

The expectations of informal carers

In early 2024, Lindsey Burrows highlighted the challenges of being the carer of Rob Burrows, the former Leeds Rhino scrum half who had motor neurone disease. The documentary also shone a light on the demanding role of being an unpaid carer, which is currently estimated to be worth about £162 billion a year in England and Wales (ITV, 2024). The under-recognised contribution of carers is not new and was evident in the early 2000s while I was undertaking research in the field of multiple sclerosis (Forbes et al, 2007; Corry and While, 2009). Recent media headlines in the UK have focused on the financial aspects of being a carer, with outcry over the Department for Work and Pensions (DWP) seeking repayment following overpayment, which breached the strict earnings limit for the Carer's Allowance (Whitworth and Smith, 2024). This is despite the overpayment only affecting a small minority of the recipients of the Carer's Allowance.

The 2021 Census (Office of National Statistics [ONS], 2023a) found that there were 4.7 million unpaid carers in England and another 310 000 carers in Wales as of 21 March 2021. This equates to 8.9%, and 10.5%, respectively, of the usual resident populations. More females provided unpaid care than men; that is, 10.3% of females versus 7.6% of males in England, and 12.0% of females versus 9.0% of males in Wales. In England, the North East region had the highest percentage of people (10.1%) providing unpaid care, while the London region had the lowest percentage of unpaid carers (7.8%). It is noteworthy that there were higher percentages of unpaid carers in the most deprived areas of England (10.1%) and Wales (11.5%) compared to the least deprived areas of England (8.1%) and Wales (9.7%). Also of note was the finding that there were 120 000 young unpaid carers in England (1.4% of 5–17-year-olds) and a further 8200 in Wales (1.8% of 5–17-year-olds).

Using age-standardised proportions, which account for differences in the population size and age structure to permit comparisons over time, there was a decrease in unpaid care in England and Wales from 11.4% in 2011 to 9.0% in 2021 (ONS, 2023b). The comparison over time also revealed increases in the hours of unpaid care per week. Therefore, while there was a decrease in the proportion of those providing 19 or less hours per week (7.2% in 2011 versus 4.4% in 2021), there was an increase in those providing

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20–49 hours per week (1.5% in 2011 versus 1.9% in 2021), and those providing 50 or more hours per week (2.7% in 2011 versus 2.8% in 2021). A larger proportion of people in Wales provided any amount of unpaid care (10.5% versus 8.9% in England). Similarly, a larger proportion of people in Wales provided 50 or more hours of unpaid care per week (3.6% versus 2.7% in England).

The Family Resources Survey (FRS) is a continuous household survey which builds on the decennial census and collects financial and housing data from a representative sample of private households in the UK. The latest survey data relates to 2021–22 when data collection continued to be affected by the COVID-19 pandemic, with most interviews conducted over the telephone rather than face-to-face. This was the established mode prior to the 2020 pandemic restrictions (DWP, 2023a). Nonetheless, the sample comprised 16 000 households, 6000 more than in 2020–21 and the response rate of 26% was similar to 2019–2020 pre-pandemic levels. The latest FRS (DWP, 2023b) reported that 7% of the UK population were informal carers, which is similar to pre-pandemic levels. There were more females (3.0 million; 9%) than males (1.9 million; 6%). Those aged 55–64 years were most likely to be informal carers (16% of this age group; 20% women versus 12% men) and one-third (34%) of informal carers were sandwich carers, caring for a parent outside or within the household alongside caring for children. Half (50%) of the adult carers were employed, of whom 34% were working full time (22% were retired and 27% economically inactive which includes students and those with a disability or sickness). Males (45% versus females 26%) were more likely to be working full time while the reverse was true for part-time working (females 21% versus males 8%).

About 5% of the FRS sample received care every week, which has been stable over recent years with the likelihood of receiving care increasing with age, with 28% of those aged 85 years and over receiving care every week. From 65 years of age, females were more likely than males to receive care so that by 85 years and over, 30% of females compared to 26% of males received care every week. Those aged 65–74 years



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were most likely to receive care once or twice a day rather than continuous care which was most often for children up to the age of 15 years.

The DWP (2024) recently published a research report derived from 1021 completed questionnaires (response rate of 23.4% for online and paper) and 42 in-depth interviews with Carer's Allowance recipients conducted during 2020–21. Just over half (54%) of the claimants lived in lower income households and 40% had a long-term health condition. Most claimants cared for close relatives, with 25% caring for a spouse or partner, 22% caring for a parent, and 39% caring for a child. Just over half (52%) devoted 65 or more hours to caring each week, which could be challenging and contributed to mental ill-health, especially over time, with 54% reporting that they had been caring for 5–20 years. Half of care recipients were under 45 years of age (25% children under 17 years) with the other half being over 45 years, including those over 66 years (45%). Interestingly claimants aged 60–64 years old were most likely to care for those over 66 years (51% versus 26% of 55–59-year-olds) and were more likely to be both the main and lone carer (77%). Claimants caring for someone with high levels of need were often supported by social workers, occupational therapists, and other health professionals with various charities (Carers UK & Age UK), providing information and advice. However, claimants generally reported that it was difficult to understand what support options and entitlements were available.

The qualitative interviews revealed the challenging and stressful nature of the caring role, including the constant worry about the family member and having to prioritise the needs of the family member to the neglect of their own needs. Few reported having had a holiday or an extended break from caring, which was echoed in the State of Caring 2023 survey ($n=10,751$ who are current carers) (Carers UK, 2023). The demands of caring were also often compounded by other challenges, including mental ill health and financial worries. But the interviews also revealed that not all claimants were struggling with some reporting that they coped well and were able to manage the caring demands in part because they had fewer financial worries and were able to rely on additional support from family members. Claimants in paid work tended to be self-employed or in work part-time (81% worked 20 hours or less a week) in lower paid jobs, which they were able to fit around their caring responsibilities.

The data appeared to suggest that claimants calculated how much to work while remaining within the earnings limit and managing their caring role and minimising the

detriment of work to their quality of life and wellbeing. Learning about the Carer's Allowance came through multiple sources, including family and friends (20%), health professionals (18%), alongside other sources and charities. Some three quarters of the sample reported it was easy to find information on Carer's Allowance, determine their eligibility and complete the claims form, although those with no formal educational qualifications found the process less easy. Not surprisingly, those with prior experience of claiming other benefits reported that the process was straightforward. Claimants were generally positive about the time lag until receipt of the first payment and the receipt of a lump sum payment for backdated Carer's Allowance. Compared to other benefits, the claimants reported that the process required little effort or contact with DWP. In the sample, only 27% had contacted the DWP to notify a change in circumstances of whom three quarters reported that it was easy. However, 11% of the sample appeared not to fully understand the requirements in terms of caring hours and earnings' limit, especially where complex calculations involving reductions due to substitute carer costs were involved. Only 3% of the sample had received an overpayment of the Carer's Allowance, mainly due to a failure to notify changes of circumstances. DWP communication regarding overpayment was variable and its impact varied depending upon whether it was expected and the repayment perceived as manageable. While the vast majority of claimants were happy with online communication, a substantial minority were not confident in using online services and continued to want paper and telephone contact, which echoes other research regarding the increasing digital divide affecting users of healthcare and other services.

There is an increasing dependence upon informal carers with the emergence of Hospital@Home schemes and virtual wards whose numbers are growing all the time in an attempt to achieve 40–50 virtual wards per 100 000 people (Hakim, 2023). In September 2023 there were over 400 virtual wards covering 10 000 beds and, it is estimated that since 2022 240 000 patients have been treated on a virtual ward (Carers UK, 2024). In England, every Integrated Care Board (ICB) ($n=42$) is expected to have at least one acute respiratory infection and one frailty virtual ward and some may have more with the expansion into other care areas (Carers UK, 2024). While virtual ward patients have been generally positive about the experience, there is limited evidence regarding the carers' experience (Norman et al, 2023). The exception is the State of Caring 2023 (Carers UK, 2023) survey data which suggests that, while carers welcomed virtual wards as a means of increasing their and the cared-for person's ownership of the care provided, they were concerned that virtual wards will increase what is expected of them. Only 3% of the sample had experienced virtual wards but reflecting on their carer experience over the last year; 42% of the sample reported that they needed more support from health services or healthcare professionals and also better recognition by the NHS of their needs as a carer. Three quarters (74%) of the sample wanted making appointments and speaking to healthcare professionals made

easier. Of particular note was the carers' perceived lack of involvement in the discharge of the person for whom they cared, with 60% reporting that they were not asked about their ability or willingness to care, and 58% reporting that they received insufficient support to provide for the needs of the person for whom they cared.

Norman et al's (2023) rapid evidence synthesis noted the lack of evidence regarding the cost implications of Hospital@Home schemes and virtual wards for carers and patients, particularly highlighting the potential of carer strain. Indeed, common flaws in the economic evaluations is an overestimation of cost savings through the use of a generic in-patient tariff (rather than a disease or unit specific tariff and disregarding decreasing care intensity over a hospital stay) as well as no attribution of carer and family costs. The HTA (2023) economic evidence review also highlighted other study limitations including the short duration of the studies and the neglect of the potential impact on health inequalities given the reliance on health technologies in the home. The latest large scale evaluation derived from over 22 000 virtual ward admissions across 29 south-east England virtual wards has reported a net benefit of £10.4 million annually while also noting that carers reported an increased burden of care and that some ethnic and socio-economic groups appeared to have less access to these new services (Private Public Ltd, 2024).

While families can be an important resource for those in need of care, it is important that statutory services including health services respect the perspective of carers who may see their role as mainly comprising emotional and social support of a relative rather than an adjunct to the health service. The NHS Confederation refers to Hospital@Home schemes and virtual wards as reducing pressure on the short-staffed NHS (Karim, 2023). There is a risk that the quest to minimise hospital admissions through the introduction of these services exploits informal carers so that they become so overburdened that they and the person for whom they care require in-patient healthcare.

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