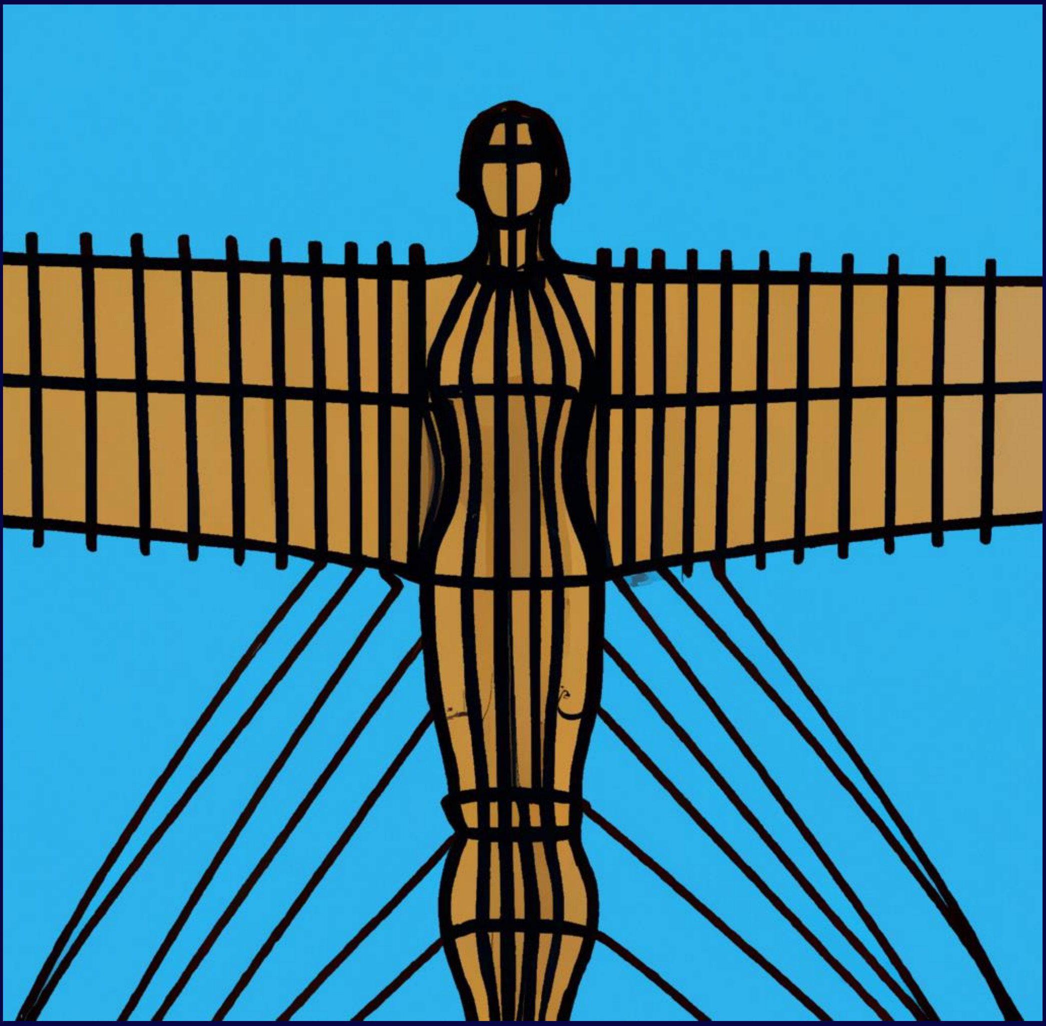


Giving Care In Gateshead

Reimagining the landscape of care

Dan Taylor, Kitty McKay and caregivers in Gateshead

The Open University

The Juggler

> The act will start with throwing three round coloured balls
> This is similar to trying to coordinate a doctor's receptionist - a GP and the district nurse to do a home visit
> If well executed and with lots of practice
> You will never drop the balls and a visit will be executed
> Next we have the juggling clubs
> This act needs really good eye coordination
> One slip and bongggggggg.....tricky...very tricky
> We only use this technique if we want to drum in some common sense which is mainly in the direction of social workers and the like
> We use the clubs if we can't see change happening
> We need three coloured clubs, red for anger yellow for hope and blue for the tears we will no doubt shed, if we don't see the mission through
> Then we have the Diabolos they use both strings and an hourglass shaped object
> To work it has to be coordinated
> In a way that show perfection
> Like dancers that were meant to be
> As caregivers this is how we support our families and friends
> We hold them tight and lift their spirits high.

- from *The Juggler*, written by "Hannah", one of our project participants

Contents

Welcome

As Chief Executive Officer of Gateshead Carers, an organisation established by people with an unpaid caring role and which is run by and for unpaid carers, I am delighted to have the opportunity to welcome both this research report and all those who read it.

What strikes me most about it is that the life stories of people who give care freely are front and centre. Their struggles, sacrifices, hopes, experiences and their collective voice is heard. That is powerful. When it's also supported, as it is in this report, by the detailed examination of the 'facts and figures' of unpaid caring then the unfairness and harshness of life for caregivers is laid bare.

We often hear that the NHS and social care are in crisis. Well, actually the whole country would look back on this time as 'the good old days' if people stopped providing unpaid care. The NHS and social care would collapse within days. Unpaid carers are in crisis and national and local Government need to recognise this and take urgent action.

I hope everyone reading this report talks about it to everyone they come in contact with. That's family members, friends, neighbours, colleagues and politicians. If you are not providing unpaid care now… you probably will be.

Steve Cowen CEO

Gateshead Carers

Overview

What is Gateshead's best kept secret?

We're not talking about picnics in Saltwell Park or a Sunday stroll by Dunston Staiths. No, we're not even talking about Antony Gormley's Angel of the North, that symbol of care looming over the town.

Often, it's hard to even see what we're talking about. Or maybe we've got used to looking away. Because unpaid carers are like the elves in the old fairy tale by the Brothers Grimm. Every night as the shoemaker sleeps, the elves work hard out of sight, making shoes to be sold the next day without a thank you or reward. They hold families, neighbourhoods and communities together, often with little recognition or government support. They do it out of love and duty. And many carers are now at breaking point.

Carers are Gateshead's best kept secret.

At least 1 in 9 people in Gateshead give care unpaid every day. Their care saves the country billions. But some are going without heating or eating. They're not getting enough support at national and local levels. They're not being involved in decision-making at national and local levels. This is resulting in errors, wastes of professionals' time and service resources, and in some cases avoidable medical negligence. Just a bit of well-targeted support and greater recognition in decision-making would make a world of difference.

What is this Report about?

This is a Report by the Open University into carers' lives in Gateshead, working in partnership with Gateshead Carers. It's based on in-depth research, interviews and focus groups with carers across Gateshead over 2022-2023. It brings together a wealth of evidence and stories based on **lived experience** that shines a spotlight on carers' varied lives in the middle of the cost-of-living crisis. Accompanying it is a film highlighting the challenges facing carers.

The aim of this Report is to understand from unpaid carers and from services that work with them:

- What are the challenges facing unpaid carers?
- What would make life better for unpaid carers?

And to use this local, on the ground evidence to contribute to policymaking and improved decision-making at a local and, importantly for us at the Open University, at a national level.

Who is the Report for?

This Report is aimed at

- Anyone who directly works with unpaid carers in a professional capacity. This includes: local adult social care services; advice agencies e.g. local Citizens Advice Bureaux; NHS services like GPs, community health teams, paramedics, clinicians and in-patient services; and community and voluntary organisations like Age UK or the Alzheimer's Society.

- Anyone who works on policy or research that relates to unpaid carers. This includes national organisations like Carers UK; Carers Trust; Joseph Rowntree Foundation; and the Kings Fund. It also includes anyone undertaking research on unpaid care at an academic or thinktank level. It also includes civil servants in the Department of Health and Social Care.
- Anyone who works in politics who is interested in unpaid carers. This is a bipartisan Report. Our findings are aimed at people in all political parties, in national government, in local government, because care is an issue that crosses the political divide and touches on all our lives. We do not simply call for more money, we call for changes and efficiencies in decision-making.
- Anyone who cares about caring. Maybe you're an unpaid carer or have given care in the past. Maybe you live in the North-East. This Report is tied together by the stories and voices of unpaid carers. We've written the main part of this Report to be as engaging and powerful as possible.

How do I use this Report?

Professionals and policymakers: we know that you are short of time.
So start with Caring by Numbers and then the Key Findings. Then skip to the Recommendations. This will take you all of 5 minutes to read. And if you're convinced, send me an email and I will provide you bespoke guidance and a toolkit for your organisation: dan.taylor@open.ac.uk.

Everyone else: if you're an unpaid carer, you're even more short of time. So take a look at the Key Findings. Read the rest at your leisure. Get in touch with me to discuss your thoughts, feelings and ideas about the work. If you're in the North-East, we can connect you to the rich and brilliant community level work happening here.

Thank you for taking the time to hear these voices.

What is an unpaid carer?

Caregivers are people who provide unpaid care to a friend, family member or neighbour, who, due to illness, disability, frailty, a mental health condition or an addiction, cannot cope without support.

Anyone can be a carer, young or old, even people with health conditions and care needs themselves, though on average most caregivers are female (around 59%) and aged between 45-65 (Carers UK 2023). But there is no one size fits all caregiver, and every experience and background is different.

Caring takes on many forms, from a few hours of support here and there to around the clock, 24/7 personal care. In our project, we heard about support including:

- Helping someone wash and dress themselves
- Housework, food shopping, managing medication and finances
- Being around to ensure the person(s) they care for is safe at home
- Taking the person they care for to medical appointments
- Companionship, company and emotional support

Caregivers are not care workers, though they are sometimes confused: care workers are people paid to provide care, usually by local councils. In that sense, the term 'unpaid carer' is the most used term; informal carer is another. But caregivers provide or give their care for free, out of a complex range of emotions including love and obligation. Economics doesn't come into it, though many told us that they are in significant financial distress and struggling to cope. In that sense, we use the term 'caregivers' in this Report.

Caring in numbers

1 in 9

According to the recent 2021 Census, 11% of people in Gateshead provide unpaid care, around 21,750 people (ONS 2023).

That number is likely to be an underestimate. Research in the last few years suggests around **1 in 6** of the population are caregivers (Carers UK 2022b). During the pandemic, it's thought that up to **1 in 4** people nationally were providing unpaid care (Carers UK 2020a).

What does that number look like? St James Park, home of Newcastle United, on the other side of the Tyne, has a capacity of 50,000. That would just about accommodate all the caregivers in Gateshead, if they took to the streets like on match day.

60%

The amount of people that will be caregivers in Gateshead at some point in their lives (Gateshead Carers 2020, p. 42).

Again, that's probably an underestimate. Although life expectancy has stalled recently, continued medical advances mean that more of us will be living for longer, and living for more years in poor health where people will be needing care, and called upon to provide it themselves.

£162 billion

How much Caregivers save the UK every year, roughly equivalent to annual spending on the NHS (Carers UK/University of Sheffield 2023).

This figure is based on using Census data on the number of carers in the UK, number of hours of care provided, then priced against a careworker average wage of **£25 per hour**. During the pandemic, it was estimated that caregivers saved the UK economy **£193 billion** a year (Carers UK 2020b).

£76,000 per hour

How much caregivers in Gateshead approx. save the UK.

That's around **£1266 per minute**, or over **£21 per second** (ONS 2023, cross-referenced against Carers UK/University of Sheffield 2023). In Gateshead alone, caregivers save £660m a year, £12.7 million per week, and over 1.8 million a day. Nationally, caregivers in the UK save the government £3.1 billion per week, £445 million per day, £18.6 million per hour (Carers UK/University of Sheffield 2023).

£76.75 per week

How much caregivers receive through Carers Allowance, in exchange for providing 35+ hours of care per week. That works out at around **£2.19 per hour** over a 35-hour week. But some of the caregivers we spoke to provide care for up to 100 hours a week, which would be priced at **77 pence per hour**.

Carers Allowance is the lowest benefit of its kind. Moreover, few caregivers are even eligible for it: anyone earning over £139 per week, including through a state or private pension, is unable to receive it. In our study, only **20%** of participants were eligible to receive Carers Allowance. Nationally, around 1.3 million claim Carers Allowance (DWP 2022).

1/3

One third of caregivers we spoke with are in significant financial distress.

Examples include having to skip meals, avoid heating their homes, or building up significant arrears with gas and electricity bills.

Nationally, a 2022 Carers Trust survey found that **1 in 7** caregivers are now using foodbanks (Carers Trust 2022b).

15

The number of caregivers we spoke with for this project. In this Report you'll discover their stories and suggestions for improving care for one and all.

Key Findings

1. Caring represents the best of us. It's at the centre of communities and towns that can thrive. It's the key ingredient for disabled, frail and elderly people to live dignified and safe lives. It is a profound form of self-sacrifice, love and service. But it is far from easy. It is often far more difficult and demanding than any paid job. For caregivers to have the capacity to care, they need security, support and power to be heard. Many caregivers need a break. Others deserve a choice: it shouldn't be expected that caregiving falls on them forever. But right now, many aren't even getting the basics.

2. Carers are being hammered by the cost-of-living crisis, unable to afford heating or eating, and getting into thousands of pounds of debt over utility bills.

3. Carers Allowance is not fit for purpose. It's the lowest paying benefit of its kind (£76.75) per week which is not enough for a carer to live a basic quality of life. Moreover, most carers can't even get it. Carers Allowance should be overhauled. Eligibility around income or receipt of other benefits like state pension must be removed. A much higher rate of payment should be pegged to accommodate a minimum income standard for carers, based on their caring responsibility.

4. Carers need urgent, carer-specific support to meet cost-of-living pressures now and in preparation for the next winter, around food, fuel and energy usage. This includes additional support with the cost of groceries and energy supplies. In the short term, this could include emergency hardship grants which could be disbursed by carers services on the ground. We also recommend that funding for carers wellbeing grants be substantially increased.

5. In the long-term, there should be no more unpaid carers. We heard this phrase time and again. It's not that carers want to stop caring, although some should at least be given the choice, for many it's a matter of pride, love, duty, obligation. And it's a highly skilled role. But there should be no more **unpaid** carers. Carers need and deserve to receive recognition and financial support for the profound contribution and sacrifice they are making.

6. Current levels of support for carers just aren't good enough. There needs to be a structured process of identification and support for carers at hospital discharge/local clinical diagnosis. There needs to be much more specific training and skills sessions for caregivers to support their cared-for. You wouldn't employ a dentist who had very little experience of treating teeth, so why do medical discharges rely on unpaid carers often providing round-the-clock care with complex disabilities for which they have had no opportunity to access training or proper financial support?

7. Carers are largely invisible and need formal power. Though no-one in government would ever dare say it out loud, for years social care and health services have functioned despite austerity *because* unpaid caregivers are making superhuman efforts to care for people when official services are pulled back. But it's no good just borrowing the language of values, rights and responsibilities (e.g. Church of England 2023) without also talking about power. Until caregivers have formal power, i.e. in the form of steering groups that guide, consult and veto commissioning and policy direction for caregivers and in social and health care, they will continue to be easy to ignore. The conversation has to shift to power.

8. If we don't act now to support caregivers, the crisis will only worsen. Our research shows that it's only in the last year that caregivers are reaching crises points in terms of the cost-of-living. Many others are unable to tend to their own physical and mental health needs because their caregiving roles are so demanding. If these caregivers aren't given support, some will be unable to continue. And that will plunge millions of people around the UK - caregivers and the people they care for - into further desperation, not to mention the cost for public finances.

9. The future of Gateshead can be a place that's centred on care. Caregivers and the services that advocate for them are the best people to understand care. Policy and commissioning decisions are best informed by these experts in care. Care represents not just the best of human beings, but also the best of Gateshead as a place with a proud history of care, cooperation and social progress despite often hard industrial work and inequalities. To thrive, Gateshead should draw on its best kept secret, the hidden elves stitching, maintaining and repairing its vulnerable social fabric - its givers of care.

The context

Welcome to Gateshead

Gateshead is a large metropolitan area in the North-East of England, with a population of around 198,000 (Census 2021). For much of its history it was a small settlement on the other side of the Tyne, defined by its relationship with the powerful cities of Newcastle and Durham. But from the 19th century it rapidly grew. Coal mining, rail works, glass and ropemaking, chemicals, quarries, and further afield, shipbuilding, brought tens of thousands to the town. Men and women, many of whom had lost their jobs in farming as land enclosures and profiteering collapsed their livelihoods, came in search of a basic living. Some would've arrived along Old Durham Road, the ancient highway that connects Durham to Newcastle over the high Fell of Gateshead

Travel up Sheriff Hill today and the view is a little different. Those industries have largely gone. St James Park and the centre of Newcastle dominates the skyline. Sheriff Hill was once known for its large and dangerous colliery. Today, most people know it for the QE (Queen Elizabeth) Hospital.

Caregiving often begins in hospitals. Hospitals involve a lot of waiting around. Waiting for a doctor to become available. Waiting for a diagnosis. Waiting for a scan. Waiting for an overworked nurse's attention in the small hours. Waiting in slee-deprived, striplight rooms where it's hard to say if it's day or night. Waiting for a prescription, or a bed, or a discharge, or medical transport, or a taxi, or a care package for when you or your loved one are finally deemed well enough to go home or into residential care.

For many caregivers, it’s hard to pinpoint the exact moment when caregiving begins. For “Tom”, it was a gradual encroachment on his life, as his wife became less and less well as a result of addiction (throughout, all our caregivers are anonymised to protect confidentiality). For “Aspers” and “Christopher”, each separately involved in caring for elderly parents with dementia, the gradual onset of the condition developed at first imperceptibly, then was marked by a series of dramatic declines in health, resulting in emergency hospital admissions. For others, relationships of dependency and caregiving strike unexpectedly and at vulnerable moments. For “Jack”, “Michelle” and “Marie”, each parents of adult children with disability, caregiving began when their children were born, and has never let up since.

As they drove out of the hospital car park on Sheriff Hill, the lives of carers like these were transformed. Relationships of equality between husband and wife or partners were now relationships of dependency and obligation. Relationships of care between parents and children were reversed. Life plans and retirement plans were now impossible. Jobs and social lives would come to an end.

Caregiving comes out of love and duty. But it is not really unpaid: immense personal sacrifices are made. Often, we found, caregivers were not given even a basic choice or simple training and advice as they crash-landed into their roles. Increasingly now, there are not even care workers available to help.

In the A&E department, doctors and nurses had been able to diagnose, treat and care for their loved ones over a matter of days. But as they head out into the world, what sources of support, training, respite and care are there for the months and years ahead?

Gateshead, a town that cares

There are two things you need to know about Gateshead.

Firstly, it's got a fantastic sense of community spirit.

Gateshead, as several of our participants put it, is made up of a fabric of close-knit communities. "Where we live in Pelaw is amazing" says "Buffy", one of our participants, "I absolutely love it. It's a grassroots community". "Joanne", another caregiver in our study who also grew up outside of Gateshead, also shared her sense of a place where care is part of Gateshead's community fabric:

> There was always elderly people looking after other people as well. … it was all ladies standing in the back alley on a Monday hanging the washing out and, you know, just that was just a part and parcel of everything that was going on

In other ways it plays out into what another caregiver, Aspers, called the “matriarchal” culture of the North-East, where women, often adult daughters, are expected to provide the brunt of care. “Being the daughter of the family and what it's like in the North-East, the daughter in the family looks after”. Others agreed. But as we discovered in our project, the reality is sometimes more complex. Men also give care, with its own pressures and opportunities for emotional closeness and connection.

Secondly, Gateshead has been hit hard by government cutbacks.

By government cutbacks, what we mean are the deliberate reductions in government spending that happened after the 2008 Financial Crisis. In 2010 the

Conservatives were elected and the new Chancellor, George Osborne, made the choice that central government debt should be reduced by cutting back on all forms of core government spending except the NHS. This meant cutting back on things like local government spending.

Local government budgets cover many things, from libraries, leisure centres, rubbish collection, public spaces, education, to social care - the packages of care that are put in place to support someone who is disabled, frail, unwell or suffering from addiction, as well as their caregivers. These packages of care might include domiciliary care workers (who provide paid care in the home), residential care (e.g. nursing homes, respite), as well as access to local support services like day centres, support workers, link workers, and carers-specific services, e.g. for advice, temporary respite or wellbeing grants. This is their duty of care, and it is a very complex and expensive role. And one that we will argue is unfairly shouldered by local authorities.

Between 2010 to 2018, the funding that central government gave to local governments was halved. This led to cuts of 8% to social care budgets at a time when demand was growing from an ageing population (Bunting 2020, p. 31; cf. Marmot 2020). By contrast, NHS budgets increased by 9%.

In Gateshead, the Council budget has been cut by £179m per year since 2010 (Gateshead Council 2023). This is a forced reduction of around 56% or £977 per resident on spending compared to 2010. As of last October, the Council was facing a budget shortfall of up to £60 million just to meet its core statutory responsibilities. This is putting the Council under intolerable pressure, having to make painful decisions as to whether to close leisure centres or cut back on core community services in order to meet growing demand elsewhere.

Nationwide: Three points of pressure

This already struggling system is now facing three simultaneous pressures: **funding**, **demand** and the **cost-of-living crisis.**

Funding

On the one hand, local councils now have far less money and resources to meet their core duties, which includes social care.

Local authorities have made social care savings in two ways. Either tightening the criteria for care, so that now 1.4 million elderly people who would've been eligible for state provided care are now ineligible (Bunting 2020, p. 31). Or, holding costs down on care contracts, which brought down wages for care workers in the sector.

One effect of this is that now more disabled or frail people are having to cover the costs of their own personal care, or rely on caregivers to take it on. As Ruthe Isden, Head of Health and Care at Age UK says: “we have seen a rapid reduction or a shrinking of the formal offer from the state. Eligibility thresholds have gone up. The amount of care that people do receive when they are in the care system is smaller; the budgets are smaller" (House of Commons 2022, p. 17). A 2021 survey by the Care and Support Alliance found that 3 in 10 people who had difficulty carrying out day-to-day activities never received any assistance. According to the Local Government Association (LGA), around one third of requests for council adult social care support result in “no support” (ibid.).

Another effect of this is that many paid care workers are leaving the workforce. The most recent available figure from Skills for Care found a vacancy rate of 11% or 165,000 unfilled posts, a rate which has grown by 50,000 alone in the last year (Morgan 2022). With 165,000 less paid care workers across the UK, that means that a comparable number of family members and friends are stepping in to provide unpaid care to plug the gaps.

Demand

But it comes at a time of rapidly growing demand for children's and adult's social care. In Gateshead, roughly around three quarters of local authority spending is now on children’s and adult social care (Gannon 2022).

Nationally, as a proportion of local authority spending, social care spending has increased from 59% in 2010–11 to 69% in 2019–20. According to the LGA, over the past decade councils have diverted £2 billion from other services to adult social care, “cutting [other services] faster than otherwise would have been the case” (House of Commons 2022, p. 34). Cutting away these services comes with real consequences, including loss of trusted local support services, experienced staff and vital parts of the community.

These cutbacks also come at a time of rising demand that will substantially grow in the future.

- ***The UK population is ageing***. People are living for longer, and that means more years in poor health, requiring care. According to Public Health England, the population of carers aged over 65 years is expected to increase to 1.8 million by 2030, and the number of dependent older people in the UK will increase by 113% by 2051 (Public Health England 2021, p. 8). The Care Policy and Evaluation Centre, London School of Economics, projects that the number of adults aged 65 and over who are unable to perform or have difficulty performing at least one instrumental activity of daily living will rise from 3.5 million in 2018 to 5.2 million in 2038.
- ***Family structures are changing***. The welfare state was built for a different time. In the large families of the 1940s women often fell out of the labour force after motherhood and were expected to provide unpaid care. In most British communities, that culture has disappeared. As the Office for National Statistics observes, ‘High levels of childlessness among the 1960s baby boomers combined with increased in life expectancy mean there

will be many older people in the future who do not have adult children' (ONS 2020). That matters because adult children are the most common providers of unpaid care to their parents at older ages when care needs are greatest.

- ***There is no coherent government strategy in place to meet these challenges***. To meet this level of demand, there needs to be an immediate and substantial investment in social care core services and workforce training. In 2020, the Health and Social Care Committee estimated that £3.9 billion additional funding was needed by 2023–24 to meet demographic changes and planned increases in the National Living Wage (House of Commons 2022, p. 18). The Health Foundation has produced more worrying forecasts. In order to meet basic future demand by 2030-31, there would need to be an additional **£6.1 billion** (2021)**.** In order to meet future demand, improve access to care and pay for more care - as the national evidence suggests needs to happen - there would need to be **£14.4 billion** per year in additional funding by 2030-31. Where is that money to come from?

In the absence of a coherent plan, more will fall on the shoulders of unpaid carers who are increasing in number while losing levels of support.

Sarah McClinton, the outgoing President of ADASS, the Association of Directors of Adult Social Services, said in April 2023:

> Never in my professional career have I seen the adult care system so close to breaking point. … Millions of people are in pain or distress because

> they aren't getting the care they need and family and friends picking up the pieces are being pushed to the edge (Booth 2023)

Cost-of-Living Crisis

And then there is the cost-of-living crisis. You will hear lots more about that in this Report.

At a national level, carers have been hit hard by the rapid rise in energy, gas and food bills over the last year. Last year, a survey by Carers UK found that 25% of carers said they were unable to afford their monthly expenses, 55% were worried about how they will manage bills in the months ahead, and 75% of carers were stressed and anxious about their finances, up from 52% in September 2021 (Carers UK 2022a, pp. 2-3). Research from Carers Trust around the same time paints a similar picture: 63% of unpaid carers are worried about being able to afford energy bills (2022b, p. 15). Our research suggests that number will have increased.

Many unpaid carers are living in poverty. As you read earlier, a national survey of unpaid carers by Carers Trust found that 1 in 7 were using foodbanks to survive (2022b). A Joseph Rowntree Foundation poverty report estimated that, in the UK in 2020/21, 24% (around million) of carers were living in relative poverty. Carers who spend more time caring have higher poverty rates: 44% of working-age adults caring 35+ hours a week are in poverty compared to 17% caring fewer than 20 hours a week (JRF 2022a, p. 59).

The situation is getting worse. As **funding** decreases and services wind down or unravel, **demand** increases and disabled people are left without formal care and increasingly reliant on unpaid care, and the **cost-of-living crisis** continues to bite, so it is inevitable that the number of unpaid carers will increase, and the number of unpaid carers in poverty and/or struggling with patchy and ineffective local social and health services will grow.

Giving care in a political storm

How will caregivers manage? Nationally, surveys indicate that more and more are being pushed out of the labour force. In 2022, Carers Trust found that 64% have had to give up work altogether or reduce their hours because of their caring role, and 41% of all unpaid carers have had to give up paid work altogether (Carers Trust 2022b, p. 12). The Alzheimer's Society have estimated that the cost to businesses in England of carers leaving the workforce or reducing their hours in order to balance work and care was £3.2 billion in 2019 (House of Commons 2022, p. 59). The Care and Support Alliance estimates an even higher cost of £5.3 billion, with 600 people a day giving up work to provide unpaid care, a number that's projected to increase to £6.3 billion by 2040 (ibid.).

So we have a storm here. And talking about big, huge numbers like £162 billion saved per year, or £14.1 billion funding gap by 2030-31, or £76,000 per hour saved by carers in Gateshead, only gets us so far. Because behind all these numbers are people's lives. And behind these numbers are decisions made about what should be funded and what can go without.

'I'm not political' said "Susie", a caregiver for four people, at the start of one of our discussion groups, typically apologetically. But, she adds, "I don't think they want to hear the truth, that's what it is". Susie says she's never really followed politics much before. But the recent strains of her caregiving role have made her want to go down to Westminster with a placard to shout at the politicians. Another caregiver in our project, Rosa, asked the question: what if caregivers went on strike? For many of our carers, at the root of the problem is a lack of power. So long as caregivers have little power or recognition in the system, so it will be easy to continue to neglect or dismiss their concerns. This Report wants to change that status quo.

Over the interviews and focus groups, we gathered together and discussed the challenges facing caregivers and what would make life better. Amid immense and growing pressures, here are stories of inspiration and resilience, ideas of hope and change, and recommendations that could help improve caregivers' lives and power across the UK. They centre on three things: financial security, support, and carer recognition and power. They centre around one key concept: **the capacity to care**.

Method

We've now taken a walk round some of the landscapes of care. But how did we go about this study?

Who we are

My name is Dan. While these days I work at the Open University, care has always been a key part of my life. When I was younger I gave care, and before I began teaching I worked in frontline charities helping disabled people and caregivers.

Close up, whether it was at the Citizens Advice Bureau or as a community worker for a carers service in South London, I saw the impacts of cutbacks to government spending on support for disabled people and carers as it played out in the private dramas of individual lives. It struck me that caregivers were often left holding the pieces when official sources of support were forced to withdraw their services due to budgetary pressures. Yet caregivers are often far downstream and out of sight of decision-making.

On this project I have been working with Kitty as a consultant. Kitty is an artist and arts worker based in Newcastle. They have been an unpaid carer and a paid care worker in the past, and spend a lot of time working with and thinking about community empowerment and activism.

Why Gateshead?

Gateshead has a proud history of community and solidarity: it contains many local voluntary and community organisations, some doing innovative, agenda-setting work. Sat on the south side of the Tyne, in what was once the world’s largest continuous industrial area, today Gateshead faces different challenges and opportunities. It has a typically older population compared to the national profile, with above average rates of multiple deprivation – though varying significantly between areas. In some parts of Gateshead, the average life expectancy is 15 years below that of central London (Gateshead Director of Public Health 2017, p. 4). It is also a remarkably friendly and welcoming area, a place that is a home to people from all walks of life. In other words, it is a place where the UK can learn a lot about care – about what works, and about what we can do, as we look forward into the future, to prepare for caregiving becoming an even greater feature of people’s lives in the future.

Funding

In 2019, I secured funding from the Society of Authors to develop a pilot project exploring care in North-East England. In the summer of 2022, I approached the inestimable Steve Cowen, CEO of Gateshead Carers, to discuss a research partnership focused specifically on caregivers in Gateshead. In July 2022 we secured £10,000 in funding from UKRI Innovate UK to undertake knowledge exchange work with Gateshead Carers. In September, we were given ethics approval by the Open University (ref. HREC/4341/Taylor) to proceed.

Format

Between December 2022 and January 2023, we recruited participants through an in-person presentation at the Gateshead Carers AGM, and through an online recruitment video and webpage which was promoted by Gateshead Carers through their email newsletter and social media, reaching a database of 4500 carers aged between 18 and 92. We also produced an information leaflet.

Eligibility was broad: participants simply needed to be current caregivers who lived in Gateshead and who were over the age of 18. As Gateshead Carers does not provide a young carers service, it was expected that caregivers would probably be older, reflecting the demographic profile both of caregiving and of Gateshead's population as a whole.

Through the call, we recruited 15 caregivers and communicated with an additional 3 who were eventually unable to participate. Participants signed a Consent Form in which they had the right to voluntary withdraw from the research at any time without giving a reason, up until the publication of the Report. With our funding, we were able to fund a Research Assistant for around 30 days; purchase shopping vouchers to be provided as a "token of appreciation" for caregivers taking part; to cover the costs of transport and parking for caregivers to attend interviews and focus groups; as well as cover the costs of room hire, a public dissemination event and film, and my travel as principal investigator.

Our callout asked a simple question: as an unpaid carer, have you impacted by the cost of living situation or changes to government spending on health and social care? The question was open. "Maybe you've seen changes in the level of support out there for unpaid carers and the people they care for, or maybe you haven't. How are things for you? We'd like to hear from you."

Here is some of the demographic profile of who we recruited:

6 male, 9 female

13 born in UK, 2 born outside UK

13 over age of 60, 2 between 35-50

We collected evidence through interviews, two focus groups, and a reflective task. For each activity caregivers were able take part in, they would receive a token of appreciation shopping voucher of £25. To avoid potential issues around benefits receipt, we were advised to disburse these vouchers through Gateshead Carers, who did so at the end of the study.

Interviews and reflective task

From the outset, recognising that caregivers often have very little free time and unpredictable responsibilities, we offered choice and flexibility. The interviews were semi-structured. Everyone was asked the same five questions:

1. Tell us about you and the person that you care for.
2. Tell us about a good day of giving care, and a bad day giving care.
3. What services do you rely on as a carer?
4. How are you managing financially?
5. What do you think would make life better for unpaid carers?

Interviews lasted between one and two and a half hours, averaging around one and a half hours. Most interviews were done at Gateshead Carers' premises at John Haswell House, 8-9 Gladstone Terrace, near Gateshead town centre. Three were undertaken at Leam Lane Community Centre, in the south-east of Gateshead. Another two were completed online using Microsoft Teams.

Interviews were undertaken at a range of times, as caregivers needed, from across the day and, when online, in the evening. They were then transcribed and anonymised.

Note: all anonymised transcripts from the interviews, focus groups and reflective tasks will be made available via the UK Data Service by September 2023. Please email dan.taylor@open.ac.uk if you are interested in reading them.

Participants were then asked to complete a reflective task. Evidence shows that small, well-structured and creative reflective tasks, wherein participants are asked to write, create, take a photograph of something at home, or reflect through WhatsApp voice notes, are all good ways of generating insights, as well as serving as a good basis for further discussion. We asked our participants a simple question: What would make life better for you as an unpaid carer? We invited responses in a range of formats, including emails, letters, poems, blogs, photos and voice notes. We collected 10 responses, most in the form of Word documents of between 1-3 pages.

Focus groups

We then conducted two sets of focus groups. Once more, we offered flexibility around locations and times. Three small focus groups were held in early March; and another three at the end of March. Of the six group sessions in total, four were at Gateshead Carers premises and two were at Leam Lane Community Centre. The groups lasted for around two hours each, with 11 caregivers attending both sets of groups, and 13 attending either one or another group.

In the first set of groups, we set out to identify the landscape of care. We asked caregivers about the services they and the person(s) they care for rely on. From there, we built on experiences to reflect on the wider system that exists to support carers. We asked carers if they felt they were getting enough support from this system. From there, we asked caregivers to imagine Gateshead in ten years time, with someone new about to take on caring responsibilities identical to theirs. "What would they need that you don't currently have? What would help them as a caregiver live the best possible life? What things would they need that you do currently have?" We also used these sessions to build links and networks between the carers. Some of them had met before, some had not. We saw the caregivers offer support and solidarity to one another.

The second set of discussion groups built on these exchanges. We used them to summarise and reflect on our initial findings, inviting caregivers to talk through and reflect on the pattern of issues emerging. We then asked caregivers to read and discuss three different kinds of public carers charter, or declarations of carer support from local NHS bodies and the local council. We asked caregivers what they would want to see on a carers charter or similar sign or manifestation of carers value and power. In the last part, we then considered financial and social support for caregivers in different parts of the world, and used that to return and reflect on practical recommendations forward that have emerged from the study. During one of these groups, we also undertook some filming for a public information film accompanying this Report.

In between the groups, we discussed ideas and observations over the phone or by email. One participant, "Jack", produced three dossiers of newspaper clippings and reports evidencing poor standards of social care for adults with learning disabilities. We then circulated a draft Report to our participants and met with them to get their ideas, feedback and approval ahead of publication.

This work is a collective achievement.

Findings: 1. No More Unpaid Carers

Our first key finding is that many caregivers in Gateshead are simply not getting enough financial support. This is causing desperate poverty and hardship. It is a social emergency. Politicians and policymakers need to act now - and this section will bring together ideas on what should be done.

The financial support caregivers can take on different forms, from carers benefits to signposting to employment rights and to sufficient respite and wellbeing funds. As a result, many are skipping meals or living in freezing conditions during the winter, storing up significant problems down the line in terms of their own mental and physical health, which in turn impacts the person that they care for. What if they can no longer cope, or are no longer around to provide expert loving care?

Every caregiving situation is different, however, and in this section we will also acknowledge the role of what one caregiver called "luck", of the experiences of other caregivers who, either through private pensions or council tenancies and homeownership, have been able to weather some of the dramatic losses in earnings and pension contributions that can impact other caregivers whose caring roles begin before retirement. We need to highlight this.

We call it **security**, and security is the first key ingredient needed for what we call **the capacity to care**.

1. The value of care

Earlier in the Report you read two figures: caregivers save the UK £162 billion a year, and around 60% of people in Gateshead will care at some point in their lives.

It is hard to put a true value on caregiving. The £162 billion figure only includes equivalent hours of paid care. It does not include:

- Reduced hospital admissions and reduced emergency care
- Reduced crisis team interventions, emergency services callouts and safeguarding issues
- Reduced cases of medical or professional negligence or failure to pursue safeguarding concerns, resulting in expensive tribunals and litigation and loss of trained staff
- Enabling people with disability to participate in activities and social life
- Enabling older people to live their final years in dignity, safety and peace of mind in their own homes.

There is no one-size-fits-all carer. In our study, 7 or just under half of participants were caring for their partner or ex-partner; 5 were caring for elderly or unwell parents; 4 were caring for disabled adult children; and 2 were caring for siblings. If those numbers look out, that's because while 9 caregivers were caring for 1 person, 6 were comparing for at least 2 people, and in 2 cases, 3 other people. 3 also gave informal care to neighbours and members of the community.

Caring begins at different times in life. Meet **Buffy**. Buffy is the carer for her partner Amy and her mum. Amy has been her partner for 16 years. Amy suffers from cognitive impairment resulting from addiction, alongside epilepsy and rheumatoid arthritis; her mother suffers from Alzheimer's and physical mobility impairments. Buffy provides full-on, around the clock care, shuttling between her partner and her mum's houses to support them with their physical needs and safety.

Buffy used to work in finance and then in health services. She was earning good money. She enjoyed going on holidays and spending time with her partner. But then things gradually changed.

> I think it was eight years ago that I had to stop work at that point. I was working 12 hour shifts … And full time care for Amy. And it was just I was averaging two, three hours sleep a night and then having to do a good job at work and at home. So it just became too much.

As Amy became more and more unwell as a result of addiction, Buffy had to suddenly acquire the **know-how** and **skills** to navigate the landscape of care and care for Amy safely at home. Much of this involved a steep learning curve. We will discuss what works well and what needs to improve for caregiver support in the next section. But in giving up her job in her 40s in order to care for one and then two disabled, vulnerable adults, Buffy has had to sacrifice several decades' worth of earnings and pensions contributions. But caring is essential to her values, the kinds of values that are shared by other caregivers we spoke with, the kind of values that make places like Gateshead thrive:

> being somebody who's really vulnerable has changed the dynamic of our relationship a lot, but at the forefront of my thinking is love, respect, engagement. And sometimes it's a challenge and I lose my patience or

> sometimes it might be a difficult day and I've got to really remind myself that, you know, you need to go back to love and care and respect.

Michelle is another caregiver. She and her husband Jack care for their daughter Lucy, who is a disabled adult with Down's Syndrome. Whereas Buffy left the labour force in her 40s, like many caregivers nationally, Michelle realised soon after Lucy's birth that she would have to end her career in insurance in order to provide full-time care.

> when you’re talking about the question, has it impacted on you, most certainly, you know, I had to… I had to give up work. Because, as I say, all of a sudden it was like, well, she’s going to have to have speech therapy, she’s going to have to go for physiotherapy, you really need to take her to the hydrotherapy pool, you know, to help her… who on earth could do all of those things?

Today Lucy is in her early 40s, and Michelle and Jack are at retirement age. Jack has had a career in business and they have been able to manage on Jack's income and combined pension contributions. Others are not so fortunate.

Marie is the third caregiver you'll meet in this part. Marie also cares for a disabled child, Andrew, who was born with a range of complex physical disabilities, including cerebral palsy, quadriplegia and epilepsy, that have always required round-the-clock care. Marie often gets very little sleep because every night she listens out to Andrew's breathing in their home in case he accidentally suffocates.

> I'm tired, and he's tired. But like I say, it's nice to be able to get out and about now and again. He loves to go out and get the sun on his face, the rain, the wind especially, he squeals with delight. He doesn't have a bad temper, I've never seen him, and he's 31 years, of having a bad temper, but I know when he's happy and when he's not just by his facial expression, and the noises he makes

Marie is an expert in Andrew's care. When her husband was still alive, he helped Marie with Andrew's care. But when he passed away, Marie was visited by the local council who set up a care package of care workers to come and visit. Andrew also attends a day centre several times a week, and stays at a respite home when it's available. Marie uses this time to sleep. In between those times, Marie provides expert loving care to her disabled adult son, involving a level of **self-training** and skill whose equivalence in a privately-run home would cost Gateshead Council potentially hundreds of thousands a year. But Marie, like Buffy, is financially struggling. She is several thousands of pounds in debt over a gas and electricity bill. And the value she receives to provide this expert care simply isn't enough to meet her basic needs.

2. Caregivers and the Cost-of-Living Crisis

All of the caregivers we spoke to were being impacted by the cost-of-living crisis. For some, this was in much the same ways as the general population, noticing higher costs of food and energy bills, cutting back in small ways. But for others it's building to a crisis situation.

Buffy and Marie both receive Carers Allowance, Income Support and Housing Benefit for providing round the clock care. Michelle received Carers Allowance in the past but this was terminated when she retired and began to receive a pension; Marie will lose her Carers Allowance in a few years once she retires and receives State Pension.

The Joseph Rowntree Foundation and Loughborough University have calculated a Minimum Income Standard, a figure by which a single person living alone can expect a decent standard of living. In 2022, that figure was calculated to be £391.98 a week, including £98.70 for rent (JRF 2022b, p. 31). There has been no calculation for disabled adults or unpaid caregivers, which would be complex, given the sheer range of disabilities, many of which require much greater expenditure in gas and electricity compared to average households to provide a safe, healthy and clean environment at home.

When we spoke to Buffy and Marie, Carers Allowance was paid at £69.70 a week and Income Support £90 fortnightly, so £45 a week. It has recently been increased to £76.75 per week, but remains the lowest paying benefit of its kind. Each was receiving Housing Benefit, though Buffy's private landlord had just increased her rent due to rising mortgage costs related to national government incompetence. She had approached Gateshead Council about increasing her Housing Benefit to match the increase. After being quizzed and asked to complete detailed forms on her household finances, her housing benefit was temporarily increased for two months only while she worked to reduce her debts. There was just one problem. Buffy does not have any debts. The assessor had either failed to read or give a true estimation of her circumstances.

Buffy talked with pride about how she manages her household budget. She was taught to budget and cook with very little from a housemate in her home country who had been a military chef in a warzone. She spoke with love and generosity about doing everything she can to make her partner and mum comfortable. But the cost of living crisis is forcing her to go without:

> some of the sacrifices I make, for example, is I'll miss out on meals … once or twice a week, I'll miss out on food, to make sure that they're fed. At Mum's, the house is on a temperature gauge, like a thermometer, my room's not heated because I can't afford to heat and so more money would improve my quality of life for sure

In Marie's household they've struggled with poverty in the past. A mother of five, she recalls of her and her husband, that "sometimes we'd had nothing so, but I would always make sure Andrew got what he needed before, before me." These days, she finds that "I can go to the shops, and I can spend £80 and look when I get home, and think: there's nothing there." But it's not just impacting her shopping basket. Marie has diabetes but is unable to afford nutritious and safe food. In the last year, Marie has also struggled to repay a gas and electricity bill. An error with a direct debit meant that a debt with Scottish Power suddenly ballooned to an unaffordable level:

> And the money was going up and up at the time, the debt, and it got to, like, £1400, £1500. And then they want £280 a month. I said, "I can't afford that." And so, they said, "Well," you know, they weren't happy about it, because they actually took £280 out.

Eventually Marie was able to get the support of the CAB to negotiate the repayment down to £140 a month. But that’s still a substantial outgoing given how tight Marie's finances are.

> it’s meaning I’m having to buy less food for me. [Pause] And just having to watch the pennies, really because it is hard, yeah. But you know what I need the electricity for Andrew for his bed, for his hoists, for hot water in the morning for his shower.

Marie is not alone. We spoke to three other caregivers who had found themselves plunged into hardship and poverty over the last year.

"Serge" is the carer of his ex-wife and mother of his two adult children. In the past he gave up a business to care for his elderly parents, his mother suffering from Alzheimer's, his father with cancer. Serge is now 73, but lost pension contributions have meant that his later years are being spent in hardship. Serge also has a number of physical health conditions like arthritis, which can be aggravated by his caregiving.

> "I don’t particularly eat well. And then because of my irritable bowel syndrome I have to have a certain type of diet, I can’t afford that diet".

Serge struggles to get by on a basic State Pension and Pension Credit. He has applied for Attendance Allowance but his claim, like 58% nationally, was turned down (Morgan 2023). He has now been told he will need to wait 18 months for his appeal to be considered. In the meantime he will struggle to get by.

"Peter" is another caregiver. When we spoke with Peter, he was caregiving for his wife who had a terminal health condition. Unlike Marie and Buffy, but like Serge, Peter had his own physical ailments - long-term impairment from a stroke which had forced him to retire early. Like Serge, Peter was much less confident and knowing about how to navigate the official landscape of services. As a result, Peter was going without some basic support, including housing adaptations and equipment for his wife, while also struggling with the rising cost of gas and electricity. Like Buffy and Marie, he needs to keep the heating on all the time. But as yet there have been no special provisions in the Warm Home Discount for caregivers.

Lastly, "Khalil", a relatively younger caregiver and asylum seeker. Khalil cares for a sibling with a physical disability; he also has a disability himself. When it came to finances, Khalil, like Peter, often spoke the most in his long pauses. Was he managing to get by on Universal Credit and Carers Allowance?

> I'll be honest with you: no actually. Honestly, it's difficult for everyone. And it's a real problem. You know, electricity and gas and other stuff. For example, you know, I mean, it's really difficult. It's been a while, it's been about like over two years. It's been absolutely tough.

For two months over the last winter, he was unable to pay his gas and electricity, which was through a pre-payment meter. For a period it was stopped. Finally, it was restored though their income hasn't been enough to keep the house sufficiently warm and safe. How often can they heat their home at present?

> Well, well. Well, it's very rarely I would say, very rarely. Yeah. We used to put, like, put it on most of the time. You know, because it's really difficult. You can't cope with the cold. … it took like a long time, like, to recover you know

> what I mean? To get like money and these stuff together, to get like back to normal. You know, it was a very difficult time, I would say. … We were like broken, financially broken.

The stories of these caregivers matches what is known about at the national level. You read about the national picture earlier of caregivers struggling the cost-of-living crisis. Here is how it plays out in real lives. As Khalil is "financially broken" by an unpaid bill, "Sal", who cares for her husband with a disability, found that she quickly built up a £600 debt with her gas and electricity. For her, it was becoming a struggle to get by. "Well, when I'm watching the figures", she said, "the £50, it’s not lasting a week".

But in another sense, we're still at the very beginning. For most of these caregivers, severe hardship is something relatively new. These are experiences just from the last winter. Some, like Serge, or "Rosa", who you will meet later, compared it to the sheer poverty, destitution and misery in much of the North-East of their parents' generation in the 1930s - the kind of poverty which the NHS and welfare state were established to protect people after the Second World War. In 2023, our creaking social security system is at another crossroads. The way forwards begins with supporting caregivers.

3. Giving caregivers more financial support

There are three clear takeaways:

a. Carers Allowance is not fit for purpose.

Carers Allowance is nowhere near enough to provide a decent income. And it is insulting that many caregivers are ineligible to receive it, particularly state pensioners. The income eligibility threshold should be removed. The allowance should also be increased to a level that provides a Minimum Income. Research should to be undertaken to assess a range of Bands by which to establish a Minimum Income Standard for caregivers. Based on JRF and Loughborough's work modelled just on a single adult, this would likely entail a substantial increase in Carers Allowance or equivalent Care Element of Universal Credit, probably in the magnitude of an increase of 100% - 150%.

Our findings match the national picture. Carers Trust found last year that 47% of carers receiving Carers Allowance found it wasn't enough to meet their basic needs as carers.

Once more it comes down to politics. If our caregivers happened to live 60 miles north of Gateshead in Scotland, then they would be entitled to not only Carers Allowance but also Carers Allowance Supplement, which this year pays carers an additional £270.50 every 6 months.

Are caregivers fundamentally different north of the border? It is unlikely. In the Republic of Ireland, people who care for more than one person receive an additional amount of Carers Allowance; it also pays a Carers Benefit as a social insurance payment to someone who gives up work to provide full-time care. There is no equivalent in England. It is time for Carers Allowance to be overhauled.

b. Carers need dedicated support to address cost-of-living pressures

Caregivers are more vulnerable to cost-of-living pressures. That's because they often need to use more power to provide safely heated homes for their loved ones who are frail or have certain medical conditions. Caregivers and their cared for are also more likely to be at home during the day. They also consume more power for certain medical equipment e.g. hoists and respirators for the people that they care for, or to continually wash soiled laundry. They often need to buy more food, and more nutritious food, to support the health of their loved ones.

So it is surprising that unpaid carers have not been supported by the UK government's cost of living support schemes. In May 2022, Rishi Sunak, then UK Chancellor, announced a package of measures providing further “cost of living support” totalling more than £15 billion, “targeted particularly on those with the greatest need”. This included one-off payments for pensioners; those with disability; those on means-tested benefits; and with energy bills. So these will have indirectly helped many unpaid carers. Yet none were tailored specifically for unpaid carers. Despite its strict income eligibility threshold, Carers Allowance is not classed as a means-tested benefit. During the pandemic, while Universal Credit and other benefits were temporarily uplifted, Carers Allowance was not.

In other words, caregiving remains unpaid, and in the process, caregivers themselves are getting into substantial debt to provide care. This isn't sustainable and it isn't fair.

c. Funding should be increased for carers respite and wellbeing funds

Around the UK, depending on the local authority, caregivers are eligible to receive a wellbeing grant that they can use to pay for activities or therapies that support their own wellbeing. Some caregivers use these for short breaks, others for back massages or one-off purchases. These grants are usually disbursed by the local carers service. In Gateshead, Gateshead Carers disburses these grants. Yet their value has plummeted: in 2014 they were able to give caregivers support up to £500 a year, but as of 2023 they can only disburse up to £200 a year.

Nationally, support for carers services has also been hit hard by austerity. Research by the Nuffield Trust last year observed a 42% drop in respite and breaks for carers since 2015 (Nuffield Trust 2022). Over that time, local authority spending on unpaid carers has dropped by 11%. All this despite the enactment of the Care Act 2014, in which local authorities are required by law to meet an adult's eligible needs, including those of caregivers. Either caregivers now have substantially less needs than a few years ago, which seems unlikely, or local authorities simply do not have the resources to meet these needs.

In addition, caregivers also need specific advice and guidance around their finances. Many of our caregivers had received this either from Gateshead Carers or Gateshead CAB. The value of this kind of advice has been enormous, protecting households like Marie and Khalil's from drifting into further financial calamity and associated mental strain. As Christopher pointed out: "if it wasn't for all the fantastic organisations such as Gateshead Carers, you think, what will we do?"

4. Financial security

But it's also important to acknowledge the role of "luck".

Meet Tom. Tom is a 73 year old man who cares for his wife Jen who is disabled as the result of addiction. Tom worked for most of his life in local heavy industries. When redundancies hit the North-East, he became a taxi driver. He was able to save and build a private pension, and was looking forward to retirement with his wife. But as her physical health dramatically declined, Tom found that his caregiving role became a full-time job.

> Fortunately by now I'm retired. I mean all this experience has been in my retirement. If this had been in my working years, I don't know how I would have coped with any of it because I either wouldn't have had time to go to work or I wouldn't have had time to chase around hospitals and all the commotion.

Other caregivers in older age reported something similar. Aspers, a caregiver for her elderly parents, one suffering from dementia, felt protected from some of the financial pressures of caregiving because she'd already been able to retire.

> I'm 63. I'm now retired, I took early retirement, as I was lucky enough to get into the job I had

Like Michelle, she could also count on her husband's income and pension contributions. Over their working lives, they'd been able to save and buy their homes. Joanne, who cared for her husband who suffered from a physical disability related to old age, could count on both a private pension and a secure council tenancy where rents remained affordable. Susie too, despite her huge caregiving role, counted herself as one of the "lucky" ones because she had built up financial security over her working life:

> And I am lucky in that way: I'm not lucky to have muscular dystrophy and cardiomyopathy, but I'm lucky in the respect that I was able to get a good pension.

But as we saw with the case of Buffy and Khalil, others are not so fortunate, particularly when their caregiving role begins before retirement and the ability to build up a lifetime's earnings and pension contributions, and where there are issues with the affordability of housing.

Rosa, a caregiver now for her daughter, who had previously cared for her husband who had suffered from an acquired brain injury since his 40s, forcing him to quit work, saw luck as working two ways. On the one hand, she felt she was "lucky" to have come from a working class family that were driven for their children to achieve. She felt lucky to have had a relatively well paying job, and to have lived in a country with, until recently, an entirely publicly owned health service.

But luck could work in other ways. Luck was also a term she had heard used by support agencies when they were deciding not to provide formal support. This came up in one focus group with Susie, Rosa and Hannah:

> **Hannah**: Do you not hear this sentence though? It drives me mad. And I'll put my house on it I haven't heard it. "Oh they're lucky to have you".
> **Susie**: Yes
>
> **Rosa**: Yeah, I've heard it
> **Hannah**: Aren't they flipping lucky, aye, they are lucky
> **Susie**: Social workers and assessment officers, they've all said it

But is financial security a matter of luck? Is it simply the case that some people get to have it and other people don't?

Is having family members around to whom all caregiving responsibility can be discharged a matter of luck? Or is it also a convenient assessment to make when the capacity to support caregivers has been so cut back?

While financial security reflects opportunities and endeavours over a life, and advantages that often begin at birth, it also ought to be in place for those who have to leave employment or education early because of caring, or who, perhaps through disability themselves, are unable to work in the same way.

Giving caregivers a basic level of financial security is a political choice. Currently we are choosing to not provide many caregivers with a basic level of social security. And that is a choice that the Treasury in Westminster is making. While many caregivers found that their struggles begin and end with the local Council, the force behind these cutbacks in England is the central UK government.

2. No More Unsupported Carers

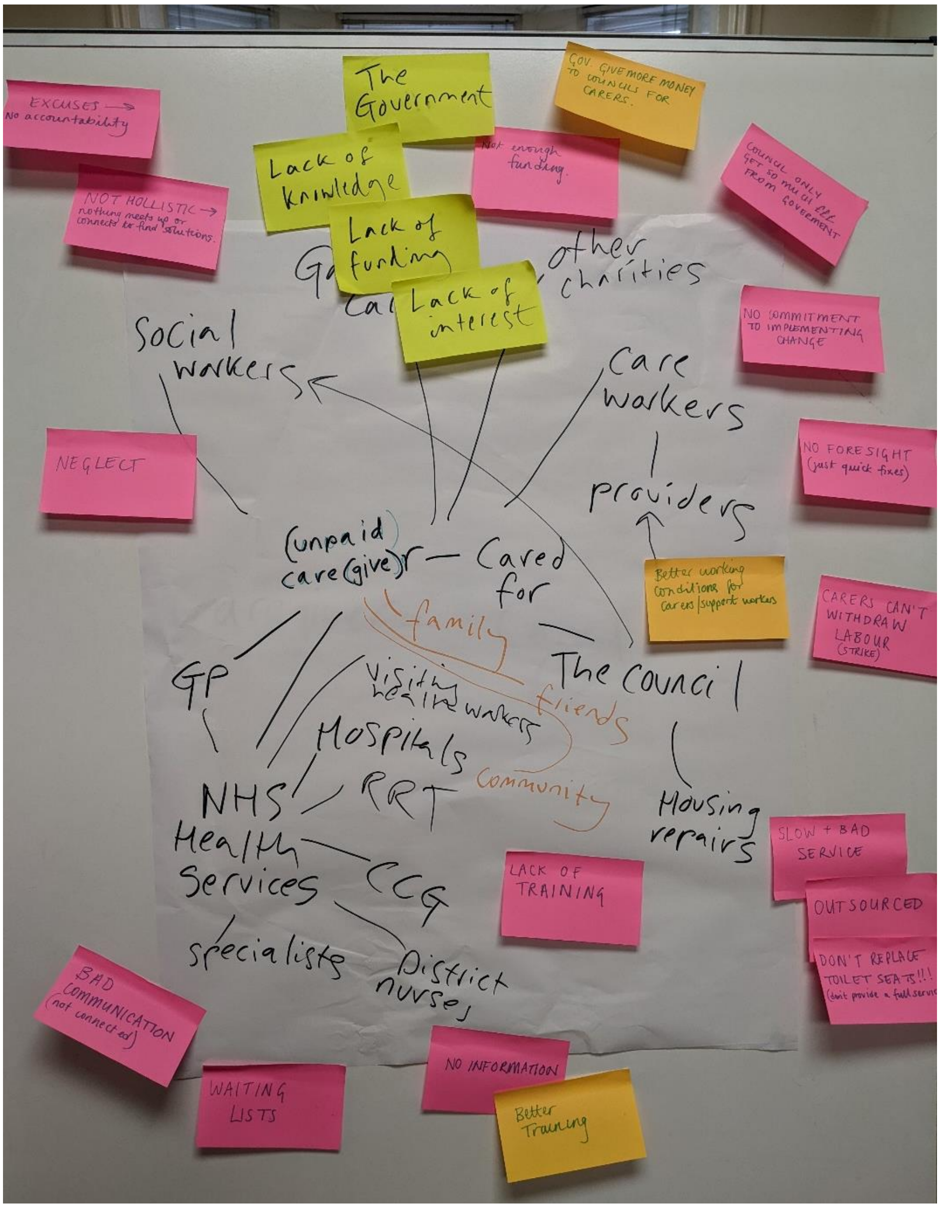
Our second key finding is that many caregivers, no matter their financial circumstances, feel unsupported, undervalued and often completely invisible. While most reported positive experiences with NHS health services, there was widespread frustration and dismay at experiences of dealing with social services. We suggest another way of working together. At present, the current system of support for caregivers needs to be much more holistic, with a clearly structured process for identifying and supporting caregivers, and providing training, from the outset before things reach crisis. While work towards integrating health and social care looks promising, there remains a risk that caregivers are not being consulted and prioritised in decision-making.

What is it that caregivers need to thrive?

In our first set of focus groups we asked caregivers what sources of help they drew upon. The answers were rich and varied. On the next page you can see what one group of caregivers came up with (please forgive the handwriting).

This is the **landscape of care**. In the centre is the caregiver and the person or people that they care for. And around them are the supports of support, official and unofficial, that they might use. They include:

- NHS health services: GPs, paramedics, hospitals (nurses; emergency doctors; consultants; specialist clinics, community clinics like the Memory Hub, occupational therapy and physical therapy, district nurses, rapid response teams, crisis teams, other visiting health workers, and disability equipment (Gateshead Equipment Service).



- Adult social care services provided by the local council, including social workers to deliver care packages
- Paid care workers, provided by care agencies and usually funded by local council care packages
- Local authority housing (tenancy, repairs, or housing benefit administered through the local authority but paid to a private landlord). Around half of our interviewees were council tenants

- Respite services - usually temporary residential care offered to a caregiver to take a break or for urgent medical treatment (e.g. Marie)
- Day centres, providing daytime activities for physically disabled or older adults, usually paid for out of care packages
- The Citizens Advice Bureau
- Other support charities. Participants talked about the Alzheimer's Society, which no longer has a presence in Gateshead; Age UK; as well as local drug and alcohol support organisations like Evolve
- Gateshead Carers - given that we recruited through Gateshead Carers it was inevitable that our participants knew about the local carers service. For many, it had provided life-changing support and advice.
- Counselling and mental health support services. Three of our participants reported very good experiences with North-East Counselling, other talking therapy services not so much
- The Department for Work and Pensions, who administer benefits that both the cared for and the caregiver might receive
- Employers. Not reflecting the national profile, only one of our participants was in formal employment, though four caregivers were involved in extensive community work of a kind that may have been remunerated in the past.

This is not an exhaustive list but captures the main official bodies in people's lives. Navigating this landscape of care is far from easy. Given that many caregivers enter their roles in a period of crisis and personal upheaval, many were surprised as they looked back that there wasn't a more structured process for identifying and supporting them as caregivers from the beginning.

1. Journeys into caregiving are unstructured and perilous

Meet **Christopher**. Christopher is the only caregiver who was in employment in our project. Christopher is an indefatigable, gregarious man of retirement age. Care has been a huge feature of his life. Like Khalil, he sees it as an integral part of who he is, his "family values". Today he gives care to his wife, daughter and, alongside his brother James, his father who has Dementia. He also works part-time as a paramedic. As he says himself, 'I've never been a person to sit around'.

Like Aspers, who had previously worked as a mental health worker, Christopher has long working experience of health services. As such, he comes into the landscape of care with already a lot of know-how about therapies, physical health and health services, a kind of knowing about where and how to find things out, and a confidence to explore and find answers, challenge medical opinions, and so on. This kind of know-how isn't something many other caregivers automatically possess, nor should they be expected to.

Five years ago, Christopher's father received a dementia diagnosis. For him and his brother James, his father's main caregiver, they were at first confused about what to do next. Would their dad need benefits? What about his house? And who could support their dad and the family to better understand what would happen next?

> Five year ago, we looked at each other, when me father was diagnosed officially, we said where do we go from here? What do we do? And that's literally where we were. And I'm thinking, you know, you do a search on care, and this organisation Gateshead Carers pops up. ... Gave them a

> ring and two days later a young girl arrives at the house and starts going through me dad's mobility and got a blue badge which meant we're able to take him out. And she said, I'll do all the forms for you.

Both Gateshead Carers and the Alzheimer's Society (which later closed locally after funding was withdrawn) were able to help the family with accessing benefits like Carers Allowance and Attendance Allowance, as well as offering guidance and support with giving care. But Christopher was also surprised that the **system was so unstructured**:

> It was all self-researched. Again, if we turn the clock back 30-40 years ago, we may have got a phone call from social services. "Hi my name's Mary, my name's John or whoever, I'm going to be looking after you". And we could have a meeting, an hour, could be two hours, we'll go through all this and go through all that. That just doesn't happen today. So a lot of what we did was like self-research.

Self-research involves a lot of things: time, confidence, language, digital literacy and, once more, luck. What if you don't know where to look? What if you don't look in the right places? What if you're too tired or fed up to even consider what might be out there? In the case of Christopher and James, they had ended up spending thousands of pounds of their own money on equipment and adaptations that may have been covered elsewhere. Why hadn't there been a structured process to support the cared for and caregivers after diagnosis? James had been forced to give up his job to provide live-in care for his father, with similar issues around caregiver poverty and the cost-of-living crisis as Buffy and Khalil.

Tom, who you met earlier, also talked about having to do so much research to be informed about his disabled wife's conditions and rights to support. He compared it to learning an **encyclopaedia**.

> So it got to that I was the encyclopaedia of all the, what medications is she on now and I can rattle off the list, and it was quite a list for a long time. And 'what's happened?' and 'what's gone wrong?' and 'why are you here today?' and 'dedededada'.

Tom had learned his encyclopaedia painstakingly. It began as he accompanied and advocated for his unwell wife, but it came into its own as he, like Christopher, struggled to navigate the "**system"** of statutory support of indirect financial support paid by local authorities and administered by social workers from Gateshead adult social care.

Following a long physical decline, Tom's wife Jen was discharged into a private nursing home because more suitable, specialist care was unavailable. This nursing home cost Tom several thousands of pounds per week:

> It just would have passed me by if I'd been busy with other stuff. So by then I was resigned to how much of Jen's assets are going to be mopped up by this bloody care home. I was facing that as a reality of my life.

Tom however discovered that his wife might be eligible for Continuing Healthcare (CHC) funding, an NHS funding source which covers the costs of residential care. Getting CHC funding is far from easy. Tom recalls:

> And everybody was always the proviso. 'Don't think so', 'Nobody gets this mind', 'doesn't look, I can't see how you'll get that through'. I thought, well

> it's only time and effort. I'm going to push it as far as I can. Again, I was retired, I had time to sit and read it.

Tom was eventually able to secure CHC funding through an uphill struggle he recounts in a blog post ("Tom"/Gateshead Carers 2022). But both Tom and Christopher found their experiences with social services at times difficult. Social services are by law required to undertake financial assessments of people's circumstances in order to determine whether they are eligible for care paid for by the local authority. As an indirect consequence of austerity, eligibility for support has become more restrictive over the last few years, as the national picture showed you earlier on.

Sat with this powerful official at a vulnerable moment, questions felt "probing" (Tom). Rather than sympathy came suspicion. As Christopher recalls, " even that's quite traumatic, to start to go through your father's personal, you know, files and finance, to look through cupboards. I didn't actually find that easy."

Of course, social workers need to identify this information. But other caregivers shared these experiences of being treated with suspicion, not sympathy, by social services. And here there needs to be a change in working together.

2. *A lack of accountability from professionals*

Jack and Michelle felt burnt by their experiences with social workers. While their daughter had a care package that funded her attendance of a day centre and activity group, the couple were always left feeling that this support might be cut off at any moment:

> **Jack**: Well, at that time, we had a social worker. And we dreaded her coming in, didn't we, absolutely dreaded the knock on the door. Because it was never, "How can we help you?" It was "Well, I've come to assess Lucy's budget this afternoon. We think she's getting too much. I'm going to take the money off her." [Sighs]
>
> **Dan**: So, you were worried that when the social worker did an assessment that you'd lose something?
>
> **Michelle**: Oh yes, and to this day, I'm still the same. I will not ring social services.

Previous social worker visits have been pretexts to assess the household's financial budget, with Lucy's care package cut back until the parents successfully won an appeal. These experiences, in which caregivers feel unsupported up until they are objects of suspicion, had left a lasting mark. As Michelle said, "We dread Gateshead Council, it's horrendous".

Meet **Susie**. Susie's a warm and friendly woman in her late 50s who is now medically retired. She's a carer for three people - her mother with cancer, her elderly aunt, and, most impacting her life, her brother with a learning disability and physical impairment as the result of addiction. Susie also has muscular dystrophy and has needed counselling. **Susie** also felt deeply frustrated and upset at her experiences with social services. Like Jack and Michelle, in the interview and discussion groups, her contributions were often focused on a sense of indignity at a lack of recognition and value from social services. Her experience had been a protracted, near two-year period of inaction and failure to pursue concerns raised by police and fire services related to her brother. Multiple safeguarding alerts had been raised and her brother even had a link worker, though one not directly employed by the Council. At one point she realised she'd made over 150 phone calls related to her brother's welfare over a three-month period. Despite pledges to support her brother, Susie felt very much unsupported.

> My personal experience is, they're all talk. That is it. Because she said to me, she says "I am I have been assigned to your brother", she says, "but you know, I'm here for all the family", and she says, "and, just talking to you today", she says "you need support as well". Never heard another thing from her.

These are all just individual experiences, but they are lived experiences nonetheless. Talking about **lived experience** matters. During the researching of this report, we drew inspiration from the Gateshead Poverty Truth Commission. This was a group of people with lived experience of poverty who met between 2020 and 2022. They produced a report, "Growing Change in Gateshead", which argued that the best way to work to end poverty in places like Gateshead is "to include the people that experience poverty in the rooms where decisions are made" (Gateshead PTC 2022, p. 20). The core principle of the Poverty Truth Commission is "nothing about us, without us, is for us".

The same applies to working with caregivers and disabled people and involving them in decision-making and commissioning, for instance on the new integrated care boards. There has already been some useful work on how this might function in mental health - the "triangle of care" that exists between the carer, the cared for and the medical professional.

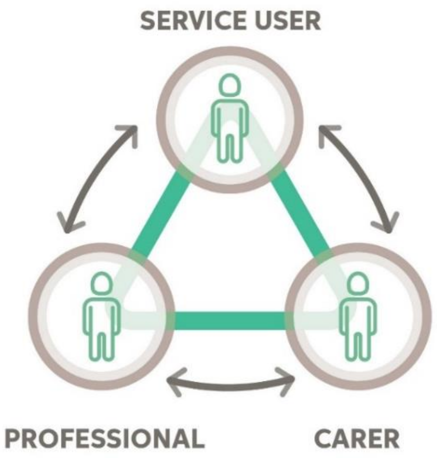


Figure 1: The Triangle of Care, NHS England (2021)

But a nicely named concept is not going to change deeply-engrained ways of working. For that, the conversation needs to shift to power - which we cover in the final part.

On one level it comes back to money. Social services have been disproportionately impacted by austerity policies, as you read earlier. Caregivers had observed that social workers were now less available and much busier, often unable to help even where meaning well. In one discussion group, Hannah pointed out to Susie that many social workers simply have too big a caseload to support everyone:

> Because like realistically, if you know the reality, it's no good asking and being fobbed off, if the social worker has got that many case loads, then it's not it's no good really being frustrated with a social worker. Do you know what I mean?

Susie reluctantly agreed. But what these experiences also point to are feelings of suspicion and a lack of care from officials. Sometimes these are magnified by encounters at very vulnerable, crisis moments where something may have been misinterpreted. For some caregivers, they contribute to a feeling that "the system" deliberately relies on unsupported carers. As Serge put it:

> So, there’s this… you are going downhill. And… [pauses] so the system is always stacked against you. There’s never a time when they came in, either DWP or social services or whatever, they came in and said, Right, we’re going to do a review. You haven’t rung us, but we’re going to do a review and see how you’re doing. That was never the case. They never initiated any meetings to assess what’s going on. Never at all in the years that I was doing this.

For Serge, recalling moments of severe mental and physical exhaustion caring alone for his two frail, elderly parents, when he had called social services for support they hadn't called him back; and when social workers came to produce care packages, they seemed all too keen to pass on the work of care to the unpaid carers. It contributed to a feeling of being taken for granted, which is an experience of disempowerment that we talk about in the final Finding section.

What's the way forward?

The answer here isn't money. **What's required is a change in working practices**. At present, the caregivers we spoke to had very little to no contact with social services. Those that did were generally scathing or dismissive; some were nostalgic about decades earlier when social workers seemed more available and generous with their time.

But the issue here is **trust** and **partnership**. There needs to be serious and careful work done at a pilot level to explore how social workers, link workers and caregivers can **work together as equals** in a therapeutic relationship that is dedicated towards the best care and dignity of the cared for person and the caregiver. All sides should find ways to support one another and cooperate. Instead of being looked upon as another potential "service user" who might consume resources that are no longer available, caregivers should be approached by health and social services professionals as **experts in care** with valid and important insights and contributions. There needs to be **transparency** and **honesty** about what services can and cannot accommodate and support. And, we heard time and again, in each case there needs to be one named and accountable figure that caregivers can approach when they need help or something goes wrong.

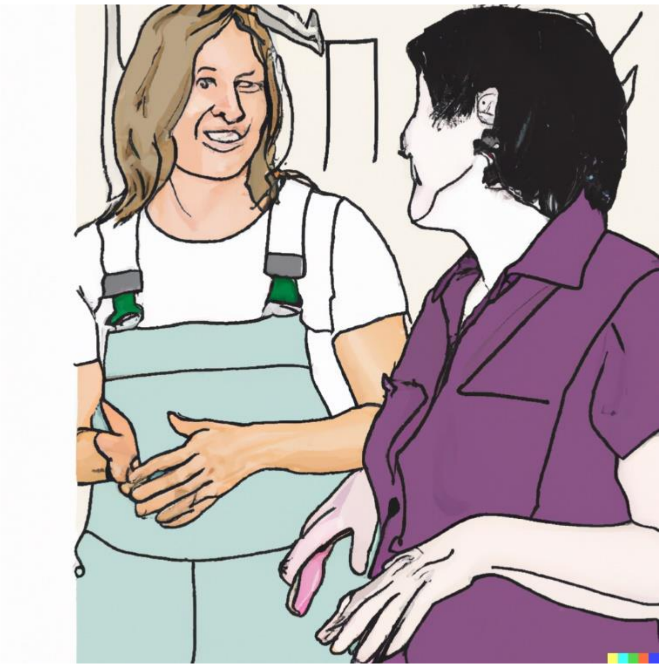
In addition to active caregiver involvement, health and social services could also meet the issue in the middle by **nominating "caregiver leads"** in teams to identify, target and understand the concerns of caregivers interacting with their services. Many staff in health and social services are themselves caregivers (up to one third of NHS staff according to one staff survey (Carers UK 2021), who could bring to these roles lived experience alongside a realistic understanding of what services can offer caregivers.

Given the economic and social value of caregivers to Gateshead, it would be good to explore the possibility of what Buffy called a "living partnership" between caregivers and social workers and health professionals, working together harmoniously as equal experts in care. This could take place at two levels:

- At the **community level**, as something embedded into the everyday practice and working routines of health and social care professionals
- At the **borough-wide level**, as a partnership board between caregivers, the local carers service, Gateshead Council Adult Social Care, Public Health, and local NHS services.

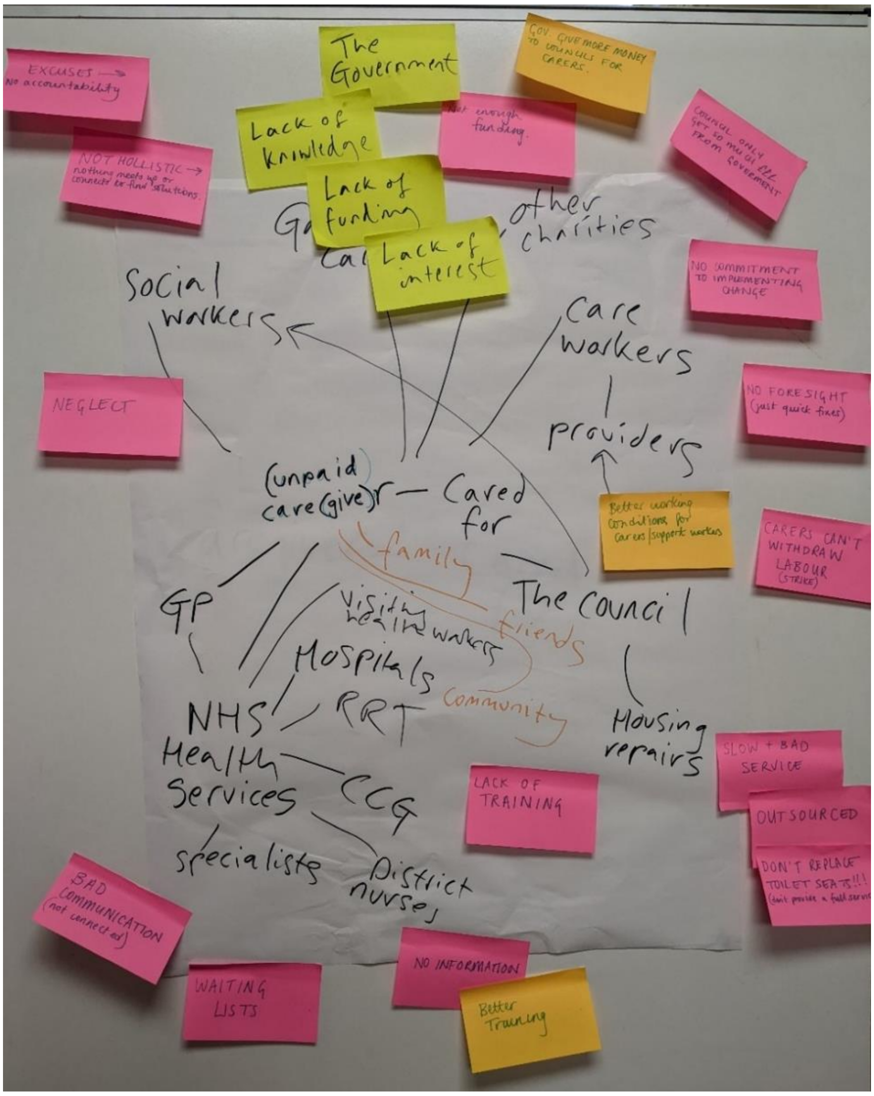
There has been some initial work at this level with the long-running consultation for the 2020-25 Gateshead Council Carers Strategy. But rather than working slowly towards a finished document, what we have in mind here is an ongoing relationship of partnership and dialogue, building towards trust.

Given that Gateshead is a fantastic place that cares, is blessed with a proactive and well-regarded local carers service, and has a Council which has been proactive in supporting other innovative research in health inequalities, then there's an open goal for innovative research.



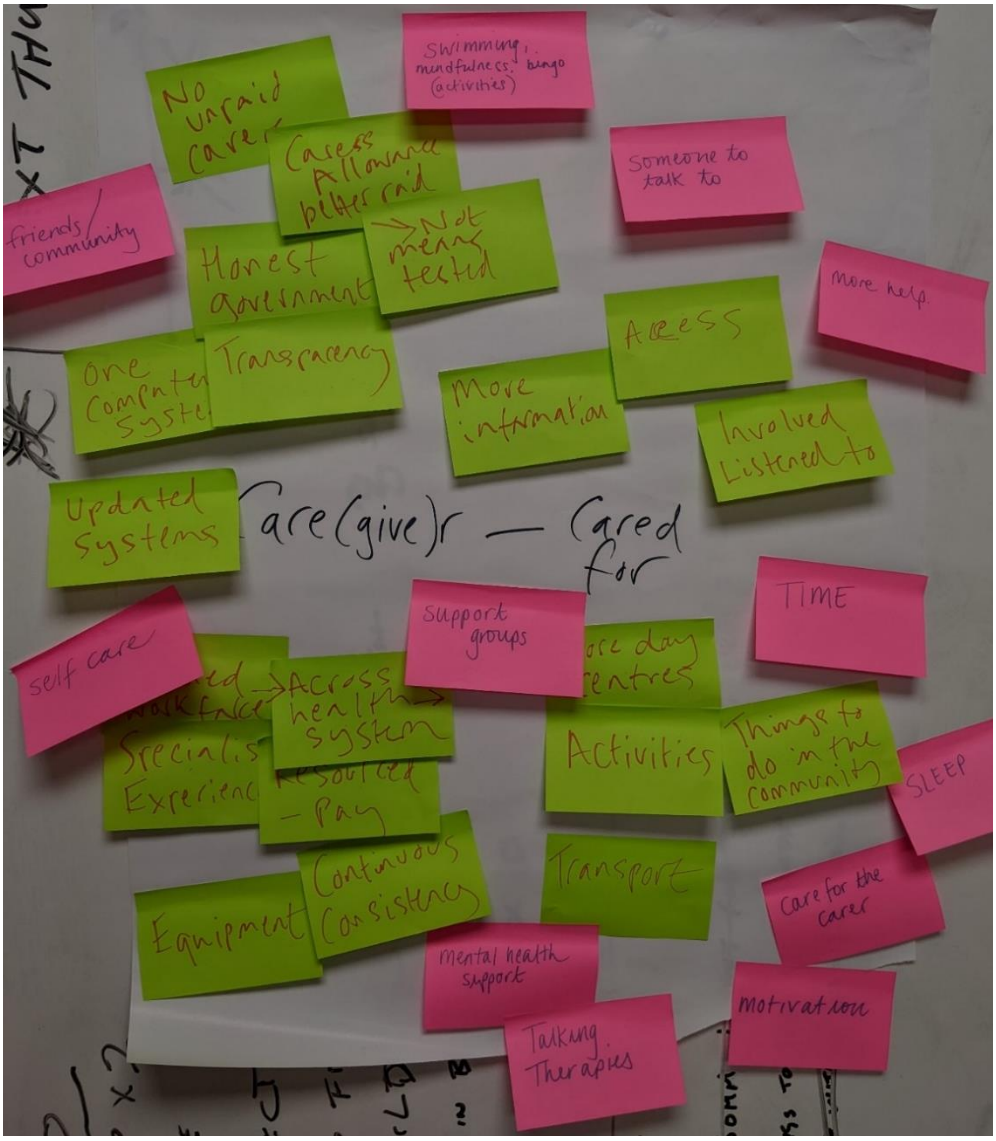
3. Time, respite, and care-centred support

Let's look back to our photo of the landscape of care. All around it were colourful post-it notes. This is because we asked caregivers what was **not working** in the "system" of care. Many of these reflect what has been discussed in this section. "Lack of training". "No information". "Bad communication". Some caregivers linked this back to the bigger picture of funding cuts, particularly in the discussion groups where it was possible to draw out reflections from common problems. Hence we see "Not enough funding", "Slow and bad service" - "outsourced", and "Better working conditions for [paid] carers/support workers".



In another group the answers were similar: "not enough information", "joined up thinking" (more on that shortly), "poor communication", "money", "training", and "basic coping".

One thing that struck us, when thinking about what support caregivers told us they would like, was how modest their expectations were. In the same first set of groups we asked: *imagine being in Gateshead in 10 years' time and someone is going to take on a caring role identical to yours. What would they need that you don't currently have?* These were their answers:



Some are features of the current system, where it is able to support caregivers: "talking therapies", "support groups" like those of Gateshead Carers; "equipment" and "transport". Others are even simpler: "sleep", "self care", "someone to talk to". "Time".

Caring needs time

Time is very important. Caregivers generally have very little of it. Even getting caregivers into a room for an interview or focus group involved a complex juggling act of scheduling and timetabling, ensuring care workers, a day centre service or another family member was around to spare our participant a couple of hours to come and talk.

Many caregivers told us that they feel they haven't got enough time for themselves. Marie's time for herself was a few hours sleep here and there. Michelle's time was when Lucy was at a day-centre. When Tom read an earlier draft of this Report, he said that we should also mention a lack of quality time. Caregivers might spend lots of time with the person that they care for, but "They have little or no quality time with friends or family". For others, like Rosa and Sal, it was necessary to keep the people they cared for with them all the time for their own safety. Neither received any official support, and so time for themselves just isn't a feature of their lives.

Aspers wrote a powerful, clear reflection for us. One of the things that she says would improve caregivers' lives is time:

> Time for a start. Time for myself to recharge my batteries. It is not only professionals who burn out. The lack of respite care in Gateshead is

> appalling. Caregivers cannot, at times, continue with their own lives. Like going out for a hair cut attending their own health appointments and attending support groups. All very necessary for our sanity and good health. I for example have not had a holiday for 4 years. At the moment I can't get even a few hours to sit with my husband, in my own home, as my cared for person has … needs 24/7 care , which I share with family members when available. What unpaid caregivers need is a decent respite service, which covers all aspects of respite, not just 15 minutes or half an hour.

Time is also about never being able to switch off. Even something simple like a mobile phone. Towards the end of one of our first groups, Susie's phone started buzzing. Everyone jumped, expecting it was a call for them related to the person or people they care for, probably intimating something bad had happened:

> **Susie**: I always have my mobile phone, and I always have it switched on. If I'm going anywhere, I'll always apologise
>
> **Hannah**: I can't have my phone off.
>
> **Rosa**: I've never got mine off.

How can caregivers get some time?

- Through paid care workers to come and provide home visits
- Through occasional respite where the cared for stays in a safe and trusted care home
- Through the help of friends, family and the community to provide informal support

The first two are funded through social care budgets. But as we saw earlier, one indirect consequence of austerity is that, for years, care workers have been paid the minimum wage for what is a highly skilled job. Many have left the sector since the pandemic, when many care home residents were inadvertently exposed to the virus by government mismanagement. As a result, as you read earlier, there are now over 165,000 vacancies for paid care workers across the UK. Anecdotally, three participants told us that they had unexpectedly had to provide unpaid care or additional unpaid care because the local authority was unable to source paid care workers.

Time is money

But at the end of the day, local councils cannot supply care workers or respite services if they have not got enough funding.

Local councils are increasingly reliant on Council Tax to cover the cost of social care. At present, it is estimated that 56% of adult social care spending nationally is funded through local council tax collections - an increase of 12% in the last 9 years (House of Commons 2022, p. 34). But this isn't shared evenly. Areas with a higher amount of people on low incomes also tend to a) raise less income from council tax, and b) have a higher proportion of residents eligible for publicly funded care. Here's an example that illustrates this: 1% of the council tax in Stoke-on-Trent raises £700,000; 1% in Surrey raises £7.5 million (ibid., p. 36).

The solution here is bigger than Gateshead. We need a bipartisan commission into the future of social care and caregiving, one with the aim of establishing a more sustainable and equitable source of funding, which is not council tax.

4. Imagining a holistic system of care

Our landscape of care is made of many little islands. Often, there isn't a great deal of communication between those islands. This can create problems. Susie and Aspers both reported issues with basic patient medical records not being shared across NHS trusts in Newcastle and Gateshead. For Aspers:

> You can't make a decision if you don't know what's going on with the history of a person. And if the doctor doesn't tell the hospital, and they don't tell the social workers. And everybody keeps asking

This can become dangerous when sensitive medical information or emergency plans are not passed on or read by medical professionals, as Aspers experienced when her mother was admitted into hospital. Doctors failed to read or pass on her emergency plan, and continued to make plans to admit her into inappropriate wards without consulting her caregiver. Fortunately, Aspers had arranged long before to become power of attorney for her mother; but many caregivers were either mystified by or had not heard of this process.

Caregiving requires becoming, like Tom, an "encyclopaedia". But not everyone has the know-how, confidence or physical capacity to make demands or ask difficult questions of such services.

The Government's white paper on Care 2021 made a number of recommendations which, if implemented, would indelibly improve caregivers' lives. Among these included "Increasing the voluntary use of unpaid carer markers in NHS electronic health records". The White Paper described the ability to identify carers as “crucial for recognising and supporting unpaid carers and improving policy making" (Department of Health and Social Care 2021). We suggest that the rollout of this service be **guided by a steering group of current and former caregivers** at national and local levels.

Caring is a public health issue

When we asked participants of our first set of focus groups whether they felt supported by the system, no caregivers put up their hands in support. Joanne nearly did - she had lots of positive experiences with NHS services for her husband. But there was an invisible pressure, perhaps camaraderie in the room. When we asked Joanne, Marie and Aspers to give a name to the system, and to what the system feels like, they used the words "broken" (Marie), "fragmented" (Aspers), disjointed" (Joanne); in another group, Michelle said "inefficient", and Jack said "fear".

According to the last Census, there are 10.4 million people (17.8%) with a disability in England or Wales (ONS 2021). The region of England with the highest average rate of disability is the North-East (around 21%). Many of those people will be supported by a caregiver; some will have more than one caregiver.

Many caregivers also suffer from poor health or disabilities that are made worse by the burden of their roles. A 2021 survey by the Care and Support Alliance found nearly 2 in 5 carers reporting that their health deteriorated because of their caring responsibilities (House of Commons 2022, p. 58). According to Public Health England, carers are 16% more likely than non-carers to live with 2 or more long-term health conditions' (Public Health England 2021, p. 22). An analysis of the GP Patient Survey found that caregivers have an increased risk of multiple long-term conditions, with arthritis and high blood pressure accounting for 44% of this. Some of these conditions are exacerbating by the physically and mentally demanding requirements of giving care; others come from self-neglect of personal health needs that result from a lack of time to attend appointments.

At a local level, we suggest that **caregiving deserves attention as a public health issue in Gateshead**. Once more, there is great scope here for innovative, partnership-led research with caregivers and carers organisations.

Training the skills to care

It is not known how many people become disabled every year, though the figure would be high. Each disability requires training, skill and expertise; each disability is unique. Caregiving is often a very skilled role though poorly compensated. There is also no structured system in place to support caregivers following a diagnosis or discharge to allow them to acquire the skills to look after their cared for person at home safely. Christopher and Aspers came with professional experience; Buffy had sometimes learned the hard way about how to manage alcohol detoxes at home.

All our caregivers suggested that there ought to be a much more structured and signposted journey for caregivers in this landscape. This could begin through more attention to the needs of caregivers by medical professionals at GP and hospital level at or before the point of discharge. It's not good enough to be told that there is someone at home to whom an unwell patient can be discharged. That someone, the unpaid carer, needs the skills and support to care safely, otherwise both the caregiver and cared for may, and do, reach a crisis of physical or mental health down the line.

As a paramedic, Christopher could recall instances of visiting the homes of married couples in their 80s, one looking after the other, often with dementia, and often lacking basic knowhow and skills to keep each other safe.

> In fact, I hear it time and time again off patients - not patients but the carers - "I was at breaking point" … . And they just don't know who to turn to, what to do. And from that, and I do tend to limit it to like friends and family, I produced a four page of A4 guidance … Benefits such as Attendance Allowance, Carers Allowance, it has a paragraph on Gateshead Carers with their telephone number

In the absence of a structured system of post-discharge support for caregivers, and in the absence of the proper resourcing for experienced, caregiver-centred social workers and carer support services, individuals like Christopher, Michelle, Susie, Peter and Serge have to battle on as best they can. Many caregivers call this "**the fight"**. They feel locked out of decision-making, invisible and unheard, unless they are able to fight, make themselves heard and be persistent. We found that in many cases, caregivers that are supported by friends, family members or the local community had more capacity to fight, though some caregivers like Tom had engaged and won in herculean struggles for support.

At the end of the day, it comes back to the **capacity to care.** Carers need financial security to provide care. And carers need specific support, training, advice and time to care - that's the second ingredient.

Three key points come from this section:

1. Caregivers need more information, support and training
2. Caregivers need more time and respite
3. The landscape of care needs to be much more holistic.

But it isn't all doom and gloom. We were also impressed to hear about what forms of support were working. Many praised Gateshead Carers for being a lifeline at a time of vulnerability. As Susie said in her interview:

> If it wasn't for friends and family. I know this sounds dramatic, but if it wasn't for friends and family, and Gateshead Carers Association, I don't think I would be here to be perfectly honest

Buffy reported the same in her interview:

> I think at the start, one of the hardest things that I experienced as a carer, and definitely Gateshead Carers Association helped me to realise, was that I am a carer. And that's one of the biggest challenges really, that I face, I thought I was just, this is what a partner or a daughter is expected to do

For Buffy, Susie, Tom, Christopher and others, Gateshead Carers had helped with financial advice, practical advice, access to counselling, but also recognising and reinforcing their basic well-being and dignity.

Nationally, there are debates about establishing a National Care Service. According to the Fabian Society, who launched a consultation on this in 2022, this would be established like the NHS, providing centralised social care free at the point of need (Fabian Society 2022). This is a promising if complex development. As others have noted, e.g. Health Foundation (2022), the sheer difficulties and upheaval of establishing an entirely new system of social care support, particularly one under central government control, could create whole new problems and flaws in the system. A great deal could go wrong in attempting to launch an entirely new, centralised system.

The contribution of our small project to this debate is this: caregivers trust local carers services, who are the experts on the ground and often well-connected with other local voluntary and community services. Any attempt to reimagine the landscape of care nationally must involve giving power, agency and the expertise of caregivers and local care services on the background. These are the experts, and there is a great deal we can learn from them.

3. No More Invisible Carers

Our last key finding is that many carers feel invisible and taken for granted in the current landscape of care. Carers give care out of love and obligation to the people that they care for. This is a role with often little formal recognition or power. Without power or recognition, decision-making - from care packages to national policy reviews - lacks the expertise, lived experience and values of carers on the ground. By giving carers more formal power, decision-making and cooperation would be improved across the landscape of care with better outcomes for all. In this last section we explore some of the ways caregivers could be afforded more power.

1. Carers are invisible because they have little formal power

Invisible is a word associated with giving care. A recent story about kinship carers called them the "invisible army"; a recent Carers Trust report on carers and poverty took its headline from a carer's remark, "I feel like I have disappeared" (2022b). The invisibility of caregiving has become a cliché. It's time to ask instead **why it is that caregivers remain "invisible" when so many millions of people around the country give care**.

What does being invisible mean if you are a carer? It can mean that your value or contributions are not recognised. It can mean that health and social professionals do not consult or update you on developments in the support of your cared for person. It can mean that you're not even able to recognise yourself. It can also reflect feeling exhausted, not having enough time for yourself, not even time to sleep. Or not having enough value to others, even enough value to have a warm house on a cold night or a nutritious meal.

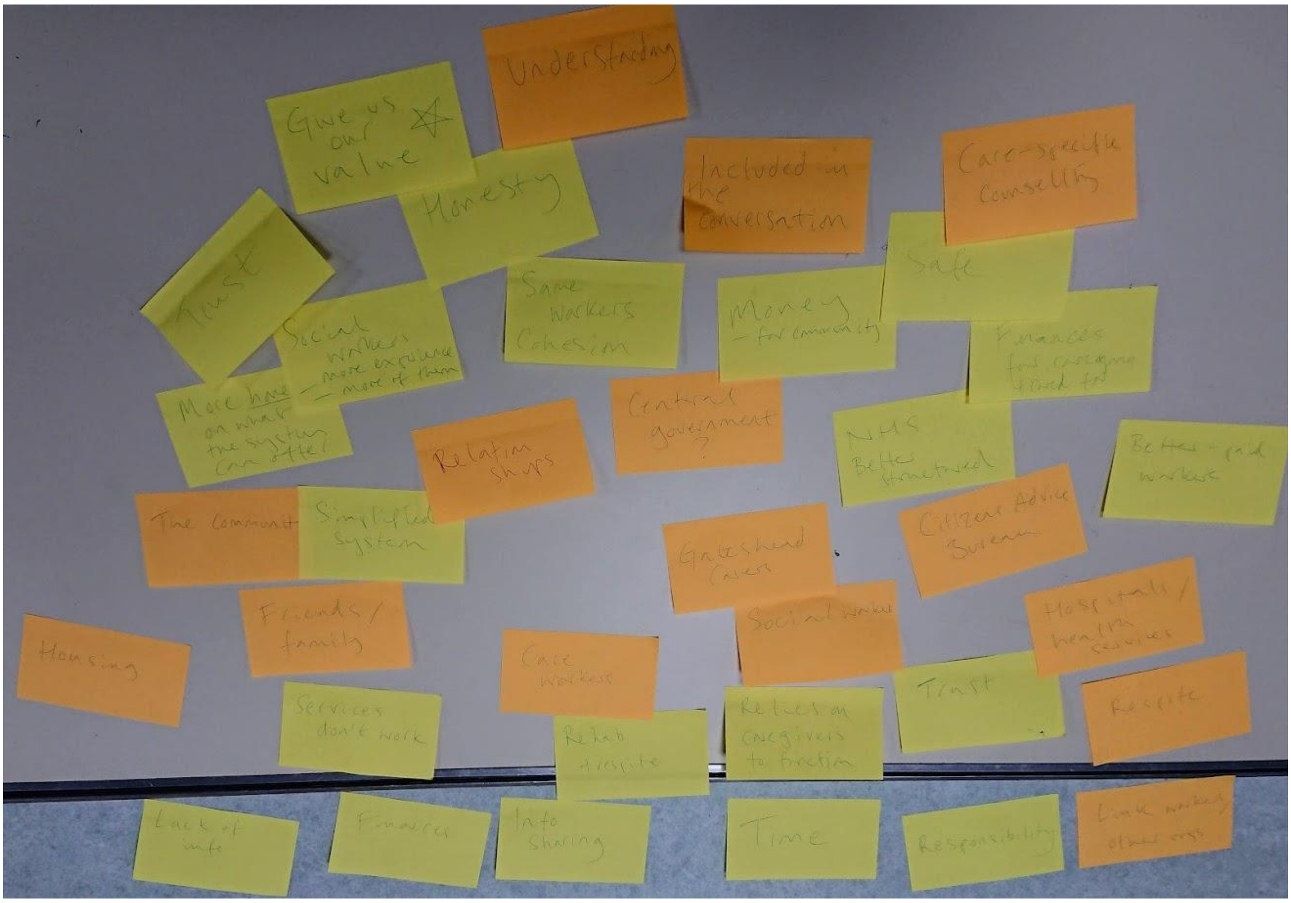
As Tom put it in the second focus group:

> I think recognition of unpaid care is a key point in the whole process. Partly, we need to recognise ourselves that we are becoming unpaid carers, but also all the systems around us should recognise that we have taken on the position of unpaid carer, which largely they don't.

Given that we know that most people will give care at some point in their lives, and that this care saves billions per year that would otherwise be spent in health and social care, **why aren't caregivers more recognised and supported?**

It certainly isn't for their want of trying. The caregivers in our study were in consensus about the help and support the local carers service, Gateshead Carers had provided them. But it's **a problem of double recognition**: many services do not recognise carers (e.g. acute emergency treatment), and many carers do not recognise themselves as anything other than dutiful daughters, sons, spouses, siblings or friends.

For all of the caregivers in our project, it was difficult to imagine the landscape of care substantially changing. In a first discussion group with Rosa, Sally, Susie and Hannah, we discussed some of the ways that the landscape could be improved for another caregiver in Gateshead in ten years' time. Their demands were surprisingly modest: "honesty", "understanding", "care-specific counselling", "included in the conversation", "trust", and "give us our value".



But there are practical and specific ways that carers could be better given their value.

The **first** is by **closer working partnerships** with health services and social services, as we have argued above.

The **second** is by **building on recent legislative success** in the UK Parliament of granting working carers' the right to a week's unpaid care leave per year. This is paltry compared to our neighbours like France, where caregivers in work can receive up to 58 Euros per day, for a maximum of 22 days per month, for up to 66 days in total (Thompson 2022). But what's significant about this legislation is that it shows that caregivers can win more power legally through parliament. This should be pursued.

One interesting idea that has been advocated by Carers UK, among others, is to make caregiving a protected characteristic under the 2010 Equality Act. This is unlikely to succeed in the medium term: the Equality Act was a rare piece of bipartisan legislation negotiated in less culturally polarised times. But it is one opportunity through which legislative means could grant caregivers more rights in law. Given that many caregivers continue to be forced out of the labour market, and given the UK economy's workforce crisis as older, experienced workers leave the labour force early - some in order to provide unpaid care - better employment rights for caregivers could ensure that organisations retain expertise, tax revenues continue, pension contributes increase and poverty in older age is reduced.

2. Statutory services need to be more serious about recognising carers rights

One of the ways in which some local NHS trusts and local authorities have gone about identifying and supporting caregivers is through the production of a **carers charter**. Carers charters are usually a list of principles or declarations to support carers that are produced by an official body in collaboration with a group of carers. In our second set of focus groups, we discussed three different examples of carers charters produced in the local(ish) area. Each of these charters was buried deep within service webpages and without any public presence or visibility. They included:

- Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust Carers' Charter (2019)

- South Tyneside and Sunderland NHS Foundation Trust Carers' Charter (no date)
- Gateshead Council, "Standards for Carers" (labelled on their website "What carers can expect from us", no date).

Each of the two charters has six points with identical or similar wording, e.g. "recognition and value"; "carer involvement/Involvement in service development"; "Help guide and support carers"/"Help and advice", "Working in partnership"/Involvement in care planning". Note: there were no charters we could find for Gateshead or Newcastle NHS Foundation Trusts.

We asked carers if they had come across such charters before (no, in all cases), and then we asked what they made of them. Most were receptive to their ideals. But some were then sceptical about the gap between words and practice. Buffy:

> Yeah I mean, it's fair enough to have lovely words on a document on a website. But if they're not, that holistic approach, if they're not living it, if that's not the DNA of their organisation, then it's not worth is it, it's not worth the paper it's printed on.

In another group, Michelle said: "They're saying the right words. But in practice, I don't think they're actually doing what they say they will do." For Jack, this gap between theory and practice for carer support is symptomatic of a wider lack of care in supporting disabled people and their carers. In the second group, he unexpectedly took a sheet of paper out and began quoting from a UN declaration:

> But Dan, it's bigger than that. Because there is actually a charter at the minute. And I've taken it off the internet, United Nations Department of Economic and Social Affairs disability, and the two sentences it starts with Article One, purpose, the purpose of the present convention is to promote, protect, ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote [*raising voice*] respect for their inherent dignity. Persons with disabilities include those who have long term physical, mental, intellectual, or sensory impairments, which in their interaction with various barriers may hinder their full and effective participation in society on an equal basis. That's actually been signed up by five EU countries, Britain being one of them, but it doesn't say anything in that charter, if we ain't got the money, we can ignore it.

Jack's point may seem cynical but it gets to the heart of the matter. What right or powers have disabled people or caregivers to hold health and social services, local councils or central government accountable when their needs are ignored? At the moment, not a lot.

Moreover, the one shortcoming with any charter or covenant is that these often end up as a wish-list of aims and principles. But if there is no accountability, enforcement or concrete action behind them, then they become little more than, in the words of Tom, an "arse covering exercise".

What if carers went on strike?

In one of our groups, two carers reflected on the recent news - riots across France over proposals to raise the retirement age, and the ongoing strikes by nurses and paramedics, teachers, train drivers and more:

> **Hannah:** There is, I mean this has come up quite a few times over the last couple of years, is that there's lots of people can go on strike and make that whatever their issue is, you know. The nurses, doctors. Carers, could you go on strike?
>
> **Rosa:** No, you can't do it
>
> **Hannah:** Could you ever...? I'm not going into me Mam... like somebody would have to deal with my 91 old parents!
>
> **Rosa:** You'll never go on strike

This idea of carers going on strike or taking part in a mass walkout came up several times by coincidence in the first set of focus groups. It shocked me and Kitty. On one level, it reflected the ongoing news of walkouts and strikes across the UK. On another, it was a sign that many carers were reaching the very end of their tether:

> **Michelle**: Yeah, it's an absolute disgrace. You know, I just think if ... you know, if all the carers packed the person's suitcase, and turned up at the council, and said, "Sorry, I'm not getting paid for this anymore. There you go. She's all yours". Yes. How many millions, billions' cost to get those people looked after?

Let's be clear. No-one we spoke to was calling for carers to go on strike. But it was a sign of desperation that reflected, to us, the core problem that carers are unpaid, unsupported and taken for granted. And it resonated with the history of the North-East, where working people had been forced to organise and strike to secure humane working hours, fair pay, safe conditions and an end to child labour.

Carers should not have to go on strike. Carers should not be invisible. Carers should not be taken for granted. In the year 2023, these basic principles of a fair and civilised society seem insane to have to state out loud. But shoulds and woulds cannot feed or heat the homes of unpaid carers. What caregivers need is power in decision-making and law. The power to hold decision-makers accountable, to guide the commissioning of services, and to be treated as equals in the landscape of care. To be recognised by health services, social services and benefits agencies as highly skilled experts.

Without **power**, the third ingredient for the **capacity to care**, caregivers become easy to ignore and marginalise. Decision-making becomes less efficient; cooperation and trust between caregivers and professionals breaks down; caregivers burn out, impacting their health as well as the health of the people that they care for; and the community fabric of places like Gateshead unravels.

But by giving unpaid carers power, recognition and greater legal rights, and by working together with carers at a local and national level, cooperation and decision-making can be improved. Because at the end of the day, it's likely that each one of us will one day provide unpaid care, if we do not or have not already. So let's look forward and plan ahead for a society which is truly centred on care. To find out how to get there, we need to involve the experts: caregivers.

Recommendations

1. Caregivers need financial security:

- Overhaul Carers Allowance: substantially increase according to an agreed minimum income guarantee, and overhaul eligibility
- Tailor carer-specific support for cost-of-living pressures
- Increase funding for carers grants, wellbeing funds and respite

2. Caregivers need proper support:

- Develop a structured process for identifying and supporting carers at or before medical discharge. This support should include carer-specific skills training, information and signposting to local carers services
- Better working relationships between caregivers and professionals involving accountability, honesty and trust, based on the triangle of care. Nominate caregiver leads within health services and social work teams.
- Involve caregivers' lived experience and expertise in decision-making at local and national levels.
- Increase funding for respite services so that caregivers can have a little bit of time for themselves and to manage their own health conditions.
- Approach care as a public health issue
- Maintain and increase funding for local carers services which provide invaluable and relatively inexpensive support, advice and information
- Involve local carers services and steering groups of caregivers in national policy decisions e.g. a national care service.

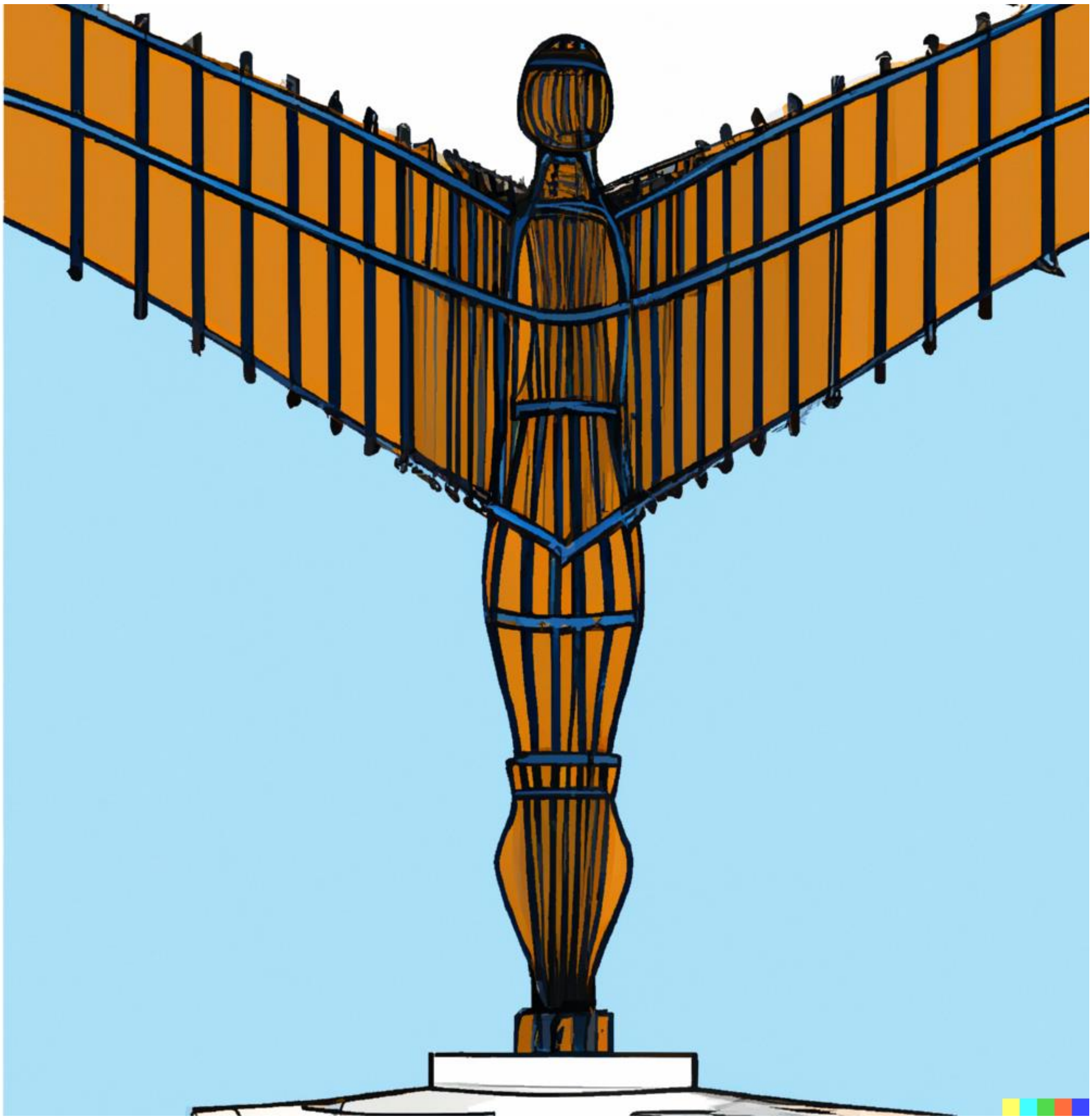
3. Caregivers need recognition, rights and power

- Get caregivers onto ongoing partnership boards and steering groups that regularly meet to guide, advice and are consulted on commissioning for local health and social care services
- Support caregivers to attend these meetings by covering costs of respite, travel and any per diem expenses
- Build on recent legislative achievements to give caregivers more legal rights, e.g. around employment and caregiving
- Implement an attitude of *action first* when producing organisational documentation like carers charters
- Act now to involve and empower caregivers in decision-making. Draw on the rich expertise of these highly skilled, motivated but often demoralised experts in loving care.

Some of these Recommendations involve money. Others involve changes in working practices at local and national levels. These Recommendations are only focused on caregivers. There is nothing here about the wider issues we have identified like how social care is funded, the funding gap, or the impact of austerity on local authorities in England and their capacity to support care indirectly. If there were substantial and major investment in health and social care and local communities to address current and future need, then the lives of caregivers would be indelibly improved.

At the end of the day, care is a political issue. Political choices are made whether to adequately support caregivers or involve them in policy and decision-making. As this Report demonstrates, the current system that supports caregivers is in crisis and is unable to meet basic needs.

But there's hope and opportunity here too. Caregivers, community organisations, health and social service professionals and policymakers all have the chance to make places like Gateshead and its wonderful, vibrant community fabric a place that's centred on care.



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