ALL that apply)



Little change reported from 2017:

- 53% of respondents care for someone with a Physical Impairment / Mobility issues.
- 35% care for someone with a Mental Health Condition
- 35% care for someone with a Long Standing Illness
- 19% care for someone with a Learning Disability
- 19% care for someone with sensory impairment
- 18% care for someone with social communication impairment

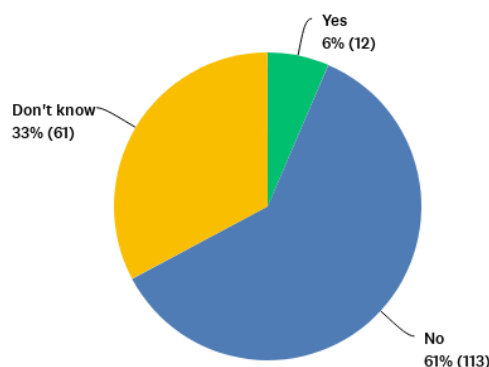
Other responses included; Dementia, epilepsy, quadriplegic cerebral palsy, PTSD, COPD, MS, Cancer, Old Age, brittle bones, Aneurysm, stroke, Autism,

Personal Health Budget for the Person Cared For

61% of respondents said the person they care for (with a condition as detailed in Q80) has not asked for or been offered a Personal Health Budget.

Of those that said Yes, only 9% chose to take the Personal Health Budget as a Direct Payment with 36% finding this helpful (9 respondents). Only 7 respondents took a direct payment.

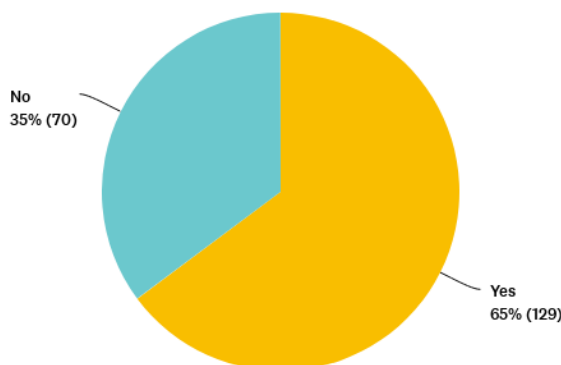
Q81 If the person you care for is in one of the categories above have they asked for or been offered a Personal Health Budget?



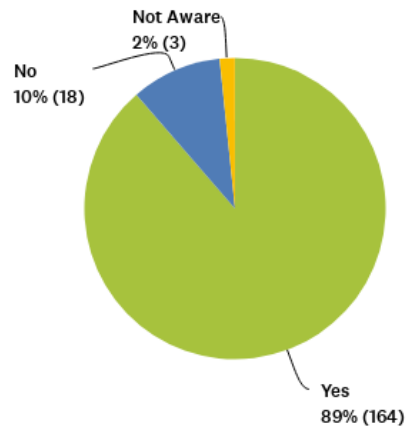
Benefits for the Person Cared For

There is increased awareness from 2017 of the benefits available for the person cared for with 65% of respondents saying Yes, compared with 54% in 2017.

Q84 Are you aware of the benefits available to the person that you care for?

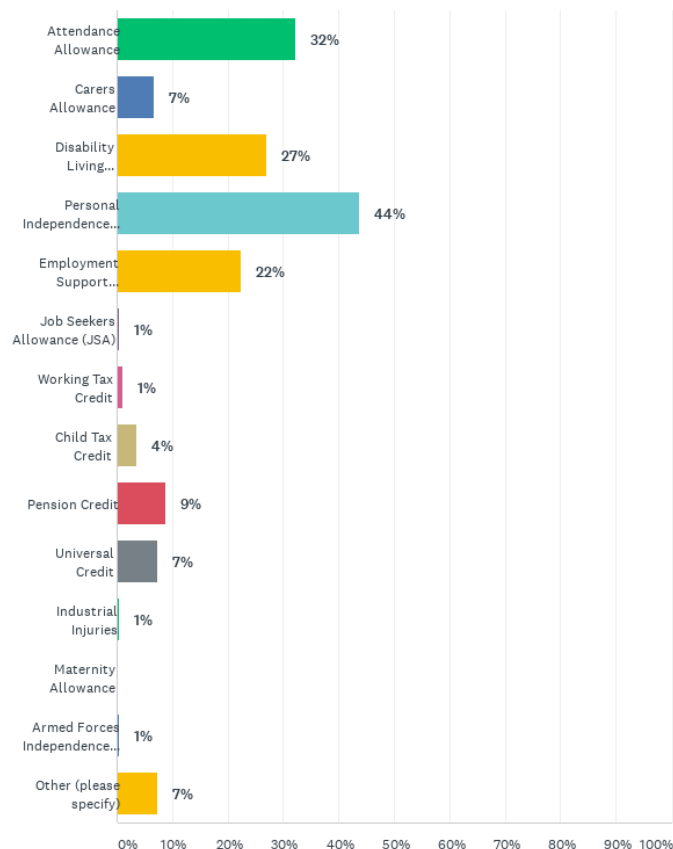


Q85 Does the person you care for claim any benefits?



This compares with 2017 when 85% of respondents said yes the person cared for claims benefits.

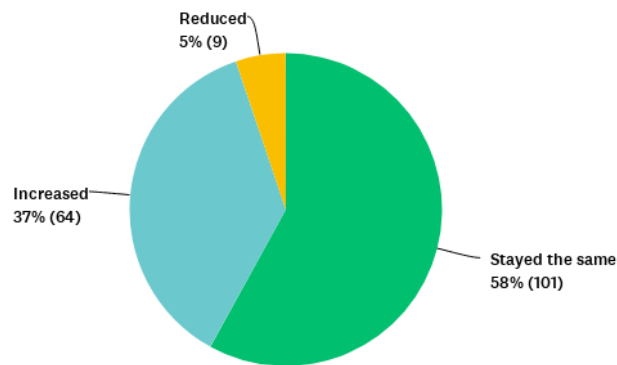
Q86 If the person you care for claims benefits, which ones? (Please tick ALL that apply)



The survey findings show;

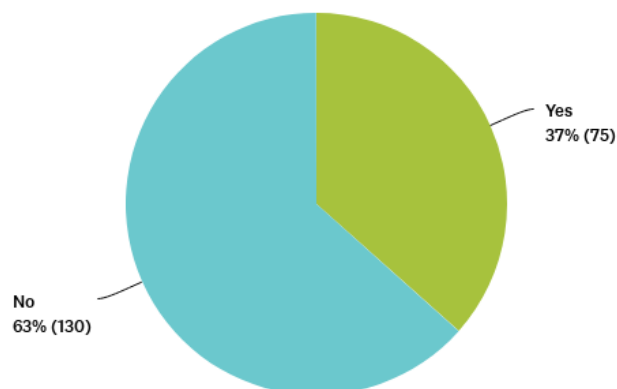
- A **drop in claims for Disability Living Allowance (DLA)** from 47% in 2017 to 27% in 2020.
- There has been a marked **increase in claims for Personal Independence Payment (PIP)** from 28% in 2017 to 44% in 2020.
- Since 2017, Universal Credit has been introduced with 7% claiming this benefit.

Q87 Thinking about the total amount received in benefits over the last 12 months, would you say they have:

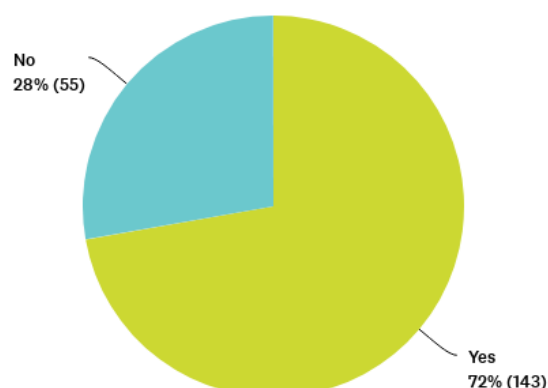


The 2017 survey showed that the total amount received in benefits over the previous 12 months had mainly stayed the same (73%) with 17% saying they had increased. 2020 sees more respondents saying there has been an increase (37%).

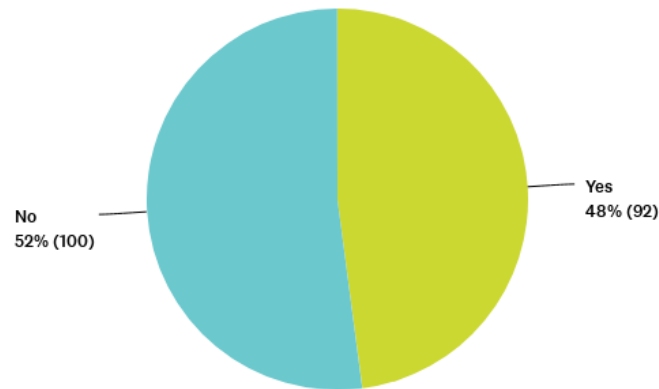
Q88 Do you feel you know what financial assistance and benefits are available for you as a carer and for the person you care for?



Q89 Do you provide practical help (e.g. to complete a benefit application) to the person you care for in order to claim the benefits they are entitled to?

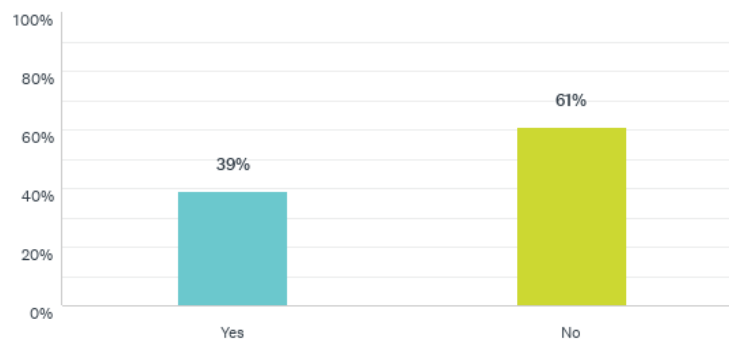


Q90 Have you or the person you care for received practical help (e.g. to complete a benefit application) in order to claim the benefits either of you are entitled to?



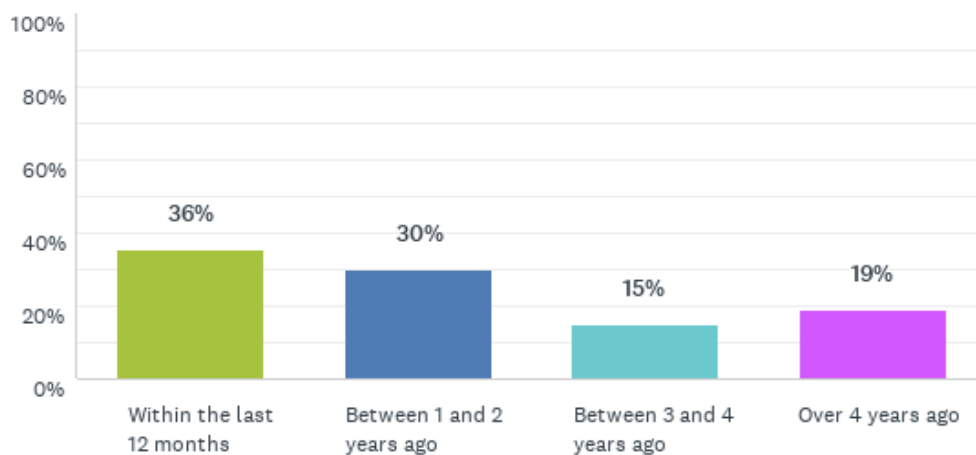
47% respondents said they received the most help from Gateshead Carers Association.

Q92 Has the person you care for had a needs assessment from social services?

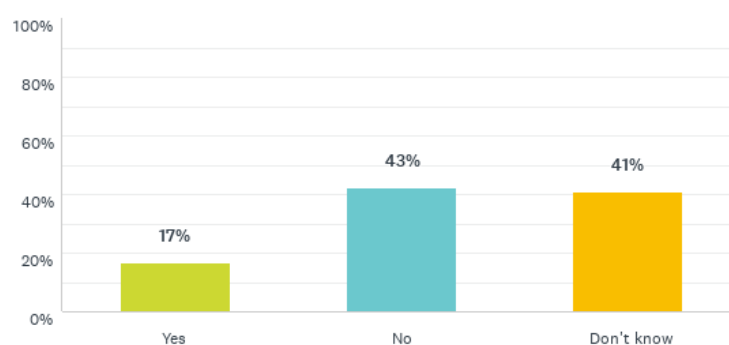


36% of respondents stated within the last 12 months, compared with 43% in 2017. In 2017, those stating that a needs assessment took place over 4 years ago was 10% - **this has nearly doubled to 19% in 2020.**

Q93 If YES, how long ago was this?

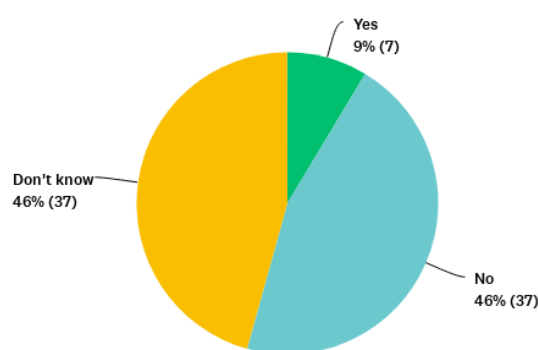


Q94 Did the person you care for receive a support plan?



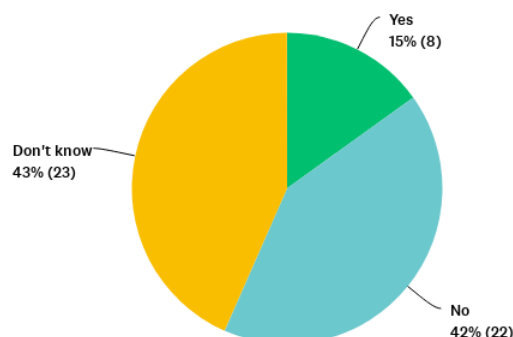
2020 has seen a reduction in the number of respondents saying that the cared for received a support plan, from 24% in 2017 to 17% in 2020.

Q95 If YES, did the support plan of the person you care for include his / her personal budget (an amount in pounds showing the cost of meeting his / her support needs)



The number saying Yes has gone down from 19% in 2017 to 9% in 2020.

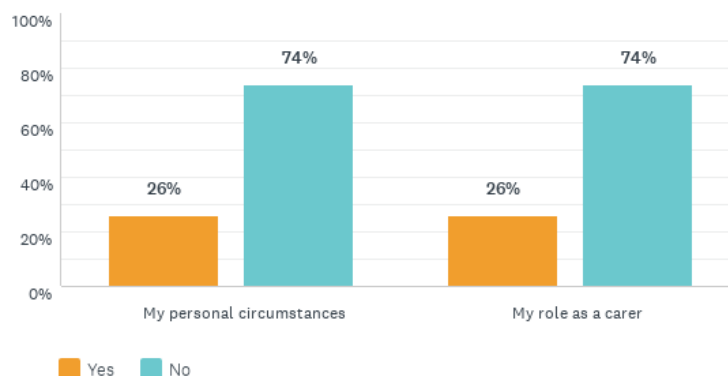
Q96 If YES, did the person you care for choose to take the personal budget as a Direct Payment (receives his / her personal budget directly so he or she could spend it on what they want to meet their needs)



There has been a decrease in the number of respondents saying the cared for chose NOT to take the personal budget as a Direct Payment from 52% in 2017 to 42% in 2020 with more respondents saying they Don't know with 33% in 2017 and 43% in 2020. Of those that chose a Direct Payment, 70% stated that this was helpful.

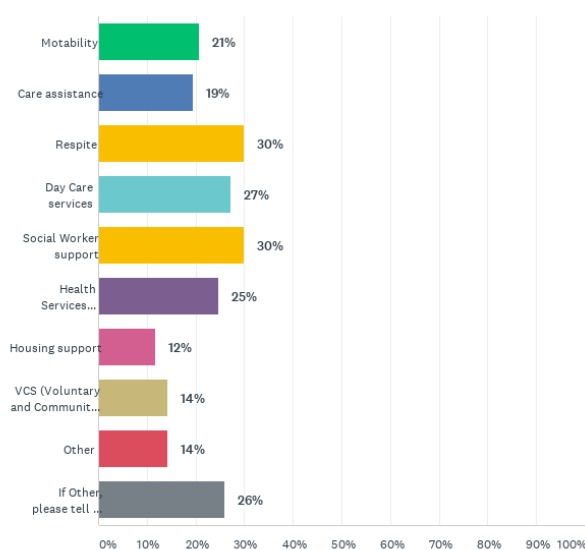
Public Funding Cuts to Services

Q98 Have the cuts to public services had an impact upon the following? For each statement, please put a tick in the box that is most relevant to you.



Cuts to public services have impacted less in 2020 according to respondents with 74% saying No they haven't impacted on their personal circumstances or on their role as an unpaid carer, compared with 69% and 64% respectively in 2017 and 2014.

Q99 Please let us know where you have experienced a reduction in services. Tick all that are appropriate to you.

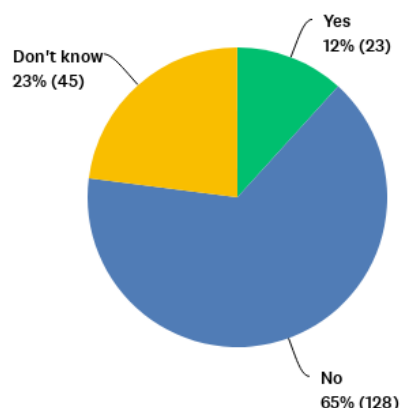


Of those respondents (26%) who have experienced a reduction in services, **there are notable differences from 2017 to 2020:**

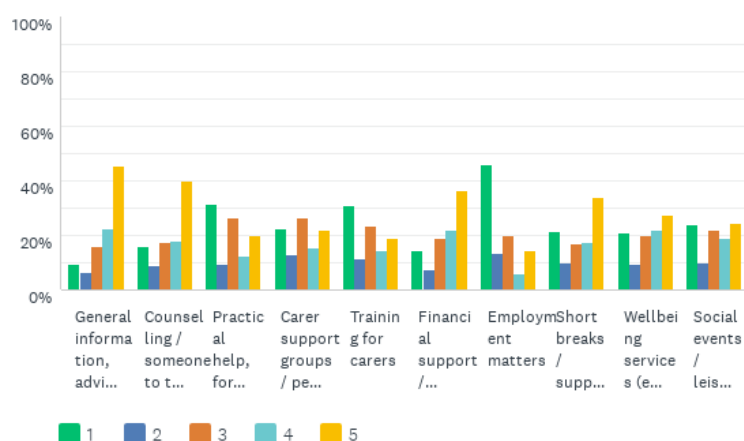
- 30% stated **a reduction in services in respect of** Social Worker Support (13.5% in 2017)
- 30% stated **a reduction in services in respect of** Respite (10% in 2017)
- 27% stated **a reduction in services in respect of** Day Care services (5% in 2017)
- 25% stated **a reduction in services in respect of** Health Services support (10% in 2017)
- 21% stated **a reduction in services in respect of** Motability (3% in 2017)
- 19% stated **a reduction in services in respect of** Care assistance (5% in 2017)

Other areas mentioned under 'other' included, care call, wheelchair services and GP.

Q100 Have you or the person you care for had council services you use withdrawn or reduced in the last 24 months?



Q101 Please rate the following types of support service by how important you feel it is in helping you in your caring role, where 1 = NOT IMPORTANT AT ALL, and 5 = EXTREMELY IMPORTANT. For each support service, please put a tick in the box that is most relevant to you.



Respondents rated the following either important or extremely important (4 & 5):

- General information, advice or support **68%** (71% in 2017)
- Short breaks / support to help you take a break from caring **52%** (65% in 2017)
- Financial support / advice on benefits, budgeting **59%** (65% in 2017)
- Counselling / someone to talk to in confidence **58%** (same in 2017)
- Wellbeing services (e.g. complementary therapies, relaxation) **50%** (same in 2017)
- Social events / leisure activities for carers **44%** (49% in 2017)
- Training for carers **34%** (42% in 2017)
- Carer support groups / peer support **38%** (40% in 2017)
- Practical help, for example with household tasks **32%** (38% in 2017)
- Employment matters **15%** (34% in 2017)

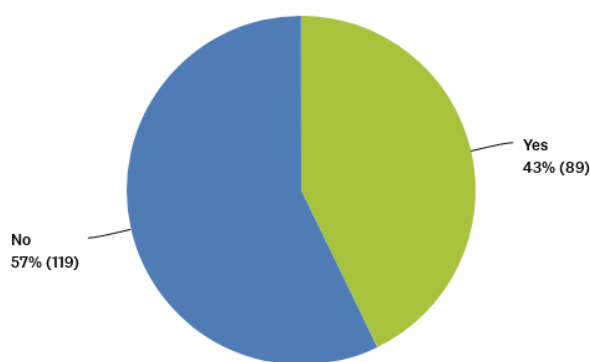
In broad terms results are comparable with the 2017 survey, although there are exceptions particularly;

- **Short Breaks** where the reported importance fell from 65% to 52% in 2020.
- **Employment matters**, where the reported importance fell from 34% to 15% in 2020.

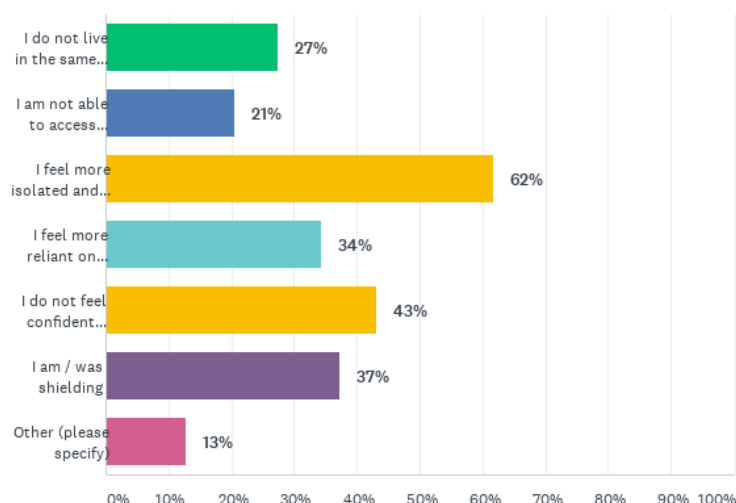
Impact of COVID 19 on Health and Wellbeing

This survey has coincided with the Covid 19 pandemic so specific questions were included in the survey on the impact of Covid 19 on unpaid carers.

Q102 Has the lockdown affected your ability to provide the level of care you would normally provide to the person you care for?



Q103 If Yes, please tick the reasons why. You can tick as many as are appropriate or tick 'Other' and tell us why.

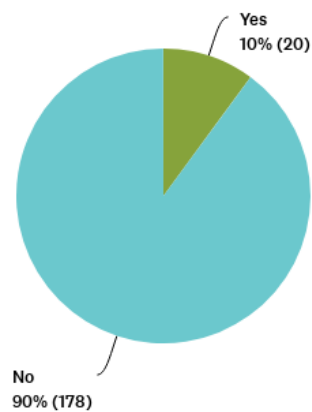


Other responses noted;

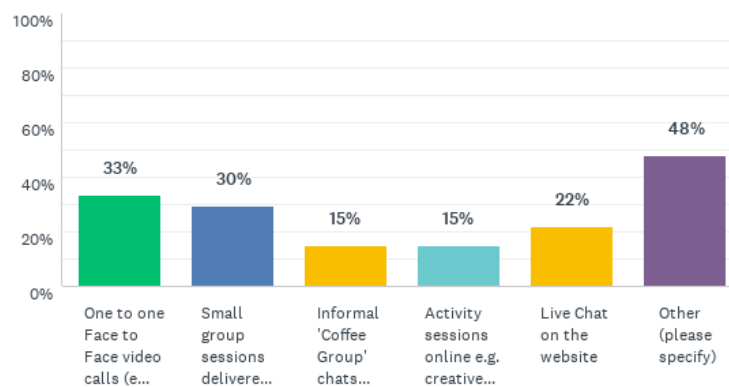
- *shops feel very full, not enough people wearing masks*
- *supposed to shield but couldn't*
- *places visited were all closed*
- *Also providing practical support for other shielding relatives.*

- *Lockdown has made my mental health worse*
- *Venues to go to severely limited.*
- *Although shielding dad was alone in his home (mam was in hospital with covid-19) he needed help and support*

Q104 Have you accessed support services online that prior to COVID 19 would have been delivered in person?

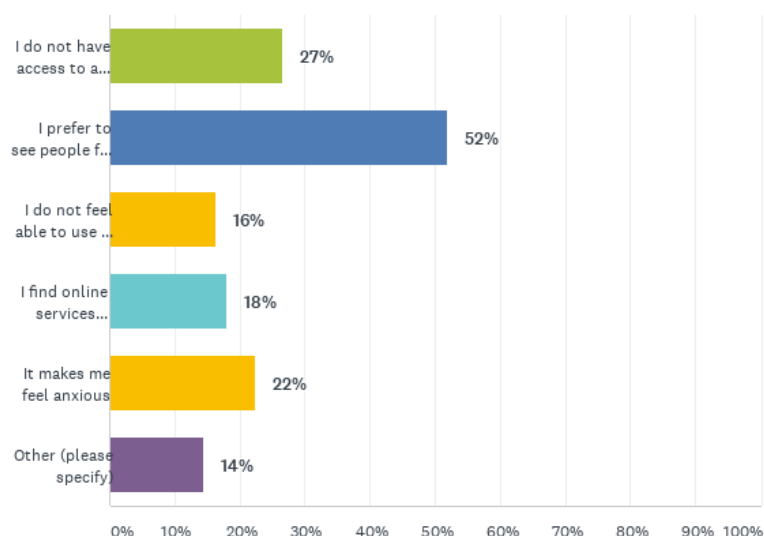


Q105 If Yes, which services have you found to be the most helpful. Please tick all that apply.



Other responses noted; Telephone consultations, Talking Therapy, Hospital appointment by phone, sight service, telephone counselling, Jehovah's Witness zoom meetings.

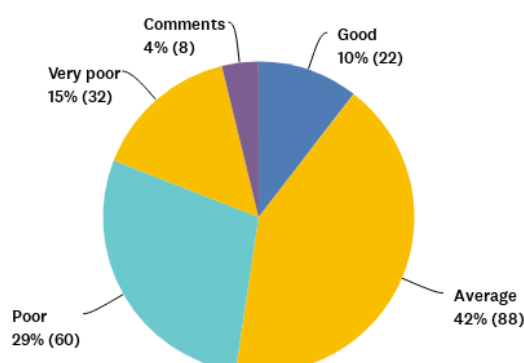
Q106 If No, please can you tell us if there are any specific reasons why you have not accessed online services? Please tick all that apply.



Other responses noted;

- *did not feel the need to*
- *osteo arthritis in hands makes having internet impossible*
- *do not do computers,*
- *I am too busy looking after my family*
- *I do not do internet*
- *I do not have internet and I am complete technophobic*
- *haven't wanted to participate, not time to do the activities while full time caring*

Q107 Since lockdown how would you rate your overall quality of life at the moment? (Quality of life is your ability to enjoy normal life activities).

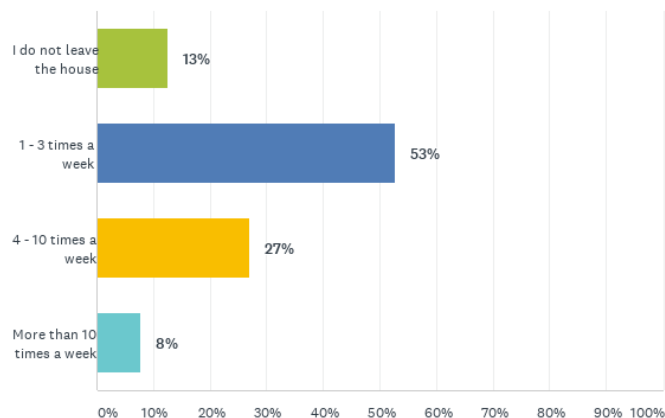


Other responses noted;

- *no quality of life*
- *do not go out of the house*
- *I was severely depressed in 1st 3 month of lockdown. I did not kill myself because I thought it would be even harder for my child to be rescued as no one would notice I'd gone.*

- *The help and support of family has meant that we feel better protected.*
- *keep in touch with friends but not the same as meeting face to face*
- *nothing to do with lockdown*

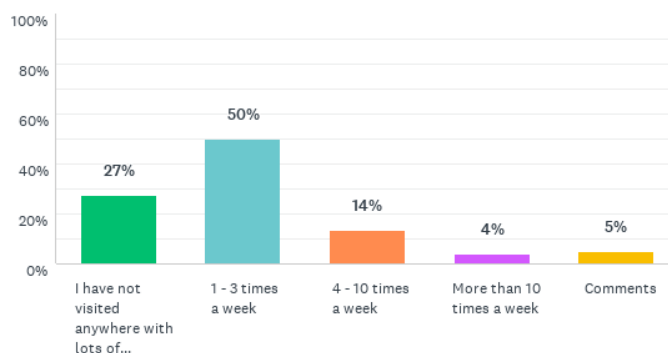
Q108 On average how many times a week do you leave your house, with little interaction with people outside your household (e.g. exercise)?



Comments noted;

- *I need to leave my home to feel safe. I live in constant fear!*
- *Go to church but difficult with latest restrictions not happy on my own shopping.*
- *Working throughout*
- *Taken up exercise seriously during covid-19 - had to do something rather than sit in the house all the time To walk the dog or shop*
- *work 2 days and support parents 5 days*
- *NOT LEFT MY HOUSE IN 6 MONTH*
- *my husband requires 24 hour help*
- *Only to go food shopping with my daughter*
- *only when I shop for mum or myself*

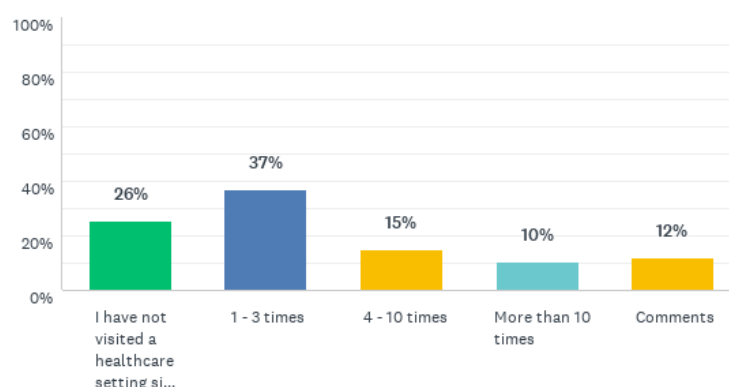
Q109 On average how many times a week have you visited somewhere with lots of people (e.g. shops, public transports, work, school)?



Other responses noted;

- *Since school reopen because my children*
- *since august I go to local shop for newspaper 6 days a week*
I see very few people approx 15 mins each time
- *I only go out first thing in morning when it's very quiet*
- *due to me working part time in a shop*

Q110 Since lockdown, on average how many times have you visited a healthcare setting, including for work (e.g. hospital, clinic, dentist, pharmacy)?



Other responses noted;

- *Chemist*
- *Work in health care (hospital visits) travel with son to Manchester for detox*
- *I have not been to work for 7 month*
- *flu jab - me and my wife blood tests - wife - cancer clinic collect script for me and wife*
- *regular blood checks*
- *consultations from GP - hospital have been by phone*
- *clinic with my husband*
- *wife in hospital*
- *all been cancelled*
At the beginning both mam and dad were in hospital, numerous times, they both had multiple appointments, checkups that they had to attend face to face, so was travelling to and from hospital numerous times. Myself I have had a yearly health check
- *ONCE TO HOSPITAL TO A&E*
- *Family members have dealt with all these matters on our behalf. I have maintained contact with eg Doctors and Pharmacy by phone as necessary. The level of support we receive from family is excellent.*
- *pharmacy once per week*
- *mostly these apps have been with my mam*

Conclusions

This section focusses on three key areas which are;

- **The lives of unpaid carers in Gateshead**
- **Gender inequality**
- **The word 'carer'**

1. The lives of unpaid carers in Gateshead

Since our 2017 survey there has been little or no overall improvement in the lives of unpaid carers in Gateshead. In fact the 2020 survey shows that the lives of unpaid carers in Gateshead has simply got more 'challenging' across the following key indicators;

- **There has been an increase in the number of hours per week providing unpaid care**
Over 50% of people with an unpaid caring role are now providing over 100 hours per week of care and support.
- **There has been an increase in the number of years people have been providing unpaid care**
42% have been caring for 10 years or more with 20% having been caring for 20 years or more.
- **There has been an increase in the number of people providing unpaid care who also have a physical disability or mobility issue**
Unpaid carers with a physical disability / mobility issues has increased from 31% to 45%.
- **There has been an increase in the number of unpaid carers with a mental health condition**
The number of carers with a mental health condition has doubled from 20% in 2017 to 40% in 2020. There has been an increase in the number of unpaid carers reporting disturbed sleep, feeling stressed, being depressed, being short tempered / irritable and being lonely.
- **There has been an increase in the number of unpaid carers who report they have a long standing illness**
This is up from 9% in 2017 to 20% in 2020.
- **More carers are reporting that they have had to give up their employment to provide unpaid care**
This has increased from 20% in 2014 to 30% in 2017 and 37% in 2020. Taking on an unpaid caring role inevitably leads to thousands of Gateshead residents having to leave employment to provide care and support. Currently only 2 out of every 10 carers (21%) are in employment and the majority that are working are in part time work.
- **Carers are finding it increasingly difficult to access GP services because of their unpaid caring role**
There has been a **dramatic fall** in the number of carers reporting that they have time to visit their GP when necessary from 78% in 2017 to 59% in 2020.

- **Taking on an unpaid caring role is a predictor of future ill health**

1 in 2 carers (50%) report that their unpaid caring role is directly impacting on their own health. Overall 7 out of every 10 unpaid carers (70%) described their current general health as 'average, poor or very poor'.

- **The quality of life for unpaid carers remains poor**

40% report feel isolated or lonely, 44% feel they have lost their independence and freedom and 57% do not have sufficient time or energy to participate in training or education. 58% feel their caring role does not allow them to continue with the paid work they would like to do. A staggering 87% worry about what would happen to the person they care for if they were not there.

- **Unpaid carers are not involved with or consulted by health and social care providers on services the cared for person receives**

1 in 2 carers (50%) report that they have had no involvement in the support offered to those they care for. It is not surprising to see that unpaid carers continue to feel unrecognised and not valued.

2. Gender Inequality

The 2020 survey has, for the first time, enquired about the experience of providing unpaid care across genders. The data produces interesting results which, whilst not conclusive, does raise questions about;

- Nationally more women provide unpaid care than men (around 60/40) and this divide is even higher in Gateshead
- Of the 10% of unpaid carers who are able to continue in employment, women who provide unpaid care are almost three times more likely to be in part time employment (61%) than men (22%). Women are also significantly more likely to miss out on promotions and training in employment because of their unpaid caring role
- The results of the survey show that there are differences in how the health and social care system supports men and women with an unpaid caring role.

Women are three times more likely to be asked by their GP if they have an unpaid caring role than men. Conversely, within social care, men are almost twice as likely to have a Carers Assessment within 6 months than women. It is beyond the scope of this report to be fully able to understand why this is happening but this data suggests that it may be associated with systemic unconscious bias or ingrained assumptions that women will provide unpaid care (GPs) and that men with an unpaid caring role need more support (social services).

43% of female unpaid carers report that there is an assumption women provide unpaid care

3. The word 'carer'

For the first time this survey has asked people with a caring role what their perception is of the word 'carer'. The results show that the majority of people with a caring role (62%) do not find it helpful. Many thought it meant 'a paid care worker' many reported that they simply did not like being referred to as a carer.

This is important because over half of all people with an unpaid caring role do not identify as a 'carer' for over one year. Others take longer, sometimes many years before identifying as a carer and seeking support.

The term 'care giver' is widely accepted and used internationally within the Carers Rights Movement and is seen as emphasising the 'giving' ie unpaid and freely.

RECOMMENDATIONS

This organisation has produced surveys of unpaid adult carers in Gateshead in 2011, 2014, 2017 and now 2020. National and local regional 'carer' strategies have come and gone throughout that time, yet nothing is changing.

The average 18 year old today will spend 12 years of the rest of their life providing unpaid care to a loved one and we know that over 60% of Gateshead's population will take on this role at some point in their lives. This is everybody's business.

To paraphrase Thomas Hobbes' poem Leviathan, published in 1651; *an unpaid caring role is;*
'solitary, poor, nasty, brutish and long'

- Solitary: because it is lonely
- Poor: because of financial hardship and having to give up work
- Nasty: because unpaid carers are not valued and recognised
- Brutish: because of the impact on physical and mental health
- Long: because of over 100 hours per week and number of years (45% caring for 10+ years) of providing unpaid care

This section is not what you would normally see in the recommendations section of a report. It is not full of easily written or forgotten platitudes. Platitudes such as asking VCS and health and social care providers to work together to ensure unpaid carers get the right support. Instead we are asking you to do something, it won't take long and here it is;

Re-read the highlighted conclusions above and ask yourself:

- Is this a life I want for myself, for my partner, for my children, for my grandchildren, for my friends?
- When will you and your organisation start to make change happen?
- How can Gateshead Carers help you do just that?

Steve Cowen

CEO, Gateshead Carers

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