

Gateshead **Carers**



STORM CAREGIVER:

SEVERE RED WARNING

**A REPORT BASED ON THE FINDINGS OF THE GATESHEAD
CARERS SURVEY 2023**

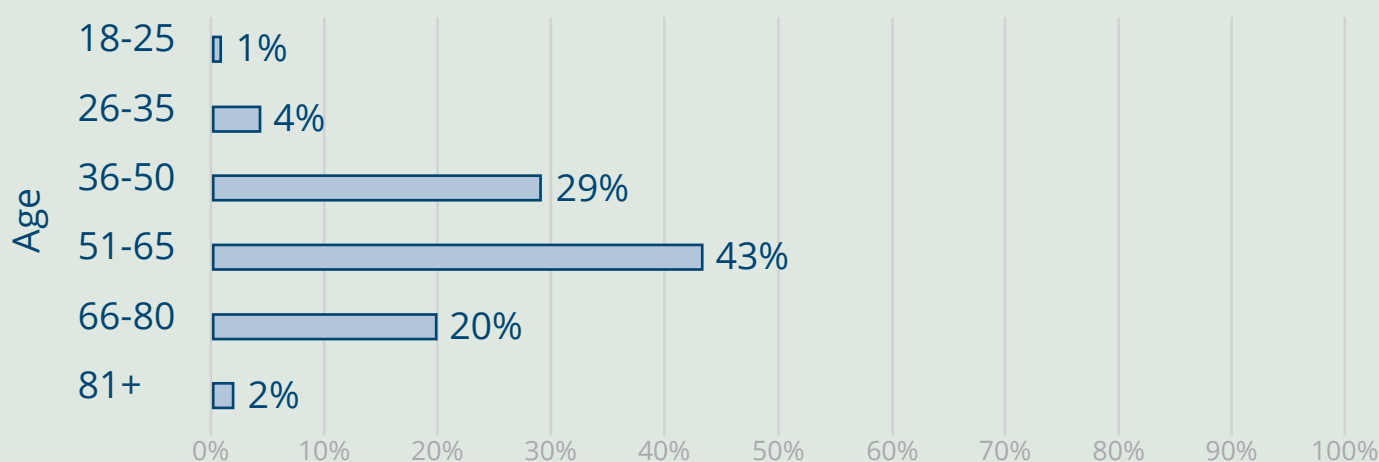
A Network Partner of
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INTRODUCTION

Welcome to our 2023 report which is based on our survey of adults providing unpaid care in Gateshead conducted between 24 July and 14 August 2023.

We conducted our first survey in 2011 and have carried out a survey every three years since then (2014, 2017, 2020). With over 90 questions this survey provides the most detailed and comprehensive information available on the reality of life as an unpaid carer in Gateshead.

This survey respondents were;



As a community, people providing unpaid care are 'time starved' and we are incredibly grateful to the **299** people who completed the survey, a task which takes at least 40 minutes to complete. We know that many people completing the survey did not have the time to complete it in one sitting and it involved returning to it on numerous occasions.

We also know that **29%** of carers completed this survey between 8pm and 8am and **16%** completed the survey between 10pm and 8am which is a clear indicator of when they had the time available.

The focus of this report is to highlight what has got better in carers lives and where the situation is getting worse. This report is based on all caregiver responses (aged 18 to 86) and across all health and social care needs of the cared for person.

In the coming months, we will release a range of further reports on specific carer groups including;

Caregivers by **gender**

Caregivers to those with **mental health challenges**

Caregivers to those with a **physical disability**

Caregivers to those with a **learning disability**

Parent carers of **disabled children**

BAME caregivers

Caregivers to those with **Dementia**

Caregivers to those who are **neurodiverse**

Caregivers to those affected by **substance misuse**

This report is intended for the caregiver community in Gateshead, friends and families of people who are providing unpaid care, leaders and decision makers across health and social care in Gateshead including Gateshead MPs, local councillors, government departments including Department of Work and Pensions, Department of Health and Social Care, Government Equalities Office, local, regional and national media organisations.

There are a number of estimates of the number of caregivers there are in Gateshead. These include the 2021 Census (18,200) YouGov 2022 (25,000) and Carers UK 2022 (28,000). For the purpose of this report we are using 25,000 as our estimated number of caregivers in Gateshead.

The ONS issued an approach with caution warning, on the 2021 Census figures for the number of unpaid carers in the UK; as the question was changed from the 2011 Census.

This report is titled “Storm Caregiver: Severe RED Warning”. The reason for this will become clear and obvious as you read the report.

The findings of this report will inform our new strategy 2024 - 2027.

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THE PEOPLE BEING CARE FOR

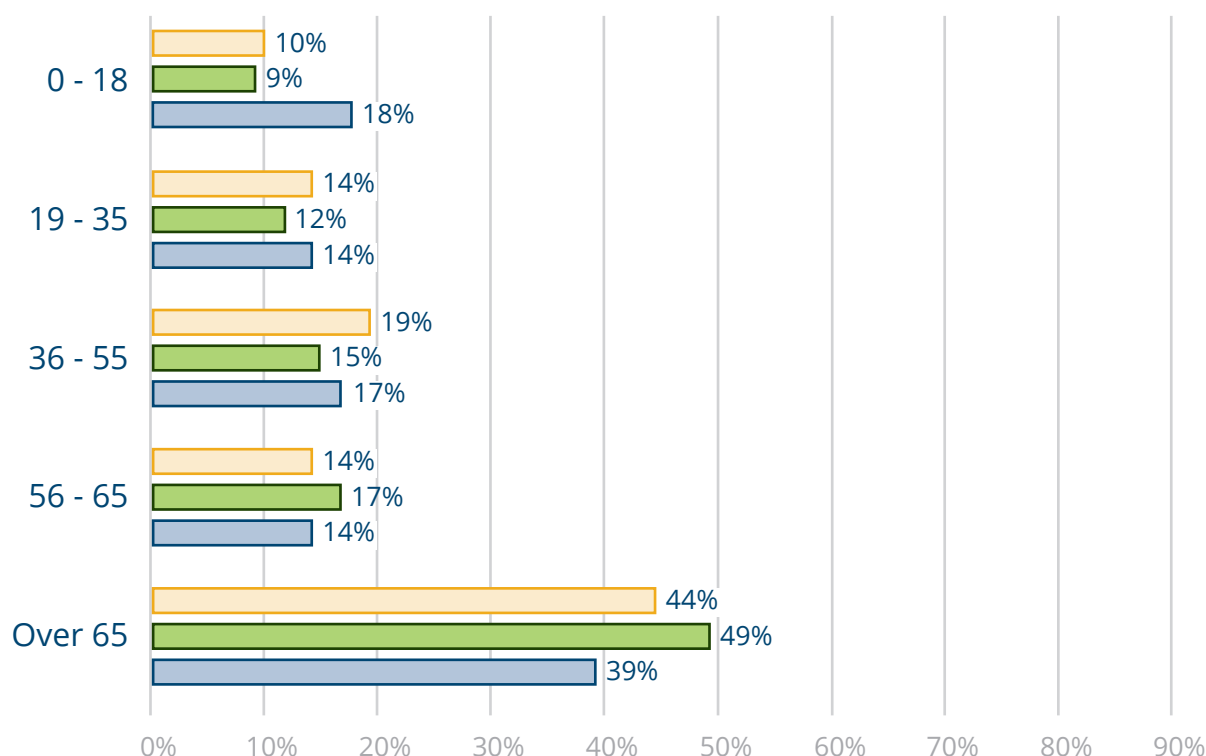
The person being cared for is most likely to be either a parent (**19%**), partner/spouse/cohabitee (**43%**) or Child (including adult children) (**34%**). Of course, the full range is wide including neighbours, siblings, friends, grandparents, aunts uncles etc.

Men (**57%**) are much more likely to be receiving care than women (**43%**). This has varied in our 2017, 2020 and 2023 survey so the average result is shown above.

In terms of age of the cared for person the largest age group is over 65 years of age (**39%**). In the last three surveys the figures across other age bands have remained largely similar. The significant change in the 2023 survey is the increase (of **94%**) of cared for people aged under 18.

How old is the person you care for?

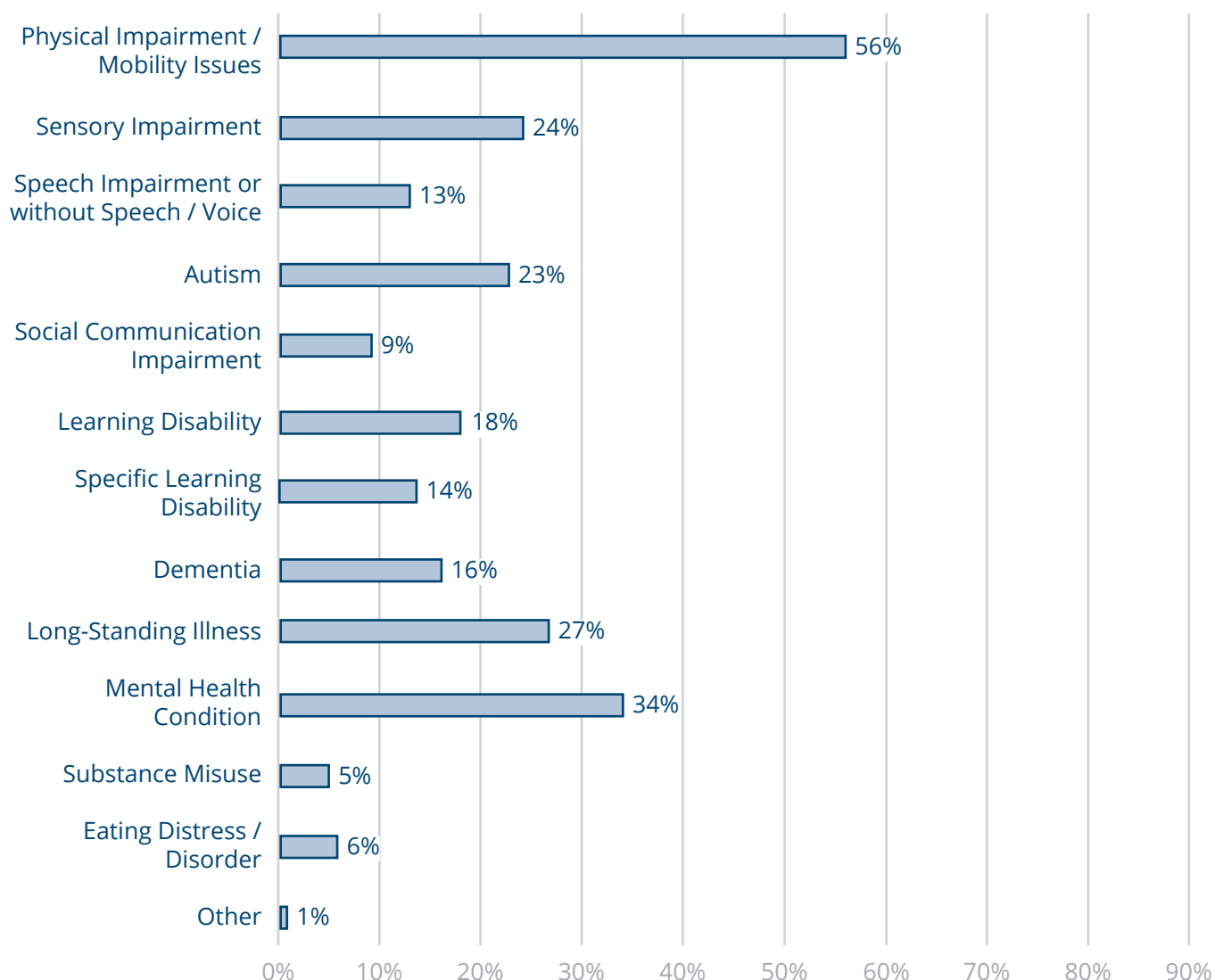
2017 2020 2023



In terms of disability/health condition of the cared for person, physical disability (**56%**) mental health (**34%**) and long standing illness (**27%**) have the highest rate, and this is consistent with our previous surveys.

There are two trends which are emerging, in the 2023 survey and our previous surveys reporting of both sensory impairment and specific learning disability has increased. Our 2023 survey was the first time we have included separate questions relating to Autism reported by 22% of respondents and Dementia reported by 16%.

Which of the following best describes the condition of the person you care for?

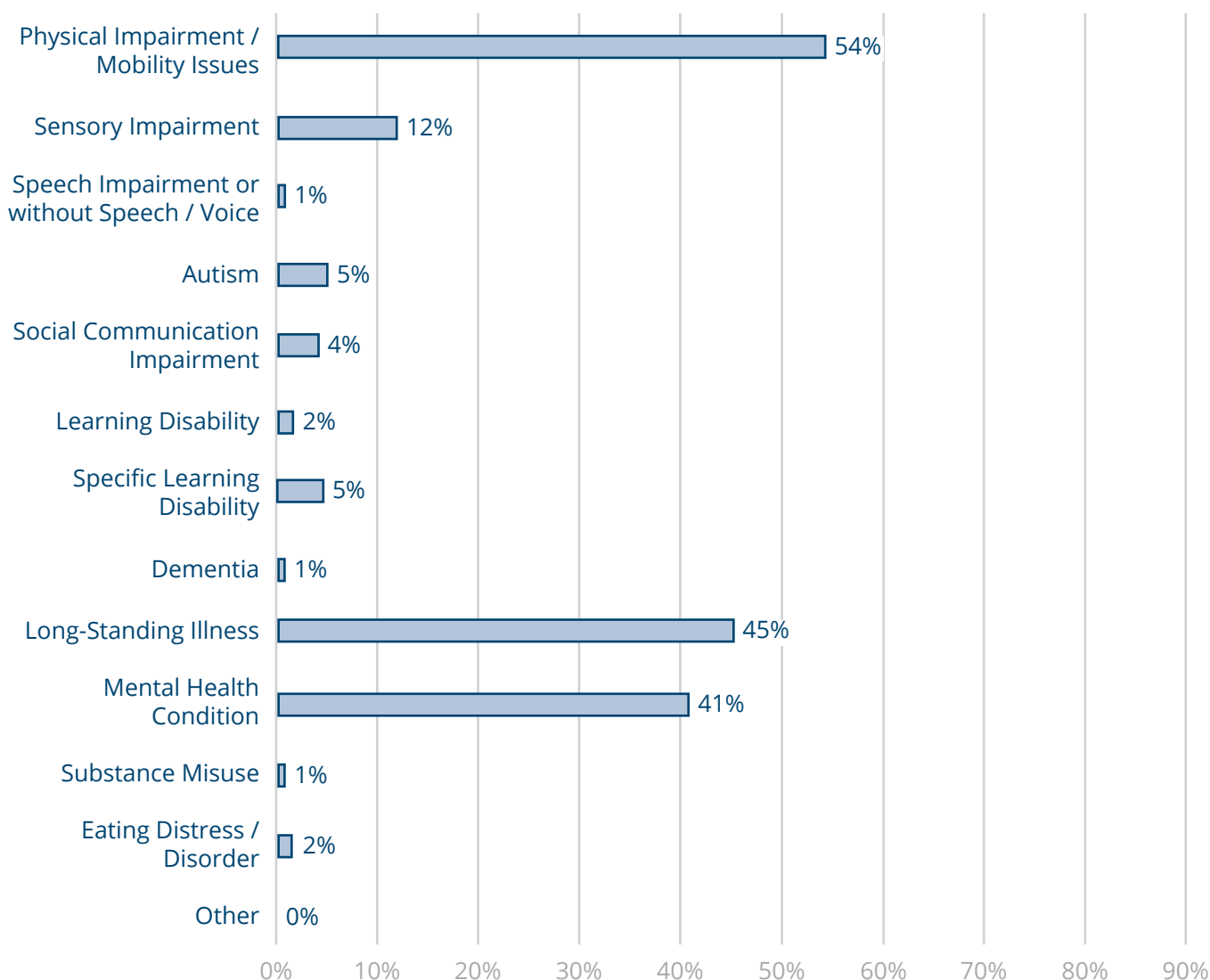


Next, we are going to focus on the health and disability of caregivers in Gateshead.

HEALTH AND DISABILITY OF CAREGIVERS IN GATESHEAD

The findings of the survey will be considered across key areas of caregivers' lives. We'll start with the health and disabilities of caregivers.

Please describe your disability or illness



Almost half of people (48%) providing care in Gateshead report having a disability or a long-standing illness themselves.

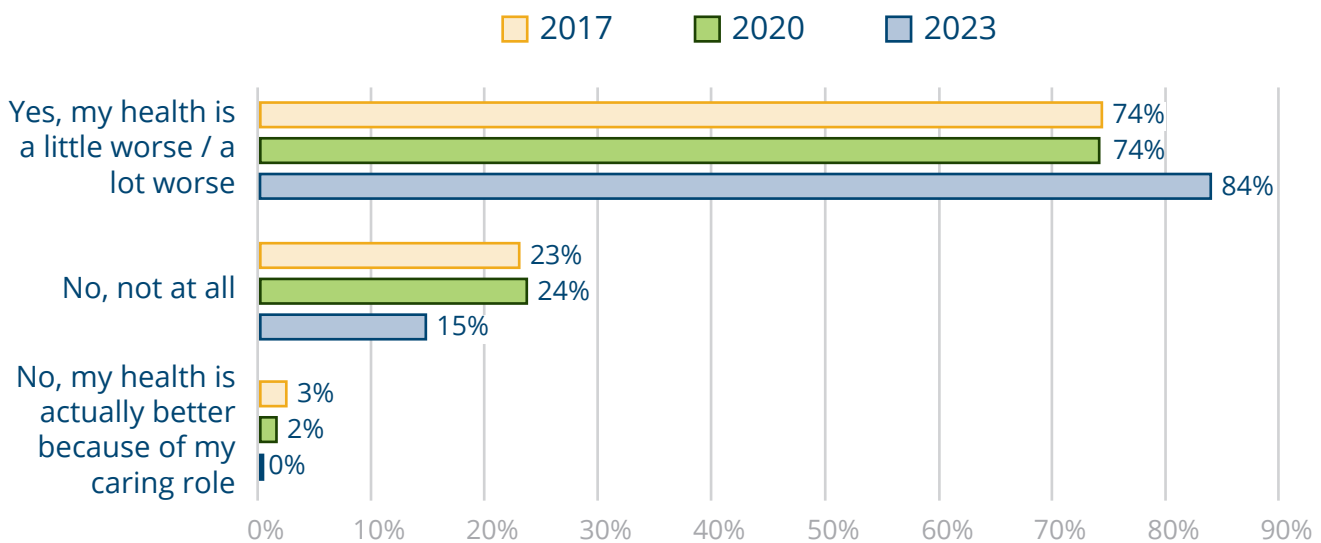


Half of all caregiver / cared for relationships in Gateshead are; the sick and disabled caring for the sick and disabled.



When we look closer at the data we find that over half of unpaid carers (54%) report that their disability or health condition is affecting or limiting the care that they are able to provide.

In the last 12 months, has your caring role affected your physical or mental health?



Over 8 out of every 10 unpaid carers (84%) report that their caring role has affected their physical or mental health.

This is an increase from **74%** in 2020.

Providing unpaid care is a predictor of poorer mental and physical health.

The survey data on carer's disabilities demonstrate a degree of comorbidity where people may have two or more existing illnesses or disabilities e.g. sight loss and a mental health condition.

54% 

of caregivers report having a physical disability.

45% 

of caregivers report having a long-standing illness.

41% 

of caregivers report having a mental health condition.

12% 

of caregivers report having a sensory impairment.

At the lower end of the scale 1 in every 100 caregivers (1%) report a substance misuse issue, 5% report they are Autistic, 2% have a learning disability, 5% a specific learning disability (e.g. dyslexia, dysgraphia, dyscalculia), 2% report eating distress. One in every hundred caregivers (1%) report having Dementia. We anticipate this figure will rise considerably over the next few years as the population ages and diagnosis improves.



Almost 7 out of every 10 caregivers (67%) report feeling anxious and stressed.

GP'S AND CAREGIVERS

Firstly, we asked 'do you feel your caring commitments enable you to have the time to contact your GP when necessary?' One in every two caregivers (52%) responded 'Yes' which of course means that almost half do not have the time to contact their GP.



What is worrying is that the number of caregivers saying they do not have time to contact their GP has increased by 118% since 2017.



Seven out of every ten caregivers report in 2023 having never been asked by their GPs or practice staff if they are an unpaid carer.



The number people reporting they are registered as a caregiver with their GP is improving. However, it remains a cause for concern that the majority of unpaid carers are not registered with their GP as an unpaid carer.



When we asked where caregivers had received support in the last 12 months 67% reported that they had never received support from GPs, practice staff or other health services.

If we look closer at the time GPs and other practice staff in Gateshead spend supporting caregivers; we can project what this actually means, based on what caregivers, NHS Digital and the British Medical Journal are reporting.

The average number of GP appointments per person in the UK is 5.1 per year¹. The average length of a GP appointment is 9.2 minutes².

If every single caregiver in Gateshead saw their GP once per year that would be 3,833 hours of support per year. Of course, we now know that it's likely that 64% of unpaid carers have not seen their GP in the last 12 months so that gives us 1,380 hours of GP support per year.

We also know that 73% of unpaid carers have never even been asked if they are an unpaid carer by a GP or practice staff. We can therefore reasonably reduce the amount of GP support across Gateshead where the caring role is even possibly going to be discussed by a further 73%.

That leaves us with a projected 373 hours of carer related GP support across all GP surgeries in Gateshead last year.

There are 26 GP practices in Gateshead, that brings GP caregiver support, at best, down to 14 hours per GP surgery per year, or 80 minutes per month, or 20 minutes per week.



That's pretty much the equivalent to two appointment slots per week, per surgery where there is even an outside chance of one patient's unpaid caring role and the impact it is having on a patient's health being discussed.

A GP practice with 10,000 patients registered will have over 1000 patients registered with an unpaid caring role.

¹ <https://digital.nhs.uk/data-and-information/publications/statistical/appointments-in-general-practice/may-2022>

² <https://www.bmj.com/content/365/bmj.l2389>

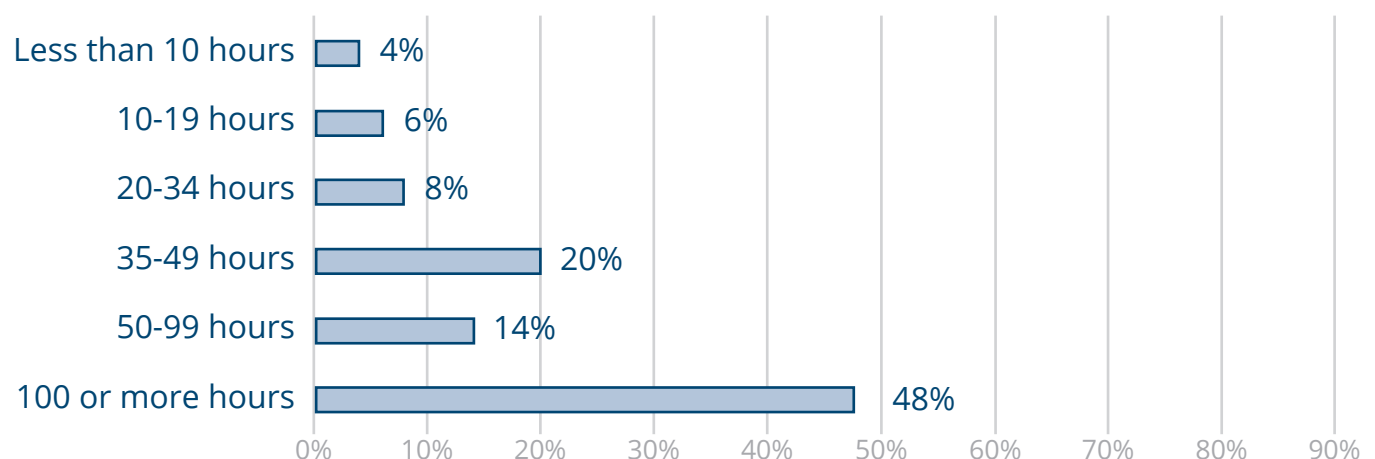
AMOUNT OF TIME PEOPLE ARE PROVIDING UNPAID CARE

Next we want to look at why being an unpaid carer is a predictor of poorer physical and mental health and consider why unpaid carers are so tired. We'll do this by first looking at the amount of care people freely provide (hours per week), then the length of time (years) people provide unpaid care followed by the range of caring tasks people carry out.

We'll look at this in two ways. Firstly, those giving care to one person and secondly those giving care to two people.

HOURS PER WEEK PEOPLE ARE PROVIDING CARE

For those who care for one person the cared for person is highly likely to be living in the same household (81%) and almost half (48%) are providing over 100 hours of care per week.



Over eight out of every ten caregivers in Gateshead (**82%**) are providing over 35 hours per week of unpaid care, the equivalent of at least one full time job. The data from our 2017 survey showed that 71% were providing over 35 hours of care per week and our 2020 survey showed 75% were doing so. The number of people providing this amount of care is growing over time.

If these figures were applied to the whole community of caregivers in Gateshead it would mean that **over 20,000 people in Gateshead are providing more than 35 hours of care per week.**



This shows 16% increase in the number of people who are now providing over 35 hours of care per week in the last 6 years.

For those who care for two people the second person is still likely, although less likely, to be living in the same household (64%). Not surprisingly, fewer hours of care are generally provided to the second person with close to half of caregivers (45%) providing up to 34 hours per week care to the second person.

Whilst the survey showed some people were caring for 3, 4 or 5 individuals the small number of people responding to this question was not sufficient to make meaningful comments. Further research is needed to develop an understanding of the number of people with multiple caring roles and the impact this is having on their health and wellbeing.

Having looked at the 'hours per week' people are providing unpaid care in Gateshead we will now look at the number of years people have been providing unpaid care.

NUMBER OF YEARS PEOPLE ARE CARING FOR

In this year's survey almost seven out of every ten caregivers (69%) have been providing care for over 5 years. In 2017 the figure was 66%. That may seem like a slight increase but in terms of the 25,000 caregivers in Gateshead that is 750 more people in Gateshead who have now been caring for over 5 years.



Our projection based on this data, is that there are now 17,250 caregivers in Gateshead who have been providing unpaid care for over 5 years.

Being a caregiver can be short term e.g., following a hip replacement but the reality is, for the majority, it is likely to be long term, for many years.

If we look at the average life expectancy in Gateshead it is 77.4 for men, and 81.6 for women. We know that close to 70% of caregivers provide care for over 5 years and 26% for over 16 years.



For males and females providing 5 years of unpaid care that is over 8% of their expected adult life expectancy.



For male and females providing unpaid care for 15 years it is close to 25% of their adult life expectancy.

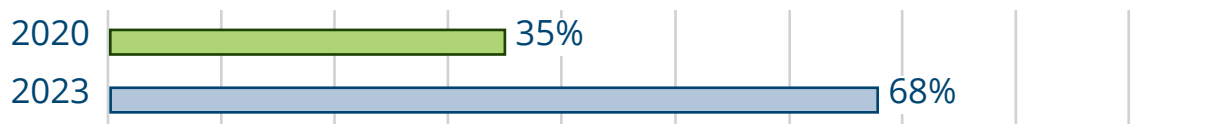
It's clear that people in Gateshead are now caring for more hours per week and doing that over more years. We'll now look at the type of care people are providing and whether or not there has been any change since our 2020 survey.

TYPE OF CARING PROVIDED

Now we will look at any changes in the range of caring tasks provided between 2020 and 2023.

Personal Care

(e.g. dressing, bathing, washing, feeding)



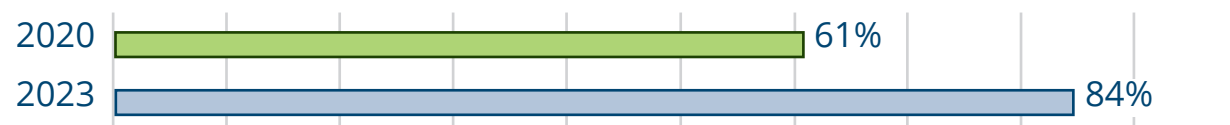
Physical Health

(e.g. help with walking, get up/down stairs, getting in/out of bed)



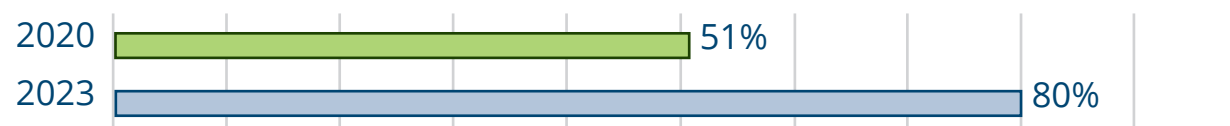
Practical Care

(e.g. preparing meals, shopping, housework, gardening, laundry)



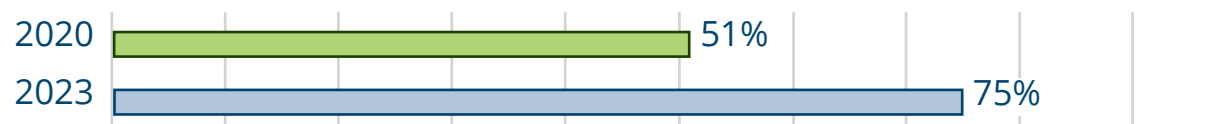
Help dealing with care services and benefits

(e.g. making appointments, phone calls, filling in forms)



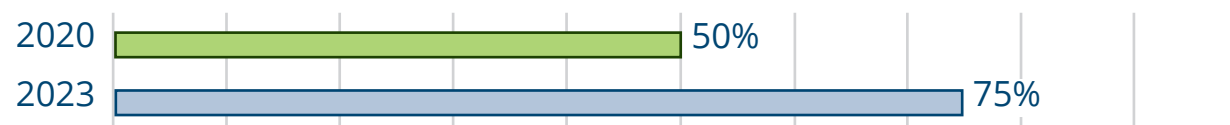
Help with paperwork and financial matters

(e.g. writing letters, filling in forms, dealing with bills, banking)

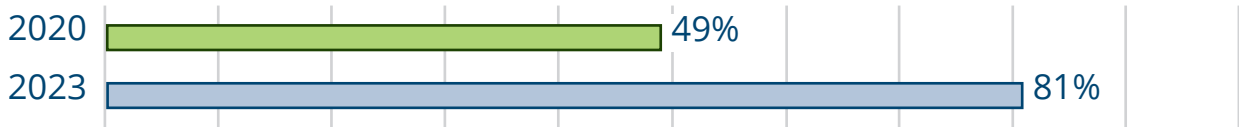


Keeping them company

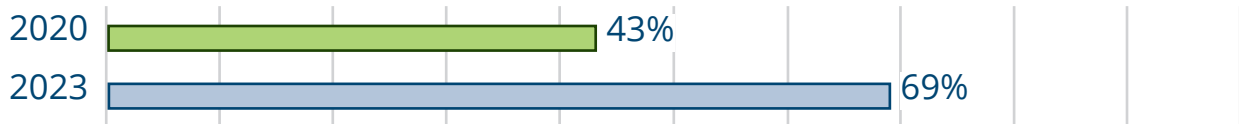
(e.g. visiting, sitting with them, reading/talking to them, playing games)



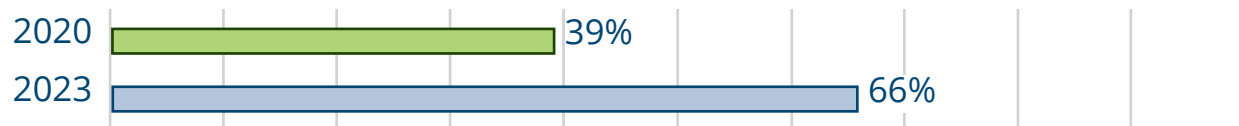
Emotional Support
(e.g. providing a listening ear)



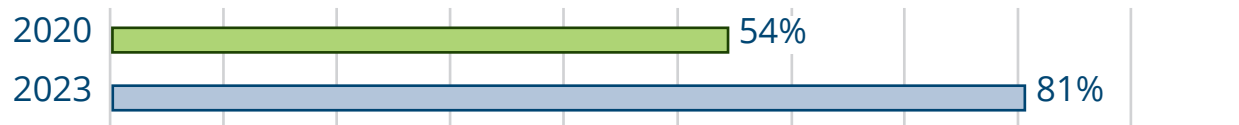
Providing Transport
(e.g. taking them to see friends and relatives)



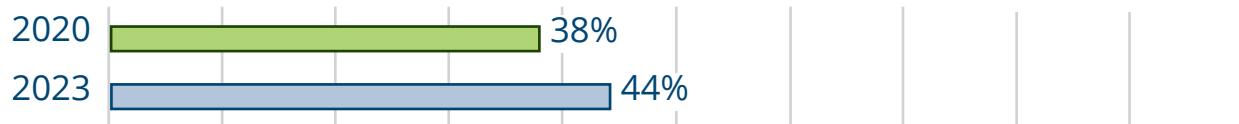
Administering Medicines
(e.g. ensuring medicine is taken, giving injections, changing dressings)



Supervision
(e.g. keeping an eye on the individual to make sure they are okay)



All of the Above



Other



The 2023 survey results show a staggering increase in the type and range of care provided across all areas. Since 2020;



Personal care: Increase 94%



Physical help: Increase 52%



Practical help: Increase 38%



Dealing with care services / appointments: Increase 57%



Paperwork and financial matters: Increase 47%



Keeping company: Increase 50%



Emotional support: Increase 65%



Providing transport: Increase 60%



Administering medicines: Increase 70%



Supervision, keeping safe: Increase 50%

As we delve into what caregivers in Gateshead are telling us it's abundantly clear that thousands of people in Gateshead are providing **more hours of care per week**, **are providing that care for more years** and **are carrying out more caregiving tasks**.

Life for caregivers is getting harder, more challenging, more tiring and this is impacting on both their physical and mental health.

Tiredness amongst people providing unpaid care is common. GPs have a word for it, TATT (tired all the time).

We'll look at why people providing unpaid care are TATT a little later, for now, we'll look in more detail at the wellbeing of caregivers.

65% 
of caregivers report feeling tired.

52% 
experience disturbed sleep.



THE WELLBEING OF PEOPLE PROVIDING UNPAID CARE

The Care Act 2015 emphasises the statutory duty of local authorities to promote the wellbeing of unpaid carers. Whilst 'wellbeing' is not defined within the Act the guidance to it is clear.

'In regard to carers, the local authority should consider how they can be supported to look after their own health and wellbeing and to have a life of their own alongside their caring responsibilities'.

This includes;

- personal dignity (including treatment of the individual with respect)
- physical and mental health and emotional wellbeing
- protection from abuse and neglect
- control by the individual over day-to-day life (including over care and support)
- participation in work, education, training or recreation
- social and economic wellbeing
- domestic, family and personal relationships
- suitability of living accommodation
- the individual's contribution to society

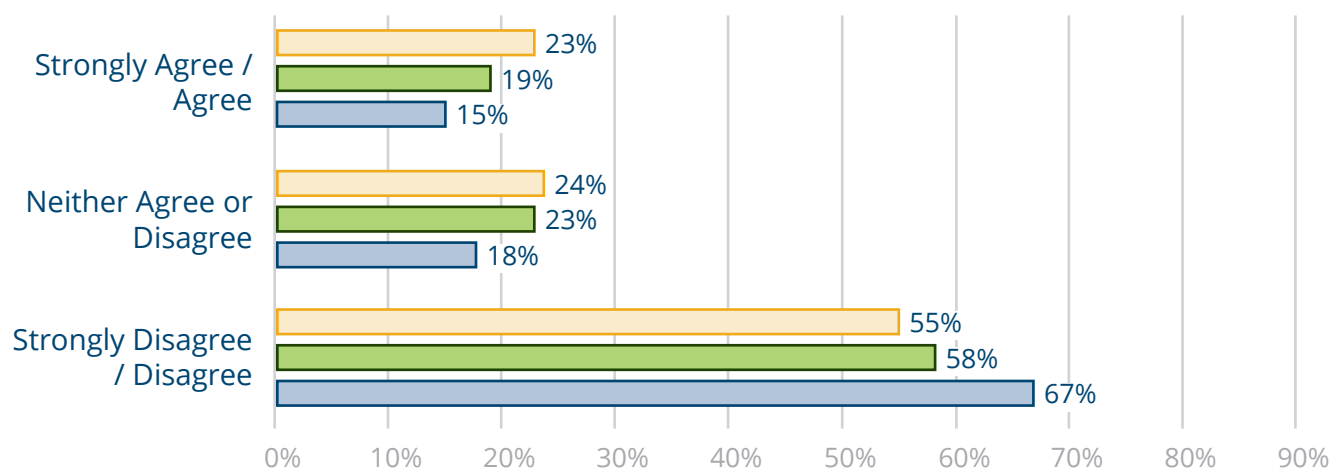
Often people think 'guidance' is something you can choose to follow or not follow. Statutory guidance is different, as it explains how the law should be interpreted. It must be followed by local authorities.

Now we'll look at what caregivers in Gateshead are reporting about their wellbeing. We'll show figures from our 2017 and 2020 reports alongside the 2023 report to see if things are improving or getting worse.

In 2017 just over half of caregivers in Gateshead reported that they were unable to spend their time as they want and doing things of value to them.

I am able to spend my time as I want, doing the things I value.

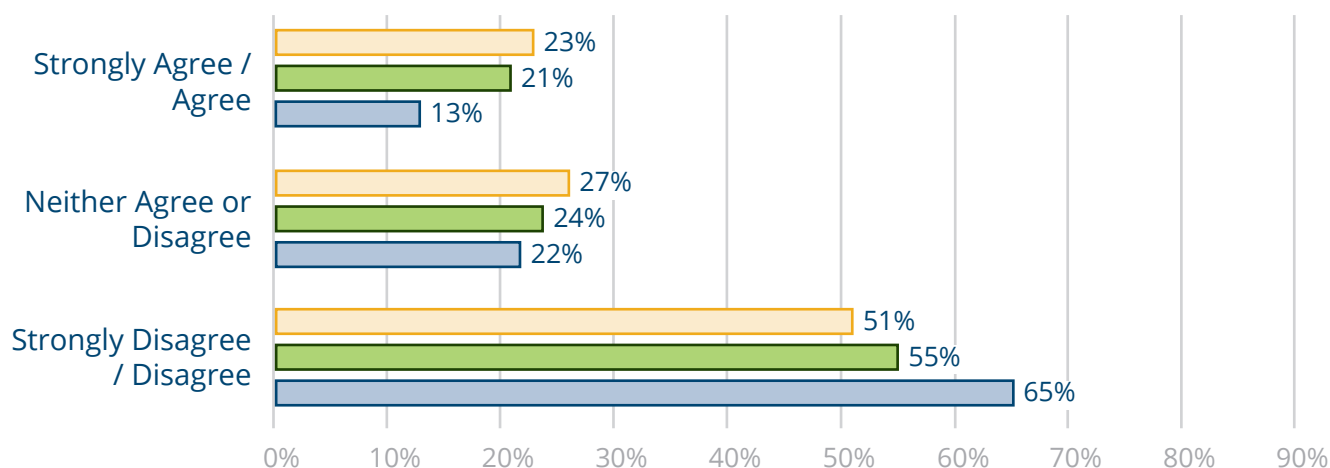
2017 2020 2023



In 2023 this has increased to almost 7 out of every 10 carers. This is a 22% increase in people reporting they don't have time to do the things they want to do.

I have the space and time I need to be myself

2017 2020 2023

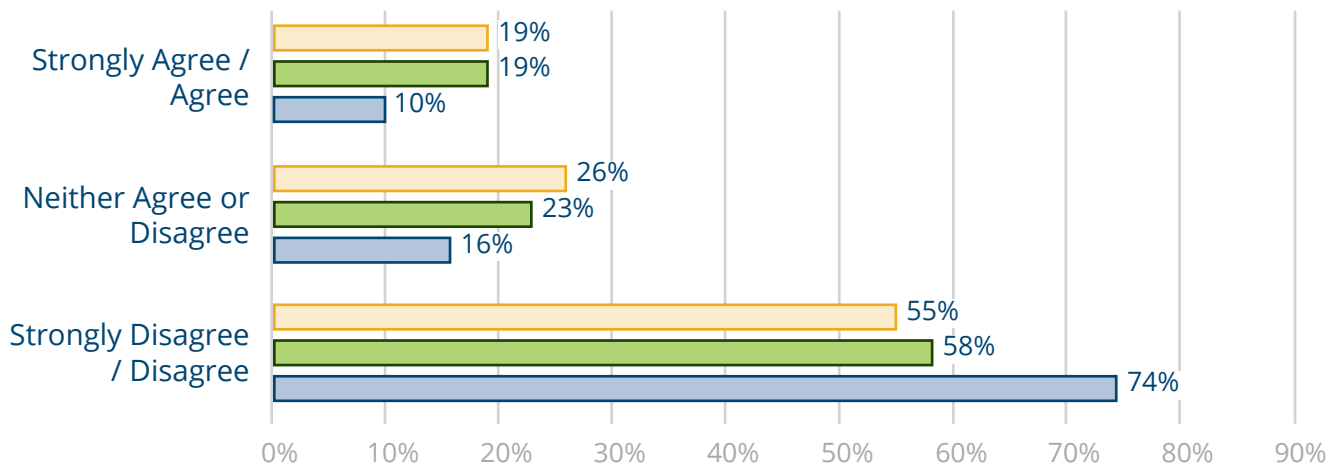




Increasing numbers of caregivers are reporting that they do not have the time and space to be themselves. **The number reporting this has increased by 27% since 2017 which means almost 7 out of every 10 caregivers feel like this. That's the equivalent of 16,250 caregivers.**

I have as much control over my daily life as I want.

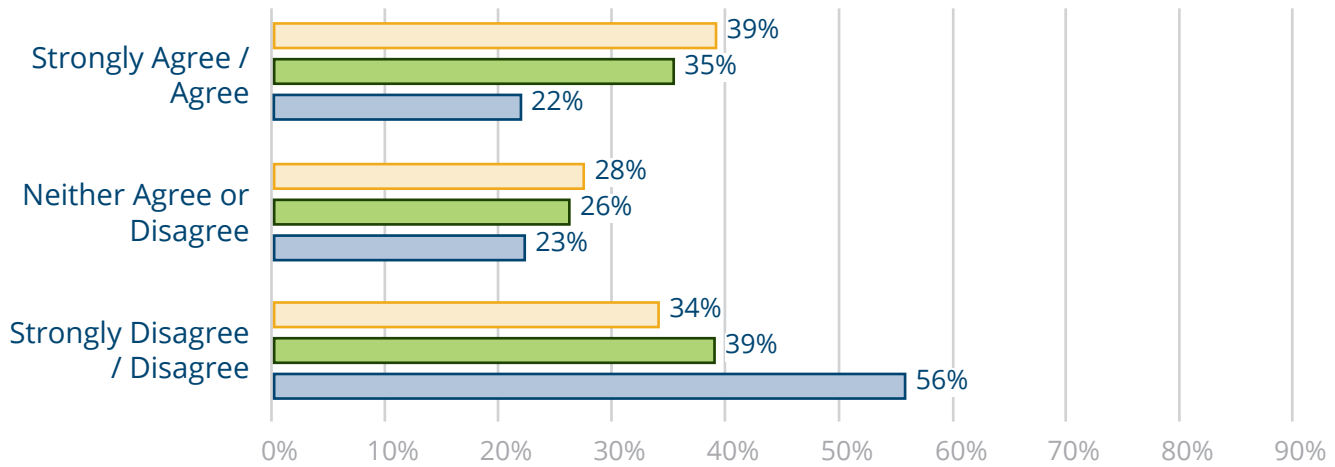
2017 2020 2023



Everybody needs to feel that they have as much control over their daily lives as they want. The reality is that in 2023 74% of caregivers do not feel that way.

I have the time I need to look after myself (in terms of getting enough sleep, eating well, etc.).

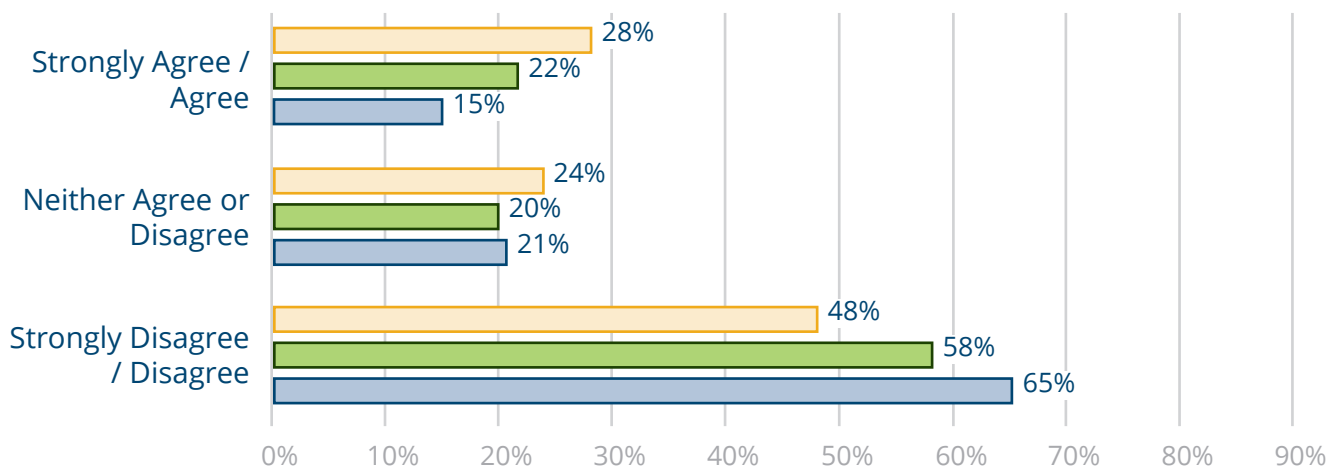
2017 2020 2023



The situation is no better when it comes to caregivers having enough time to look after themselves in the most basic yet essential ways – getting enough sleep and eating well. Almost 6 out of every 10 caregivers are unable to do this. That is a shocking 52% increase since 2017.

I have as much social contact as I want with people I like.

2017 2020 2023





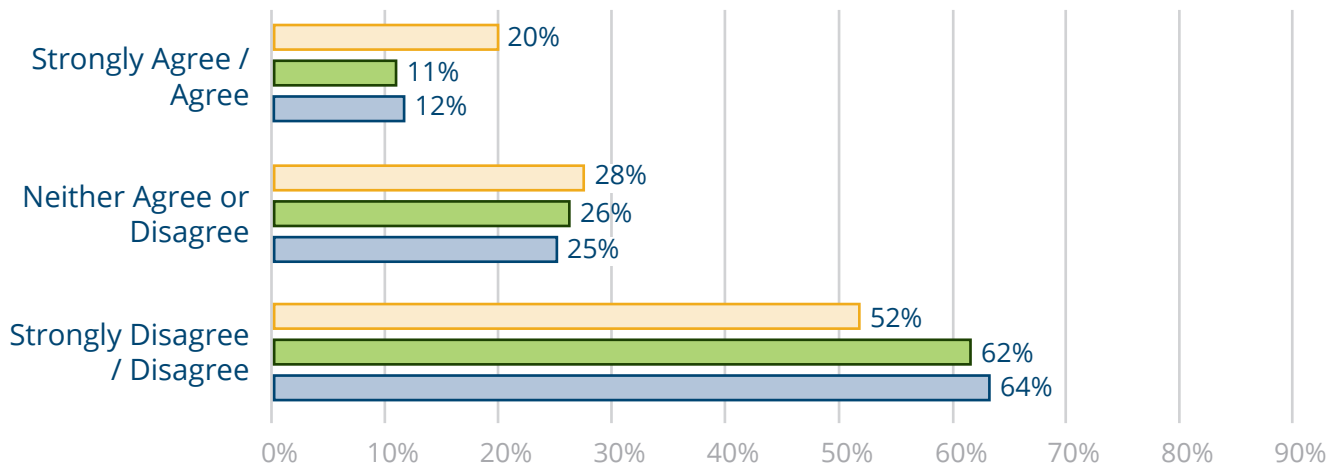
Are caregivers able to have social contact with people they like? In 2023 nearly 7 in every 10 caregivers are not able to do that. That is a 35% increase since 2017.

We know that people coming to this organisation for information and support often describe themselves as being 'just a carer'. Providing unpaid care brings loss, it brings the loss of people's sense of self, who they are and loss of their hopes and dreams. **Unpaid care is all-consuming.**



I am able to enjoy opportunities in the local community (e.g. volunteering).

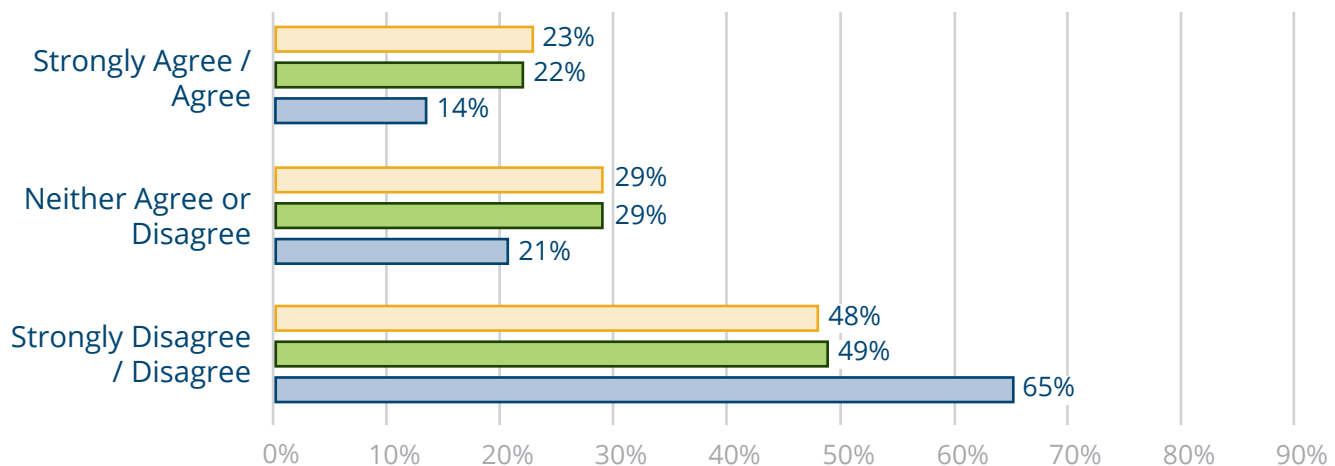
2017 2020 2023



Over 6 out of every 10 caregivers (64%) report in 2023 that they are unable to access local community opportunities in 2023. Here we have a 23% increase from 2017.

I am getting sufficient breaks from caring.

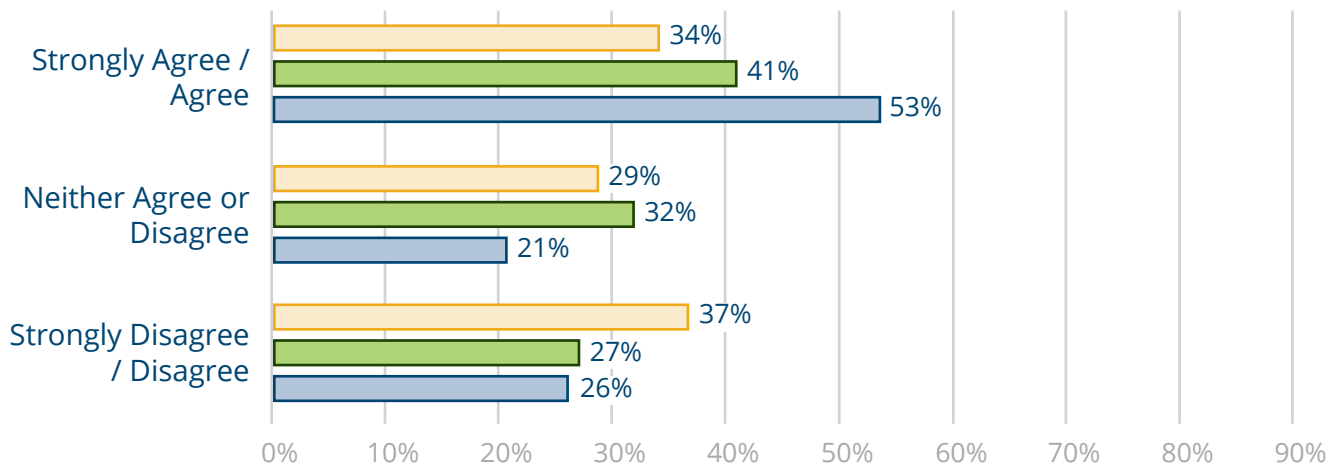
2017 2020 2023



A break from the caring role is essential for every caregiver. In 2023 nearly 7 out of every 10 caregivers report they do not have sufficient breaks.

I often feel isolated or lonely.

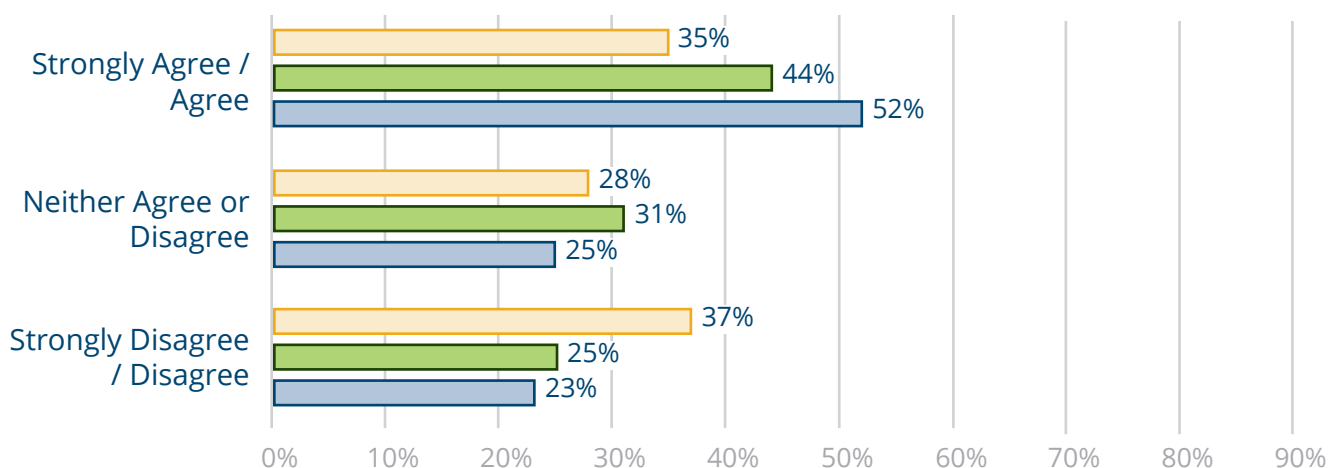
2017 2020 2023



Over half (53%) of all caregivers in Gateshead feel isolated or lonely. That equates to over 12,500 people in Gateshead. This is a 56% increase since 2017.

I feel I have lost my independence / freedom.

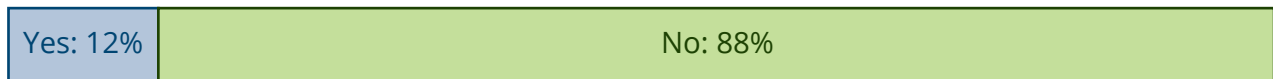
2017 2020 2023



Over half of caregivers (53%) report their loss of independence and freedom. That's an increase of 48% since 2017.

Another indicator of wellbeing is volunteering, it provides an opportunity to meet new people, gain new skills, have some fun, become connected and part of a community, do something different and contribute to society. Let's look for a moment at unpaid caregivers and volunteering.

Do you currently do any voluntary work?



Our 2023 survey shows that almost 9 out of every 10 caregivers are not currently volunteering. The Community Life Survey (2021 /2022) reported that 27% of the UK population had volunteered in the previous 12 months.



Unpaid carers are nearly three times less likely to be able to volunteer than the general population. This is understandable and likely to be the case because caregivers, as outlined earlier, are 'time starved'.



The responses to questions relating to carer wellbeing show clear and worrying indicators of the worsening of caregivers' wellbeing across multiple criteria.

Of course, wellbeing is also linked to employment and access to education and training opportunities. It's also heavily associated with money and household income. In the next section we'll outline what caregivers are telling us about these areas of their lives.

CAREGIVERS AND EMPLOYMENT

The employment rate in Gateshead is 72.1% (ONS 2023). This survey shows that the employment rate (full-time or part-time) of caregivers in Gateshead is 31%.



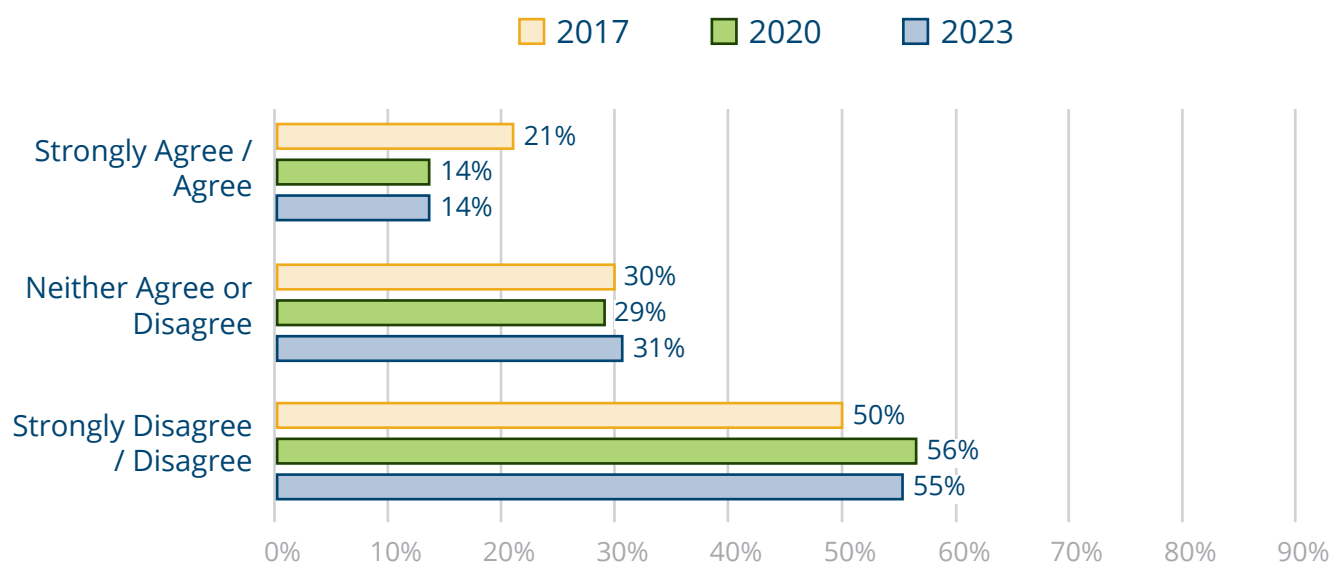
It's difficult to explain how low that employment rate is, but if caregivers in Gateshead were a country, it would be very close to having the worst employment rate in the entire world.

25 Countries with the lowest Employment Rate ¹	
Country	Employment Rate (%)
Columbia	58
Saudi Arabia	58
Brazil	57
Cape Verde	57
Chile	56
Mongolia	55
Bulgaria	54
Spain	52
Serbia	50
Costa Rica	50
Rwanda	49
Turkey	48
El Salvador	46
Ecuador	46
India	46
Macedonia	46
Georgia	45
Argentina	45
Moldova	44
Puerto Rico	42
Bosnia and Herzegovina	41
South Africa	40
Morocco	39
Kosovo	34
Caregivers in Gateshead	31
Jordan	26



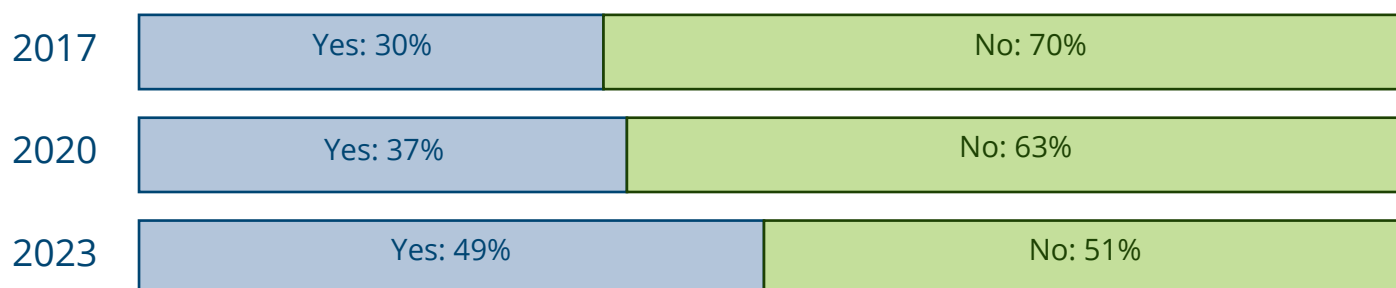
The table below shows that over half of caregivers (55%) in Gateshead believe they cannot continue with the paid work they would like to do because of their caring role. This shows a 10% increase from our 2017 survey.

My caring role allows me to continue with the paid work I'd like to do.



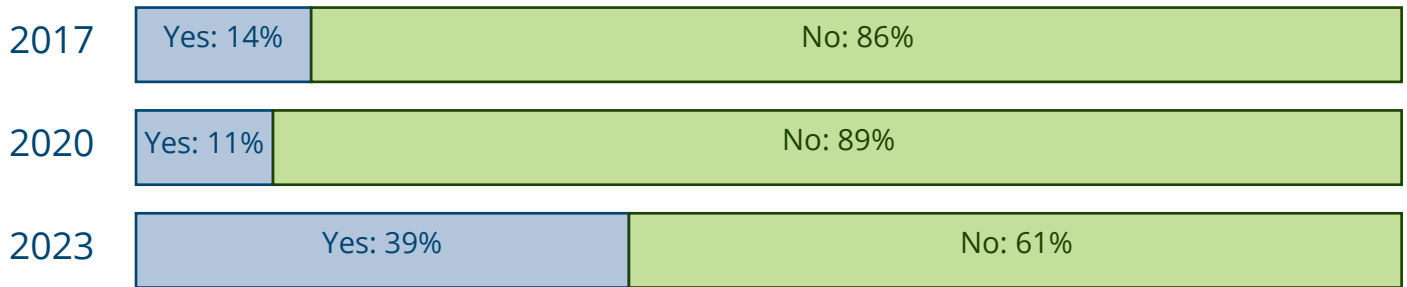
The number of caregivers who have had to give up employment to provide care, either fully or by reducing the hours they work, shows an alarming upward trend.

Have you had to give up work fully or partially because of your caring role?



1 in every 2 carers report having to give up employment fully or partially in 2023 which is an increase of 63% since 2017.

Have you been unable to progress in your job, (e.g. promotions), because of your caring role?



For those able to continue in employment, four out of every ten (39%) report that their unpaid caring role is having an increasing and significant impact on their ability to progress in their work (e.g. promotions, career development).

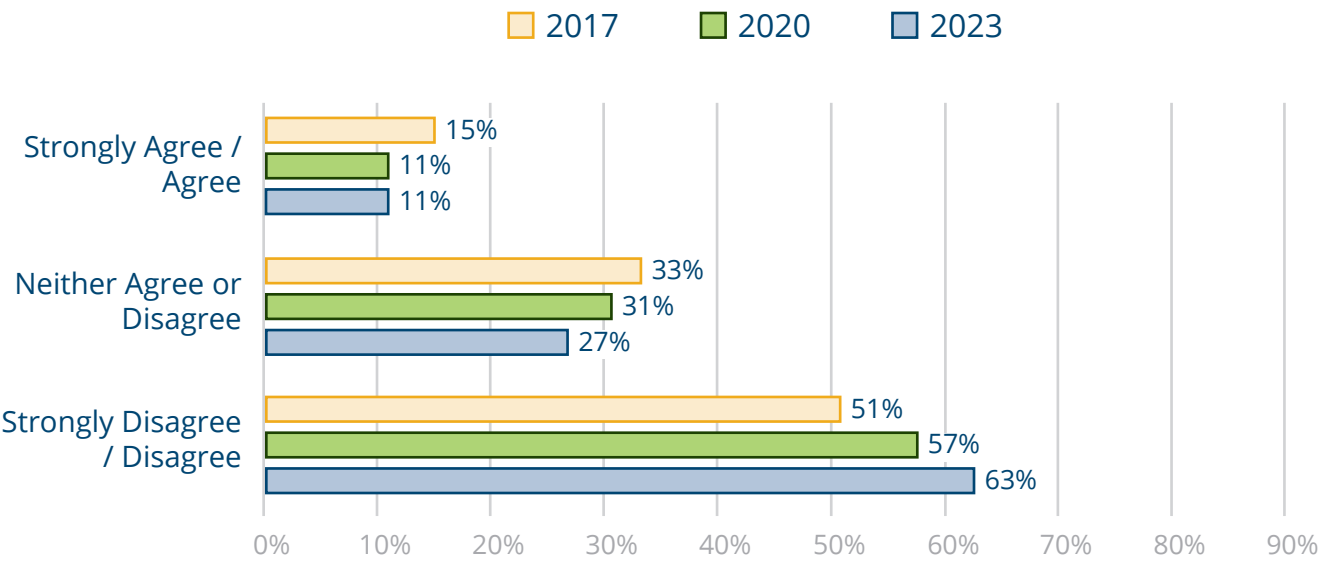


The number of people who are reporting an inability to progress in their careers, because of their caring role, has increased by over 200% since 2020.



A key element of getting into work or progression at work is the ability to access training and education. The number of caregivers reporting that they do not have the time or energy to do that is increasing.

I feel I have sufficient time / energy to participate in training and education.



Our 2023 survey shows that over six out of every ten caregivers (63%) now don't have the time or energy to participate in education or training. That's an increase of 24% since 2020.

The next section will look at the financial position of unpaid carers.

CAREGIVERS FINANCIAL SITUATION

Things are looking no better in terms of the financial situation of caregivers.



Almost half of all caregivers (47%) in Gateshead live life through state benefits. Six out of every 10 (61%) report that providing unpaid care has caused them financial difficulties.

The most common cuts in household expenditure caregivers made in the last 12 months are;



Had to reduce gas and electricity bills by heating the house less **67%**



Had to reduce expenditure on entertainment and leisure **54%**



Had to reduce phone and internet usage **33%**



Had to reduce or miss meals **24%**



Had to access a food bank **8%**



Had to take out loans **21%**

One in every five caregivers in Gateshead have had to take out loans to pay household bills.

Almost seven out of every ten caregivers in Gateshead have had to cut their use of electricity and gas to heat their homes. These are homes where sick and disabled people are living and being cared for. Homes which need to be kept warm and homes which need wheelchairs charging and equipment such as dialysis machines and stairlifts, hoists operating.

In the UK in 2022, just under 3 million people used food banks (Trussell Trust report 2022) which equates to 4.4% of the population. Our survey findings show that 8% of unpaid carers use Food banks.



This means that unpaid carers are almost twice as likely to use Food banks than the general population.



One in every four caregivers are skipping or missing meals for themselves in order to provide the person they care for with the food they need.

Our report on the 2020 survey of caregivers in Gateshead was called Everybody's Business, because it is. Over 60% of Gateshead residents will take on an unpaid caring role at some point in their lives. Everyone in Gateshead is likely to know one or more people who are providing unpaid care to family member or friend. We finished our last report by asking one simple question which was.....

Is this a life I want for myself, for my partner, for my children, for my grandchildren, for my friend?

Unfortunately, since 2020 the lives of people providing unpaid care has worsened across multiple criteria, caregivers physical and mental health has worsened, people are providing more hours of care, people are providing more years of care, people are doing more caring tasks than ever before, caregivers financial health has worsened, more caregivers have had to give up work to provide unpaid care, caregivers feel more isolated and have a poorer quality of life than ever before.

The amount of money which people providing unpaid care save social care and health services is well documented. But let's set it out again using Dr Dan Taylor's report (Giving Care in Gateshead; Reimagining the Landscape of Care 2023)¹.

'In Gateshead alone, caregivers save £660m a year, £12.7 million per week, and over 1.8 million a day'.

That is over twice the size of Gateshead Council's entire budget (£290 million 2023 / 2024).

¹ <https://www.gatesheadcarers.com/News/giving-care-in-gateshead-new-report-about-unpaid-carers>

Surely with that freely given economic contribution caregivers in Gateshead at least feel recognised and valued. Sadly not, to the survey question 'Do you feel recognised and valued by;



GP and health services: 66% said I do not.



Gateshead Council: 72% said I do not.



The Government: 91% said I do not.

The question which needs to be asked is why is life getting worse for unpaid carers year on year?

We'll look at three probable reasons for this;

1. THE CRISIS IN CARE

The focus in this section has to be about the impact on caregivers of the crisis in care which is driven by the huge challenges faced by homecare providers to recruit and retain paid care workers. Having a care worker visit the home and assist, for example, with getting the cared for person out of bed and washed in the morning does make a significant difference to the caregiver who may not be able to do that themselves.

However, we are increasingly hearing from caregivers that paid care workers visits are cancelled with little or no notice, we are hearing that paid care workers do not arrive on time leaving the cared for distressed as they can't get out of bed and the unpaid care stressed, anxious and guilt ridden because they can't physically do that task.

The Association of Directors of Adult Social Services report (Waiting for Care May 2022) highlighted that there was a staggering **increase of 671% in the number of homecare hours it was not possible to deliver** From Feb-Apr 2021 to Jan-Mar 2022.

One in every three Local Authorities reported to ADASS that **'they were having to ask unpaid carers to take paid or unpaid leave from work as care wasn't available'**.

As Helen Walker Chief Executive of Carers UK said, the care crisis means....

“even more pressure on even more families who are propping up a chronic shortage of services”¹

Linked to this, is that we have an ageing population. Unpaid caregivers are also likely to be providing more care to those over 65. The population of the over 65s in the UK rose by 20% between 2011 and 2021 (ONS Census 2021). In 10 years' time, this will have increased to almost 13 million people or 22% of the population².

Clearly this means more people being of an age when care needs are more likely. To add to this, over this period there has been a reduction of 22% in the number of over 65s residing in care homes since 2011 (ONS Census 2021).

The care that may have previously happened in a care home is increasingly happening at home and it's a family member or friend who is providing that care.

¹ <https://www.bbc.co.uk/news/uk-61413697>

² <https://ageing-better.org.uk/summary-state-ageing-2022>

2. THE CRISIS IN THE NHS

The problems within the NHS are well documented and includes bed shortages, bed blocking, long waiting lists, staff recruitment and delayed ambulance services. Caregivers in Gateshead are affected by all of these things, half are disabled or have a health condition but it's the impact on their unpaid caring role which we will explore here.

Bed blocking is an interesting example. The NHS answer is to introduce 'Discharge to Assess'. What this means is that as soon as patients are clinically well enough to go home, they will be discharged to their home.

This replaces the previous system where the assessment to make sure the home environment was safe and appropriate would take place prior to discharge.

The Discharge to Assess process now looks like this;

- Pathway 0 – Non-complex discharge
- Pathway 1a – Reablement, Social Services, Volunteer, Warmer Homes
- Pathway 1b – Acute and Community Therapy
- Pathway 1c – End of Life care (EOL) and Fast-Track
- Pathway 1d – Medicines Management and Nursing
- Pathway 2 – Intermediate Care
- Pathway 3 – 24-hour care placement (permanent or temporary)

We know, because caregivers have told us, that across a number of these discharge pathways, people are being discharged to home environments that are not appropriate or safe, caregivers receive short notice of discharge, caregivers are not consulted, social care assessments are delayed, care packages are taking weeks to set up.

Throughout this time the caregiver is placed under tremendous stress, their daily lives are full of anxiety and worry, the amount of care they provide increases, the range of caring duties increases.

People who provide unpaid care are again seen as the 'answer' to a problem, this time it's bed blocking. The main reasons for delayed discharge from hospital are;

- 'Delays in obtaining assessments of post-acute care needs
- Delays in organising and coordinating any care and support needed, or in organising a discharge to assess pathway' ¹

Getting people discharged before a package of care is in place frees a hospital bed, saves the NHS money, gets another patient off the waiting list but... it does not solve the problem. It transfers the problem to people who are providing free care at a great cost to themselves emotionally, physically and financially.

3. STRATEGIES THAT FAIL: GOVERNMENT, LOCAL AUTHORITY, NHS (INTEGRATED CARE SYSTEM)

The third thing we want to look at when trying to understand why the lives of unpaid carers continues to get worse in terms of their mental and physical health, financial health and quality of life is strategies.

¹ <https://www.health.org.uk/publications/long-reads/why-are-delayed-discharges-from-hospital-increasing-seeing-the-bigger>

The failure of national, NHS, and local government caregiver strategies.

Despite numerous national, NHS, and local strategies from government and local authorities over the last 15 years life continues to get more and more difficult for people providing unpaid care. People are providing more hours of care, more years, and more types of care. The physical, mental, and financial health of caregivers continues to worsen.

The Nuffield Trust is an independent health think tank which aims to improve the quality of health care in the UK by providing evidence-based research and policy analysis and informing and generating debate. This is what they have to say about carers strategies (Falling Short: how far have we come in supporting carers in England Nuffield Trust 2022) This is what it has to say about carer strategies.

‘Key to explaining this mismatch between the promises of better support for carers and the reality for the rising number of unpaid carers are:

A lack of accountability and agreement on who is responsible for policy success and failure.

A lack of clarity on who is responsible for what within local systems.

A failure to set out how policy success might be measured.

A false assumption that legislation alone can secure change.

The invisibility of carers in wider policy decision-making.

Funding pressures and budgetary constraints.

A lack of data needed to support service commissioning, and to evaluate policy success’.

In Gateshead unpaid carers are invisible in key strategies



Gateshead Council Thrive Agenda – unpaid carers not mentioned.



Gateshead Council Health and Wellbeing Strategy – unpaid carers not mentioned.



Gateshead Council Health Inequalities Strategy (Mind the Gap) – unpaid carers not mentioned.

The borough of Gateshead is part of the North East and North Cumbria Integrated Care System (ICS). Earlier this year the ICS released its draft 4 year forward plan. Unpaid carers were not listed as one of the ICS priority areas. In fact, unpaid carers were not mentioned at all. After representations were made unpaid carers got two mentions in the final version of the 4 Year Forward Plan.

They are still not seen as a priority group and the references made to unpaid carers were bland and meaningless 'we will support unpaid carers'. It gives no detail of what that means, there is no ownership, responsibility, or accountability. There's probably a reason for that and the reason is likely to be because the ICS does not have a Caregivers Strategy.

Identifying people with an unpaid caring role

The vast majority of people giving care are unknown locally, regionally and nationally. There is clearly a need to identify more people with a caring role in Gateshead. As an organisation we are engaged with 5,600 of the 25,000 we estimate there are in Gateshead. However, there are challenges engaging with 'unknown caregivers'.

The majority of people do not like to be called a carer, or think it means a paid care worker. Others, see themselves as a carer but do not seek support until they are in crisis. Others simply do not want to engage or seek support at all. Others would gladly have support if they knew how to access it.

Research by the Health Foundation (Can you tell we care? Identifying unpaid carers using local authority and GP records Nov 2023) confirms that the information known about local caregivers is limited. The research looked at four local authority areas and found that the numbers of caregivers known across local authorities and GPs was substantially below the numbers who identified as a caregiver in the 2021 census. The number known to LAs and GPs was between 1% and 3% of the local caregiver population. They also found that;

- GP sources identified up to 15 times more carers than local authority sources
- Local authority data tended to identify more older carers than GP data
- Less than 7% of carers identified were found in both GP and local authority data.

The conclusions of the Health Foundation research are given below.

- The under-recording of carers means that local authorities cannot properly understand need in their area and thus target support to those who need it most. Without more complete data, GPs may not be able to provide proactive support to keep carers both physically and mentally well. Nor can national policymakers reliably assess the degree of unmet need. This under-recording of carers also raises questions about how well integrated care bodies understand the health needs of their populations.

- National policymakers, local NHS and social care bodies and GPs all have a part to play in improving the identification of, and recording of data on, unpaid carers. Approaches could include the use of incentives, training and guidance.
- Better data and identification are a start, but to fully support carers, the NHS and social care need adequate resources and to appropriately prioritise carer support, reflecting the value of their work.

The Health Foundation is absolutely right in its conclusion that the NHS and social care need adequate resources to support adult caregivers but the provision of that support for caregivers is a statutory duty under the Care Act 2015. The need for adequate resources cannot be ignored.

It's also right to draw attention to how the reducing and inadequate support given to local carer support organisations is a key reason for strategies failing.



CONCLUDING REMARKS

Storm Warning

Storm Ciaran and Storm Debi caused havoc across Gateshead. This report is a severe warning that Storm Caregiver is not just approaching it is over Gateshead now. Caregivers are saturated by unpaid care and are at breaking point. Storm Caregiver will inevitably lead to floods of caregivers saying enough is enough.

Caregivers are increasingly coming to this organisation and saying;

“I can’t cope anymore”, “I’m drowning”, “This is killing me”, “I can’t do this any longer”.

Storm Caregiver will result in more and more caregivers saying they are no longer able or willing to provide care. Of course, that is a caregiver’s right under the law. It is at the point now, not next month or next year, when it is the only option caregivers have to protect their own health and wellbeing.



This will inevitably lead to hundreds more statutory assessments or reviews of the adult’s need for care and support. In turn this will lead to substantial increased demand on already stretched LA and NHS services.

It's not just this organisation which is saying this. The Association of Directors of Adult Social Services survey of more than 100 councils showed that (ADASS:Autumn 2020 Review);

'63% (of local authorities) report growing numbers of people seeking help because of the breakdown of unpaid carer arrangements'

In it's submission to the government's 2023 Autumn spending review ADASS said;

'Many people are still missing out on care and support and there are half a million waiting for care to begin, a care assessment or a care support payment. Often, it's unpaid carers who are shouldering the burden, risking their health and facing financial difficulty as a result'.

Unlike storms Debi and Ciaran this will not pass in a couple of days. It will remain centred over Gateshead unless urgent and sustained action is taken now by; The Government, The Local Authority, and the NHS (North East and North Cumbria Intergrated Care System).

Caregivers are saturated and Storm Caregiver will inevitably lead to floods of caregivers saying 'enough is enough'

This 'Storm Caregivers: Severe RED Warning' issued by caregivers in Gateshead must be listened to and acted on with purpose, vigour, energy and speed by the Government, Gateshead Council and the NHS.

There is no other option.

**Steve Cowen
Chief Executive Officer
Gateshead Carers Association
November 2023**



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