

Giving Care In Gateshead

Reimagining the landscape of care

Dan Taylor, Kitty McKay and caregivers in Gateshead

Executive Summary



Briefing

The Open University has undertaken in-depth qualitative research into the lives of 15 unpaid carers in Gateshead over the last six months, in partnership with Gateshead Carers.

The aim of the research has been to understand how unpaid carers have been impacted by the cost-of-living crisis and changes to government spending on health and social care.

To coincide with Carers Week 2023, we are publishing a Report and Film called *Giving Care in Gateshead* with a public community launch event on 6 June.

The Report and Film use carers voices and lived experiences to set out a new approach to supporting unpaid carers.

The Report and Film highlight three things:

- 1. No more unpaid carers: Carers are being hammered by the cost-of-living crisis. Many need carer-specific financial support. Current forms of support e.g. Carers Allowance are failing many. We suggest what and how.
- 2. No more unsupported carers: many unpaid carers are struggling with their care responsibilities and managing their own health conditions. Caring is a public health issue.

Unpaid carers need more support to continue in their roles, e.g. more respite services, greater availability of care workers, more support with care worker

charges. Many haven't had basic training in what are very skilled roles. There also needs to be a sea-change in working relationships and partnerships with health and social services in supporting cared for people. We suggest how, building on the "triangle of care".

3. No more invisible carers: many unpaid carers are at the end of their tether. They feel taken for granted and invisible at a local and national level. Some that we spoke to talked about going on strike or walking out. While that will never happen, unpaid carers need greater formal and legal power at a local and national level. This will improve decision-making related to carers and disabled people as well as improving support and recognition for unpaid carers.

The full Report has been written for policymakers and professionals who work with unpaid carers. It explains the local and national context of unpaid care then uses unpaid carers' experiences and ideas to develop its recommendations.

The authors are Dan Taylor, Kitty McKay and caregivers in Gateshead.

It is not tied to any political party or approach. Around half of its recommendations relate to changes in working practices and cultures; the rest relate to increased and better-targeted funding in health and social care.

Care represents the best of us, and as UK society ages, more and more people will be expected to provide unpaid care. As a society we have a great opportunity to prepare and plan for this eventually. As we argue, caregivers need three things to thrive: security, support and recognition. We call this the capacity to care.

To discuss any aspect of the report or film please contact the lead investigator Dr Dan Taylor at the Open University: dan.taylor@open.ac.uk.

Caring in numbers

1 in 10

According to the recent 2021 Census, 10.1% of people in Gateshead provide unpaid care, just under 20,000 people in a population of 196,200 (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 2022). During the pandemic, it's thought that up to **1 in 4** people nationally were providing unpaid care (Carers UK 2020a).

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). That figure is based on 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.

£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.

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 2022).

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.

Sources

Carers Trust (2022). "I feel like I've disappeared: An Urgent Call to Action from the UK's Unpaid Carers". pp. 1-29. https://carers.org/downloads/ct-reporti-feel-like-i-have-disappeared.pdf (accessed 1 June 2023).

Carers UK (2020a). Carers Week 2020 Research Report. The rise in unpaid carers during the coronavirus (COVID-19) outbreak, pp.1-32. https://www.carersuk.org/media/gfjf3nz3/cw-2020-research-reportweb.pdf

Carers UK (2020b). Unseen and Undervalued: The value of unpaid care provided to date during the COVID-19 pandemic, pp.1-10. https://www.carersuk.org/media/gilb4oup/unseenandundervalued.pdf

Carers UK (2022b). Heading for Crisis: Caught Between Caring and Rising Costs. London: Carers UK, pp.1-20. https://www.carersuk.org/media/q33ba3ae/heading-for-crisis_1-3.pdf

Carers UK / University of Sheffield (2023). *Valuing Carers 2021: England and Wales.* Maria Petrillo and Matt Bennett. London: Carers UK, pp. 1-36. https://www.carersuk.org/media/2d5le03c/valuing-carers-report.pdf

Gateshead Carers (2020). Everybody's Business: Gateshead Adult Carers Survey Report 2020. pp.1-42. https://www.gatesheadcarers.com/Handlers/Download.ashx?IDMF=a6a373e0-12be-4ce9-a158-8022d903c7dc

ONS (2023). How life has changed in Gateshead: Census 2021. https://www.ons.gov.uk/visualisations/censusareachanges/E08000037