Connecting Carers

A better life for unpaid Carers in Highland

HIDDEN IN PLAIN SIGHT

The Impact of the Caring Role on Unpaid Carers with Disabilities and/or Long-Term Health Conditions in Highland.

A Research Report by Connecting Carers

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Executive Summary:

This report examines the experiences of unpaid Carers in Highland who themselves live with disabilities or long-term health conditions. Drawing on focus groups, interviews, and two surveys, the research highlights the dual pressures faced by this often-invisible group and the systemic barriers that limit their ability to live healthy, independent, and fulfilling lives.

Key Findings

1. The caring role significantly worsens Carers' own health and wellbeing
Carers frequently deprioritise their medical needs due to time constraints, lack of respite, and overwhelming responsibilities. Many miss essential treatments, experience worsening conditions, and report chronic exhaustion, pain, and emotional burnout.

2. Social isolation is widespread and deeply felt
Participants described "Groundhog Day" routines, loneliness, and reduced social interaction, often compounded by mobility limitations, mental health conditions, or rural isolation. Even when support groups exist, geographic and logistical barriers frequently prevent attendance.

3. Carers with disabilities remain largely unseen within social, professional, and policy contexts.
Many reported that friends, community members, and even health professionals failed to recognise or take seriously their dual identity as both Carer and care recipient. This invisibility affects access to support and contributes to self-doubt and emotional strain.

4. Service access is fragmented, inconsistent, and difficult to navigate.
Carers repeatedly described poor coordination between agencies, unclear pathways, long diagnostic delays, limited availability of social work support, and a lack of awareness of core entitlements such as Adult Care Support Plans or Self-Directed Support. Rural Carers face additional barriers such as long travel distances, limited transport, patchy broadband, and service shortages.

5. Caring responsibilities have serious financial consequences.
Nearly half of participants did not claim any welfare benefits, often due to confusion, poor signposting, or stressful application processes. Many reported significant drops in income after taking on caring roles, unexpected costs associated with disability, and difficulty accessing financial guidance.

6. Despite significant challenges, Carers demonstrate resilience
Carers use humour, routines, alternative therapies, technology, and peer networks to cope. Access to cleaners, prepared meals, or small amounts of respite, when available, provides essential relief. However, these strategies cannot compensate for systemic gaps in support.

Conclusions

The findings reveal an emerging care crisis shaped by rising care needs, decreasing service capacity, and structural inequalities, particularly acute in the Highland region. Carers with disabilities occupy an especially vulnerable position and face disproportionate burdens. Although Scottish policy has strengthened Carers' rights, practical implementation often falls short, leaving many unsupported until crisis points are reached.

Recommendations

The report proposes 10 evidence-based recommendations to enhance recognition, support, and inclusion of unpaid Carers with disabilities:

1. **Introduce a national Carer health-screening programme** to prevent untreated health deterioration.
2. **Improve cross-agency coordination** through information-sharing frameworks and clear care pathways.
3. **Increase public and professional recognition** of Carers with disabilities.
4. **Guarantee minimum respite and crisis support**, planned and emergency.
5. **Address rural inequalities** through mobile multidisciplinary teams and improved digital infrastructure.
6. **Enhance benefits and financial guidance**, including proactive entitlement checks.
7. **Develop Carer Wellbeing Hubs and peer networks** to reduce isolation.
8. **Strengthen employer obligations** through flexible policies and care-aware training.
9. **Improve diagnostic pathways** and allow provisional support where diagnosis is delayed.
10. **Embed lived experience in policy design** to ensure services reflect real-world needs.

Overall Summary

Unpaid Carers with disabilities or long-term health conditions are "hidden in plain sight": essential to the functioning of families, communities, and the social care system, yet frequently overlooked. To ensure their wellbeing, and by extension, the sustainability of social care, Scotland must move from procedural recognition to practical, transformative support.
This report offers a comprehensive framework for that change.

Acknowledgments

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Preface

I remember vividly the soft footsteps of my maternal grandmother approaching. She appeared in the doorway and asked whether I had seen my grandfather. When I told her he was outside, she seemed reassured and left. Moments later, she returned and said, “That’s my father in the garden.”

My grandmother had Alzheimer’s disease. In the early stages, she was cared for at home before eventually moving into residential care. When I was in my early teens, we relocated to a house with its own grounds, and the following year we extended it to accommodate my maternal grandparents. Although I cannot claim that I was a Young Carer, I had a front-row seat to the challenges unpaid Carers face, particularly those who are also managing long-term health conditions of their own.

My grandfather was the principal Carer for my grandmother. Despite being an active and independent man, he lived with several long-term health issues. As her illness progressed, her behaviour became increasingly difficult. She often searched for deceased relatives—her parents and a maiden aunt, all of whom *she* had once cared for during their own experiences with dementia. At times she confused my grandfather with her father or, occasionally, with a stranger. These moments filled her with anxiety and frustration, sometimes leading to hostility or even physical aggression.

In addition to managing these behavioural changes, my grandfather also supported her with personal care. Although a cleaner helped with housework once a week, he carried the full weight of the remaining household responsibilities. My brother and I were still at school, and both of my parents worked; my mother later reduced her working days to four per week to give my grandfather some respite. Eventually, my grandmother began attending a weekly day centre at the local community hospital, which offered brief but valuable support.

Over time, the physical and emotional strain of caring for her became increasingly evident. The stress worsened my grandfather’s own health conditions, leaving him exhausted both physically and mentally. When my grandmother eventually moved into residential care, his health improved significantly and his long-term conditions became manageable once again.

Through this research, I am acutely aware that for many Carers, particularly those living with disabilities or long-term health conditions, support such as residential care, respite, or help from professionals, paid Carers, or even family and friends is far from guaranteed. This inequity is a profound injustice. It is my earnest hope that this research will contribute, even in a small way, to meaningful change for those who shoulder these responsibilities every day.

Introduction

Unpaid Carers with disabilities or long-term health conditions occupy a complex and often overlooked position within Scotland's social care landscape. While their contribution is indispensable to families, communities, and the wider health and social care system, the dual demands of managing their own health needs alongside intensive caring responsibilities place them at heightened risk of physical, emotional, and economic strain. Despite policy developments over recent decades, including strengthened rights under the Carers (Scotland) Act 2016, many Carers continue to report limited recognition, inconsistent support, and structural barriers that prevent them from accessing the resources they need to live well.

This report responds to these concerns by examining three interrelated research questions:

1. **What impact does the caring role have on unpaid Carers who themselves live with a disability or long-term health condition?**
2. **Do pathways exist that enable these Carers to live their best and most independent lives?**
3. **How can their recognition and inclusion within mainstream narratives and service delivery be meaningfully strengthened?**

Drawing on focus groups, interviews, and survey data collected across Highland, the study highlights the profound consequences of caregiver burden, the emotional dimensions of care, and the systemic gaps that leave many Carers unsupported until crisis points are reached. At the same time, the findings reveal the resilience, creativity, and expertise demonstrated by Carers in navigating complex systems and sustaining care under challenging circumstances.

By situating lived experience at the centre of analysis, this research aims to contribute to a more inclusive and realistic understanding of unpaid caring, one that recognises Carers with disabilities as a distinct group whose needs must be fully integrated into policy, practice, and public discourse. The insights and recommendations presented in the following chapters seek to inform future service design, promote more equitable support structures, and ensure that the voices of unpaid Carers are heard, valued, and acted upon.

Care, Disability and Intersectionality

The terms 'care' and 'Carer' are multi-faceted. They may refer to the 'activity' of caring whether that be for children, the elderly or vulnerable adults – in policy research, definitions do not include 'childcare' i.e. care of children because of age. Traditionally social policy researchers employed the dual classification of 'formal' and 'informal' to incorporate those

giving and receiving care by family members or contracted 'care workers' typically within a home setting (Alcock, et al, 2002, 25). Though not dissimilar, the terms 'paid' and 'unpaid' are more compatible with the current policy context of Scottish social care to which 'Personalisation' and 'Individualised Budgets' are fundamental (Needham et al, 2023). The number of unpaid Carers in Scotland has increased by 27.5% since 2011. The current figure equates to 11.9% of the population aged 3 and over (Scotland's Census, 2025).

In addition to whether care is paid for, the 'type' of care is a central component to understanding care as an activity. Arguably 'personal care' is the largest classification, and includes feeding and nutrition, dressing, assistance with bodily functions and personal hygiene as well as support with medication and medical treatment, including conveying to and from medical appointments. Other notable care activities include help with household tasks like shopping, cleaning, cooking and meal preparation – help with household budgeting and personal finances may also be included as a care activity. Entangled with the practical dimensions of care and caring are prominent emotional ramifications. According to Emily Kenway, alongside the previously described practical elements, care has prominent emotional connotations, chiefly care as an expression of 'affection' and 'love' (Kenway, 2023, 15-16). Emotions within care and caring are not mutually exclusive, the emotions are often intertwined with a sense of duty, responsibility or obligation to provide care, especially if the care recipient(s) is a close relative. Duty, responsibility and obligation do not solely shape the agency or individual Carers, historically, they have shaped policy responses towards unpaid care.

Like care 'disability' is a multi-dimensional concept. Disability theorists stipulate that to understand disability, the term 'impairment' must be defined first. Impairment is defined as the absence, shortage or loss of physical and/or mental function i.e. senses, mobility, etc. Typically, said impairments are distinguished from symptoms of illness because of permanence. Disability refers to the social disadvantage encountered by citizens living with impairments (Scott, 2014, 176). A detailed analysis of the merits and weaknesses of the core theoretical models employed by disability theorists is outside the range of this report, nevertheless it is essential that we examine the debate between the 'medical' and 'social' models of disability because it is the crucible of discourses in the sociology of disability and ultimately relevant to the thesis of this research. As the name suggests, the medical model (also known as the 'individual model', 'personal tragedy model' or 'medicalisation') measures disability from the perspective of limitations attributed to individual impairments (Oliver, 1996, 31). Devised by disability theorist Michael Oliver, and informed by disabled citizens, the 'social model' quantifies disability as the consequence of the exclusion of disabled people by mainstream society, typically on the back of norms based on the medical model (Carson, 2009, Oliver, 1996). This research is informed by social model, critiquing its compatibility with unpaid Carers with disabilities. It should be noted first that in the context of this research it is inappropriate to segregate impairment between 'disability' and illness' because of permanence. Whilst some did, not all our informants with a long-term health

condition, self-identified as disabled. The obligation of the latter as a prerequisite of the permanence of an impairment(s) is misleading. It goes without saying that care and disability overlap greatly, yet their relationship is far from amicable. The historical medicalisation of impairment caused care policy and practice to enhance the narrative of dependency, leaving disabled citizens disempowered and subjugated within both the welfare state and their communities (Garbutt and Saltiel, 2020, 251). Fortunately, lobbying from disability rights activists such as Michael Oliver has successfully shifted narratives away from medicalisation; impairment is no longer defaulted as dependency and disempowerment. Not to invalidate the undeniable progress made in revising the narratives shaping the disability-care relationship, ideas around disability and care provision and receipt remain skewed towards disabled citizens as the latter. The long-term impacts of intensive prolonged care on health and wellbeing of unpaid Carers, known as 'caregiver burden', have been explored quite extensively by social care researchers. However, the findings of past studies reviewed in undertaking this research measure the adverse health effects of caregiver burden on Carers assumed to be able-bodied and without notable impairment (physical and psychological) attributed to disability or long-term health condition, before assuming a caring role. The concept 'intersectionality' is an effective tool in overcoming theoretical and methodological barriers when researching complex demographic groups. The Glasgow Centre for Population Health (GCPH) defines intersectionality as the recognition of identity being multi-faceted and dovetailed and a key determinant in shaping our experiences. Moreover, they champion intersectionality informed analytical frameworks for providing greater depth of analysis (GCPH, 2025).

The Care Crisis Explained: Demographic Trends and Policy Choices

This section first outlines the demographic drivers of the contemporary 'care crisis' before examining how policy and labour market changes have intensified reliance on unpaid Carers. In this research, we define the 'care crisis' as the structural mismatch between rising care needs and the diminishing capacity of both the state, market, and households to meet them. Economist Emma Dowling underlines how the term 'care crisis' appears frequently in both the mainstream media and policy agendas (Dowling, 2022).

Developed western countries are experiencing significant population ageing, a key demographic driver of the contemporary care crisis. In 1950, individuals aged 65 and over accounted for approximately 1 in 13 of Europe's population; today, this figure is closer to 1 in 4. In Scotland, the most recent Census data indicates that 1 in 5 residents is aged 65 or over (Merritt, 2025, 65, Scotland's Census, 2025b). An ageing population is associated with a higher prevalence of long-term health conditions, as increased longevity does not necessarily equate to extended periods of good health. Many individuals now live longer while managing multiple, concurrent conditions, placing sustained pressure on health and social care services. At the same time, disability prevalence among younger adults is also

rising. For example, increasing diagnoses of autism in childhood are contributing to a growing population of autistic adults, often supported by ageing parents (Ljungberg and Schön, 2023, 929). Medical advances have further extended the life expectancy of people with previously life-limiting disabilities and long-term health conditions, many of whom now reach older age. While this represents a significant social achievement, it simultaneously shifts the parameters of care provision by lengthening both the duration and intensity of care needs (Needham et al, 2023, 128). These demographic trends are compounded by declining family sizes and reduced capacity among working-age adults to provide informal care, thereby intensifying reliance on unpaid Carers. For Carers themselves who live with disabilities or long-term health conditions, this convergence of trends exacerbates existing inequalities and deepens the structural pressures explored in this report.

'Deinstitututionalisation' and 'marketisation' are the pivotal changes in policy approaches to care over the last fifty years. Commencing principally in the 1980s, policy makers shifted the care of citizens with significant impairment from hospitals and similar facilities to the community, or more acutely to households and families. Many rightly welcomed the emancipation of disabled citizens from the excessive regulation of institutions. Nevertheless, these changes were partly driven by the neoliberal fiscal ambition to reduce public spending and expand market-based welfare provision. Both central and devolved administrations have altered care policies in accordance with ideological stances, manifesto pledges, and financial constraints, yet the market and private sector remain prominent in formal care provision and make their own contribution to the care crisis. Private care companies typically offer care jobs as controversial zero-hours contracts. This employment model generates instability within the paid care workforce, undermining continuity of care and increasing the likelihood that unpaid Carers must compensate for service gaps. Migrant labour once played a crucial role in sustaining paid care services. However, central government policy shifts towards restricting immigration have reduced the availability of care workers, exacerbating workforce shortages across the sector. As gaps in formal care provision widen, unpaid Carers are increasingly required to compensate for these deficits, deepening the pressure placed upon them.

While Scottish policy has progressively expanded the formal recognition of unpaid Carers through legislation and service rights since the mid-1990s (Lloyd, 2025, 116), this section argues that such recognition has largely remained procedural rather than transformative, particularly for Carers with disabilities and long-term health conditions. Carer recognition in Scotland began prior to legislative devolution with the Carers (Recognition and Services) Act 1995. When implemented in April 1996, the Act placed a statutory duty on local authorities to assess a Carer's ability to provide care. Although significant as the first formal acknowledgement of unpaid Carers, its emphasis on assessing capacity rather than supporting Carers' own needs laid the groundwork for later policy debates and reforms (Legislation.gov.uk, 2026).

In 1999, the newly devolved Scottish Executive introduced the Scottish Strategy for Carers, marking one of the first coordinated national efforts to recognise and support unpaid Carers. The strategy aimed to integrate Carers' needs into the wider public services landscape—including education—ensuring their contributions were acknowledged across sectors. It also emphasised the diversity of unpaid Carers and promoted more personalised, flexible approaches to service provision (Lloyd, 2025, 41).

The most fundamental post-devolution change came in 2002 with the passage of the Community Care and Health (Scotland) Act. The act introduced free 'personal care' for elderly citizens within their homes, relieving substantial pressure from unpaid Carers. Provision under the Act was extended in 2019 to adults under 65 deemed in need. The Scottish Government published the *'Caring Together: The Carers Strategy for Scotland'* in 2010. The Social Care (Self-Directed Support) (Scotland) Act 2013 firmly embedded the principles of Personalisation and Individualised Budgets within mainstream Scottish social care provision (Needham et al., 2023; Lloyd, 2025).

A major shift in social care policy across the UK has been the move toward tighter integration of health and social care services. Health and Social Care Integration (HSCI) aims to improve efficiency and conserve resources. Key objectives include reducing unnecessary hospital stays, supporting patients' recovery at home and in the community, and implementing preventative strategies. In Scotland, this policy direction was formalised through the Public Bodies (Joint Working) (Scotland) Act 2014, which required NHS Boards and Local Authorities to establish 'integration authorities' responsible for commissioning and coordinating health and social care services. By 2016, thirty-one integration authorities had been created, including the Highland Health and Social Care Partnership (Needham and Hall, 2024, 89–90; Scottish Government, 2026a).

Alongside increasing recognition, policy has sought to cement service provision as a 'right' for Carers. The Carers (Scotland) Act 2016 gave Carers the right to an Adult Care Support Plan (ACSP) or Young Carer Statement (YCS), agreed with core services and modified as appropriate. ACSP and YCSs also sought to streamline the process of accessing advice and support. Section 36 of the 2016 Act implemented the Carers' Charter – a formal 'constitution' of the rights of unpaid Carers under the Carers (Scotland) Act. In July 2025, the Care Reform (Scotland) Act was implemented, which, alongside tightening existing rights to service access, introduced the right for Carers to take breaks, and provided funding to the Third Sector to facilitate delivery of short breaks (Scottish Government, 2025).

A notable recent development within reserved matters—those policy areas retained by the UK Parliament—was the passage of the Carer's Leave Act in 2023. Originating as a Private Members Bill sponsored by Wendy Chamberlain, Member of Parliament for North-East Fife, and Lord Christopher Fox, the Act, designed to support working Carers by recognising the pressures of combining employment with unpaid care, introduced a statutory entitlement

from April 2024 that allows employees who are unpaid Carers to take up to seven days of unpaid leave annually for caring responsibilities (UK Government, 2026).

Despite these advances in formal recognition and rights-based provision, evidence suggests that policy gains have not translated into meaningful support for many Carers, particularly those whose complex needs remain poorly understood or invisible within service systems. Lloyd (2025, 94) maintains that the needs of unpaid Carers, especially those of 'hidden Carers' with complex needs remain unrecognised. For Carers with disabilities or long-term health conditions, invisibility is compounded by assessment frameworks that prioritise the needs of the care recipient while underestimating the Carer's own impairments, thereby delaying support until crisis thresholds are reached (Lloyd, 2025). Consequently, although framed as rights-based, policy responses towards unpaid Carers remain largely reactive, offering support only at points of crisis rather than addressing the structural conditions that produce caregiver exhaustion, exclusion, and declining wellbeing.

Caring Across Distance: Unpaid Carers in the Highlands

Geographic and Economic Context

At nearly twenty-six and half thousand square kilometres, comprising both its mainland and constituent islands, Highland Local Authority has a diverse physical geography. This includes the longest coastline in Scotland, numerous Lochs, mountain ranges such as the Cairngorms, and vast boglands such as the Flow Country in Caithness and Sutherland. The diversity of the landscape is undoubtedly a virtue, yet it poses complex challenges for residents. With an average of eight people per square kilometre, Highland has the lowest population density in Scotland (Highland Council, 2025). The impressive countryside and rich heritage mean that 9.2% of those aged 16 and over work in the hospitality industry, though the health and social care sector (including social work) is the largest industry (15.2%), which in hindsight comes as no surprise when the following demographic characteristics are considered (Scotland's Census, 2025a).

Population Ageing and Migration

At the time of writing, the population of Highland, according to the National Records for Scotland (NRS), was 237,290, making it the seventh most populous of Scotland's thirty-two local authorities – sandwiched between neighbouring Aberdeenshire and Aberdeen City (NRS, 2025). Between 2001 and 2021, the population of Highland increased by 13.9%, 5% higher than the Scottish average (Highland Council, 2025b). Though projecting a rate lower than the national average, the NRS predicts that the population of Highland will increase by

2.20% by 2032 (NRS, 2025). Highland does not simply mirror national trends regarding the ageing population, it exceeds them. On the 2022 Census Day, those aged 65 and older were the largest demographic group (23.7%) followed very closely by 50 to 64 (23.5%) – consequently, only 53% of the Highland population was below 50 (Scotland's Census, 2025b). Between 2001 and 2023, the population of residents aged between 65 and 74 increased by 59% compared to the national average of 35%. Those aged 75 and over rose by a staggering 72% relative to 42% for the whole of Scotland (NRS, 2025). What accounts for this in part is Highland's popularity as a retirement destination – excluding southern Scotland, after adjacent Argyll and Bute and Moray, Highland has the highest percentage of residents born in England (16.8%).

Prevalence of Unpaid Care in Highland

The latest Census figures confirm that there are 26179 unpaid Carers aged 3 and over in Highland, 11.4% of the population, which is the sixth largest in Scotland and the highest outside the Central Belt. 2.7% of the Highland population provide 50 or more hours of unpaid care a week. Whilst the percentage of Carers under 16 has declined slightly since 2001, Carers over 65 have increased from 20.81% to 23.45%. 32% of unpaid Carers in Highland (1 in 3) manage their own disability or long-term health condition alongside providing care for another person(s), though the actual number will be higher because not everyone with a disability or long-term health condition disclosed this.

Service Access and Structural Inequalities:

The complexity of both the physical and social geography of Highland poses monumental challenges to health and social care provision. A report by the Scottish Human Rights Commission (SHRC) highlighted that numerous communities have no GP practice. The same report acknowledged that social care services are spread thinly and unevenly across Highland; access being described as a *"postcode lottery"* and Sutherland and Caithness *"care deserts"* (SHRC, 2024, 60-61). Limited access to support and respite services forces Carers in Highland to accept a lower quality of service provision compared to Central Scotland. Many are hesitant to complain through fear of having services withdrawn. Premature discharge of patients from hospital without proper care plans and no follow-up care added greater pressure to unpaid Carers in Highland (SHRC, 2024, 61). Deficits in care service provision in Highland and other rural local authorities diminish the choices available to users of SDS. Many are compelled to select Option 1 and accept payments to recruit their own support, thus reinforcing the issues raised by the SHRC (Rummery et al, 2023, 190).

Data Collection

This principally qualitative study used four methods: focus groups, individual interviews, and two online surveys.

Focus Groups and Interviews

Data collection began under the previous Research and Engagement Officer, who organised two focus groups in May 2022. After a recruitment pause, two additional groups were held in July 2024, with further sessions resuming in February of the following year. In total, ten focus groups and interviews were completed. Most were conducted online via Zoom due to participants' geographic spread and limited capacity to step away from caring responsibilities. One interview took place in person and another by telephone. All sessions were recorded and later transcribed with the participants' consent. The topic guide for both the focus groups and interviews invited participants to discuss balancing their own needs with caring responsibilities, their experiences with service providers, gaps in provision, and ideas for improving support and independence.

Surveys

The first survey was adapted from a draft created by the previous officer, with only minor modifications. Its content largely mirrored the interview schedule. The survey link was shared internally with Connecting Carers users and externally with professionals and community organisations, including community councils, religious groups, GP surgeries, and libraries. Elected representatives were also asked to share the link with constituents. This survey received 31 responses, and although paper copies were available, none were requested.

A second survey— 'Carer Critique'—formed part of our ongoing monthly engagement with Carers. Each edition contained two open-ended questions on rotating topics. This survey generated 45 responses. While we made efforts to reach Carers with disabilities or long-term health conditions, participation remained intentionally inclusive to avoid excluding any Carer who felt isolated or unsupported. This approach also ensured that Carers without a formal diagnosis could contribute.

Data Analysis

Qualitative data were initially coded manually using a straightforward system that was refined as themes emerged. Microsoft Copilot was then used to identify any concepts that might have been overlooked manually. Quantitative data from the surveys were used to support and triangulate qualitative findings where appropriate.

The appendices at the end provide supplementary evidence that supports and enriches the findings discussed in this report. Appendix 1 presents graphical summaries of the key quantitative data, offering a clear overview of the statistical patterns underpinning the analysis. Appendix 2 providers thematically organised extracts from the qualitative data, selected to complement the results section and deepen understanding of core issues explored in the study.

Research Ethics:

Given the sensitivity of health and social care topics, the research followed strict ethical standards to minimise participant discomfort and protect personal information. All procedures complied with GDPR and internal data protection policies. Interview transcripts excluded names, and although survey respondents could provide contact details for follow-up support, these were passed to the appropriate teams and then deleted before analysis. To preserve anonymity, quotations included in the results section retain their original wording but omit identifying characteristics such as age, gender, and relationship to the cared-for person.

Results

Participant Demographics and Caring Contexts

Geographic Distribution: Almost half of survey participants (n=15) lived in Inverness or nearby settlements, with a further 29% (n=9) residing in Ross and Cromarty. The remaining participants were spread across Lochaber, Nairn, and Sutherland. 23% (n=7) identified as residing in remote or rural areas. This distribution reflects the geographic diversity of unpaid Carers across Highland.

Gender and Identity: Most respondents were female (74%, n=23), with 19% (n=6) male and two identifying as non-binary. Only two participants identified as a sexuality other than heterosexual. All respondents identified as white Caucasian and self-described as Scottish, British, or Irish.

Age Profile: Of the 27 Carers who reported their age, the mean age was 44. Ages ranged from early twenties to early seventies, with the largest group aged 50–59 (35%, n=11).

Employment and Caring Hours: Participants were evenly split between those in paid employment (n=15) and those not working (n=16) alongside their caring responsibilities. Caring intensity was high: 42% (n=13) provided 50 or more hours of unpaid care per week, while 39% (n=12) had been Carers for 10–20 years.

Caring Relationships: Carers supported a wide range of people, including spouses, parents, adult children, children with disabilities or long-term conditions, siblings, and friends. Most lived with or within a short distance to the person(s) they cared for.

Interview and Focus Group Demographics

Focus group and interview participants were all women who self-identified as White and as being from the British Isles. Their demographic profile was broadly comparable to that of the survey sample. Participants were evenly split between those in paid employment and those not currently working, the latter group comprising individuals who were retired or living with health conditions that limited their employment capacity. Across the sample, participants undertook a wide range of caring roles, reflecting the diversity of caring contexts represented in this study.

Double Duty: Managing Disability While Caring for Others

Participants reported living with a wide range of disabilities and long-term health conditions, including autoimmune, neurological, respiratory, cardiological, and gastrointestinal disorders, alongside mental health conditions such as depression, anxiety, ADHD, and borderline personality disorder. Many managed multiple conditions simultaneously, reflecting the complex physical and psychological health needs within the group.

These conditions significantly restricted their ability to undertake everyday tasks, both within and beyond their caring roles. Symptoms such as breathlessness, chronic pain, fatigue, brain fog, and memory loss made routine activities challenging and, in some cases, impossible without support. For Carers with limited mobility, these difficulties also contributed to pronounced isolation, as leaving the home was often physically or logistically unmanageable.

The combined pressures of managing their own health needs while providing intensive, ongoing care created a cycle of strain that affected every aspect of daily life. These findings underscore the importance of recognising Carers with disabilities as a distinct group whose needs are often overlooked in policy and practice.

On Borrowed Energy: Managing Care While Living with Ill Health

Carers with disabilities and long-term health conditions face a persistent struggle to balance their own healthcare needs alongside those of the person or people they support. In practice, this tension results in a recurring pattern of self-sacrifice, whereby Carers deprioritise their own wellbeing as a coping strategy within highly constrained support environments. This commonly manifests in delayed or foregone medical treatment, withdrawal from self-care activities such as respite and exercise, and continued engagement in physically and emotionally demanding caring responsibilities. Participants demonstrated a clear awareness that these practices contribute to worsening physical and mental health outcomes yet felt compelled to persist due to the absence of viable alternatives:

“I tend to prioritise my caring role over my own needs.”

“I definitely need to look after myself but feel I haven't got the time I do neglect myself.”

“I am in pain all the time. I cannot afford the physiotherapy needed for my physical disability and I often miss appointments and am unable to schedule appointments for medical care.”

“Being a Carer means that your perspective of an independent life has to change. For instance, booking a holiday needs to be well planned and can never be a spur of the moment adventure.”

"I feel like my life is now just an extension of that of the young adult I care for. Everything I do revolves around them, my time is so limited, it's difficult to take any space for myself. I have completely forgotten how to relax. Sometimes the weight of responsibility is overwhelming, but I have no choice and must keep going."

"I have to mask (or try to) my symptoms because it can cause additional stress to my cared-for people. This can build up and lead to emotional burn-out. I don't prioritise my wellbeing enough."

"I get overwhelmed and overstimulated, causing extra stress and fatigue and reducing the time I have to look after my own needs. I have additional pain and fatigue due to having to do all housework and physical care for [cared-for person], when really, I could do with having help myself. I get very little mental downtime to decompress and relax."

"It can affect me in many ways, if I do too much with my [cared-for person], who I care for, then I am bed bound the next day. I push myself too much and this affects my pain levels and my fatigue. I definitely don't look after myself properly and rest when I should. I have missed appointments with physio as my [cared-for person] has been sent home not well and I don't have anyone else to care for them. I have also missed days at work for the same reason."

"I've probably got a bit of asthma, but I haven't been to the doctors for three years. My [cared-for person] says "go to the doctors, go and get an inhaler for your chest; go and speak to them about your needs" … I don't go… I need to go to the opticians, get my eyes tested again… overdue a dental appointment. But that's all gone on the back burner, because I don't… if my [cared-for person] said they needed to get [optician], I'd probably… I did, I phoned and got them to come to the house and do it. If they said they wanted to go to the dentist, I'd put them in the back of the car and take them to the dentist. But I don't for myself."

"I'm doing all the meals and stuff and, you know, I put them in the freezer, try to do it once a month. And that's becoming more and more difficult to do now just with my own disability as well… it can be really, really stressful."

"I can go out for a walk, but there's going to be a time I can't do that because [cared-for person] not going to be 'self-caring' enough for me to do that, I don't know what I'm going to do when it gets to that point, we will wait and see. I try hard to keep fit and I try hard to exercise, but if someone can't even turn their back on someone, how are you supposed to do anything like that."

"Carers are not going for their health screening… I mean, going to the dentist, it's hard enough to find a dentist, but going to get your eyes tested, going to get your teeth done, it all depends on you leaving that person or taking them with you… but as the Carer, there are barriers to attending. And we get told to make time for ourselves for our mental health, but where not told when you go for your breast screening "I'll sit with the person"."

"My paid job is also physical and emotional caring, so it can contribute to getting very overwhelmed to the point that I sometimes feel I am going to go into a crisis myself."

"I used to get support from [paid care provider] once a week, but they stopped that a while ago. So, I don't get support anymore, but my [cared-for person] gets it two days a week and I do miss having my Support Worker, but what can I do! There's not much I can do about it."

"Groundhog Day": Everyday Isolation in the Lives of Unpaid Carers

Participants consistently described experiences of loneliness and social isolation associated with their caring roles. For many, this isolation stemmed from the intensity and constancy of caring responsibilities, which restricted opportunities for social interaction, rest, and engagement beyond the household. In other cases, participants' own long-term health conditions compounded this isolation by limiting mobility, energy, and emotional capacity. Rather than actively choosing not to seek support, Carers often described feeling unable or reluctant to reach out, citing concerns about burdening others and a perceived lack of understanding from those without caring responsibilities. The accounts below illustrate how these dynamics manifest in Carers' everyday lives and emotional wellbeing:

"Realising I'm not alone, that's what I need."

"I very rarely go out or do anything now. I suffer badly from [mental health condition] and avoid people as much as possible. I have gone from someone who was able to work and thoroughly enjoy doing so to feeling like I am 80 years old."

"I do not talk to anyone about my own health and wellbeing; friends have their own stuff to deal with and so I generally keep much of everything to myself."

"I'm in my early 40s; none of my friends are in this situation yet… so, in my little social circle, nobody else has got this going on, so they can't really understand… it's quite lonely because you don't really have anyone to talk about it with if they're not experiencing the same thing, do you."

"I have found myself fairly socially isolated. Whilst this reduces my need to communicate and interact with others, it does leave you feeling lonely and isolated."

"I feel very isolated. I worked in an office full of people who were my friends, and we laughed and joked. And suddenly, I can go a whole day without speaking to anybody but [cared-for person], which isn't healthy… and that's pretty much it every day, 'Groundhog Day', I call it… If it wasn't for the fact there's different things on the television, I wouldn't know what day it is."

"I visit friends occasionally when I can. I sometimes just take myself off to a coffee shop, between doing the shopping, and I'm always in and out of the garden. That's about it really."

The Invisibility of Carers with Disabilities and Long-Term Health Conditions

The survey explicitly asked participants whether their friends, family, colleagues, and wider community recognised them as unpaid Carers who also live with a disability or long-term health condition. Most respondents reported a lack of recognition, describing experiences of being overlooked, misunderstood, or having their dual roles minimised. This perceived invisibility was not limited to informal social contexts; interview data further substantiated these findings, with participants providing detailed accounts that illustrate how their caring roles and own health needs frequently remain unacknowledged by those around them.

"There is going to be a huge debate now, given that in America, a Carer died and then the cared-for person died[1], its highlighted hugely the importance of the Carer being first, they need to look after their own health first, because when they're gone that's it, and a lot of them burn out, and they put off operations, and they put of things because they know they won't be able to cope, it's an huge issue, and I haven't got a clue how they can solve this, only that, they are going to need help to get their screening."

"I don't think they do. As it's my [person] I care for. So, they just see it as me just being their Carer. Connecting Carers, they really listened and help with things moving forward."

"No, I haven't met anyone who understands. People seem to think I am not allowed to have negative thoughts or feelings."

"At a Carers meeting I was at recently, somebody said "I shouted at [cared for person], and I felt so guilty", and I said "I never feel guilty because they won't remember in ten minutes, but I said I would have shouted at them if they didn't have dementia", we are human beings, we just need to flip at times and that's it."

"I haven't felt supported as a Carer, either when growing up or as an adult. I also don't think my [Young Carer Child] gets any."

"I feel at the moment, due to the length of time my ongoing treatment is taking, as well as the fact people can't necessarily "see" my disability and forget that I'm an unpaid Carer, I'm unheard in the majority of situations."

"I could really do with someone to be on my side to sort of back me up and show signpost me in the right direction for help and what's available and what can be done rather than me getting doors slammed in my face and been told there is nothing we can do, short staffed or no."

"And you know, you know, it's like, and I say this as an unpaid Carer, but it's like Carers' voices need to be like so loud, but it's so, so hard, so hard to actually have like a Carer's voice heard because you are literally just so like by the end of the day or by even first thing in the

[1] Informant referring to the death of actor Gene Hackman and his wife

morning, you know, you can just be, it's the energy that it takes to do that or, you know, being able just to jump into… like this kind of suits because I can jump in."

"Don't feel it's taken as a job and rather as a personal commitment."

Recognition operates as a dual process. Alongside external validation, unpaid Carers often navigate an emotionally strenuous form of internal or 'self-recognition', through which they come to understand and accept their identity as Carers.

"I've come to the point now where I appreciate, I'm not in the best of health and we need help."

"I know my situation is different, but that's the crazy thing about being a Carer or anyone could be a Carer at any moment. You just you just don't know."

"I think it suddenly dawns on you when you've got someone with cognitive decline, because you see these things happening and you think it's down to age or something else or something else, then you realise it's getting worse and then, it occurs to you one day that you are the 'Carer'. You would never describe yourself as the Carer, because the person is still walking around and doing stuff, and I suppose it's the same with anyone who looks after someone with any mental health issue, do they describe themselves as the Carer, do they identify as the Carer?"

"I feel very resentful as I am very tired, but I still have to soldier on."

"And then all of a sudden everything is mine, on my shoulders, everything, and I quite resented [cared-for person] for that. And, were do you go as well for the anticipatory grief as this person is disappearing in front of your eyes, and what you expected to do with your life has gone, what you expected to do with your retirement has gone, everything has changed, and for me, they're not my [spouse] anymore, they're just this old person I look after. Their personality has completely changed, everything has completely changed, I don't recognise them."

"What people don't like to face the caring role, I don't think, and I think that's a lot of reluctance, because reality hits if they accept, they are going to be a Carer, I suppose it's a bit scary".

"It [cared-for person's condition] progressed really quickly. Total life change, they are totally 100% dependent on me now."

"Treat me as a person in my own right."

Rights in Principle, Barriers in Practice: Engaging with Care Services

Carers participating in this research engaged with a broad range of services to support both their own health and their caring roles. Only a small proportion reported not using any services—less than 10% for both health and caring needs, and 13% for caring needs alone. Primary care was the most frequently accessed resource, with 58% (n=18) using GP practices or community medical centres for their health needs. Additionally, 29% (n=9) engaged with hospital-based healthcare professionals, and 42% (n=13) accessed support from Connecting Carers. These findings highlight the central role of primary care and third-sector organisations in meeting Carers' needs.

55% of Carers (n=17) were unaware that the Carer (Scotland) Act 2016 entitles them to request an Adult Care Support Plan (ACSP) or Young Carer Statement (YCS)—a significant gap in awareness. Encouragingly, of those who were aware, 79% (n=11) had successfully requested and completed a plan. Two Carers were still waiting for completion, while one declined the offer.

Our data indicated that Carer services frequently operate in silos, resulting in inconsistent and fragmented support. The same number of participants who lacked awareness of their rights under the Carers (Scotland) Act 2016, reported that social workers and primary care providers failed to offer additional assessments or support options, including those available from external agencies. This pattern highlights a persistent communication gap between services, leaving Carers without clear guidance and, in many cases, without the help to which they are entitled.

Both the interview and survey data reveal the complex and interlocking barriers unpaid Carers face when attempting to access and engage with service providers. Participants frequently described feeling misunderstood or dismissed by professionals, particularly when seeking support for needs that fell outside narrow diagnostic or eligibility frameworks. These difficulties were exacerbated by persistent communication gaps between Carers and statutory services, especially where Carers were required to act as intermediaries for the cared-for person. In this context, Carers' experiential knowledge was often marginalised, leaving them excluded from decision-making processes that directly affected their lives. Alongside these relational barriers, participants highlighted significant inconsistencies in service provision, including unclear points of contact, delayed responses, and contradictory advice. Collectively, these systemic failures intensified stress and uncertainty, compounding the physical and emotional burdens already experienced by Carers and contributing to deteriorating health and wellbeing:

"We didn't have a link worker at first, and so it was a bit hit and miss."

"Although they listen, I have not received anything other than medication and some physio few years ago."

"I'm not quite sure I understand the question . . . other health professionals are unlikely to know that I also have a long-term health condition."

"My GP Practice are absolutely excellent, but my new GP does not know [cared-for person] and although they are aware how much stress [cared-for person] puts me under, all they can do is listen and sympathise. I have absolutely nobody to support me despite repeated requests for help from CMHT, CPN, Psychiatry, and because they see me coping and functioning, I am not seen as a priority. I am just left to get on with it and again I have lost complete faith in the professionals.

"Do I have a social worker? I was told "no", [cared-for person] doesn't have a social worker? Then "yes, they should. No, they don't, yes, they do, no they should." And I eventually last year, on the verge of a nervous breakdown, I just broke down in tears, and I was shouting at the GP over the phone and then they decided to have a group meeting and then a social worker was sent out, but it was just an emergency social worker. And then [cared-for person] was taken into respite for three weeks and that was the first that I knew about anyone being taken into respite for three weeks. But the GP, as far as the GP is concerned, is you're doing all right. You know, I have to phone them and say "should you not be doing a review of their medication?" "You should, you know, not come out and assess them?" "Nope, they're doing fine. They're all right." So yeah, none I've got."

"Apart from bowel screening, which you can do in your own home, aortic aneurysm screening has to be done in a hospital, you can't get that done in a local surgery and there isn't a van that comes round to do that… Someone asked about breast screening, when they make appointments, are they aware of the home situation? The answer to that is no, they will not have a medical history apart from the last breast screening. So, there are barriers for Carers to access screening and that is the first port of call for finding out a lot of stuff."

"I get regular phones calls from a Community Support Worker, and they really help just by listening to me. This it's due to end in a couple of weeks."

"I was at a recent pre-op assessment appointment, and I was actually asked outright about my caring role in their assessment. It's the first time ever I've been directly asked about my caring role in a healthcare setting in roughly 15+ years of caring for [cared for person]! They were very good at checking whether I had the right resources on hand and whether there would be someone to look after [cared-for person] whilst I recovered. Just thought I'd make a note of it here, since it was a little moment of joy that made me feel seen in relation to my caring role."

"It is all piecemeal and services are not connected. If anyone listens, you have to tell the story over and over again. There is also no holistic family support. Example my [partner] has an undiagnosed borderline personality disorder, and we have an adolescent with suspected autism. We have now broken apart as a family. Perhaps if there was a service which looked at the family as a totality and dealt with problems as a totality, we may still be together."

"Connecting Carers gave me wonderful counselling so so helpful. Our GP service has been second to none, great support for many years."

"There's no GP input with regards to caring. We only contact the GP if we need to see them for medical issues. We have had excellent input from Allied Health Professionals (AHPs) over the years and can't fault them. I'd say that Connecting Carers, although I've not used them enough, has been an excellent support and does provide lots but sometimes I'm too busy to attend."

"We've got… we've applied for, and we've got the… the funding for Carers, the self-funding. But now we've got this funding coming through, I don't know where to find carers, so I was reaching out to Connecting Carers to get some help and support, how to find Carers to come in and help me. Just a couple of hours a day, uh, give me a break… so that's why with the self-directed care we've got. If I can engage these Carers that can come for a couple of hours, that gives me a break, and that's sometimes what I need, is a break… the NHS Carers didn't work because they had to just come in at a certain time. That they could do a lot for us. At least if we're employing our own Carers, we can be saying," we want you here at these times." Um, so I can't wait to get… to find somebody, the right person who is going to fit in, get on with [cared-for person]. My [cared-for person] going to be comfortable with them, and that will give me such a break… so that's been really good to find out about. But it's sitting there in the bank waiting for me to find the right Carer. And I don't know how to do it".

"It was suggested to me, and someone did contact me, and they said "it's probably better if you can find someone that already works for and knows your [cared-for person] so that they are not going to get used to somebody else." And that was fine. And I did have a local person that was going in doing sort of caring. But all [cared-for person] would let them do is make a cup of tea. And [paid Carer] would rather that she sat down for the two hours with [cared-for person], and she would rather that [informant] sat down and, but they'd be like, "oh no, I'll hoover for you, I'll do whatever it is you need done; things that are in the house that [informant] can't see to do." And [cared-for person] was like "no, no, no, no, [informant] will do that. It's fine, don't worry about it" … But then I asked [paid Carer] about the self-directed care, and I said, "would you be able to do it on a more regular basis?" And they said "no". And then suddenly, she stopped coming. So, I think I would find it very hard to find anyone."

"It seems we have reached an uncaring stage in UK Health care. GPs seem too busy to get involved and do not really seem to care about the long-term effects on the Carer, nor the cared for. Other sections of caring - social work and other health professionals including management are not interested either. My marriage has broken down due to this. At the same time third sector and voluntary organisations are expected to take up the slack - whilst they get their funding cut."

"They [service providers] often have poor understanding of Asperger's and autism."

"Easier access to appointments - trying to get a GP appointment is near impossible! Some surgeries are now implementing online triage systems which make it even harder and that's before accessibility is considered. I can't stop caring and supporting my people however unwell I am, there's no time off and definitely no sick leave."

"ME is not believed as a real condition and it's impossible to get an appointment at GP. Because I see doctors so little, they don't have time to listen properly."

"More counselling, this has been invaluable for me. A safe space to pour your heart out."

"We only talk about my health etc. and not discuss the effects of being a Carer with a long-term health condition."

"Some services have been great (like pre-op, who identified my caring role and associated needs) but my GP practice often rotates patients between different doctors, making it hard to advocate for my caring role."

"We're lucky to have an amazing Social Worker who advocates and listens. However unfortunately this cannot be said for the entire 'team around the [cared-for person]."

"So, the help and support from the NHS apart from [specialist] has been… just bashing your head against a brick wall… our local doctor surgery… you don't have the same… you don't speak to the same doctor all the time… so, the level of care hasn't been great. The District Nurses can't fault them; I love them to bits… they [District Nurses] encouraged me to stop being stubborn and trying to do everything myself."

"Having an invisible condition, people think I am fine."

"It would be nice to see a Carer Centre which has drop-in where Carers can pop in for a cuppa and there was always a staff member there to chat to. It would be a hub with info too."

My [cared-for person] is banned from all NHS care homes due to them escaping. They've got dementia. Private homes don't allow respite to be booked in advance so impossible to plan a holiday etc."

Interview data revealed that the absence of a formal diagnosis for care recipients' functions as a formidable barrier to Carers accessing both statutory and third-sector support:

"There are people floating around who have never had a diagnosis, and them therefore their Carer doesn't know where to go, because they don't have a diagnosis, no Link Worker, no-one to show them away. Some don't even know about Connecting Carers… They just don't know where to go because there is no diagnosis, no drug therapy, no Link Worker, they are just floundering."

"So, a couple of people have been referred straight to the elderly psychiatry at [Community Hospital] so they see a psychiatrist there, but if they're insisting that it's only early cognitive

changes, or this is cognitive changes and it's getting a bit worse, is there anything we can give them, and people say that's not a diagnosis as such, no-one gives them any information, but they are still a Carer, they can be here there and everywhere."

"Services are being cut left, right and centre and diagnostic services are non-existent. We have been waiting 6 years to even get on the waiting list, and it looks like we will have another wait of a year before getting an assessment - despite our [cared-for person] having suicidal ideation."

"The agencies and folk who try to help are almost always lovely, but the left hand does not always talk to the right. Also, no one has asked me, or I suspect my [partner], how we are coping. They are doing about 30+ hours a week just now, not always caring in person but organising appointments, paperwork, thinking about what is or could be needed, this mental burden is draining on us both but especially [partner]. The mental burden is often most wearing and can have consequences downstream."

Accessing services was consistently experienced as difficult, with informants describing prolonged struggles to secure support, a process that contributed to exhaustion and emotional depletion:

"We haven't been able to get any kind of diagnosis, despite us, being determined 'warrior parents'."

"We had to really fight tooth and nail to get it [SDS], we had to really fight hard."

"It very much feels like you have to be a detective to find things, I'm sure other people with children with additional needs would say the same, you literally have to be a detective to find out what is available in your area, and then trying to get access to those services is very difficult, sometimes you have to be, like, it's like another full-time job on top of a full-time job, so, yeah, that's us."

Carers using services in Highland experienced significant structural barriers associated with living in a vast and predominantly remote rural local authority. Long travel distances to services—frequently compounded by limited and unreliable public transport—restricted access and increased time pressures. Chronic local shortages of care provision further reduced Carers' choice and flexibility in service use. In areas with poor broadband connectivity, digital exclusion created additional obstacles to accessing information, online services, and virtual support. For Carers whose families lived outside Highland, the absence of informal support networks intensified isolation and reliance on already stretched statutory services. Taken together, these intersecting barriers deepened inequalities for unpaid Carers and amplified the practical and emotional demands of caring in rural contexts.

"I'm worried about leaving [cared-for person]. Because for me it involves a whole day trip just for a 10-minute hospital appointment or a 15-minute hospital appointment, you know, to travel 50 miles by trains. And there aren't many trains… the face-to-face groups are anything up to 50 miles away and I can't get to them, you know, because there's never a train or a bus that gets me in on time and try to navigate and find my way to different locations and stuff. So that's just impossible. I can't take part in them. That's why things like this [online sessions] are brilliant for me because I'm in my own home. I'm still within 4 doors and my [cared-for person]; they do need me."

"Nevertheless, the service [neurodevelopmental] is in chaos, it's virtually stopped doing assessments in the Highlands. So, we got to a point where it was like, okay, we need to make a formal complaint about this, so again, that takes time, more letters, more emails, more communication, only to be told that, "yes the service is in chaos and we are remodelling the whole service, it's a three to five year recovery plan." That's not what you want to hear as by that time our child will have finished school, and then they will become a Vulnerable Adult."

"I remember trying to get onto Teams or get decent Wi-Fi in my [cared-for person's} house, which is very rural."

"And it's hard because Highlands such a big area… you have a lot of folks, especially in the rural and remote areas that are unpaid because there's no care. So, they have no choice."

"I'm the only person [cared-for person] has. I have a half-sibling but they're a stepchild and they live in the Central Belt."

"We are so lucky here in [town] for support and help is invaluable."

"Access to anything relevant given I live in [North Highland]. Resources are sparse there. Organisations seem to think everyone lives in Inverness."

"Care Changed Everything": Financial Life After Caring Begins

Unpaid Carers of all demographics live on lower incomes relative to those without caring responsibilities, often at the expense of their financial wellbeing. The data justified how the pertinence of this issue among Carers with disabilities and long-term health conditions.

Among the survey participants, a worrying 48% (n=15) did not claim any Welfare Benefits for themselves. Of the remaining 52% (n=17) who claimed at least one benefit, 71% (n=12) claimed Adult Disability Payment (ADP) or still had an active Personal Independence Payment (PIP) claim whilst waiting to transfer to ADP. Another had a legacy Disability Living Allowance (DLA) claim. Only 35% (n=6) were in receipt of either Carer Support Payment (CSP) or Carers' Allowance (CA).

Both the survey and interview data identify several interrelated reasons why Carers did not claim welfare benefits. Participants described the social security system as complex and opaque, with limited and poorly signposted information about entitlements available to both Carers and the people they support. As a result, many Carers struggled to identify appropriate sources of financial assistance at a time when support was most needed.

The abrupt onset or intensification of caring responsibilities often triggered a sudden and severe reduction in household income, leaving little opportunity to research or navigate income replacement options. This financial shock was further compounded by bureaucratic eligibility rules, through which Carers' financial need was effectively downgraded due to the presence of modest savings or previous financial security. In addition, widely publicised injustices within benefit administration and pension eligibility regimes fostered distrust and reluctance to engage with the system. Taken together, these findings suggest that benefit non-take up among Carers with disabilities or long-term health conditions is not a matter of choice, but a consequence of structural design failures that inadequately accommodate crisis, complexity, and cumulative disadvantage.

"I found it really difficult to get information. I found it difficult on all the Benefit System, what to apply for, what not to apply for. And I just think that… the Carers do… I appreciate them how… the job they have to do now, how difficult it is… and I've gone from earning £25,000 a year to £10 a day to care for my [cared-for person]. And I don't get my pension for another 4 years."

"I know [SDS] is available for some people but no idea what the criteria is or how to go about it."

"Never heard of it [SDS]."

"I was not aware of this at all [SDS]… How do you apply and what can it be used for?"

"When my [cared-for person] got ill, we didn't know about getting a Wheelchair Accessible Vehicle (WAV) through Motability, because you've got to get PIP to get that. We didn't know about that, so we went out and forked out £20,000 on a suitable car that we could get him about. We went out and spent £4,000 on a wheelchair. We didn't know you could get them through the NHS. So, we… it was… it's been a learning curve over the past 3 years."

"So, we had a good income, holidays abroad, good life, good standard, living a happy life, and then this [cared-for person's illness] has come down like a ton of bricks on us."

"What can you do? I think perhaps the Carer's Allowance. I've always thought, perhaps. With PIP, you can get the different levels of PIP depending on your disabilities. Perhaps the caring levels should come have tiers the same, so, if you're caring for someone who's got high dependency, you should get a higher Carer's Allowance."

“As a Carer who has a full-time job, I feel there is nothing for me to support my role as a Carer.”

“Benefits are only aimed at low-income Carers which I totally understand, however if I was not able to care for my husband then a care package would have been required.”

“When I've been sitting down for a long time, when I first stand up, I can hardly walk. My [cared-for person] said, “you could probably get PIP as well”, you know, but… I don't go to the doctors; I don't do anything like that.”

“I feel I fall between stools. Too ill to cope, but not ill enough to get help. My [cared-for person] is the same. They get PIP, and people who will accompany them a couple of times a week to go for a walk for a few minutes but doesn't get enough help to be able to improve their life.”

“I could really do with someone to be on my side to sort of back me up and show signpost me in the right direction for help and what's available and what can be done rather than me getting doors slammed in my face and been told there is nothing we can do, short staffed or not.”

“I have had financial support which has been helpful, but I cannot access a lot of the other support as I work during the day.”

Beyond Survival: Building Resilience in the Face of Care Challenges

Carers demonstrated remarkable resilience in managing both their caring roles and their own health challenges. A positive mindset—particularly a sense of humour—was highlighted as a key coping strategy. Many Carers incorporated self-care into daily routines, such as exercise, relaxation techniques, alternative therapies, and hobbies like gardening. Those with financial resources, including access to SDS or welfare benefits, eased their workload by using ready meals, takeaways, eating out, hiring cleaners, or outsourcing laundry. Technology also played an important role: Carers used video platforms like Zoom to connect with support groups and, in some cases, employed AI tools for scheduling and reminders. These strategies collectively helped Carers reduce stress and maintain a sense of balance despite significant challenges.

“But you see, there was awful humour. You need, you need, you need humour to deal with those situations.”

“So, I've coped with that as well, and try… Chief Jollification Officer, but that is my normal day… It's a difficult world, so you've got to work together, and you've got to just stay positive.”

"I think we do a lot of things automatically now as we learn through trial and error, and there is quite a lot in there that we do because that's what works".

"Walk the dogs, meds, massage, hire a cleaner. Takeaway or eat out at weekends."

"I take medication, I listen to meditation a lot. Talk to friends, get a takeaway; I get a massage once a month. I take vitamins; I watch stuff on TV that I'm interested in. It takes my mind off the pain."

"I am trying to exercise and keep myself healthy, but it's difficult to find the time."

"We have a cleaner and a gardener every 2 weeks."

"Gardening, listen to music read. I do not watch Telly, go out or socialise as I don't really have anyone to go out with."

"Alternative therapies do help."

"I suppose, independent life outside; I visit friends occasionally when I can. I sometimes just take myself off to a coffee shop, between doing the shopping, and I'm always in and out of the garden. That's about it really."

"Trying to manage time well, ensure relaxation. Go to football matches."

"We have accessed Connecting Carers services over several years, like I say, for ourselves, I go to regular classes mostly online, it's quite good to have a mix of online and face to face, and as we come out of the Pandemic, it's nice to see some services being available… if you could continue with that mix, as not everyone can access face-to-face things, whether it's time, not being able to get there; whether it's not being able to get care for the cared-for person. It's good to have the option to do the same activity online as well as face-to-face."

"You need to recognise in yourself what you need, and you do have to carve that time out, it's almost like it has to be in your diary and you have to make it happen, otherwise life just takes over. You find yourself thinking, "I'll just do this, I'll go make the dinner" you know, it's very easy to forget about yourself, particularly when things are hard, when, you know, other life events come along, or there are more demands on your time, or whatever stage of live that you're at."

"I've got cameras in the house just in case [cared-for person] falls. And then I can be alerted as to what room they're in and whereabouts they are… my [cared-for person] has got 'Telecare', but they only push the button obviously when they fall and stuff and I'm the first point of contact… well, the lady beginning with A, I hope everybody knows who I mean. I won't say her name because she'll probably answer me. She's been a boon to my life since I added it to my [cared-for person's] house as well. And I've written on a whiteboard to ask Lady A what day of the week it is, what time it is, that sort of thing, set reminders on them. So, I've sort of stepped back a little bit. I'm not going in quite so often now even though it's

like 6 times a day still. But well, it was 8 times a day. But at least now I can relax a little bit, and I've taken Sunday off for the last year."

Listening to Lived Experience: Carers' Ideas for Change

Carers participating in the survey, Carer Critique, and interviews were invited to share their ideas on how their quality of life could be improved. Given the unique circumstances of each informant, the suggestions reflected a wide range of needs and preferences. Despite this diversity, several common themes emerged. Many improvements could be achieved by enhancing awareness, streamlining interagency communication, and improving access to existing services. For example, help with household tasks may be available through Self Directed Support (SDS), while advice on benefits and finances can be obtained from local agencies such as the Citizens Advice Bureau (CAB) and Highland Council. Preferences for support varied: some Carers favoured digital participation due to its convenience, while others missed in-person gatherings and called for their return. Several Carers also advocated for broader reforms within the health and social care landscape, including increased funding and changes to employment law to expand leave entitlements for those with caring responsibilities. Together, these insights underline the need for both practical improvements in service delivery and wider systemic changes to ensure that unpaid Carers receive meaningful, consistent support.

"Given the monies Carers save governments, health services and social care - the Carer role should be supported by the state and employers much more than it is. I find it galling the celebrations and attitudes that gave Carers more time off work - unpaid. Carers need much more support than this."

"It felt like with Connecting Carers I was given a lot of information at once and then just kind of left to my devices. I'd greatly appreciate help with applying for some of the things (esp. council funding for things like the SDS funding, which I was told about but am too overwhelmed and confused to apply for on my own). Would also love check-ins as I don't know when my eligibility for certain things 'resets' and I feel guilty about asking for too much help unless prompted to do so."

"A support package would help… possibly having someone to talk to, having someone who knows where to access services."

"I don't know how to improve it; I don't expect there is money for out of hours support or for assistance for people who are not severely disabled themselves. I also don't know how to get around how much additional mental burden there is as an autistic person trying to reach out to strangers for help."

"Some support with my wellbeing might be helpful"

"I actually don't know. Help take my children for fun things, or overnight. Help with budgeting or housework. Help with making me feel nice, a massage or hair wash."

"Paid time off work that isn't restricted; obviously there needs to be a limit as any employer can't afford to allow staff to take paid time off constantly."

"Transport for [cared-for person] to hospital appts; they don't drive and would be unable to, given their condition(s)."

"Reduce the mental burden, stress and confusion about how the 'system' works, e.g., easier roadmap to accessing services for the person we care for, more cross agency communication, that sort of thing. Everything we do takes a huge effort, every crisis requires days and days of follow up appointments and phone calls to try and get and maintain the care we feel they need."

"In an ideal world I would be able to get some help with housework, but I don't think I would qualify, since if I lived alone, I could cope with this. It is only because I am doing everything for two people that I am overwhelmed."

"I really don't know as these kinds of things come to me as and when I need them (if that makes sense). I think personally, having time off from work when needed."

"They [social work] were good, but once my [child] got to a certain age, and my [second child] as well, they no longer really got involved. They are still involved with the Transitions Team until they are twenty-five, but they haven't got Social Workers anymore, the last one left and was never replaced… I had a Social Worker involved a while ago briefly with my [relative] when they were really poorly. They got them a hospital bed, because I was struggling, and got them a couple of aids. Other than that, they've gone. I suppose they do what they can and then they're off. Sometimes, I could do with a check-in if you know what I mean, but nobody's got the staff."

"If I could pay for somebody to come in and look after things sometimes, so I can have a break."

"I like in-person events, I don't really do computers. Since COVID, before that I used to go to a lot of Carers groups and there were always things on, and with COVID it all stopped and went online, and I find that quite isolating, because I don't feel comfortable doing stuff online, and, I have a long-term health condition and I look after three other people… … I do miss the in-person events, because that was my excuse to get out of the house for those couple of hours, right I'm going to be there… I just like a cup of coffee with someone else, and having a moan, hearing from people in the same situation, we can help each other as well that way, "do you know about this grant, or whatever, and vice versa… Yeah, also if I was online at home I wouldn't be able to do it as I wouldn't get peace. I have to be out to get that peace."

Discussion:

At a broader level, our findings support Emily Kenway's argument regarding the strong emotional dimensions of the caring role. Participants described significant adverse impacts on their physical and mental wellbeing, alongside feelings of imprisonment, isolation, anger, and resentment directed both at the caring role and, at times, the cared-for person. Despite these challenges, many Carers continued to demonstrate a profound sense of duty and responsibility. These insights highlight why unpaid Carers require greater recognition within policy and practice, and why their contributions must not be taken for granted.

The findings closely align with contemporary theoretical and policy debates concerning unpaid Carers with disabilities or long-term health conditions. Although Michael Oliver's social model offers a more compatible framework than the medical model, the experiences of these Carers do not fit neatly within either approach. This underscores the importance of adopting an intersectional perspective—one that recognises how multiple, overlapping identities shape the realities of unpaid caring.

Despite growing societal awareness of Carers with disabilities or long-term conditions, dominant narratives still assume that a 'Carer' is physically and mentally healthy—a status that can deteriorate as caring responsibilities intensify. The evidence presented here challenges this assumption by demonstrating the demographic diversity of Carers and the wide-ranging conditions under which care is provided. As such, policymakers and service providers cannot rely on one-size-fits-all approaches and must instead engage with the complex and varied experiences revealed by this research.

Together, these insights highlight the need for more nuanced theoretical models and more flexible, inclusive policy responses that better reflect the lived realities of unpaid Carers with disabilities.

The findings indicate that Carers with disabilities or long-term health conditions experience a disproportionate level of caregiver burden. Their dual roles require them to balance their own health needs with those of the person(s) they support, often resulting in the systematic deprioritising of their own care. This self-neglect is exacerbated by limited external support, service gaps, and the emotional demands of intensive caregiving. Consequently, many Carers seek help only once their physical or emotional resources are exhausted, underscoring the urgent need for more proactive, accessible, and coordinated support structures.

The research provides strong evidence of an emerging care crisis. Interview and survey data illustrate how ongoing funding cuts at both local and national levels have significantly reduced the capacity of health and social care services. As resources have become increasingly strained, many Carers, particularly those managing their own disabilities or long-term health conditions, are forced to choose between accepting inadequate support or going without it altogether. Workforce shortages further intensify these pressures, with

numerous participants describing the difficulty of securing public, private or third sector assistance despite clear need. The complex geography of the Highland region compounds these structural challenges: services and professional support remain heavily concentrated around Inverness, leaving more remote northern and western areas with minimal provision. Limited public transport, patchy broadband connectivity, and the distance between communities all restrict Carers' ability to access consistent and timely support. While our sample unintentionally over-represents Carers living in or near Inverness, the contributions received nevertheless highlight persistent regional inequalities and the cumulative strain experienced by Carers living in rural and isolated areas.

Although social care policy in Scotland has expanded Carers' rights and access to services, our findings show that progress remains limited. Service provision was often inconsistent, particularly within Primary Care—the service most frequently used by Carers. Many participants described providers who failed to recognise their needs independently of the cared-for person or who followed rigid procedures that did not reflect Carers' circumstances. When support was effective, Carers emphasised its value, underscoring how uneven current provision remains.

A lack of awareness also emerged as a major concern. A significant proportion of survey respondents were unaware of their right to an Adult Care Support Plan or Young Carer Statement under the Carers (Scotland) Act 2016. Knowledge of Self-Directed Support (SDS) was similarly limited, with many respondents either unsure of what it entailed or unaware of it entirely.

This pattern extended to welfare benefits, where many Carers did not claim available support due to unclear information and a general lack of guidance. These gaps across policy awareness, service access, and financial entitlements point to systemic communication failures that continue to hinder Carers' ability to secure the support they are entitled to.

What the Data Doesn't Show: A Deeper Reflection

Because very limited research exists on unpaid Carers with disabilities or long-term health conditions, we recognised from the outset that this study would be methodologically demanding. These challenges were compounded by the Highland region's vast geography, dispersed population, and complex social landscape, which made recruitment, engagement, and representation particularly difficult. Together, these factors highlighted the importance of undertaking this work, while also underscoring the gaps that remain in understanding the experiences of this vulnerable and often overlooked group.

The research was unable to capture the perspectives of Young Carers, despite producing a condensed survey with support from the Connecting Carers Young Carer Team and making sustained efforts to engage them. Although this gap does not compromise the overall

findings, Young Carers—many of whom have disabilities or long-term health conditions, diagnosed or not—will likely become Adult Carers, making their experiences vital for shaping effective, sustainable policy and support in the future.

Despite targeted efforts to engage participants from all Highland districts, the final sample was concentrated in Inverness and surrounding areas. Additional participation from Carers in Caithness, Sutherland, Lochaber, Lochalsh, Skye, and the Small Isles would have strengthened the study by capturing a fuller picture of regional variation, including both common challenges faced by Carers across Highland and the unique issues arising from remote and rural geography.

Although several limitations remain—particularly regarding sample diversity and geographic coverage—these gaps highlight important directions for future research by Connecting Carers and other regional or national advocacy organisations. Despite these constraints, this study makes a meaningful contribution to understanding the experiences of unpaid Carers with disabilities or long-term health conditions, an area that remains significantly under-researched. While further theoretical and policy-focused work is required, the findings presented here provide a strong foundation on which subsequent studies can build.

Conclusion and Recommendations

This research seeks to answer three core questions concerning the experiences of unpaid Carers with disabilities or long-term health conditions. The first two questions are explored in the ensuing discussion, where the findings provide the analytical basis for understanding the impacts of the caring role and the pathways available to Carers. The third question focused on enhancing recognition and integration within policy and practice, is addressed through a set of recommendations informed by the study's qualitative and quantitative evidence.

The caring role has multiple impacts on unpaid Carers who also live with disabilities or long-term health conditions. Like all Carers, they experience significant caregiver burden, isolation, self-neglect, and increasing difficulty accessing overstretched services. Despite these challenges, many demonstrate considerable resilience.

From an intersectional perspective, the impact of caring is shaped by Carers' dual and often overlapping identities as Carers, patients (both formally and informally), and even care recipients. These identities are fluid rather than distinct, and movement between them creates additional emotional and practical complexity.

Unpaid Carers who manage their own health conditions must balance their personal needs with the demands of supporting the cared-for person(s). This constant negotiation often requires them to deprioritise their own wellbeing, contributing to heightened vulnerability and, in many cases, increased social exclusion.

Against the backdrop of daily challenges, pathways for unpaid Carers with disabilities or long-term health conditions to live their best lives are difficult to identify, but they do exist. Two of the most significant are meaningful inclusion and active participation. When service providers listen to Carers and treat them as stakeholders in both their own and the cared-for person's welfare, Carers report feeling more empowered and better able to manage the dual demands placed upon them.

Participants also highlighted the value of connecting with other Carers, whether in person, online, or through blended formats. These interactions reduce feelings of isolation and reinforce a sense of shared experience, which can be particularly important for Carers whose responsibilities, health conditions, or geographic location limit their opportunities for support. Simply knowing they are not alone, even in the most basic psychological sense, offers substantial emotional benefit.

In terms of how we can enhance the recognition and integration of unpaid Carers with disabilities and long-term health conditions within mainstream caring narratives and service delivery, the research generated the following key recommendations:

1. Establish a National Carer Health-Screening Programme

Rationale

Carers with disabilities or long-term health conditions frequently delay or miss essential medical appointments due to caring responsibilities, lack of respite, and logistical barriers. Many reported persistent pain, fatigue, worsening conditions, and foregone treatment, often for years.

They also face structural barriers to screening access, especially for hospital-based screening programmes.

Recommendation

- Introduce a routine, opt out health screening programme for all registered unpaid Carers, delivered through Primary Care and linked with annual reviews.
- Replicate best-practice models from existing screening services to ensure early detection and prevent crisis-point deterioration.

2. Strengthen Cross-Agency Coordination and Information-Sharing

Rationale

Carers described service systems as fragmented, forcing them to *"tell their story over and over again,"* with agencies failing to communicate effectively.

Large knowledge gaps persist around ACSP/YCS rights, SDS options, welfare entitlements, and diagnostic pathways.

Recommendation

- Develop an interagency **Carer Information Sharing Framework** that enables health, social care, and third-sector partners to share relevant information (with consent).
- Implement a "**tell us once**" mechanism for Carers entering the system.
- Require each Health & Social Care Partnership (HSCP) to publish **a clear, public roadmap** of available services and pathways.

3. Enhance Recognition of Carers with Disabilities and Long-Term Health Conditions

Rationale

Carers with disabilities and long-term health conditions routinely reported being unseen, misunderstood, or dismissed by professionals, colleagues, friends, and community members.

They also reported a lack of internal and external recognition of their dual identity as both Carer and disabled person.

Recommendation

- Fund a national public awareness campaign to challenge assumptions that Carers are healthy, able-bodied individuals.
- Develop mandatory professional training across NHS, social work, and third sector services to ensure Carers' own health needs are not overshadowed by the needs of the cared-for person.
- Begin exploratory work on adding **"Carer" as a protected characteristic** within equalities legislation.

4. Expand Access to Respite and Crisis Support

Rationale

Many Carers reported going more than a decade without any meaningful respite or practical support.

Lack of replacement care prevents Carers from attending medical appointments, participating socially, or maintaining employment.

Recommendation

- Establish guaranteed minimum respite entitlements for Carers with disabilities, with both planned and emergency options.
- Provide flexible, needs-led respite that recognises intensity of care, not just diagnosis or eligibility categories.
- Ensure respite options are available **in advance**, addressing Caregivers' inability to plan holidays.

5. Address Rural Inequalities in Access to Services

Rationale

Carers in Highland face lengthy travel times, lack of public transport, digital exclusion, and insufficient local services.

Organisations often assume proximity to Inverness, neglecting remote northern and island communities.

Recommendation

- Fund mobile multidisciplinary teams (MDTs) to deliver health, social care, assessments, and respite directly to rural communities.
- Expand online and hybrid participation for support groups, ensuring Carers with mobility limits can join from home.
- Provide investment in rural digital infrastructure (Wi-Fi reliability, telecare systems).

6. Improve Welfare, Benefits, and Financial Guidance

Rationale

Almost half of Carers were not claiming any benefits, and many were unaware of SDS eligibility or criteria.

The benefit system is described as complex, opaque, and difficult to navigate during crises.

Recommendation

- Implement automatic, proactive **Carer Income and Entitlement Checks** at key points: diagnosis, ACSP review, hospital discharge, and during transitions.
- Create a national **Carer Navigation Service** providing 1-to-1 support for SDS, ADP/PIP, Carer Support Payment, and wider entitlements.
- Review the adequacy of Carer Support Payment, with consideration for **tiered payments based on dependency levels**.

7. Create Carer Wellbeing Hubs and Peer Networks

Rationale

Carers consistently reported social isolation, loneliness, and difficulty accessing social support.

Many expressed a desire for in-person gatherings, drop-ins, and peer-to-peer spaces.

Recommendation

- Establish local Carer Wellbeing Hubs offering drop-ins, wellbeing activities, benefits guidance, digital support, and social connection.
- Ensure provision of both interpersonal and digital support to meet differing access needs.
- Fund peer-led groups, recognising Carers' expertise and desire to learn from one another.

8. Strengthen Employer Responsibilities Toward Carers

Rationale

Carers face major employment challenges, including exhaustion, missed appointments, night-time caring, and lack of workplace understanding.

Carers report that current leave policies are insufficient and often unpaid.

Recommendation

- Encourage employers to adopt care positive policies: extended paid leave, flexible working, Carer Passports, and care aware HR training.
- Introduce tax incentives for employers who offer enhanced support for Carers with disabilities.
- Align employment policy with the intensity of caring roles, not outdated assumptions about who qualifies as a Carer.

9. Improve Access to Diagnostic Pathways and Professional Support

Rationale

Carers described prolonged delays for diagnosis (sometimes six years or more), and lack of formal diagnosis prevents access to essential services.

Difficulty navigating systems exacerbate stress and emotional burnout.

Recommendation

- Prioritise investment in diagnostic services (e.g., neurodevelopmental, dementia, mental health) with mandated waiting-time targets.
- Permit provisional access to support for Carers whose cared-for person **does not yet have a diagnosis**, preventing years of untreated need.

- Introduce multi-service “early-concern” assessments that bypass diagnostic backlog.

10. Embed Lived Experience in Policy Design

Rationale

Carers’ knowledge is repeatedly overlooked despite their central role in managing risk, wellbeing, and care continuity.

Carers described a powerful desire to be heard and taken seriously.

Recommendation

- Require HSCPs and local authorities to codesign Carer services with unpaid Carers who have disabilities or long-term conditions.
- Introduce participatory panels or advisory groups that influence service design, monitoring, and evaluation.
- Provide remuneration for Carers’ policy contributions, recognising their lived expertise and the time they sacrifice.

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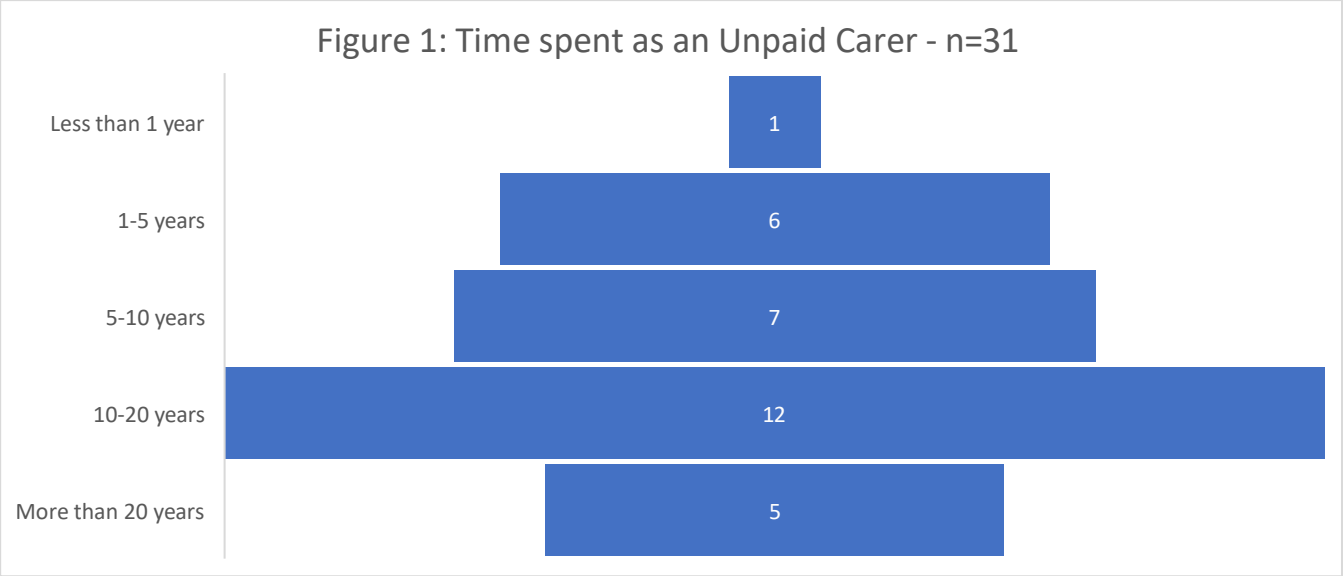
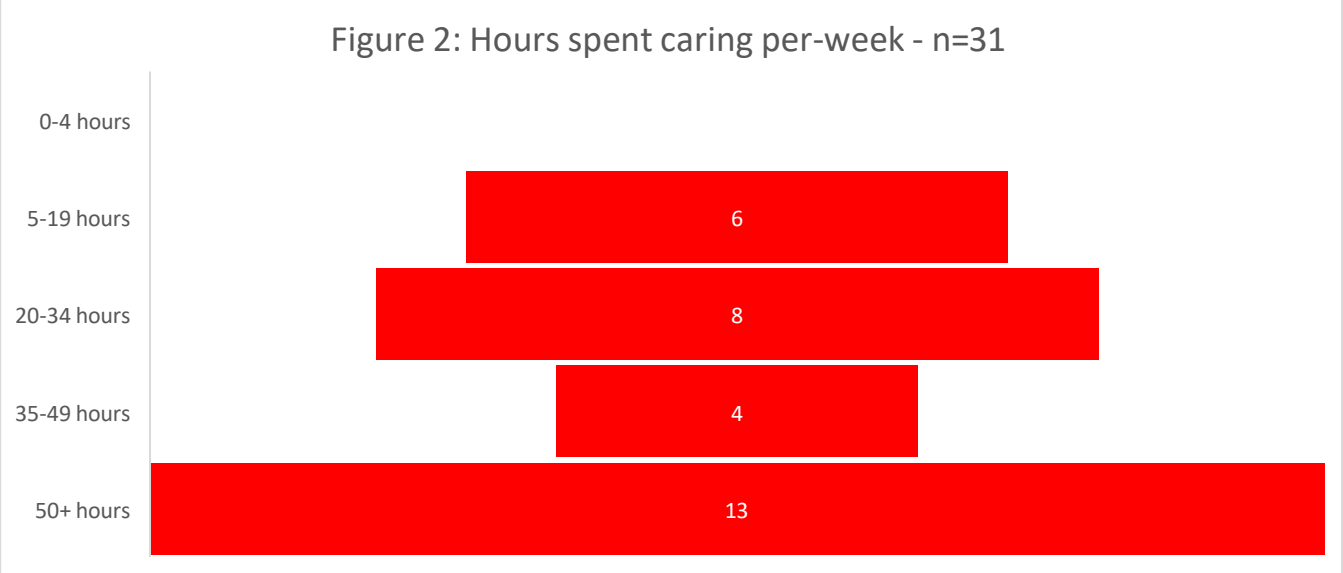
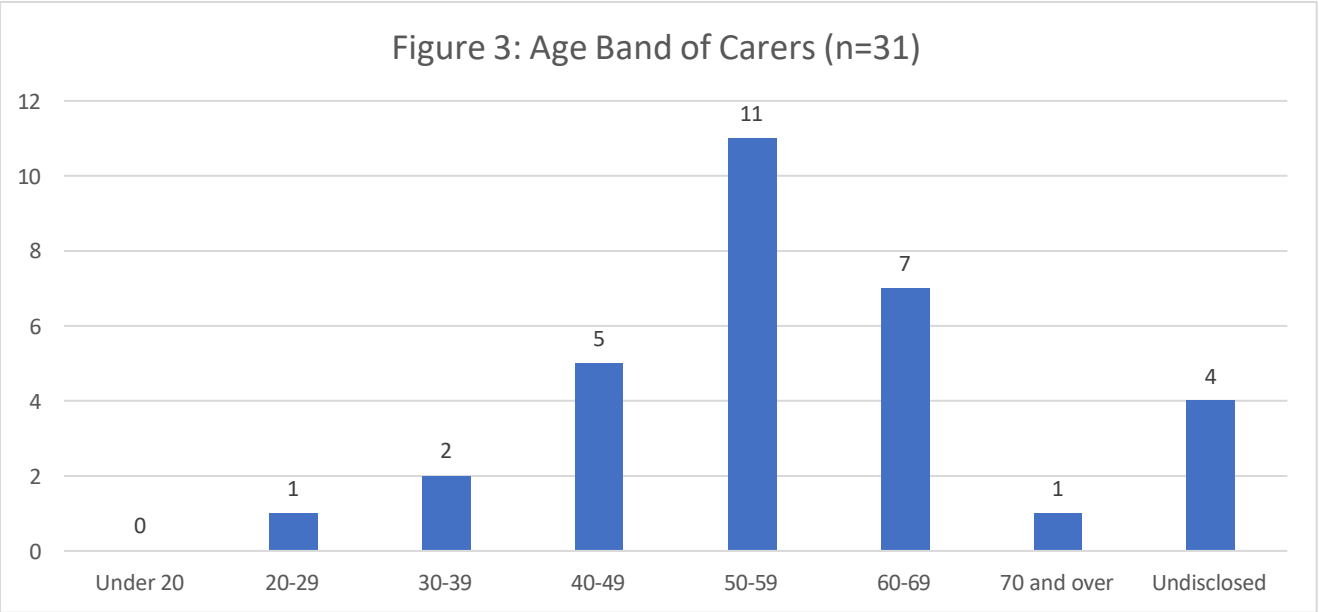
Appendix 1: Statistical Insights into Carers' Experiences

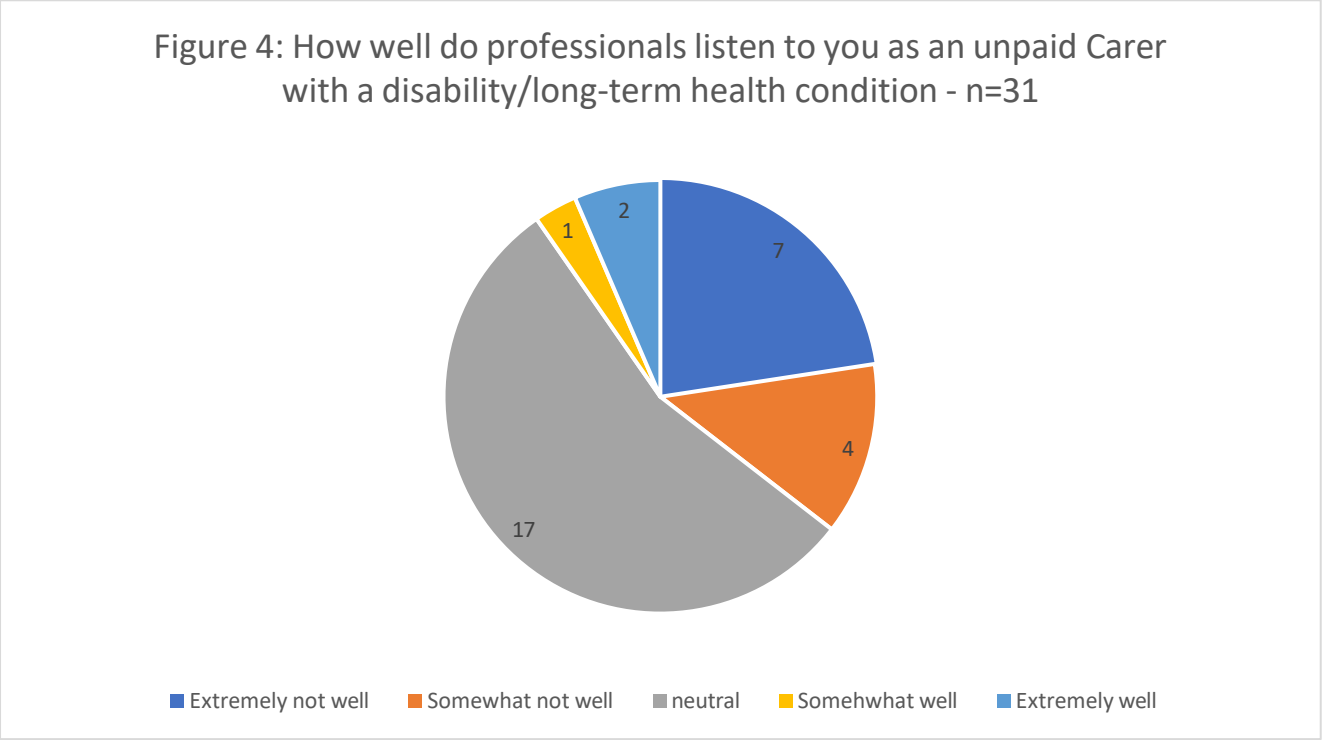
This appendix provides graphical breakdowns of statistical data used in the results section.





Connecting Carers
A better life for unpaid Carers in Highland





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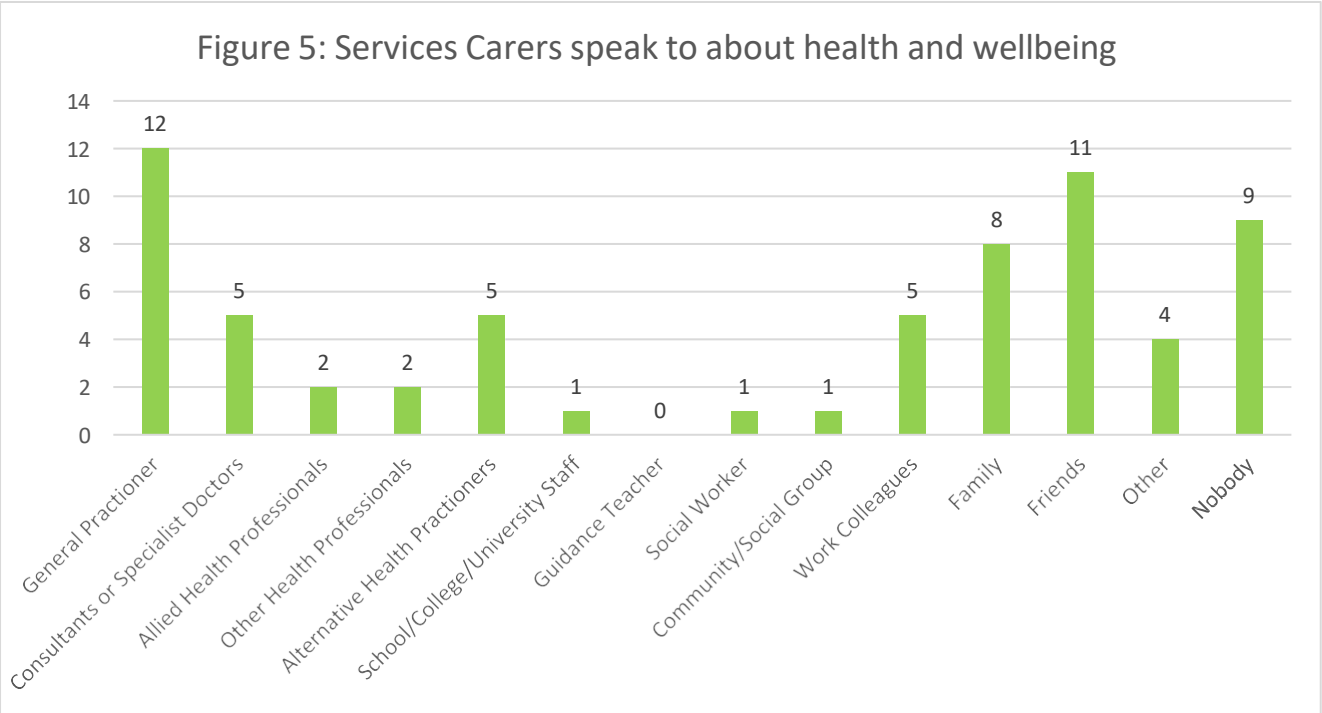
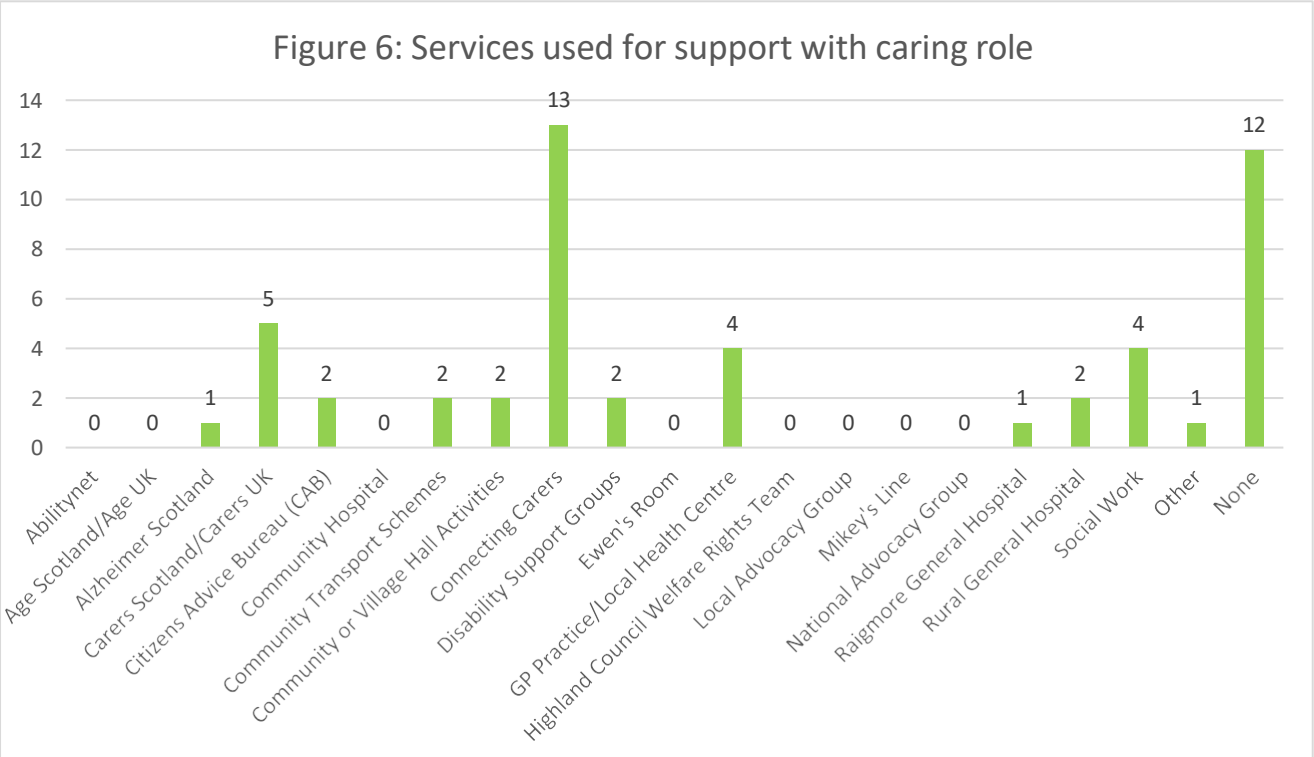




Connecting Carers
A better life for unpaid Carers in Highland

Figure 7: Welfare Benefits claimed by Carers

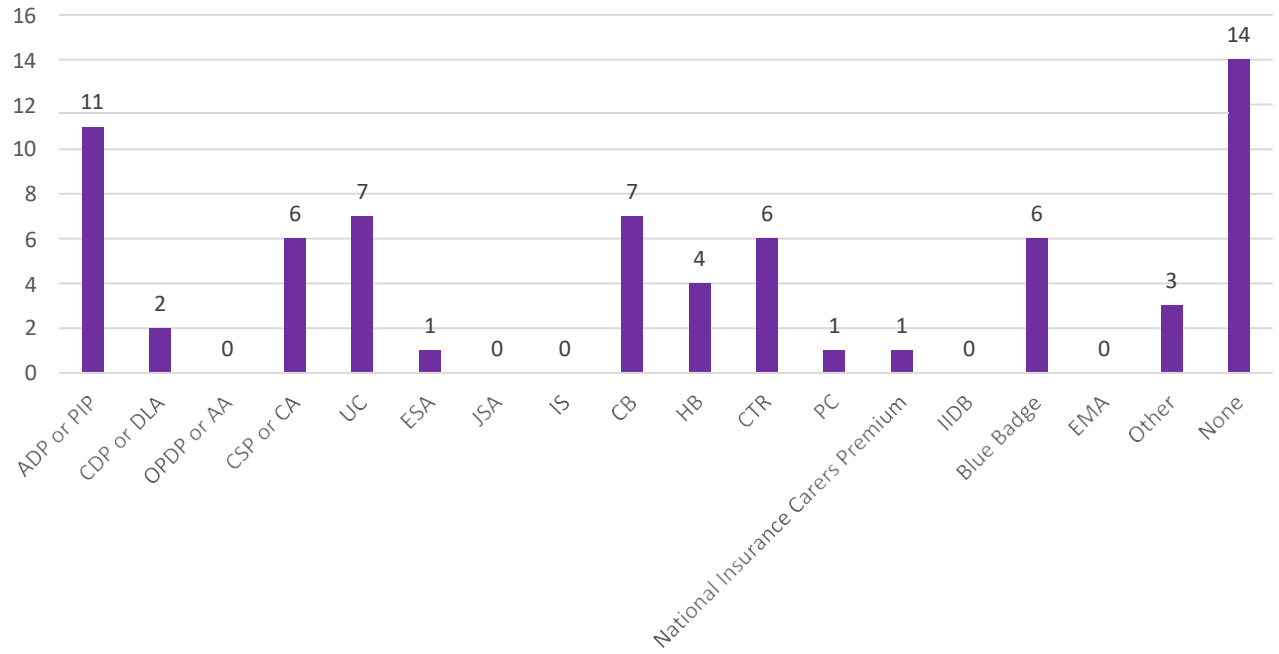
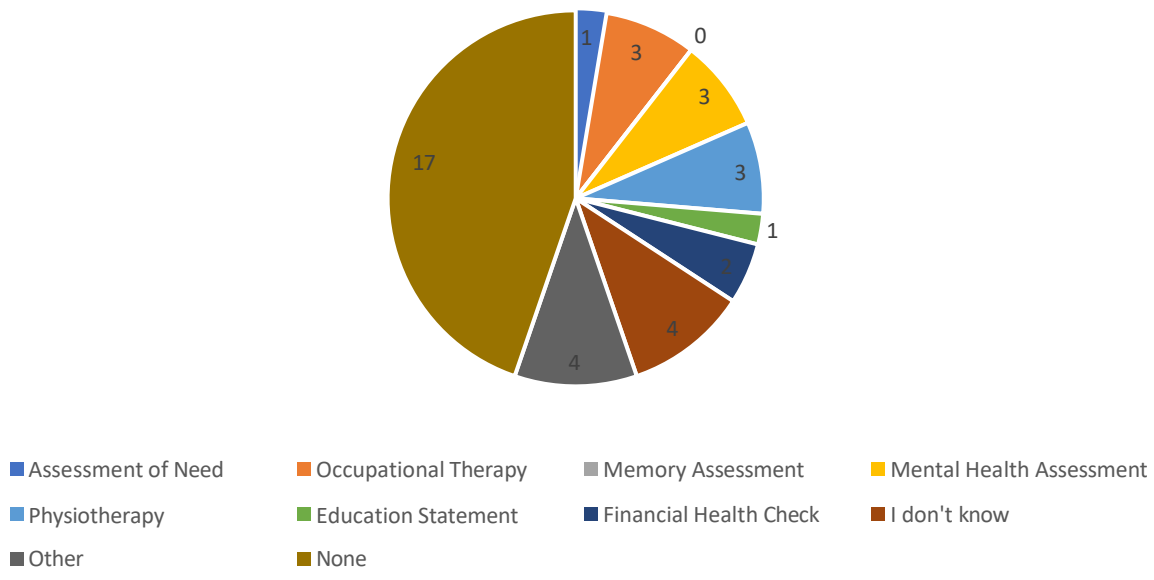


Figure 8: Asessments/Plans offered/completed



Connecting Carers
A better life for unpaid Carers in Highland

Appendix 2: Supplementary Qualitative Data

This section presents additional extracts from focus groups, interviews, and surveys that reinforce and further illustrate the findings discussed in the results section.

On Borrowed Energy: Managing Care While Living with Ill Health

"I don't have much time for my own needs; I do miss my own appointments sometimes or get the wrong days/months."

"I have only had 3 week-long respite sessions in over 20 years. I have just been off work with stress for 3 weeks. I am regularly awake for at least 2 hours during the night and then am at work the next day."

"Laterally [cared-for person] could do nothing for themself in the last 18 months of their life, and I did all that they didn't want [paid] Carers in. And I had done it all. And then after they passed away. You have to drag yourself up by the bootstraps or die."

"You know, in some weeks I'm feeling really overwhelmed, you know, and I'm tired and I'm just like, oh, you know, in other weeks I can manage it a bit better. It just, well, it just depends I suppose, what's going on. But yeah, I do. I do find it quite difficult."

"When I think about it, I'm [late sixties] now and I was fifty when I was diagnosed with [physical condition], so I think it's become the norm in our household, [cared-for person's] diagnosis is the new thing and mine is on the backburner."

"I find it really hard because I've got my own health conditions, my disability, I've got a [physical] condition, so I have to go to the hospital regularly for scans and things. I must take my own medication. So, I am finding it really, really difficult to cope with my own health conditions. And because I'm constantly putting them first, I've turned down hospital appointments because I'm worried about leaving them... I've just been told off actually at the weekend by friends who were like, "if you don't start looking after yourself, then how are you going to look after [cared for person]?""

"Even with friends and family when they ask, "how's [cared-for person] how's things?" well [cared-for person] isn't in pain getting up in the morning, your sort of, because of what I have has become the norm, I cope pretty well, the emphasis has shifted to [cared-for person] and I don't get asked by the family very much at all… I didn't tell my [adult child] I was having surgery, so I got told off for that, they said "why didn't you tell me?" and I said "well what could you do about it, I needed to have it done", "well I need to come up" and they did shock me because they did come up, but, yeah, that would be a good thing, I would like to be on that."

"Affects - unpredictable pain, & mobility, are worst but every area is affected from organisation to forgetting important things, needing help myself with my own stuff to enable me to provide help to my [cared-for persons]."

"I buy some ready meals for my [cared-for person] so I know they are getting good stuff that he needs and a couple of days a week we go out for lunch, I make four for us both a couple of days a week so we can eat together, but on a few days I just grab something quick for myself like chips or cereal. As long as my [cared-for person] eats that's all that matters."

"Groundhog Day": Everyday Isolation in the Lives of Unpaid Carers

"I tend not to seek support when I should due to reluctance to engage with folk."

"I have found myself fairly socially isolated. Whilst this reduces my need to communicate and interact with others, it does leave you feeling lonely and isolated."

"I've become insulated myself, isolated myself. And I don't speak to my friends or want to even go out, because I feel conscious looking at my watch all the time."

I haven't seen as much of my friends, but then we're kind of in that age where we're also busy anyway, you know, like we have to organise it about 5 months in advance before everybody's free."

"Am worried about own mental health. Due to combination of caring role and [neurodiversity], don't get out much so no real friends. Social isolation is a worry."

The Invisibility of Carers with Disabilities and Long-Term Health Conditions

"I have my full-time job and then I am up during the night as well. I am always on high alert, just waiting for the next medical incident. I am worried and anxious. I don't like to burden my work colleagues, so try not to talk about it too much. People say I have a lot on my plate, but they don't really understand and I know they don't know how they can help really as they haven't been in this situation."

"Not just even as Carers, but just as humans, because we do, you know, life is busy and it is, but it's getting it's getting that really important care voice out there and heard."

Rights in Principle, Barriers in Practice: Engaging with Care Services

"When I went to the doctor's, they did write me a sick line, but there was no other offers of extra help or a discussion of what I could do to make things improve."

"But they won't because they won't. They've said "no, no, no, they're still fit enough to understand." But yeah, they might be, but they're not retaining the information. So, I feel like I'm beating my head off a big brick wall with that. Even at [cared-for person's] bedside, they wouldn't talk to me. It was a case of they would talk to [cared-for person] the whole time. They weren't keen on me being there. So, I'm just going to throw it in there because this is stuff that feel free guys connecting here as anyone to tell me if I'm saying it wrong people, you have a right to be a part of your cared for a person's treatment condition."

"I think just better communication with the with the Carers, more care, more support because at the moment I just keep getting told "but they're mobile, they're managing, they're okay."

"I wish my GP practice was more understanding and responsive to my caring role and how this impacts my health conditions and general wellbeing."

"No real interactions with them, but when I do, they tend not to listen. They seem to assume that they know better than myself."

"I haven't mentioned [caring role] to my GP, and when I say to the physio, we look after [cared-for person], it does not convey the depth and scope of what needs to be done, so there is no real 'ask' for them to listen."

"So, [cared-for person] hasn't got a Social Worker. It was an OT that came out to do the assessment. And they've actually been fantastic. And my [cared-for person] wants them; they ask them to do stuff. So, but they has been big, you know, and she's been checking in on me as well, which has been really good… The GP has actually been really good as well, because that same GP had been the person that came out when my [cared-for person] wasn't well and got them put to hospital… So that doctor has actually been really good in playing the role of GP, like as it's meant to be really written on paper. You know, they've checked in with my [cared-for person], checked in with me… We don't have any input from Social Work at the moment because the OT has been doing all the assessments and stuff. But yeah, if we've got two professionals that are pretty good, then that's good going, I suppose. Yeah, because that's still one of the tricky things just now."

"So, doctors, our doctors aren't brilliant at all… they've got a couple of permanent doctors now, but it's always somebody different, so there's no consistency, you know, about your history. Health Visitors are not involved at all… Yeah, there's a new GP at our surgery, I actually went in with a list of my conditions, because you know, they would be

treating me for one thing and I would say "actually, are you aware that I have all this?" and they were like "oh, I don't have time to look back at everything" and I said "this is all relevant."

"I just, I just have to get on with it. And because I left so long and no one listened, I felt I basically just all came to a head and I just got just, yeah, exploded in my head and I just wasn't myself. And then I went back to the doctor and finally someone listened, and I knew it wasn't just me. It wasn't in my head. I knew that something wasn't right."

"They just seem to ignore [caring role]."

"They seem empathetic but not much comes from it except empty promises."

"They try to listen but can't understand the extent. Sometimes they seem as though you are being dramatic."

"Hard to know if they would listen to me differently if I didn't have any conditions . . . also, they may not know about my health conditions, only those of who I care for."

"If you've got a diagnosis, you get this Link Worker, this person is sent to you, if you don't have a diagnosis, you don't get this information early on."

"For one, we are still masking due to COVID. This gets us treated like hypochondriacs and labelled (in healthcare settings) as being 'COVID-anxious', despite COVID having put one of my [cared-for persons] in the hospital after one infection. Having to explain why we are home-educating and wearing masks around others is profoundly demoralising, as it requires having to defend our shielding to people who - in theory - should be fairly well educated about COVID, but who are (almost without exception) not only profoundly ignorant on the subject, but judgmental - which often clearly impacts their desire to help, as shielding from COVID is seen as something we 'choose' to do, rather than something we have been forced into."

"I have met many Carers whose spouses are in early stages not even diagnosis, and they don't know where to go, they don't know that there's support groups, they don't know that there's Connecting Carers, they could have this Benefit, you can do this, you can do that."

"I try to exercise but also have a long-term injury which impacts on that. The nearest swimming pool is half hour away, so I would need to find a minimum of 2 hours to allow for travel there, park, swim, change, travel. Just don't have that amount of free time."

"Trying to access services to try to get some help is very difficult and can be frustrating."

“Care Changed Everything”: Financial Life After Caring Begins

“We were mortgage-free, and we sold the house to fund our retirement, because we've got savings now. You don't get any help at all, benefit-wise, so we're on a very limited income now… you look at websites, you research benefits. And the minute we say that we've got over £16,000 in the bank savings, which we've worked for all our life to retire with, they just go, oh no, you've got money, you're not getting anything… so, you think, it worked all my life. To give myself over a time, and I'm just being penalised for it now.”

“Financial side can be a bit tricky and getting the right information, and I’ve asked the same question to so many different people and get different answers.”

“I keep getting told, “well we’ll give you the number for the Highland Council and they can do an assessment” but I don’t want an assessment, I just want to know what the ground rules are, it’s just really tricky, but as you say, local authorities have different things, it’s not going to be easy is it.”

Beyond Survival: Building Resilience in the Face of Care Challenges

“So, when we're having a really bad day, we get out our memories. And we laugh at the stupid things we've done. Um, and no, it keeps you going. It's not all doom and gloom.”

“But I also think that actually we can lose the community-based and the in person and the actual seeing a face and sometimes just that hug. You know, sometimes you don't need to do anything other than actually just give somebody a little hug, whether that be an in-person hug, an over Teams hug. You know, we've virtual hug, but sometimes that can just make somebody feel they're just not alone and it's not just them that are that are going through that.”

“I exercise daily and also meditate and I'm trying to spend time doing nice things for myself, like getting my nails done etc.”

“Take medication. Try to keep relaxed with relaxation techniques. Sometimes I have managed to pay a cleaner or launderette. I often buy takeaways or convenience food.”

Bi-monthly social sports group (1.5-2 hours). Bath (15-20 minutes). Medication (prescribed but needing to pay out of pocket and quite costly). Frequent takeaway (about 3-4 times a week). Laundry service (once a week).”

“I think it’s about recognising what each person needs, cause what I need to do is physical exercise, for someone else it might be sitting down and painting, going into the garden, going for a bike ride, meditation, so I think, you know, Connecting Carers offers such a wide range of activities, I think that’s probably a good thing because what I need will be different to what someone else needs.”

“I'm on the app and it's really good just seeing like a feed of people just talking about their caring role. And sometimes they're up at like 2:00 in the morning because it's just, they just want to chat to someone because it's just, you know, someone's not sleeping.”

“I try and swim and I do have a massage every now and again. I try and do some Yoga and Stretching. I try and do meditation. I am waiting for help with my pain and had a video chat with the Chronic Pain Team last week, so I am just waiting for the next step. We try and get a takeaway now and again, so I don’t have to cook.”