Understanding the experience of carers on the North Coast

In 2024, Healthy North Coast (HNC) completed a regional health needs assessment (HNA), which provided an overview of health and service needs across the region. While comprehensive, the regional HNA did not allow for detailed exploration of specific population groups, including carers. To address this, HNC committed to a series of targeted needs assessments to better understand the experiences, needs, and service barriers faced by different communities living on the North Coast. This report focuses exclusively on insights gathered through a specific survey for carers, supported by findings from national datasets and published literature.

Recognising and supporting carers is not only a social imperative but an economic and public health priority. Understanding their experiences, challenges, and needs is essential to ensure carers can sustain their caregiving role while maintaining their own health and wellbeing.

Carers help care recipients remain in their communities, maintain social connections, and enjoy a better quality of life – while reducing demand on hospitals and aged care, making them vital to community wellbeing and the health system.

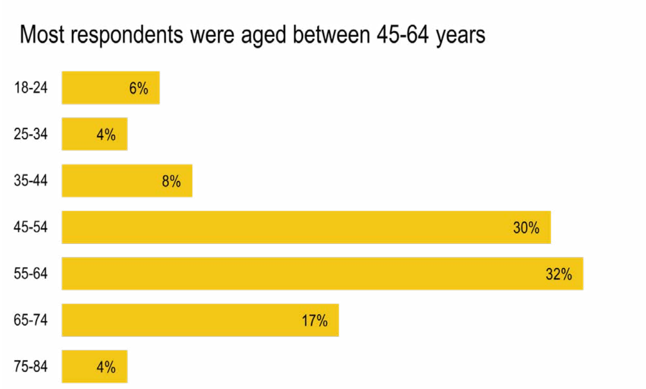
The value of carers extends far beyond the personal support they provide. In 2020, carers in Australia were estimated to provide 2.2 billion hours of unpaid care, representing a substantial economic contribution that would otherwise need to be met by formal health and social services (Carers ACT, 2022).

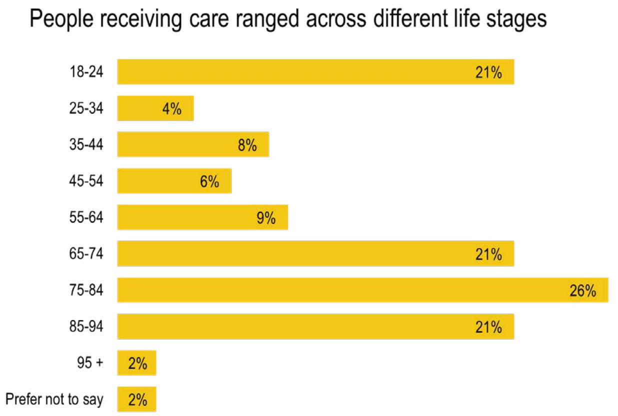
Unpaid caring plays a significant role in supporting community wellbeing across the North Coast region. In 2021, 11.3% of North Coast residents provided unpaid assistance to someone with a disability, health condition, or age-related need. The highest proportions of unpaid carers on the North Coast were recorded in Nambucca Valley (13%), Kyogle (12%), and Kempsey (12%) local government areas, while Byron reported the lowest rate at 9% (ABS, 2021).

There are rising care demands driven by an ageing population, alongside the ongoing support needs of younger people with disability or chronic health conditions.

The Carers Survey received 61 responses, with 8 participants not completing all questions. Partial responses were included in the analysis where data was available.

Most carers were aged between 45 and 64 years (62%), suggesting that many are balancing employment and other family responsibilities alongside their caring role. The people they cared for were primarily aged 75–84 years (26%), with additional caring responsibilities reported for younger adults aged 18–24.





Of the carers on the North Coast:

43% provide care for people living with a disability

31% provide care for people living with age-related physical or mental decline

26% provide care for people living with mental illness

21% provide care for people living with dementia or Alzheimer's disease

These findings point to the diverse and often complex needs of care recipients, underscoring the importance of ensuring accessible, coordinated, and flexible support for carers across the region.

More than half of participants (55%) reported providing over 21 hours of care each week and a further 17% providing 11–20 hours, highlighting the significant time commitment and potential strain on carers. Among care recipients, 47% had accessed My Aged Care, 38% used the National Disability Insurance Scheme (NDIS), and 23% had not engaged with either service. This suggests that while many carers and care recipients are connected to formal support systems, a substantial proportion may not be accessing available services.

Methods

This analysis of the document draws on data initially collected as part of the Older People's Needs Assessment, which included a dedicated survey stream for informal carers. Following the volume and significance of insights provided by carers and recognising that their experiences and support needs warranted deeper consideration, a decision was made to produce a separate report focused specifically on the carers findings.

Survey activities

Carer Survey (August–September 2025)

> Focus areas: Caring responsibilities, service navigation challenges, wellbeing, support needs, loneliness, and impacts of caring.

The survey was voluntary, anonymous, and distributed region-wide.

Data was analysed using PowerBI and qualitative data was analysed with an inductive thematic analysis approach using NVivo.

Carers have an increased risk of physical and mental health problems due to the emotional and financial strain of caregiving.

Caregiving can significantly impact carers' lives, limiting leisure, social activities, and employment opportunities. Caregiving is a chronic stressor that increases carers' risk of physical and mental health problems. Informal carers often neglect their own health particularly their mental wellbeing and may engage in poorer health behaviours compared with the general population (Mohanty & Niyonsenga, 2019). Carers survey participants reinforced this, highlighting that caring responsibilities have profound effects on physical health, mental wellbeing, work, finances, and social lives. Many participants described chronic sleep deprivation, poor diet, and lack of time for exercise or medical care, as their own needs often come second to those of the person they care for.

When participants were asked what would make it easier for them to use health services, the top responses were:

Bulk billing or more affordable care (55%)

GPs who understand carers challenges (47%)

More time to themselves to attend appointments (47%)

There is an opportunity for health professionals to proactively engage carers about their wellbeing and strengthen protective, preventative health strategies.

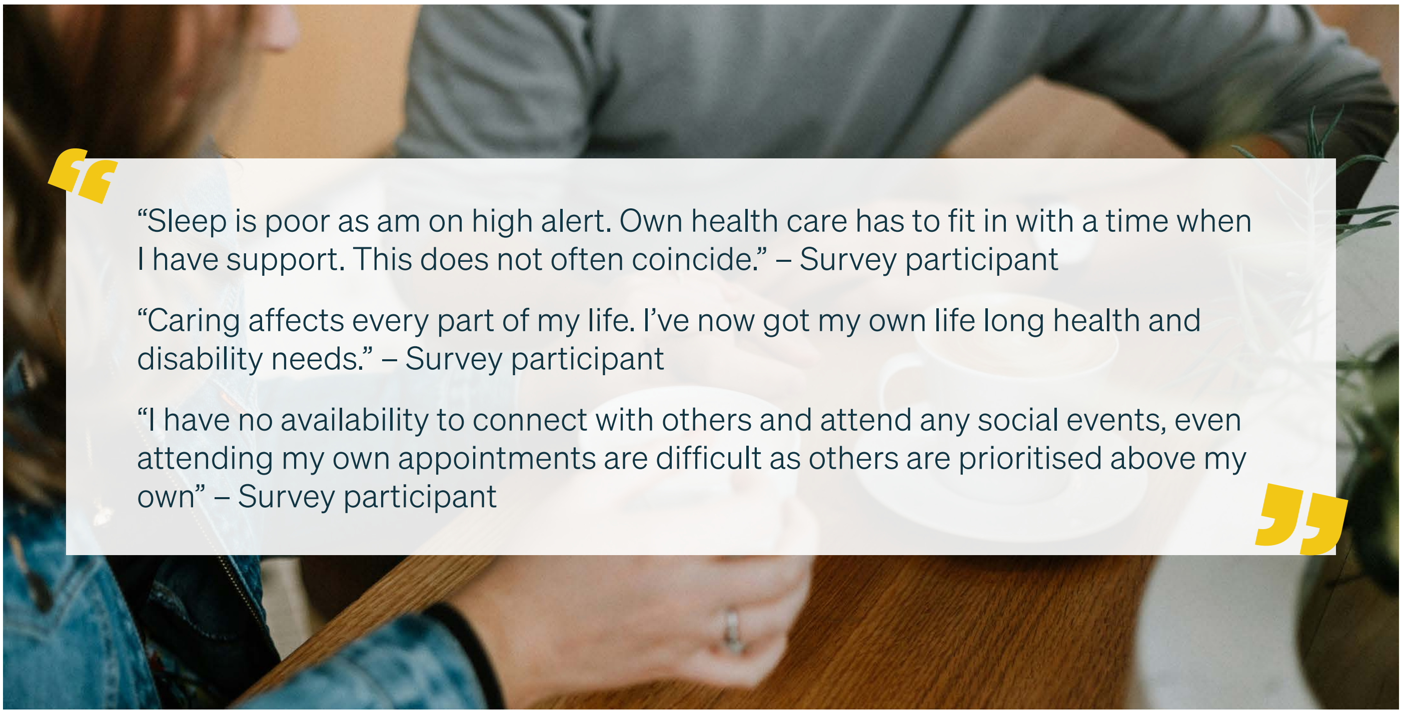
31% of participants had spoken with a GP or health professional about how their caring role affected their own health, while 27% had not but would like to.

57% reported that they had never been asked about their needs as a carer when attending appointments with the person they care for.

Early identification and routine check-ins could facilitate timely referral to appropriate supports, help prevent burnout, and strengthen carers' resilience, although appointment time constraints and funding structures may limit opportunities to do so.

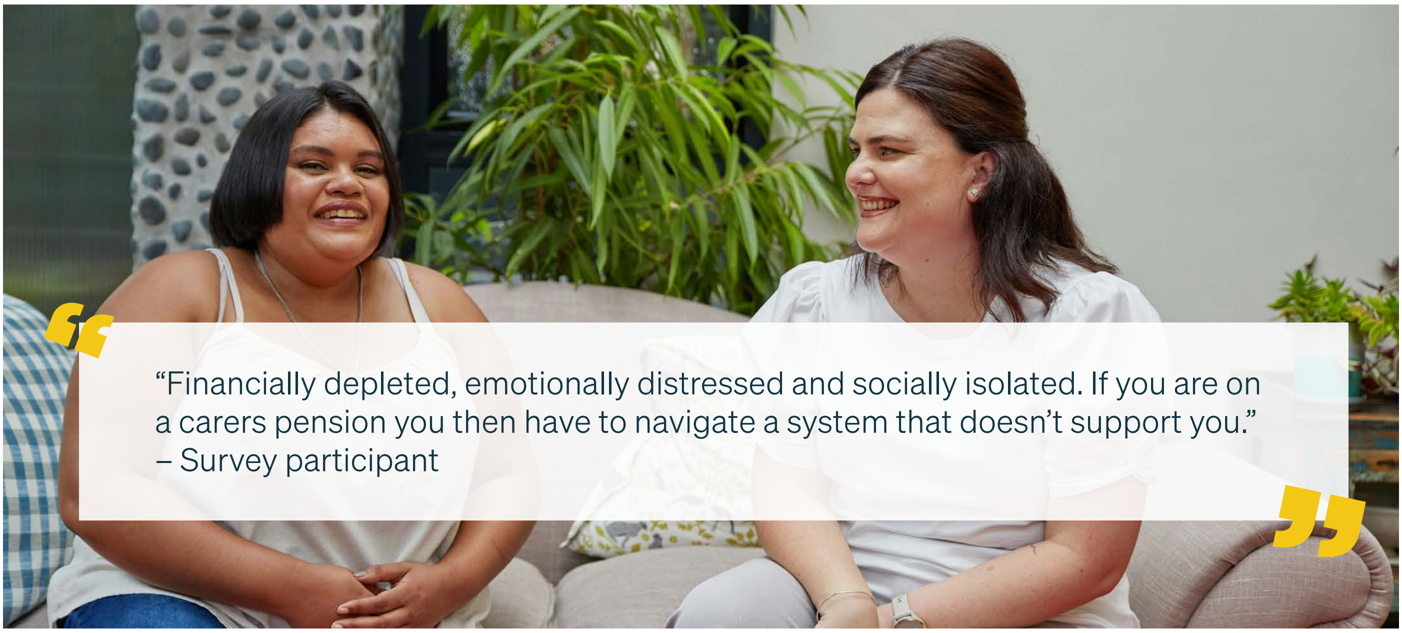
Accessing support is an important way to maintain wellbeing, yet many participants reported limited engagement with formal services.

Over a third of participants (35%) had not accessed any support, while 30% had used some form of counselling or mental health support. Family and friends were identified as the primary source of support by 46% of participants, closely followed by GPs and other health professionals (26%).



> “Sleep is poor as am on high alert. Own health care has to fit in with a time when I have support. This does not often coincide.” – Survey participant
>
> “Caring affects every part of my life. I’ve now got my own life long health and disability needs.” – Survey participant
>
> “I have no availability to connect with others and attend any social events, even attending my own appointments are difficult as others are prioritised above my own” – Survey participant

The emotional strain of caregiving (particularly for loved ones with complex health, disability, or mental health needs) was commonly linked to stress, anxiety, guilt, and burnout. Over half of survey participants (52%) suggested they weren’t able to prioritise their own health, while 41% said they could only sometimes do so. The financial burden was substantial, with many participants noting reduced work hours, lost income or superannuation, and out-of-pocket medical costs. Several participants highlighted the difficulty navigating services such as My Aged Care and the NDIS, and the emotional challenge of transitioning from a family member to a carer role.



> “Financially depleted, emotionally distressed and socially isolated. If you are on a carers pension you then have to navigate a system that doesn’t support you.” – Survey participant

It is important to recognise and support carers, not only through practical assistance but through social and emotional validation of the role they play in the health and wellbeing of those they care for.

Many survey participants (43%) reported that they did not feel understood, recognised, or valued in their role as a carer. This lack of recognition can contribute to emotional strain, decreased self-esteem, and feelings of isolation. When carers feel unappreciated, it can exacerbate stress and burnout, reduce overall wellbeing, and negatively impact the quality of care they provide (Blom, Reis, & Lencastre , 2023).

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Survey participants highlighted that, to support their own health and wellbeing, they most commonly focus on; eating well, exercising, and staying socially connected. Many engage in hobbies and leisure activities.

Experiences of loneliness can compound carer fatigue, leading to poorer physical, mental and social health.

Loneliness is more than a feeling; it is a significant wellbeing issue with wide-ranging impacts on physical, mental, and social health. Loneliness can contribute to stress, poorer sleep, higher rates of anxiety and depression, and a greater risk of chronic health conditions (AIHW, 2025; Weng Cheong Poon, Hofstaetter, & Judd-Lam, 2022).

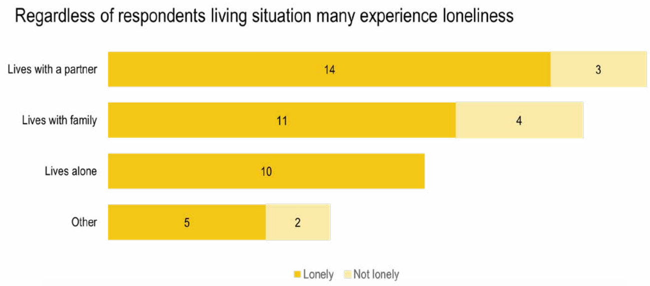
Loneliness can be intensified by the demands of the caring role, which often limit opportunities for social interaction, reduce time for self-care, and create a sense of being solely responsible for another person's wellbeing. Over time, loneliness can compound carer fatigue, contribute to burnout, and reduce resilience, ultimately affecting both the carer and the person they support (Vasileiou, et al., 2017).

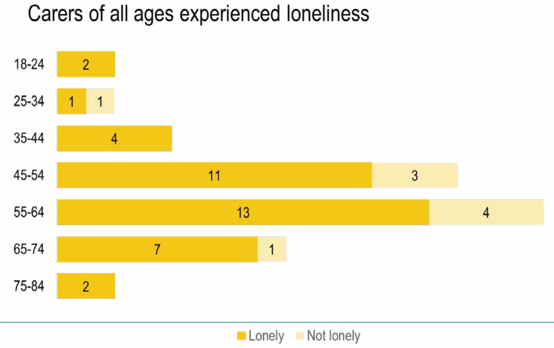
Within the survey, carers reported experiencing social isolation, as irregular schedules and a lack of respite made it difficult to maintain friendships or participate in social activities.

Understanding the drivers and impacts of loneliness among carers is critical to designing supports that protect their health, strengthen social connections, and reduce the emotional burden of care.

Using the UCLA-3 Loneliness Scale, well over half the respondents of each age group reported feeling lonely. Loneliness was evident across all living situations, including carers living with a partner or family. Household social connection does not necessarily prevent isolation. Carers living alone also reported high levels of loneliness, highlighting the emotional impact of caring responsibilities regardless of living arrangement.

Support measures identified by respondents to reduce feelings of loneliness included respite breaks (54%), counselling or mental health support (44%), and regular contact with friends or family (42%).





Opportunities

- Strengthen recognition and inclusion of carers within the health system
- Improve access to flexible primary and community care
- Enhance navigation support for My Aged Care, NDIS, and local services
- Increase availability, flexibility, and awareness of respite options
- Strengthen mental health and social connection supports for carers
- Build stronger local data and insights on carers
- Support carers to maintain their health and participation through primary care partnerships

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