



SUBMISSION

**Queensland Parliament
Community Support and Services Committee**

**The nature and extent of the impact of social isolation
and loneliness in Queensland**

Submission Title:	The nature and extent of the impact of social isolation and loneliness in Queensland.
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CARERS QUEENSLAND

The activity and impact of providing care is best understood in terms of its context; as a relationship between two or more individuals, rooted in family, friendship, or community. Caring is a role rarely chosen by most, nor does it discriminate. Children and young people, people of working age and older people, people with disability, people who identify as culturally and linguistically diverse, indigenous Australians, people with diverse bodies, genders, relationships, and sexualities and those living in rural and remote Queensland provide care to family members or friends daily. For some caring is a short-term commitment whilst for others, it is a role that literally lasts a lifetime.

Family and friend carers provide unpaid care and support to family members and friends who have a disability, mental illness, chronic medical condition, terminal illness or are frail aged. Carers come from all walks of life.

Carers Queensland is the peak body representing the diverse concerns, needs and interests of caring families in Queensland. Carers Queensland believes that all carers regardless of their age, disability, gender expression or gender identification, sexual orientation, religion, socioeconomic status, geographical location, or their cultural and linguistic differences should have the same rights, choices and opportunities and be able to enjoy optimum health, social and economic wellbeing and participate in family and community life, employment, and education like other citizens. Carers Queensland's mission is to improve the quality of life of all carers throughout Queensland.

We aspire to provide an independent platform from which to advance the issues and concerns of the 533,200 carers in Queensland and believe our knowledge and expertise in carer issues means we can provide the Government with relevant and trusted information that will ensure that the needs of carers will be recognised, respected, and acted on.

Our submission is informed by national and international peer reviewed data, our own experience as a service provider and the personal and often difficult admissions of carers, those people who provide unpaid care and support.

INTRODUCTION

In Queensland, 533,200 people including children and young adults (1 in 10 of the population) will provide 357.4 million hours unpaid care and support to a family member or friend, the replacement value of which is estimated to be \$16.511 billion per annum.

While caring can be rewarding and brings about life affirming experiences, without appropriate support, it can have significant long term and inter-generational negative effects on the health and wellbeing, relationships, employment and social and financial inclusion of individual carers and caring families.

Australian and international research highlights the clear relationship between providing unpaid care and the diminished health and wellbeing of the individual carer. Caring relationships, particularly those of a longer duration or very intense responsibilities, can result in carers becoming separated and isolated from their immediate family and informal network (their herd) and their community (their tribe).

Humans are social beings. We need our social groups to nurture, sustain and protect us. Separated from our social groups, we cannot discover our personal identity and have no sense of belonging and we don't function well. When family and friends don't step up to the responsibilities of those herd relationships the potential emotional damage is serious and the emotional consequences catastrophic, as the social isolation morphs into a sense of social exclusion, emotional isolation, and feelings of alienation.

When people feel isolated and cut off from their herd, a natural part of that separation is to feel anxious. When people feel anxious, they tend to withdraw even further and become more isolated and self-absorbed, rather than reaching out for contact, which is, one of the best antidotes for anxiety.

Isolated at home, in terms of personal relationships and family relationships, many carers are living in domestic situations below the suboptimal herd size and because of their caring responsibilities are not connecting with their tribe of community networks. The implication is clear. If carers are not feeling connected to a functioning herd and tribe, not feeling a part of a nurturing and functioning family and neighbourhood, friendship circle or workplace, the effect on their mental health is quite serious.

The physical and emotional impact of social isolation and loneliness

Social isolation and loneliness impact on quality of life and wellbeing with demonstrable negative health effects. Being lonely has a significant and lasting effect on blood pressure, with lonely individuals having higher blood pressure than less lonely peers. Such an effect has been found to be independent of age, gender, race, cardiovascular risk factors, medications, health conditions and the effects of depressive.

Loneliness is also associated with depression (either as a cause or a consequence) and higher rates of mortality. Lonely individuals are more likely to be depressed and more likely to be anxious about social interactions; higher levels of loneliness are associated with higher levels of social interaction anxiety, less social interaction, and poorer psychological wellbeing.

The world shrinks

Caring is such an important part of life. It is simply part of being human. Carers hold family together, enabling loved ones to get the most out of their life. However, providing care and support is a double-edged sword. For many carers their world simply shrinks.

The caring role takes over, the days and the weeks become structured around completing the myriad of tasks needed to ensure the safety, health and wellbeing of the family member or friend. Friendships may diminish or disappear, particularly if the carer has given up work. Invitations to social functions or to participate in group activities can fall away as others do not know how to respond to the concerns of carers or because the relationship is no longer reciprocal. Friendships may wither because of a fear of rejection.

British research suggests that:

- 14% of the population feel lonely 'often or always.'
- 81% of carers have felt lonely or socially isolated because of the caring role
- more than a third of the elderly felt overwhelmed by loneliness

Research conducted by the Australian Centre on Quality of Life indicates that more than 30% of people in Australia are lonely. Our own research supports the findings of the Centre on Quality of Life.

In the 2019 annual quality of life survey, we explored the extent of social isolation and loneliness and its impact of carers in Queensland. Sadly, many of the respondents to the survey experience the negative impact of not being a part of a nurturing and protective support network:

- 19% are lonely most of the time
- 30% identify as socially isolated
- 18% have sufficient time to participate in social and community activities
- 42% of respondents of working age believe that their caring role is not recognised or supported with their community and feel lonely at work some of the time
- 46% of all respondents experience low role recognition and respect
- 39% experience chronic anxiety, and 6% identify as completely anxious

- My relationship with my spouse has declined to where I am just the servant..... Other relationships? Over the years, I have got more and more isolated, so I hardly see people.
- I have no time to form deep personal relationships. If it was not for Carers Queensland and the retreats... my friendship network would not exist.
- Most of my time is spent with my two dependent sons. I feel quite isolated. The ONLY friendships I have in local area are people I have met at Carers Queensland support groups. I usually see them twice per month. I would like to have better personal relationships, spend time with extended family... and I would also like more of a social life.

- I feel undervalued and am considered unemployed by my family and society, yet I work an average of 14 hours a day seven days a week and am still expected to do more.

Social wellbeing encompasses social acceptance, actualization, contribution, and a sense of support and belonging and social integration. Social wellbeing thrives in healthy communities.

Making and sustaining social connections is not always easy. Research has shown that how a carer or caring family is perceived by others in the community is based on an individual's perception or interpretation of disability or illness.

In our *Carer Conversations*, carers tell us of being sidelined and eventually marginalised because of the behaviours of the person they care for and support. Many become fearful of going out with the person they care for out of fear of judgement by others. This is particularly so for those individuals with an 'invisible disability' such as neurodiversity. Others experience the 'if only you were a better parent' syndrome, the belief held by some that the behaviour is the result of poor parenting rather than integral to the disability or diagnosis.

Caring families who have experienced embarrassment or shame due to the negative or ill-informed attitudes or behaviours of others may come to fear future encounters, resulting in an ever-diminishing spiral.

- People don't understand dementia behaviour, so instead, they judge us - him and me. It can be embarrassing and isolating. It makes me feel anxious having to justify his behaviour all the time, to explain 'he has dementia' and apologise when he breaks social protocols.
- People have told me my son's behaviour is because I didn't 'thrash him' enough when he was a kid. My son is on the autism spectrum.
- Friends have dropped by the wayside; family love a five-minute visit, often saying if you need me ring me, when rung they are too busy with life. Even neighbours have stopped invitations to social events.
- I am very withdrawn and feel afraid to share my heart and how low I constantly feel because I am afraid of driving the few people I have in my life away completely ... I feel 'unknown, misunderstood and as though I have become an empty shell'.

The assumption that caring is only a family responsibility renders carers and the impact of caring invisible within the broader community. With invisibility, carers lack appropriate support that can address social isolation and other stressors associated with the carer role.

- Caring has cost me my health and my house, but my son needs me, he cannot cope without my support, and because I love him, I continue to try and help him despite my own difficulties. No one is helping me, though because no one seems to recognise my suffering.
- I don't think I can keep juggling work and caring for much longer. Trouble is nobody else wants them.....I am alone. I'm afraid that my family will consume me completely.

Co-resident carers and those with long-term responsibilities can become socially isolated and lonely – experiencing a reduced social network and seeing few others beyond support staff and the health and allied health professionals; these relationships with support workers become pivotal to the mental and social wellbeing of the carer and the carer’s ongoing capacity to continue in the caring role.

The rise of digital technology such as Zoom has enabled some carers to connect with others throughout the pandemic lockdowns, but it is no substitute for face-to-face connection and the sense of belonging that comes through shared experiences. Not everyone understands or has access to technology. In our *Carer Conversations*, carers have told us of their increased isolation during the pandemic.

- Increased feeling of isolation since previous [locally based] offerings were ceased.
- Extremely stressed out with no support from the carer network.
- Zoom cannot offer safe spaces/hub to share and engage with likeminded people.
- Face-to-face connection with other carers provides a sense of ‘time-out’ and provides companionship and any opportunity to learn and share in a relaxed atmosphere.
- During the 2020 pandemic lockdown 39% of the 1280 carers surveyed reported a decline in their mental health

The community benefits when social isolation and loneliness is mitigated

Having a strong social network – a group of supportive people who nurture and protect – is vital to social wellbeing. Creating and maintaining a strong social network is not easy for some carers, particularly those whose caring obligations are such that they are unable to work or volunteer or participate in regular social activities and those from marginalised communities (e.g., LGBTIQ, CALD) and those in rural and remote locations.

At the individual level, mitigating loneliness and social isolation will improve quality of life. People with a strong social network have a 50% increased likelihood of survival than those with weaker social networks. Supporting people to socially engage has broader health and social care implications. People with strong social networks are less likely to be dependent on costly intensive support packages or services. Similarly, reducing social isolation enables a possible harnessing of potential contribution to the community through volunteering.

Research conducted by the UK Campaign to End Loneliness revealed that every £1.00 spent on successful interventions, returned £2.00 to £3.00 in saving for the community. Similarity, meta-analysis conducted by the London School of Economics showed a similar return on investment over a five-year period.

Recommendations

Carers Queensland commends the Palaszczuk Government for its commitment to addressing social isolation and loneliness in our communities, among our most vulnerable citizens.

Recommendation 1:

We note the commitment of the Government to developing and implementing a strategy to further address social isolation and loneliness.

Carers Queensland would welcome the opportunity to work collaboratively with the Government to develop and implement strategies to support carers and caring families.

Recommendation 2:

Carers Queensland understands the importance of real social and emotional connection (e.g., face-to-face engagement with others, sharing laughter over a meal, the impact of a simple touch on the arm or a shoulder to cry on) and accepts that for many carers connecting via digital platforms is no substitute. Anecdotal evidence suggests that many of the interventions offered by Carers Queensland contribute to a lessening of the social isolation and loneliness experienced by the participating carers.

We respectfully recommend that the Queensland Government:

1. adopt an evidenced based approach to the funding of new interventions that address social isolation and loneliness of people in at-risk populations groups including carers.
2. support funded services to conduct a social and financial impact analysis of existing programs and services to objectively ascertain the impact of interventions on addressing loneliness and social isolation of the specific population cohort.

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