



**Submission: House of Representatives Inquiry into
Sleep Health Awareness in Australia**

October 2018

AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

ABOUT CARERS AUSTRALIA

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a:

- disability
- chronic condition
- mental illness or disorder
- drug or alcohol problem
- terminal illness
- or who are frail aged

Carers Australia believes all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians.

They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

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“I worry that one day one of us will just keel over dead because we’re so overtired”

Carer of child with complex disabilities and in pain needing 24/7 care.

THE IMPACT OF SLEEP DEPRIVATION ON FAMILY AND FRIEND CARERS

This submission goes to two of the Inquiry’s Terms of Reference:

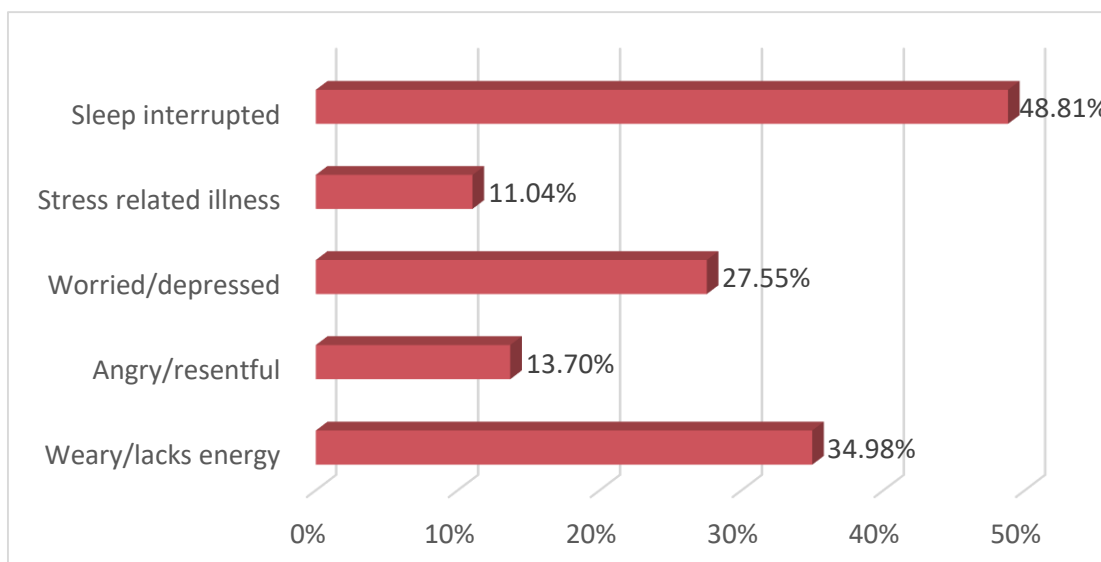
- The potential and known causes, impacts and costs (economic and social) of inadequate sleep and sleep disorders on the community.
- Current national research and investment into sleep health and sleeping disorders.

Carers Australia welcomes the opportunity to draw attention to a problem that seriously impacts on many carers’ health and wellbeing and their capacity to sustain care.

It should be no surprise that carers report that providing care can be very stressful. What may be surprising is the extent to which sleep interruption negatively affects their wellbeing.

Australian Bureau of Statistics (ABS) 2015 data, as shown in the chart below, revealed that nearly 40 per cent of primary carers identified that caring has one or more negative impacts on their physical or emotional wellbeing. More than a third (35 per cent) indicated they were weary and lacked energy. Over a quarter of carers surveyed had been worried or depressed, while 14 per cent reported being angry and resentful, and 11 per cent said they had been diagnosed with a stress related illness. However, it is sleep interruption which was identified as having the biggest single negative impact – with nearly half of all primary carers (49 per cent) reporting interrupted sleep.

Negative impacts on physical and emotional wellbeing of carers¹



However, the research does not show the **extent** to which these factors interact and, indeed, the extent to which sleep deprivation is a leading cause of anxiety and depression, other stress related illnesses, and anger and resentment. It is, self-evidently, a significant cause of being tired.

Some carers will suffer from sleep interruption and deprivation for much the same reasons as other people. For example, some will suffer from sleep apnoea. Others will have insomnia or sleep interruptions which can be attributed to lifestyle and poor sleep habits. And some may be losing sleep because of their own poor physical, psychological or emotional health which may or may not be related to their caring role. In these cases, their sleep may be improved by following usual recommendations: get more exercise, avoid stimulants before sleep time, keep regular hours, avoid use of mobile phones and computers in bed, meditation, visit a sleep clinic to check for apnoea, consult your doctor about medications, and so on.

However, many carers suffer from sleep deprivation because of the nature of their caring role, with few ways to address the situation.

A research report from the United Kingdom entitled *Caregiving at Night: Understanding the impact on carers* identified five different causes and consequences of carer-specific sleep deprivation:

1. attending to the night-time physical needs of the person with care needs
2. anticipating night-time care needs

¹ Source: Australian Bureau of Statistics (ABS), Survey of Disability, Ageing and Carers, 2015

3. monitoring a person's wellbeing throughout the night
4. disruption caused by people with challenging behaviour (for example, wandering around the house, causing a commotion, shaking or prodding the carer into wakefulness)
5. worries and anxieties about the person being cared for, even if it is not necessary to attend to their needs.²

The study also concluded that sleep disturbance was likely to be more or less profound depending on the reason for the interruption. For example, generally speaking, attending to physical needs had less effect on the capacity to go back to sleep than sleep interruption caused by challenging behaviours or persistent anxiety, **providing** that the physical caring activity is not too extensive and, in itself, a major cause of stress.

Alarms go off multiple times each night and we have to get up to check. There's only been two occasions in the last two months where we have had a whole night of undisturbed sleep.

Mother of a child with spastic quadriplegia cerebral palsy

Six times a night I would get up to go (with wife) to the toilet, and waking, waking all the rest of the time. [Sometimes] it was only two or three times a night, but each time would take half an hour literally to get her up there, or to get her onto the commode, and so I used to dread nights ... I used to absolutely dread nights and, in retrospect, I can see how I was sailing close to the limit of my own endurance.

76-year-old former carer of his wife

Where sleep interruption is caused by intense psychological and emotional anxiety – as happens when the person being cared for is presenting with challenging behaviours or intense

² Sarah Arber and Susan Venn, *Caregiving at night: understanding the impact on carers*, Journal of Ageing Studies, Vol25, Issue 2, April 2011, pp.156-165, <https://www.sciencedirect.com/science/article/abs/pii/S0890406510000836>

pain, or whose condition is life-threatening – carers are likely to find it harder to go back to sleep.

The research identifies a number of studies which highlight the extent of health impacts of sleep deprivation on carers (including decreased immune function, increased risk of diabetes, coronary heart disease, stroke, depression and anxiety disorders). Such health consequences, and even just the accumulative experience of sleep deprivation, can significantly reduce their ability to provide high quality and emotionally supportive care. Indeed, sleep deprivation is likely to be a major reason for carers deciding that they can no longer provide care at home.

She used to go into bed fine, and then within an hour, she was up again, and then coming in to see what I was doing, sort of thing. So, I think that probably sort of triggered everything off (bad sleeping).

Anyway, in the end it got so desperate. It is 24 hours a day. I don't care what anybody says, you cannot look after somebody all that length of time. And I went to the doctor and dissolved into tears, and said 'I am sorry, but I just can't go on'. So, he said 'Come on, we have got somewhere now (a local care home)'... She was in there (care home) for 18 months. I didn't want to have to do it, but I just had to.

71-year-old former carer of mother with Alzheimer's

WE UNDERSTAND THE PROBLEM: BUT WHAT IS TO BE DONE TO ALLEVIATE IT?

There are some ways to help family and friend carers caught in what can seem like a hopeless bind between sleeping and caring.

In some cases, it may be possible to improve the sleep of those they care for; for example, through medication or devices to address breathing and other physical problems which keep them awake or interrupt their sleep. Monitoring devices may also help to relieve persistent anxiety about whether a person is sleeping safely.

For many carers the only real solution is to alternate with another person who will assume the responsibility for some nights. This may be a partner or other relative. However even close family members are not always there to help out, especially when it means a regular loss of sleep.

In this context, it is interesting to note that the National Institute of Labour Studies (NILS) Final Report on the evaluation of NDIS trials found:

“In the quantitative survey, carers reported high levels of dissatisfaction with family support to relieve stress, the availability of outside help to take care of all family members, opportunities to pursue their own interests, and the availability of friends or other people to provide support.”³

Under these circumstances, it would help to have regular access to paid carers to take on the night shift. While this kind of respite care can be accessed through aged care Home Care Packages, it is expensive and Home Care Packages are price capped, making it hard to get. The capacity to get funding for regular, overnight paid care can also be difficult to access through the NDIS, where the services are primarily there for the benefit of the person with care needs, rather than for their carer.

It would be both useful and interesting to undertake research on the relationship between caring, the extent of sleep deprivation experienced by different kinds of carers, and the likelihood of carers relinquishing their caring role due to lack of sleep and the effects of sleep deprivation. Against a background where it is estimated that the replacement cost of unpaid family and friend carers is over \$60 billion per year, the additional costs associated with subsidising overnight replacement care may not seem so significant.

³ National Institute of Labour Studies (NILS), Evaluation of the NDIS; Final Report, February 2018, p.147
https://www.dss.gov.au/sites/default/files/documents/04_2018/ndis_evaluation_consolidated_report_april_2018.pdf