

INQUIRY INTO PREVALENCE, CAUSES AND IMPACTS OF LONELINESS IN NEW SOUTH WALES

Organisation: NSW Carers Advisory Council

Date Received: 29 October 2024

Committee Chair
The NSW Legislative Council's Standing Committee on Social Issues
NSW Parliament House
6 Macquarie Street, SYDNEY, NSW 2000

Re: Inquiry into the prevalence, causes and impacts of loneliness - NSW Carers Advisory Council submission

Dear Committee Chair,

The NSW Carers Advisory Council (the Council) writes to you regarding the terms of reference for the inquiry by the Standing Committee on Social Issues into the prevalence, causes and impacts of loneliness. We raise significant concerns to the Inquiry about Carers in NSW which we feel require attention and responses from Government. Carers often face several hidden issues that they may not want others to know about as they are already a population group who exist on the peripheries of society within strong discourses and paradigms that beholden caring as a duty. We know carers will fail to highlight their struggles, often due to feelings of guilt, shame, or inadequacy.

The response from Council is also prefaced with how we have understood the concept of loneliness and isolation and how this may be different for different population groups based on cultural expectations of social connection. We therefore suggest that there must be consideration of the various interpretations of loneliness and social isolation. We have used the description of 'Social isolation' as 'a state in which a carer lacks a sense of belonging socially, lacks engagement with others, and has a minimal number of social contacts and therefore is devoid of quality relationships'. Accordingly, we have interpreted 'loneliness as a 'subjective feeling, often linked to emotions, which is based on the carer's perception of the quality of their social connections. From this viewpoint, the concept of loneliness and social isolation are distinct as a carer may have social connections and still feel lonely or be objectively isolated but not experience loneliness.

Throughout our submission the Council highlights that there are hidden issues related to caring which are well documented and are often kept private due to societal expectations, a desire to appear strong, and the fear of stigma, which further compounds the challenges carers face. Social isolation is commonly reported by carers. This statement is backed with a plethora of research which evidences that more than a quarter of carers of people with psychotic disorders experienced social isolation. Carers may lose important social support or withdraw from others to cope with the demands of caring. Relatives and friends may also distance themselves from carers due to a lack of relational reciprocity and the long-term nature of caring duties. The stigma associated with health

conditions and disabilities in some communities may further influence carers to withdraw from social interactions and activities.

The Council provides advice to the NSW Government on legislation, policy and other matters relating to carers. For more information, about the Council and our members, the majority of whom are carers, please visit our website at <https://dcj.nsw.gov.au/community-inclusion/advisory-councils/nsw-carers-advisory-council.html>.

Following are the Council’s responses to the terms of reference.

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<p>a) the extent of loneliness and social isolation in NSW and how this is measured and recorded, including opportunities for additional and/or improved data capture</p>	<p>Given the increasing burden of loneliness and its impact on health and wellbeing, it is imperative that this public inquiry is the catalyst for public and policy interest in loneliness and social isolation and we are specifically focused on advocating for the interests of Carers. However, to put this into context we highlight there are issues with the quantification of the extent of or how loneliness and social isolation are measured in NSW. We know that the number of carers is under measured as many carers fail to identify or fail to realise that they are carers. Therefore, for the Council it is problematic to provide several carers who have issues related to loneliness. COVID-19 is evidenced to have increased loneliness and isolation for many groups of carers and whether we can overcome this and dissipate the burden of isolation is still being investigated.</p> <p>We know from anecdotal evidence and from our networks that carers report high levels of loneliness, and this is of concern to the Council, and we therefore highlight some of our concerns.</p> <p>Concerns About Loneliness Impacting Carers:</p> <ol style="list-style-type: none"> 1. Emotional Exhaustion and Burnout: Loneliness can increase emotional strain, leading to burnout and negatively affecting the carer's well-being. 2. Isolation from Social Networks: Carers often become isolated from friends and family due to the demands of their role, leading to feelings of loneliness. 3. Mental Health Decline: Persistent loneliness can exacerbate feelings of depression, anxiety, and stress, affecting the carer's overall mental health. 4. Physical Health Deterioration: Carers experiencing loneliness may neglect their physical health, leading to fatigue, illness, and decreased life expectancy. 5. Lack of Peer Support: Without a support network of fellow carers, individuals may feel isolated in their struggles, lacking emotional outlets or shared experiences.

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	<p>6. Social Stigma and Invisibility: Carers often feel overlooked or undervalued by society, which can contribute to loneliness and a sense of invisibility.</p> <p>7. Financial Strain: Loneliness may arise from limited opportunities for employment and income due to full-time caregiving responsibilities.</p> <p>8. Loss of Identity: Carers may feel that their personal identity is lost as they focus solely on their caregiving role, leading to isolation and loneliness.</p> <p>9. Reduced Access to Resources: Carers, especially those in rural or underserved areas, may feel cut off from services, support, or respite care, exacerbating feelings of isolation.</p> <p>Suggestion: Social mapping of the personal networks of people who are not carers and people who are carers would demonstrate how impoverished the circumstances of carers are by comparison with other people. Then we could assume that there are some validated methods by which to correlate the density or paucity of social interactions with social isolation and loneliness.</p>
<p>b) the identification of populations most at risk of loneliness and social isolation</p>	<p>Carers often become isolated from friends and family due to the demands of their role, leading to feelings of loneliness. It is not that they seek to be distant, however, it is often a symptom of the burden juxtaposed with the reality of caring that something must give. Carers are everyone, they are me, they are members of our Council, they are family members, they are people next door. They are not categorised into any one category however they all face significant challenges with loneliness and yet it is one of the least discussed issues being faced as related to strong discourses that ‘we should care’ or ‘it is our role to care’.</p> <p>We suggest that there are groups within society who may be more at risk of loneliness due to caring responsibilities and we continue to brief Minister Harrison on these issues, for example, carers living in rural, regional and remote areas, young carers, CALD carers, First Nations Carers may be at greater risk of social isolation due to particular issues within their belief systems and communities which prevent support being provided, or being available. The isolation from social networks is not a choice, it is one of the easiest things to give up when carers are trying to juggle multiple demands with limited time.</p> <p>Carers frequently experience isolation as their caregiving responsibilities prevent them from maintaining friendships or social activities, but admitting this may feel like a personal failure in managing their life, we highlighted this with a vignette of a carer from Council networks:</p> <p><i>Naomi’s Silent Struggle: Naomi is 65, living in regional New South Wales. By trade she is a nurse, she is a career long carer, she is a wife, a mother, a sister</i></p>

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	<p><i>and there is little left after this - she wears many hats – carer, worker, and the backbone of her family. She cares for her 91-year-old father who lives alone and won't consider living with Naomi, this situation is becoming more and more difficult as he has increasing physical needs. Naomi has guardianship and caring responsibilities for her 62-year-old cognitively impaired morbidly obese sister, who has complex health needs, she cannot read or write, she depends on Naomi for day-to-day support. Despite her age, Naomi is still working part-time, trying to balance her job with the immense responsibility of navigating the complex aged care and disability systems. She spends hours arranging appointments, filling out paperwork, and coordinating care services, only to find that gaps in these systems leave her covering the shortfall. She retells her story many times, the gaps in the system mean there isn't one place to hold all the information related to her caring responsibilities, the frustration she feels impacts on the isolation of trying to be everything to everyone.</i></p> <p>For Naomi, its endless. Her days are long, often spilling into sleepless nights worrying about what will happen when she's not around. Exhaustion has become her constant companion. While she takes pride in her role and feels it's her duty to manage things on her own, the weight of it all is crushing. She's fiercely independent and refuses to let others in, believing this is her burden to bear alone. But behind the pride, Naomi is lonely. Her social life has withered away, her health is deteriorating, and stress has become overwhelming. She avoids talking about how much she's struggling, afraid of appearing weak, and convincing herself that asking for help would mean she's failing her family. Each day feels like another mountain to climb, with no end in sight, and the physical and emotional toll is beginning to feel unbearable.</p> <p>Suggestion: To the extent that leisure activities provide people with connection and social engagement we feel that policy, funding and programs should be developed to encourage connected for carers who do not have leisure opportunities / skills / behaviours or at risk for social isolation and loneliness. Poverty which is a compound issue of caring due to limited employment opportunities creates further barriers to social connection a. We suggest that these populations or cohorts could yield previously unidentified groups at risk; however as already stated we suggest that concerted attempts need to be made to measure the quantum of carers. We have previously briefed Minister Harrison on the lack of data which attempts to look at the dispersion of carers particularly in rural, regional and remote areas where supports are limited.</p>
<p>c) evidence of the psychological and physiological impacts of loneliness on people, including young people, the elderly, those living with a</p>	<p>Persistent loneliness can exacerbate feelings of depression, anxiety, and stress, affecting a carer's overall mental health. Recognising loneliness as a mental health issue is a positive step because it highlights the emotional impact of caregiving, ensuring that carers' mental health needs are taken seriously. If the outcome of this Inquiry was to lead to increased access to support services such as counselling, peer networks, and policies designed to help carers manage their emotional well-being this would be good however the design of any such supports would need to be flexible to take on board the difficulties and complexities of carers even being able to give time to being involved in such consultations.</p>

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<p>disability, those living in regional areas and the bereaved</p>	<p>Statistics and research support what we know that many carers suffer from depression, anxiety, or loneliness but may hide these feelings to avoid being seen as mentally fragile or unfit for the caregiving role. Recognition of the mental health impacts on caring and the isolation that comes with it could help reduce the stigma around seeking help for loneliness and other mental health challenges, we would like to encourage carers to reach out without feeling ashamed. However, this recognition can also unintentionally further stigmatise the role of caring. We also know that many carers don't want to be identified as carers, many do not recognise the role that they play as a carer as they believe it to be their duty, others just take each day and don't have the mental energy to enter the narrative about caring.</p> <p>The Council supports all carers and suggest that labelling loneliness as a mental health issue, it might create perceptions that caregiving inherently causes emotional fragility or burnout which it doesn't – it is the lack of systemic supports, the changes to the NDIS and the accessibility of support for carers that causes us to be mentally overwhelmed. Carers being isolated, exhausted and mentally challenged does overshadow the positive and rewarding aspects of the role of being a carer and many carers would not change this – but they do sometimes need a breath, their own space and some time to regroup and rebuild their resilience. We also caution seeing all carers as the same, they are not a homogeneous group and seeing the uniqueness of caring, their social environments and situations should be viewed with caution otherwise we reinforce negative stereotypes, such as the notion that carers, especially and more often women, are more vulnerable or emotionally burdened. This risks pathologising the caring experience, potentially devalue the strengths, resilience, and significant contributions that carers make. To address this, public discourse should balance acknowledging carers' emotional challenges with celebrating their resilience and contributions, while ensuring access to mental health support is normalised and seen as a sign of strength rather than weakness.</p> <p>Suggestion: we consider primary health services and care are a good starting point for gathering evidence, if GPs have the time and the training to ask the right questions of carers who may often take the person, they care for medical treatment we can hope to build our profile of carers challenges with loneliness. For example, there are specific measurement tools for carers of people dying which monitors the physical and psychological health of these carers throughout the palliative care journey. Palliative care is the only medical speciality which specifically focuses on a patient AND family / immediate carers with a view to providing support for physical, social and spiritual care. It could be useful to look for evidence within the end-of-life space for the impacts of isolation where good pall care is unavailable, perhaps.</p>

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	<p>We also suggest specific mental health services for Carers: Implement mental health initiatives specifically for carers, including counselling and support hotlines, to address emotional exhaustion and loneliness.</p>
<p>d) evidence linking social connection to physical health</p>	<p>Without a support network of fellow carers, individuals may feel isolated in their struggles, lacking emotional outlets or shared experiences. Caring does become physically draining as well as mentally and socially isolating. The aftermath of caring often leaves older people depleted and their bereavement unbearable as their identity as a widow becomes the next identity after being a carer. Whilst caring experiences occur across the life span, 50% of people aged over 60 are at risk of social isolation and one-third will experience some degree of loneliness later in life. They are unable often to carry this new mantle and withdraw into further and increased social isolation. Their physical health manifests, often because they have not had the time to focus on their own health issues during intense periods of caring.</p> <p><i>Jim is a strong, silent man, the kind who quietly carried the weight of the world on his shoulders without ever asking for help or letting us know the reality of his caring situation. When his wife Jenny, 15 years his junior, was diagnosed with lung cancer at 50, Jim was devastated but determined. They had always done things together, even joining a Cancer Support Group in the early days of her illness. But as Jenny's condition worsened, they slowly withdrew, retreating into the isolation of their two-storey home. For five years, Jim cared for her on his own, never complaining, never letting on how hard it had become. Each night, it took him three hours to get Jenny up the stairs to bed. The process was gruelling, and every step felt like an insurmountable task. But Jim never told anyone. He feared that if people knew how difficult it had become, they might think he couldn't care for the woman he loved so deeply. He couldn't bear that judgment, so he kept his pain and exhaustion to himself.</i></p> <p><i>When Jenny finally passed, Jim was left with nothing but silence. At 80 years old, he felt hollow, as if her death had taken away any reason he had to keep going. The support group was a distant memory, and reconnecting felt impossible. His home, once filled with the warmth of their shared life, now felt like an empty shell. His loneliness deepened, but Jim couldn't imagine reaching out. He just sat in that quiet house, surrounded by memories, feeling like the world had moved on without him. His own issues became the pressing consideration daily, his breath restricted and his tiredness overwhelming. Jim was offered open heart surgery, the only option to now give him extension of his own life – he has chosen not to accept this. The situation is so immensely sad, he cared for my mother and now he chooses to die to join her and not to accept treatment.</i></p> <p>The individuality of the experience of loneliness and isolation may cause difficulty in the delivery of the design and delivery of standardised interventions. As we have shown with Jim's story he is not alone, and we</p>

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	<p>suggest that there is no one-size-fits-all approach to addressing loneliness or social isolation especially in older people who have often given all that they have left to caring for the one that they have loved for their whole life. Suggestion: We strongly recommend tailoring interventions to meet the unique needs of individuals, specific groups, and varying degrees of loneliness. Targeted efforts are essential to identify which interventions are most effective for whom, in which contexts, and by what means.</p>
<p>e) factors that contribute to the development of transient loneliness into chronic loneliness</p>	<p>This is a significant issue. The experience of loneliness is normal and requires less or more resilience to manage as part of the human condition. However, the transition to chronic loneliness is linked to those factors which have eroded resilience to the point where social engagement and self-help strategies are no longer sufficient to manage loneliness as an episodic experience. This is analogous to the experience of poor mental wellbeing which can slide into mental illness when a person's resilience/self-help strategies no longer maintain mental wellbeing within a bandwidth which maintains function according to the person's circumstances. This question invites reflection around the role of other people in assuaging loneliness and where we must tackle loneliness at an existential level by ourselves i.e. the differences between being alone and being lonely. As with all forms of adversity, our understanding of resilience is key here.</p> <p>Loss of identity: Carers may feel that their personal identity is lost as they focus solely on their caregiving role, leading to isolation and loneliness, again we are able to provide the voice of a carer to illustrate the reality of this situation.</p> <p><i>Amber spends much of her time lost in thought as the weight of the day presses down on her. Somewhere in the blur of responsibilities, she has lost herself. She is a carer now, a woman consumed by the endless tasks of looking after others – her aging mother, her young nephew. She can't remember the last time she'd done something just for herself. There was a time, not so long ago, when Amber felt alive. She used to travel with friends, laughing on beaches, exploring new cities, and filling her days with excitement and adventure. Those memories felt distant, like they belonged to someone else. She had been so full of energy, driven by a sense of purpose that was her own. She barely recognises the woman staring back at her in the mirror. Every day is the same – appointments, medication schedules, and the relentless demands of caregiving. The responsibilities had swallowed her whole, leaving her with no time to dream, to feel free, to be Amber. She has become someone different, someone defined by duties she hasn't chosen, and she doesn't know how to get back to who she once was. Most days, she isn't even sure if that version of her still exists. The silence in the house is deafening, she doesn't know who she is anymore.</i></p> <p>Amber represents many of the carers we know and the carers we represent. As Carers, we often feel we have lost our personal identity, it is hard to not be defined by their caring role. We feel ashamed and reluctant to express that we wish to be something different than what we are now,</p>

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	<p>we fear we sound ungrateful or selfish. We know there is no-one to hear anyway, so what difference does it make? This Inquiry could make and be the difference, by listening to the carers stories that we present, and by curiously exploring the possibilities to empower carers and give them options.</p> <p>Solution: To address this issue, it is essential to acknowledge and validate the complex experiences of loneliness and identity loss that many carers, like Amber, endure. While loneliness is part of the human condition, chronic loneliness results when resilience erodes, and personal resources are depleted – as highlighted earlier in our submission. For carers, whose roles often redefine and restrict their identity, a solution lies in empowering them with opportunities for social engagement and identity renewal beyond caring. Supporting initiatives that build resilience, such as structured respite, community support networks, and access to counselling, can help carers reconnect. Additionally, broadening societal awareness of carers' experiences and providing practical options for them to pursue personal goals will foster a sense of belonging and self-worth. This Inquiry has the potential to create meaningful change by giving carers a platform to share their experiences, enabling pathways for personal fulfillment alongside their vital caregiving roles.</p>
<p>f) the financial costs of loneliness to the NSW budget and the state economy and steps that can be taken to reduce the financial burden of loneliness</p>	<p>Loneliness may arise from limited opportunities for employment and income due to full-time caregiving responsibilities. There is data available through Carers NSW which I presume they will provide to this Inquiry about the burden and cost of caring. The Carers + Employers program (C+E) defines best-practice standards for supporting staff with caring responsibilities and is the only accreditation program that formally recognises carer-friendly employers in Australia.</p> <p>This is clearly demonstrated with the need and push for workplaces to be more carer friendly. However, we also know that the percentage of workplaces who provide flexibility for carers is limited and whilst some government departments in NSW are leading the way this is a whole area that must be pursued.</p> <p>Occupation is a known factor is good mental health, and the links between good health and absence of loneliness yield some useful data therefore occupation and employment must be supported. Without adequate policies, workplace support and paid carers to take over from the carers we support this again compounds loneliness as work is often difficult to maintain. The workplace accreditation via Carers NSW available throughout Australia seeks to create, advocate, support and build the number and opportunities for carers to be part of carer-friendly workplaces. have a positive impact on staff wellbeing, workforce management and wider corporate social responsibility.</p> <p>This can be a struggle, Hannah the brave relative of a Council member, explained how this becomes juxtaposed with the impossible:</p>

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	<p><i>As time goes on, the weight of responsibility grew heavier for her. With bills piling up and the financial strain worsening, she was forced to return to work, despite the emotional and physical exhaustion that lingered from years of caring. The decision to enter the paid workforce wasn't one wanted to make, but the family had no choice. Money was running out, and without her husband's income, the family was barely scraping by. Hannah thought that work might connect her with people however the workplace responsibilities and culture meant that she couldn't join the social activities as she needed to go home.</i></p> <p><i>The more hours she spent working, the more the responsibility of caring for Tom fell onto Anna, now just 14. It wasn't fair, but life had stopped being fair a long time ago. Anna tried her best, but caring for her brother was overwhelming. Tom's condition had worsened since their father's death — he rarely spoke, refused to eat meals with them, and was now completely disconnected from reality, locked away in his room. Anna would knock gently on his door, pleading with him to come out, but he never did. Instead, she'd leave food outside his door, often untouched by morning.</i></p> <p><i>The burden on Anna grew daily. She struggled with school, barely able to focus on her own work while worrying about her brother. At night, she could hear her mother crying softly in the other room, though they never spoke about it. Both were crumbling under the weight of Tom's needs, but neither could find a way out. Hannah carried the guilt of knowing that Anna was losing her own childhood to care for her brother, just as Hannah had lost so much of herself. They were trapped in this exhausting isolating cycle, financially struggling, emotionally depleted, and without the support they desperately needed. Despite their love for Tom, the isolation was unbearable. Each day felt like an uphill battle, and the once tight-knit family was slowly being torn apart by the weight of caregiving, grief, and financial despair. Even when they were together, the loneliness and helplessness between them seemed impossible to bridge.</i></p> <p>Hannah's situation is just one example of the financial strain which in part, creates isolation for carers who face significant financial difficulties due to reduced work hours or the high costs of care, yet they may not disclose this because they feel embarrassed, or fear being seen as inadequate providers.</p> <p>Solution: To address the deep-rooted loneliness and financial strain that carers face, we need to advocate for policies that enhance workplace flexibility, financial support, and social integration for those with caregiving responsibilities. Programs like the Carers + Employers (C+E) initiative exemplify the standards needed to support carers, but adoption across workplaces remains limited. Advocacy should focus on expanding C+E accreditation nationally to build carer-friendly workplaces that allow carers to balance paid employment with their caregiving roles. This includes advocating for flexible work hours, flexible working options without explanation, and dedicated carer leave policies, which would enable carers like Hannah to rejoin the workforce without compromising their caring responsibilities or further burdening family members.</p>

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	<p>Additionally, financial support through government subsidies, paid respite care, or carer stipends would address the financial strain and the resulting social isolation that comes from reduced income. By prioritising these policies, we can create pathways for carers to stay connected, supported, and economically stable easing the cycle of isolation that so many experience.</p>
<p>g) the identification of existing initiatives by government and non-government organisations to mitigate and reduce loneliness and social isolation</p>	<p>As we already highlight whilst carers are identified the data is problematic as it does not break carers into specific groups, nor does it focus on geographic location therefore any initiatives would first need the data to focus on those most at risk primarily. We believe that initiatives that could be suggested are provided below but these are not exhaustive:</p> <ul style="list-style-type: none"> • Access to Resources: Carers, especially those in rural or underserved areas, may feel cut off from services, support, or respite care, exacerbating feelings of isolation. The Council in our Strategy are prioritising the access to resources specific to digital resources. We have recently briefed the Minister about issues of resources and impact of digital for Carers in Regional, Rural and Remote areas of NSW. We have highlighted the pros and cons of access to resources to reduce isolation and provide support with digital platforms. • Technology and Virtual Platforms: Promote the use of technology (e.g., apps, online forums) that enables carers to connect with others, access services, and participate in virtual communities. The Council has prioritised the explored and impact of digitisation on carers in our 2024-2025 Strategy (https://dcj.nsw.gov.au/community-inclusion/advisory-councils/nsw-carers-advisory-council/overview.html) • Struggles with Asking for Help: Many carers are reluctant to ask for help because they don't want to appear weak, burden others, or admit they're struggling, which perpetuates their isolation and stress. <p>Strategic Solutions to Overcome Loneliness Among Carers:</p> <ul style="list-style-type: none"> • Enhanced Respite Care Programs: Governments and organisations can increase access to respite care services, allowing carers time to rest and reconnect with social networks. • Carer Support Networks: Create or strengthen local and online peer support groups where carers can share experiences and resources, reducing isolation. • Public Awareness Campaigns: Raise public awareness of the challenges faced by carers to reduce social stigma and acknowledge their vital role in society, fostering a sense of inclusion. • Community-Based Programs: Develop local community initiatives that involve carers in social and recreational activities, providing opportunities for connection outside of their caregiving role.

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	<ul style="list-style-type: none"> • Recognition and Inclusion in Health Systems: Recognise carers as key partners in health systems and include them in decision-making processes regarding the care of their loved ones, reducing their sense of invisibility. • Accessible Carer Training and Education: Offer education and training for carers to improve their skills and confidence, reducing the emotional burden and sense of isolation. <p>There are also examples of programs which could be utilised that are known to connect Carers which are used overseas, For instances, increasing interest in the “Compassionate Communities” approach to better cross sector collaboration and functional communities is a good example of an initiative which can mitigate loneliness and social isolation, particularly in regional, rural and remote settings i.e. place based network contexts (https://compassionatecommunities.au/).</p> <p>Solution: To effectively support carers, we advocate for this Inquiry to prioritise a comprehensive data-driven approach that identifies carers most at risk, particularly in geographically underserved areas. This involves refining data collection to segment carers by specific needs, group demographics, and locations, allowing for targeted support where it's most urgently needed. Access to resources is vital, especially for carers in rural, regional, and remote areas where isolation is exacerbated by limited services. Digital platforms and resources can play a crucial role, so we urge investment in technology solutions to connect carers with services, virtual communities, and peer support networks, as outlined in the NSW Carers Advisory Council Strategy 2024-2025. In addition, enhancing respite care services and developing community-based programs would provide carers with needed relief and social interaction opportunities, while public awareness campaigns can destigmatise help-seeking and promote greater societal understanding of carers' challenges. We hope that our submission also shines light on the need to recognise carers as key partners in health systems, involving them in care decisions to reduce their sense of invisibility and provide them with accessible education and training programs. Drawing on successful overseas models like the "Compassionate Communities" initiative, which strengthens local support networks, would bolster cross-sector collaboration and community resilience, particularly in isolated regions. By implementing these strategic measures, we hope that we can address carer loneliness in a meaningful and sustainable way</p>
h) developments in other jurisdictions regarding the implementation of policies and initiatives relevant to the treatment of loneliness as a	Exploring the "compassionate communities" approach implemented by Primary Health Networks (PHNs) and Local Health Districts (LHDs) in other states offers valuable insights for addressing loneliness and social isolation sustainably. A key aspect of this model, as seen in the Mendip (UK) initiative, is social prescribing, which promotes collaboration between public health and community sectors to drive the systems change necessary to combat social disconnection. Social prescribing enables healthcare providers to refer carers who are identified as being at risk to community-based support systems, which helps foster a more inclusive community culture that addresses not only physical health needs but also the social and emotional well-being of individuals.

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public health issue	<p>By giving carers a prominent voice in our submissions, the Council leverages its role to highlight the unique challenges carers face in NSW, emphasising their needs directly to Minister for Carers, Minister Harrison. This approach ensures that carers are not only acknowledged in policy discussions but are also integrated into the broader strategy, promoting their health and well-being through compassionate and community-oriented solutions. The Council would therefore welcome the opportunity to provide a verbal submission to the Inquiry, ensuring that the voices of carers are directly heard and their needs effectively represented.</p> <p>Solution: To address loneliness as a public health issue, NSW can take actionable steps inspired by successful initiatives documented in empirical evidence, particularly through integrating social prescribing within community health models. We believe that more could be done in NSW to enable health providers to connect carers at risk of loneliness with local resources, peer groups, and social support, shifting from solely medical responses to holistic, community-focused interventions. Additionally, establishing pilot programs through Primary Health Networks (PHNs) and Local Health Districts (LHDs) would help evaluate and refine these strategies, with insights directly informed by carers' experiences and needs. This approach would not only provide much-needed support for carers but would position NSW as a leader in addressing loneliness through preventive, community-empowering public health solutions.</p>
i) steps the State Government can take to reduce the prevalence and impacts of loneliness in the community	<p>To reduce the prevalence and impact of loneliness, we advocate for a focus on strengthening existing services and systems to promote meaningful connection and engagement within communities, without building new structures. This approach includes enhancing informational support through diverse platforms, such as digital media, in-person community groups, and word-of-mouth initiatives. By focusing on peer-to-peer connectivity, particularly within cohorts at risk of chronic loneliness (e.g., carers or isolated individuals), storytelling and shared experiences can foster a sense of community and mutual support.</p> <p>We have highlighted throughout our submission that carers must be made visible and efforts to de-stigmatise the concept of “being alone” can help individuals view solitude as a natural part of life, reducing the shame associated with loneliness. Educational programs and resilience-building workshops could empower people to manage episodic loneliness and to seek support without hesitation, especially in areas with low connectivity or resources. Such measures can normalize periods of isolation, promote mental health, and strengthen individuals' ability to navigate loneliness, creating a supportive social environment for all community members.</p> <p>Solution: To reduce loneliness in NSW, the Inquiry should focus on the following key actions related to Carers:</p> <ol style="list-style-type: none"> 1. Enhance Existing Services for Carers: Strengthen digital and physical platforms to improve accessibility to information on support options for at-risk groups of carers. 2. Foster Carer Peer Connections: Expand community-based initiatives such as peer-to-peer programs, storytelling forums, and

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	<p>shared-experience workshops to encourage meaningful social engagement.</p> <p>3. Destigmatise Carer Loneliness: Launch educational campaigns to normalize loneliness as a natural experience and provide resilience workshops to help individuals cope with isolation.</p> <p>4. Targeted Outreach for Carers: Implement communication efforts in lower-resource and remote areas through community ambassadors and digital hubs to increase support access.</p> <p>These actions will promote mental health, create pathways for connection, and build a more resilient and inclusive community which we believe in turn should build the wellbeing of carers.</p>
<p>j) steps that community, technology/social media companies, organisations, and individuals can take to reduce impact of loneliness on individuals and the community; and</p>	<p>There have been many previous attempts to combat loneliness and huge global movements concerned about how loneliness impacts people. Many of these are generic and not carer focused – we advocate for the need for Carers to be forefront as improving their health and wellbeing will in turn reduce the burden on the government and health services through carers being able to thrive. If a carer is unwell and unable to care, then their person needs to be cared for.</p> <p>The Council have previously provided submission to the NSW public consultation to develop the state’s first Digital Inclusion Strategy. As already stated, digitisation is a priority for the Council in terms of providing solutions for carers who may choose to be connected via digital platforms, however we do not suggest that this provides a solution for the complexities of loneliness and social isolation. It may be one option for certain groups of carers should they chose this. Should this Inquiry be interested we are able to provide a copy of our Submission as it focused on different groups of carers and their specific issues.</p> <p>Solution: To effectively address loneliness and social isolation of carers, the following actionable steps can be taken:</p> <ul style="list-style-type: none"> • Prioritise Carer Health: Place carers at the forefront of initiatives aimed at reducing loneliness, recognising that their well-being directly impacts the quality of care they provide and the overall burden on health services. • Leverage Digital Inclusion: Encourage technology and social media investment to enhance digital inclusion strategies that support carers in connecting with peers, accessing resources, and engaging in online communities, while ensuring that these platforms address the unique challenges faced by different groups of carers. • Tailored Programs: Develop targeted programs that focus on the specific needs and experiences of carers, incorporating feedback from previous consultations to create solutions that resonate with their circumstances. • Promote Community Engagement: Foster local organisations to create carer-focused and outwardly reaching groups and support

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	<p>networks, who can offer face-to-face interactions that can mitigate feelings of isolation.</p> <ul style="list-style-type: none"> • Continuous Evaluation: Regularly assess and adapt programs to ensure they effectively meet the evolving needs of carers, using insights from carer experiences and challenges in accessing support. <p>By implementing these steps, stakeholders can cultivate a more supportive environment that alleviates loneliness for carers and, in turn, enhances their capacity to provide care.</p>
k) any other related matters.	<p>Carers need to be visible in all discussions, we need to highlight the needs of carers as they are a large population group who are both isolated and socially vulnerable.</p> <p>Concluding our submission, I would like to use some seminal research work which is applicable to carers. John Bowlby’s work on attachment theory provides valuable insights that can be applied to understanding and addressing loneliness and isolation among carers in NSW in 2024. They key lessons we can draw from his research:</p> <ol style="list-style-type: none"> 1. Importance of Secure Attachments: Bowlby emphasised the significance of secure emotional bonds in promoting psychological well-being. For carers, fostering strong connections with family, friends, and support networks can mitigate feelings of loneliness. Programs that encourage the development of these relationships can be beneficial. 2. Recognition of Emotional Needs: Bowlby’s work highlights the emotional needs of individuals, which is especially relevant for carers who often prioritise the needs of those they care for over their own. Initiatives that recognise and address the emotional well-being of carers, such as support groups and counselling services, can help alleviate isolation. 3. Impact of Separation: Bowlby noted that prolonged separation from loved ones can lead to distress and feelings of loneliness. Carers often experience isolation due to their caring responsibilities, which can limit their social interactions. Addressing barriers to social engagement, such as providing respite care, can help mitigate this issue. 4. Social Networks: Bowlby’s research underscores the importance of social networks in providing support. For carers, developing strong peer networks and community connections fosters a sense of belonging and shared experiences, which are crucial for reducing feelings of isolation. 5. Holistic Approach to Care: Bowlby advocated for a holistic understanding of attachment and relationships. This approach can inform policies and programs aimed at supporting carers by integrating mental health resources, community support, and

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	<p>practical assistance, recognising that these elements are interconnected in addressing loneliness and social isolation.</p> <p>6. Community Engagement: Inspired by Bowlby’s emphasis on the importance of community, strategies can be developed to create inclusive environments that promote social interaction among carers. Initiatives such as community events, workshops, and collaborative activities can help build relationships and networks.</p> <p>7. Raising Awareness: Finally, Bowlby’s work can inform awareness campaigns to reduce stigma around loneliness and caregiving. Educating the public about the challenges faced by carers can foster empathy and encourage community support, helping to create an environment where carers feel valued and connected.</p> <p>By applying these insights from Bowlby’s research, this important Inquiry in NSW can better understand the complex emotional landscape of carers and develop targeted strategies to reduce loneliness and enhance their well-being in 2024 and beyond.</p>

On behalf of the Council and carers across NSW, I ask that you review our feedback taking into consideration needs and the role of carers. In your review of our submission and our hope that the Inquiry can recognise the need for Carers to be highlighted I use the work of Arthur Frank and his concept of generosity, from his work *The Wounded Storyteller*. Frank emphasises the transformative power of storytelling and the shared experience of suffering, which we have done in our submission. For carers grappling with loneliness and isolation, embracing generosity can manifest through the creation of supportive networks where they can share their narratives and hear those of others. This mutual exchange fosters empathy and connection, combating feelings of isolation by reminding carers that they are not alone in their struggles. By prioritising generosity in our communities – whether through formal support groups, informal meetups, or digital platforms – we can cultivate an environment where carers feel valued and understood. In a world increasingly marked by disconnection, let us remember that the act of sharing our vulnerabilities as we do as members of the Council we offer and support others and in turn, hope that this compassion can bridge the chasms of loneliness, transforming both our own lives and the lives of those we care for. Ultimately, it is through these acts of generosity that we can build a more inclusive society, affirming that no one’s story is too small to matter, and every connection counts.

We provide permission for our submission to be published and if possible, would like to make representation to the Inquiry to further explore and expand upon the issues provided in our submission.

If you wish to discuss this further, please contact me on 0405849568 or at NSWCarersAdvisoryCouncilSecretariat@dcj.nsw.gov.au.

Yours Sincerely,

Dr Melanie Bournell, GAICD
 Chair – NSW Carers Advisory Council