

Evaluation of respite service provision for Respite Care for QBN - Yvonne Cuschieri House

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Evaluation of respite service provision for Respite Care for QBN Yvonne Cuschieri House

Executive summary

UNSW Canberra has conducted a review of Respite Care for QBN's planned Yvonne Cuschieri House against these criteria:

1. Value for money
2. Likelihood of supporting carer and client wellbeing
3. Community need

The proposal was evaluated by assessing like facilities globally, literature on caring, consultant reports on caring, information and publications from peak bodies and research on carers, respite and provision of services to alleviate distress. Respite Care for QBN provided the research team all their related design and policy documentation and engaged in repeated discussions with the team.

We have found that Respite Care for QBN's planned Yvonne Cuschieri House will offer significant overall cost savings to the NSW and Federal Governments (even accounting for funding received from government). It will reduce carer burden, reduce burnout and alleviate social isolation—all key risks for carers. The Queanbeyan-Palerang region is in urgent need of non-clinical respite services with very limited services currently available. Yvonne Cuschieri House will fill a particular gap in service provision of respite for 18 to 60-year-olds in the region.

Key findings from this report include:

- Informal care in Australia in 2020 was worth \$77.9 billion and in NSW, to replace the care provided, the NSW Government would have to spend more than \$25 billion each year.
- Non-clinical respite can cost as little as 10% of the cost of a hospital stay. This is a significant future saving as currently carers in need of respite only have hospital stays as an option.
- Benefits of non-clinical respite include improved outcomes for carer and patient in the form of reducing stress, anxiety and depression; increased rest and sleep; providing information and education, and social networking for greater ongoing support.
- Carers Australia in their 2022 national survey of carer experience found that 50% of carers were suffering high or very high psychological distress. They also found that in comparison to the general population (75% rating) carers had much lower subjective wellbeing levels at 58%. Social isolation was a major impediment, being experienced by 56% of carers. Respite services are a fundamental part of the policy mix to alleviate this burden.
- One in three carers told Carers NSW that they “never get time out from their caring responsibility” and nearly half were experiencing “high or very high psychological distress”.
- Queanbeyan is home to at least 4500 unpaid carers. Regional demand for respite for those aged 18 to 60 is strong, with thousands of people petitioning for more than six years to secure funding for a new respite centre in Queanbeyan.

- 89% of carers have never accessed respite services—indicating a huge unmet need in the community. Non-clinical respite can relieve approximately 50%¹ of the overall cost burden from public hospital admissions and can cost as little as 10% of the cost of an Emergency Department visit.^{2(p.36)} Despite this, carers aged 18 to 60 are faced with few suitable options when it comes to respite services which places a heavy burden on the thousands of people in unpaid carer roles. The savings may be far higher, with Magill (2021) calculating “that the average cost of an acutely distressed person visiting” (non-clinical respite) “is approximately 10% of the cost of them visiting an ED [Emergency Department] instead”.^{2 (p.36)}

Carers Australia in their 2022 National survey of carer experience found that 50% of carers were suffering high or very high psychological distress. They also found that in comparison to the general population (75% rating) carers had much lower subjective wellbeing levels at 58%. Social isolation was a major impediment, being experienced by 56% of carers.³ According to Deloitte's national study, 89% of primary carers have not used respite services. One in three carers told Carers NSW that they “never get time out from their caring responsibility” and nearly half were experiencing “high or very high psychological distress”.⁴

Carers are 2.5 times more likely to have low wellbeing than the average Australian.⁵

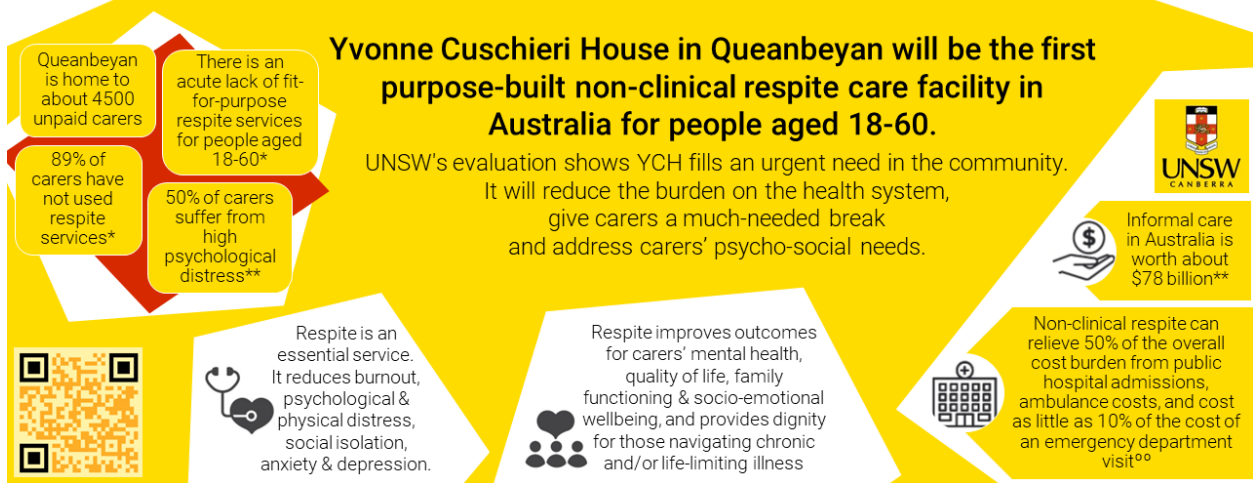
Respite has been shown to reduce burnout, psychological distress and social isolation and as such is an essential service to alleviate the care burden.⁶ There is an “overwhelming need for respite services to provide time” for carers to attend to “personal appointments, stress management activities, leisure activities, spiritual practices, rest, and socialization”.^{7(p.580)}

There is much research over the past few decades that shows the provision of appropriate respite reduces burnout and results in improved outcomes for carers’ mental health, physical distress, anxiety, depression, psychological distress, quality of life and family functioning.^{8,9,10,11,12,13} Respite services reduce the overall health burden and greatly assists carers and family socio-emotional wellbeing.

Not only is respite saving the public health system money, beds and precious resources, but it is providing uncountable intangible benefits, quality of life and dignity for those navigating chronic and/or life-limiting illness.

Yvonne Cuschieri House will be embedded in the local community so will be easily accessible to carers in Queanbeyan and the surrounding region. As it stands, the facility will ensure a well-earned break for carers and their loved ones. It will keep people out of hospital and take much-needed pressure and costs off the health system. We strongly recommend that the NSW and Federal Health Departments commit to ongoing funding of Yvonne Cuschieri House.

Respite Care for QBN



Placemat style visual representation of key findings.

Respite Care for QBN



Queanbeyan is home to about 4500 unpaidd carers

89% of carers have not used respite services*

There is an acute lack of fit-for-purpose respite services for people aged 18-60*

50% of carers suffer from high psychological distress**

Yvonne Cuschieri House in Queanbeyan will be the first purpose-built non-clinical respite care facility in Australia for people aged 18-60.

UNSW's evaluation shows YCH fills an urgent need in the community. It will reduce the burden on the health system, give carers a much-needed break and address carers' psycho-social needs.



Informal care in Australia is worth about \$78 billion**



Non-clinical respite can relieve 50% of the overall cost burden from public hospital admissions, ambulance costs, and cost as little as 10% of the cost of an emergency department visit^{2,30}



Respite improves outcomes for carers' mental health, quality of life, family functioning & socio-emotional wellbeing, and provides dignity for those navigating chronic and/or life-limiting illness



Respite is an essential service. It reduces burnout, psychological & physical distress, social isolation, anxiety & depression.



Introduction

A key exhibit in the 2015 Royal Commission into Aged Care Quality and Safety on the economic value of informal care in Australia¹⁴ stated that approximately one in eight Australians is an informal carer, and most carers are aged between 35 and 54 years. For those individuals with a life-limiting illness who are in their final stages of the journey, more than 70% would prefer to die at home.^{15,16,17,18} Regrettably, it is estimated that only 12% of people do so.¹⁹ A key barrier to dying at home is a lack of respite care, resulting in carer burnout and the intervention of clinical services for both the carer and their loved one.

Across NSW, there are approximately 854,300 carers^{20,21} and to replace the care they provide the NSW Government would have to spend more than \$25 billion each year.²² As Australia's population continues to age "the demand for informal care among those of all ages with a severe restriction living in the community will grow from around 1.25 million in 2020 to 1.54 million in 2030 (a 23% increase). Over the same period, the supply of informal carers for this cohort will rise at a slower pace from 674,000 to 780,000 (growth of 16%)."²³

*"Most hours of informal care are provided by primary carers. These individuals are estimated to spend an **average of 35.2 hours per week providing care** compared with an assumed 5 hours of weekly care for non-primary carers. For primary carers, 28% spend more than 60 hours per week, while 25% spend between 1 and 9 hours per week."^{23 (pp.ii-iii)}*

What this means is that the burden of care will increase on those that provide it.²³ Deloitte in their review of care in Australia note the risk this presents and they recommend: "Improvements in access to, and awareness of, carer support services such as respite care to encourage service utilisation and alleviate the impact of caring."^{23(p.5)}

Over the next decade, Australia's health and welfare management will face significant challenges due to a shortage of informal carers. This issue is particularly concerning as the elderly population continues to increase. If not addressed, the mismatch between the demand for care and the available supply of carers is likely to put a strain on the formal health sector and result in poorer health outcomes for those who are unable to access care through formal channels.²³ This mismatch, unless addressed, will further burden the clinical health system with higher demands on ambulance and hospital resources.

Providing care involves substantial financial, emotional, and health-related costs for informal carers. While not all carers experience adverse health effects due to their role, they are more likely to face negative physical and mental health consequences. This risk is especially high for working carers who provide a substantial amount of informal care.²³

Respite Care for QBN has recognised the community need for respite services in the Queanbeyan-Palerang region and are constructing Yvonne Cuschieri House. This respite service will assist people 18 to 60 years of age, with a chronic or life-limiting illness, by providing respite services. The plan involves six rooms and common areas including lounge space, a kitchen, and outdoor areas. This report is an evaluation of Respite Care for QBN's proposed respite service on three criteria:

1. Value for money
2. Likelihood of supporting carer and client wellbeing
3. Community need

The proposal was evaluated by assessing like facilities globally, literature on caring, consultant reports on caring, information and publications from peak bodies, and research on carers, respite and provision of services to alleviate distress.

Overall, Yvonne Cuschieri House will provide desperately needed respite services in a cost-effective manner and significantly alleviate the burden for carers. It will result in direct and indirect cost savings to the health system. As respite provision significantly reduces the burden on the health system, both the NSW and Federal governments should fund the services being provided.

Policy frameworks

The vision of Respite Care for QBN for Yvonne Cuschieri House is to provide residential respite for carers or those suffering from a terminal or chronic illness aged 18 to 60 years of age. This responds to and sits within national policies for the social and emotional wellbeing of carers (those caring for someone with a medical condition, chronic illness or life limiting illness) in Australia which is framed by the National Palliative Care Strategy 2018,²⁴ national (and state-based) mental health policies such as the Carer Recognition Act 2010 (Cth), the National Strategic Framework for Aboriginal and Torres Strait Islander Peoples' Mental Health and Social and Emotional Wellbeing 2017-2023 and the (2021) National Mental health and Suicide Prevention Plan. The latter includes five pillars of care: prevention and early intervention, suicide prevention, treatment, supporting the vulnerable, and workforce and governance. The principles of prevention, compassion and care that are core elements of the National Mental Health Plan²⁵ are also well placed to frame respite services for unpaid carers.

The Australian Commission on Safety and Quality in Healthcare has named access to health care services as the first of seven basic rights for health consumers in the Australian Charter of Healthcare Rights.²⁶ Access, safety, respect, partnership, information, privacy and the capacity to provide feedback form the overarching framework for healthcare rights in Australia. With much of the responsibility for health care now expected to be taken by health consumers as part of a world-wide push towards person-centred care,²⁷ health interventions are now balancing preference-driven ideologies within the constraints of a neoliberal economy and ever-decreasing budgets.²⁸

Health Consumer Advisory Panel

As the primacy of the consumer and person-centred care is now integral to health care, a Health Consumer Advisory Panel (CAP) should be established and active throughout the building stage of the project and then as an ongoing consumer advisory group.²⁹ The CAP should constantly be involved in the review of results and translation of those into service provision changes at Yvonne Cuschieri House. This commitment includes developing policies and strategies for consumer involvement, building consumer and community capacity, and creating accessible communications and information for consumers, for nationwide translation. Ultimately, the goal should be to establish a permanent consumer advisory body for Respite Care for QBN and Yvonne Cuschieri House.

To encourage diverse applicants and build skills, local and national/state organisations with a local presence should be asked to share an expression of interest for CAP membership with their consumer base. This outreach should include culturally and linguistically diverse community organisations, Aboriginal and Torres Strait Islander communities, rural and remote areas (as Yvonne Cuschieri House is expected to draw clients from across the SE NSW), individuals with diverse socio-economic backgrounds, young adults, and people with disabilities. Health consumers should be encouraged to bring their unique perspectives.

The CAP will contribute to decisions on their appointments and terms of reference. The panel could provide input on research questions and working with community members or focus groups and engage in discussions on ethics, recruitment, communication, and research dissemination. Choosing panel members through existing community or health networks will be crucial for disseminating project information and supporting Yvonne Cuschieri House to become embedded in the care landscape of the region.

Urgent need for services

In line with global factors affecting carer burnout and the need for respite services worldwide, there is an urgent need for the provision of respite services in the Queanbeyan-Palerang region. According to Deloitte's national study, 89% of primary carers have not used respite services. The report also highlights that the lack of access to suitable respite services, particularly in recent times, deters carers from seeking such services.²³ Regional demand for respite for those aged 18 to 60 is strong, with thousands of people petitioning for more than six years to secure funding for the new centre in Queanbeyan.^{30,31}

Carers Australia in their 2022 national survey of carer experience found that 50% of carers were suffering high or very high psychological distress. They also found that in comparison to the general population (75% rating) carers had much lower subjective wellbeing levels at 58%. Social isolation was a major impediment, being experienced by 56% of carers.³

Respite has been shown to reduce burnout, psychological distress and social isolation and as such is an essential service to alleviate the care burden.³² There is an “overwhelming need for respite services to provide time”^{33(p.580)} for carers to attend to “personal appointments, stress management activities, leisure activities, spiritual practices, rest, and socialization”.^{7(p.580)}

There is a lack of available or suitable respite services^{34,35} for those aged 18 to 60, who are not registered with the National Disability Insurance Scheme (NDIS) and do not qualify for an aged pension where respite or home care packages may be subsidised. This places a heavy, often unmanageable burden on carers.³⁶

There is also often a lack of general knowledge about respite care. The confusing nature of respite services was highlighted in the March 2023 ACT Government survey of 2937 people on Voluntary Assisted Dying (VAD).³⁷ An open-ended question asked respondents to provide suggestions for safeguards and eligibility criteria. One of the more common responses was to query access to support options (including but not limited to respite care).

The complex nature of the service environment, a lack of referrals for support services, particularly for dementia carers,³⁸ and a general lack of carer awareness regarding available services,³⁹ all contribute to further barriers to carers using respite services that are available. These barriers are particularly pronounced for the more than 235,000 carers under the age of 25, carers with disabilities (which occurs at more than twice the rate of non-carers), Aboriginal and Torres Strait Islander carers, and the women who make up nearly three-quarters of all carers, particularly if English is not their first language.^{40,41}

A review of the global literature on carer burden & respite services

Respite Care for QBN serves as a model for both the Charter of Healthcare Rights and the acceptability of non-clinical health care interventions,⁴² in that it also clearly responds to the seven components of the Theoretical Framework of Acceptability of health care interventions, namely:

1. Affective attitude (positive feedback from health consumers)
2. Burden (the perceived amount of effort required to participate)
3. Intervention coherence (participant understanding of the intervention)
4. Ethicality (fits with individual and community values)
5. Opportunity costs (cost of engagement for the participant)
6. Perceived effectiveness (likelihood of achieving its goal)
7. Self-efficacy (participant's capacity to participate)^{42(pp521,522)}

This framework is an academic/practitioner accepted means of assessing if a new health care intervention is likely to be successful and meet its aims.

Carer burden and the need for respite services - burnout

Carer fatigue and burnout are core themes in the academic literature on palliative care.⁴³ It is well accepted that unpaid carers are at risk of poor mental and physical health due to chronic stress.⁴⁴

Attributes of burnout include, but are not limited to, physical symptoms such as headaches, tiredness and palpitations;⁴⁵ psychological, spiritual and financial distress; impaired social relationships, and disruptions to daily life including post-traumatic stress disorder (PTSD).⁴⁵ While all family caregivers experience varying degrees of burden,³² particular care needs to be paid to managing carer quality of life in cases of chronic illness and uncertain diagnoses, where the uncertainty adds to the fatigue and emotional burden of carers.⁴⁶ Where community services are scarce or not used by carers, they tend to prioritize the patient's needs over their own health.⁴⁷ Carers can also find it difficult to accept help as it engenders feelings of inadequacy.⁴⁷ An unsupportive workplace, for those carers also working outside the home, and for those who are self-employed, means that fatigue and symptoms for carers can be exacerbated.⁷

While there will be regional differences, some common factors in carer burnout¹⁴ include:

- multiple and concurrent stressors
- lack of social support

- the culture of the family or state of the relationship between caregiver and cared-for, uncertainty, and overall psychosocial adjustment.⁴⁸

That burden increases if the caregiver is the spouse and providing more than 21 hours of care per week, including daily living activities, and managing behavioural problems of the care-recipient.⁴⁹ If the carer and recipient live alone, have a low income, a high level of patient dependency and relationship distress, the caregiver burden is likely to be even higher.⁵⁰ A persistent or increasing burden puts caregivers at risk either throughout the illness of the patient or increasingly over time, respectively.⁵⁰ Carers who are also in paid work during the caregiving period require more support from employers and healthcare professionals (such as occupational therapists) “during the illness trajectory and after death to facilitate their return to work”.¹³ The more hours of care provided, the less likely a primary carer is to engage in social activities outside the home.⁵¹ Knowing that 7 out of 10 carers are women, half of those carers live in “a household in the lowest two equivalised gross income quintiles, twice that of non-carers”.⁵¹ One in three carers told Carers NSW that they “never get time out from their caring responsibility” and nearly half were experiencing “high or very high psychological distress”.⁵² This tells us that respite is badly needed for high-load carers, most of whom will be women and many of whom may not be able to afford to pay for respite. The Carers NSW 2016 report on [40 years of carer surveys](#) in NSW reveals the financial disadvantage that impacts carers has barely changed over more than 40 years.

Deloitte note that “additional efforts may need to be undertaken to promote greater awareness of the health risks and effects of caring among carers themselves. A stronger prioritisation of the health and wellbeing of informal carers may encourage greater access to and use of respite services, resulting in better health outcomes and quality of care for carers and recipients alike”.²³

Measurements of resilience have shown that carers who have a greater capacity to maintain relationships and external support from family and friends and have access to, and use services, have greater capacity to cope.⁵³ Resilient carers stay positive despite care demands and maintain relationships while accessing respite care and innovative schemes.⁵⁴ They have support from family and friends who offer emotional and practical advice. By focusing on positive aspects of caregiving, they can better manage the burden of their role. Sharing knowledge within support groups is encouraged, as these groups provide individual and community-level resources. Formal services such as Respite Care for QBN can aid those who lack resilience or knowledgeable peers.⁵⁴

Respite services and care provision

There is an overwhelming volume of research over the past few decades that shows the provision of appropriate respite reduces burnout and results in improved outcomes for carers’ mental health, physical distress, anxiety, depression, psychological distress, quality of life and family functioning.^{55,56,57,58,59,60} Respite services reduce the overall health burden and greatly assists carer and family socio-emotional wellbeing.

Respite is “the most commonly requested type of caregiver assistance” (in the context of information assistance, education, training and other caregiver support services).^{61(p.303)} This is largely due to the impact of the shift from institutional to home-based care over the past couple of decades; the 18 to 65-

year-old population base which is more likely to depend on their families as carers;⁶² and eligibility for services, and support, which is more likely to be available for the patient rather than the carer”.^{36(p.303)} The presence of secondary caregivers, particularly for those who use few other respite services, and the presence of informal support services can be determining factors as to whether or not carers are likely to know about, seek information about and/or use respite.⁶³

For respite care to be effective, it requires more than “just organising a respite session”.⁶⁴ Supportive care programs such as the Supportive Care Framework⁶⁵ can help patients and their families to manage the challenges they face throughout the course of a life-limiting illness. Carers and the cared-for require assessment for the stage of their respective individual situations.⁶⁶ Findings from the growing research in this area also reveal that the needs of family members vary over the course of a life-limiting or chronic illness as treatment and the need for assistance changes.⁶⁷ Those with an increased level of burden over time, particularly those with little family or workplace support (resulting in having to take sick leave themselves), who find they are unable to adjust to changing circumstances, face an increasing risk of burnout.⁴⁵ Those with a “persistent level of burden”^{45(p.19)} (or a “moderate burden over time”^{19(p.6)}) “often had a positive attitude, shared care tasks with others, and had flexibility and autonomy at work”.^{19(p.6)} It is noteworthy that those who fare better over time include those with some knowledge of or professional background in the health system; those with supportive, flexible workplaces; and people who find caregiving rewarding.¹⁹

Interventions based on stress management (such as education and developing a greater understanding of the illness using informal and formal supports) or stress coping (changing behaviours and approaches)⁵⁶ could be considered: the use of allied health care such as physiotherapy and occupational therapy can attenuate the risk of burnout: “A standardized needs assessment for caregivers could help policymakers and healthcare practitioners to identify caregiving” spouses “at risk of burnout and provide early intervention”.⁴⁷ The standard of nursing care required; opportunities to take part in “rehabilitative activities”;^{66(p.615)} stress about continuity of care concerns the carer may have for the person with the life-limiting or chronic illness need to be allayed, therefore it is important to regularly re-assess the needs of the carer and the cared-for,^{61,68} and maintain continuity of care (re relationships with health and other professional supports) as much as possible.⁶¹

Gender differences

The majority of informal carers in Australia are women.⁶⁹ Whether it is providing care for family members with chronic physical or mental health conditions or caring for family members with a life-limiting illness, women represent 69.3% of primary carers.⁵

Married heterosexual women are also most affected by an increased risk of divorce when they are the ones who become ill.⁷⁰ Research into the effect of serious illness on marriages has shown that in a cohort of nearly 3000 couples about 6% of those marriages ended in divorce⁷⁰ and of those separations, when women are affected by brain tumours, general oncology and multiple sclerosis (MS), they are the affected partner in 88% of recorded separations.⁷¹ Glantz et al (2009) suggest that the motivation to stay in a relationship with a seriously ill spouse reflects the healthy partner's commitment to the relationship. Additionally, they suggest that this commitment is more quickly formed by women than by

men. Research has indicated that men may be less capable of taking on caregiving responsibilities and managing household and family duties compared to women. As a result, women may be more inclined to commit to the challenges of caring for a sick spouse earlier in the marriage.⁷¹

There is a dearth in research regarding health outcomes for chronically ill women when their male partner leaves. Literature on division of labour among lesbian couples is described as “shared”^{72,73} but whether similar rates of separation are recorded in gay or lesbian couples is not clear.

There are gender differences in the challenges faced by male and female caregivers in heterosexual relationships. There is evidence to suggest that male caregivers’ distress tends to increase as challenges increase, across cancer types.⁷⁴

“Gender-specific attitudes prevented male caregivers from supporting their own self. Male caregivers dealt with problems that arose in the caregiving congruent with their masculinity, such as minimizing disruptions, focusing on tasks, and keeping their own stress to themselves.”⁷⁵

The unmet needs of informal carers, generally, includes challenges managing daily life, emotions, and social identity.⁷⁶ The most common challenges and unmet needs for male caregivers include “changes to sex life, fear of recurrence, and lack of practical information”.^{77(p.244-45)} Male carers tend to self-silence more than women because it is seen as a normal part of masculinity, whereas female carers see self-policing as part of “constructions of idealized femininity”. When couples avoid discussing emotions in this situation, it is damaging to their relationship and their capacity to cope.⁷⁸ While there is an urgent need for the provision of support specifically for informal carers of men with breast cancer,⁷⁹ due to its rarity and usual focus on women, women are more likely to want and to have discussions on emotional, social or religious needs, including the topic of death and dying, a topic men are more likely to want to avoid. This can also result in an increased risk of non-beneficial end-of-life care.⁸⁰ Services provided during respite, such as education, counselling and networking, could be beneficial to lowering that risk.⁸¹ Respite services offer a way to support men more effectively through their caring journey.

Clinical and non-clinical care

Respite comes in many forms: residential, home-based, day care, community, leisure/social provision, funded holidays and emergency.⁸² Respite aims to alleviate caregiver burden⁸³ by providing rest to the carer. It can be provided in the carer’s own home, by allowing the carer to take a break outside the home or on a holiday, in an institutional or medical setting or in a non-clinical facility. The clinical aspect of respite tends to be institutional/medical. This may be via in-patient mental health services (if they qualify as mentally ill), in-patient hospital care (if their physical symptoms are severe enough to require hospitalisation), or other (usually aged care) residential respite services.

Non-clinical care

Non-clinical respite tends to be a service for carers with “psychological distress” who do not “have a serious mental illness”.^{2(p.26)} A non-clinical respite space must meet the needs of palliative care or chronically ill patients and their carers, whether they are attending alone or with family (including young children and/or with family pets where applicable).^{105,84,85} Information about the respite service and

what carers can expect from the service must be clear, particularly when a carer may “not know what to ask for”.^{66 (p.615)} Research also shows that it is just as likely that psychological distress in either the carer or the cared-for will result in distress in the other and attention must be paid to both.⁸⁶ High-quality respite therefore needs to consider couples and whole families, where they are involved, as a strong relationship between the carer and the patient contributes to caregivers experiencing greater self-esteem, who “value their role as a caregiver”.^{50(p.111)} Ensuring social supports, organization and planning, physical activity, family time, leisure activities other resources and self-care are available and/or utilised post-respite,⁵⁰ can contribute to maintaining health and wellbeing.

Palliative care in Australia

The Australian Institute of Health and Welfare reports that in 2019-20, there were 86,900 hospitalisations for palliative care in Australia. Most (84%) were in public hospitals; about half had a diagnosis of cancer; just over half of those were aged over 75; one in ten were under 55; rates of palliative hospital care in the lowest socioeconomic areas were twice as high as those in the highest socioeconomic areas; the highest rates of palliative care hospitalisations in public hospitals were in inner and outer regional areas.⁸⁷

Philosophy of care

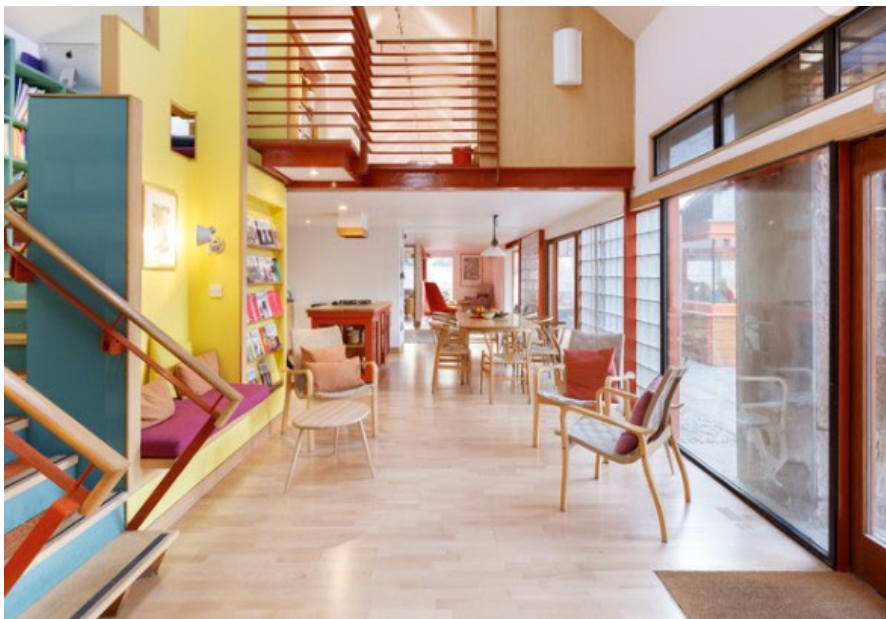


Figure 1 – Maggie’s Edinburgh showing multiple-use design features, colours and materials within one living area. Note the view from the front door through to the far end of the building creating an open, welcoming space.

The design of respite spaces has implications far beyond just providing a room or a facility for rest. “Privacy, homeliness, safety and access to gardens”^{101 (p.149)} support wellbeing “far beyond the patient room”.^{88 (p.149)} As is pointed out in the architectural brief for the Maggie’s Centres in the UK, respite must be underscored by a philosophy of care where the design of the spaces can support “the delivery and overall experience”^{101(p.150)} of care, highlighting the values that underpin the relationship between design and experience.⁸⁹ This will be space that is comfortable and homely enough for family and friends to



Figures 2 & 3 – Outdoor spaces at Maggie’s Cheltenham

visit and maintain privacy. It might be used by somebody during or after treatment, whether on their own or by somebody they love, or it may be used by someone after somebody they love has died.

The design of palliative care spaces, with separate and/or combined indoor/outdoor spaces supports the delivery of care as well as an underlying philosophy that responds to the dignity of patients.⁹⁰ Inclusion of sound-proofing, family suites, play areas for younger children, creative spaces, mixing privacy and communal living, airconditioning that meets the needs of the immunocompromised, universal access etc. all convey the values, feelings and needs of the recipients.⁹¹

Affording “privacy, dignity and family interaction”⁹² within the care space might include a separate space within a single occupancy room (or an adjoining outdoor space) where private conversations can take place. This might be a small, nearby room, veranda or outdoor setting attached to a private room or garden spaces.

McLaughlan and Pert⁹³ provide an example of a “draw your ideal hospice” design for children’s hospice care. While designed for a slightly different purpose, it neatly illustrates best practice design for any kind of respite space by incorporating bedrooms with direct outdoor access at one end, and direct access to a communal living area at the other; a clear and obvious entry and reception area from where access to staff is possible from any part of the space; a private admissions space; and multiple spaces for the different needs of the residents, including art and music spaces, play spaces, a tv space, medicine

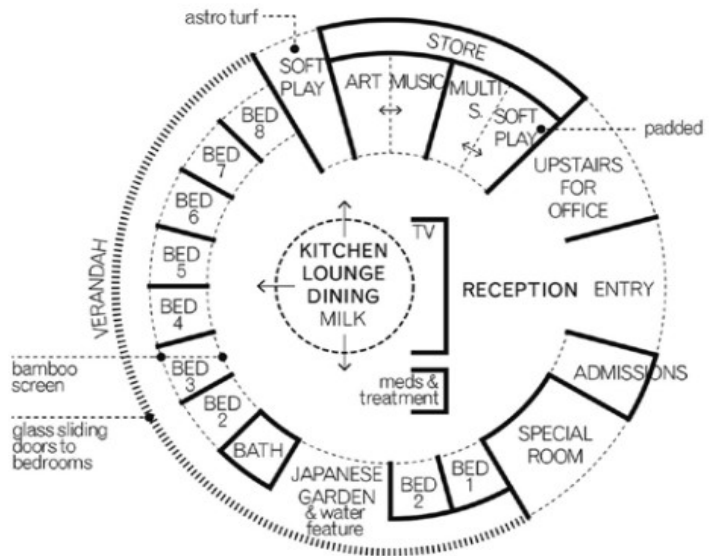


Figure 4 – A result of a group of parents and staff of children in hospice care taking part in a ‘draw your ideal hospice’ exercise.

space, a soothing Japanese garden and water feature and a space in the centre for a combined kitchen/dining/lounge. With a design such as this, staff have a view over the entry, and every single room and space. It is inclusive and welcoming.

Best practice respite design

A consistent and prominent finding at the design and experiential level for both respite care and end-of-life care is the need for spaces that are “home-like” or homely - explicitly designed to create a feeling of being at home. The building design, interior design, colour, materials⁹⁴ all contribute to spaces that create safety, dignity, privacy and rest. Homeliness is not just about materials or the look of the space: “It’s about the activities and behaviours that spaces and materials *afford*”.⁹⁵ The theory of affordances⁹⁶ includes elements an environment offers, provides or furnishes—good or bad.⁹⁷ Composition, layout and design, afford “distinct behaviours”.⁹⁷ For example, “single-patient rooms, private discussion areas, or carpeted flooring are associated with greater family presence and interaction”.^{97(p.55)} What this means is that a whole-of-design approach needs to be taken to ensure that all the components of a building create the sense of being home and *not* in clinical medical-style spaces. The design needs to invite and then enable a person to feel like they are in a space that mimics comfort, care and safety. Respite care needs to be able to accommodate different forms of privacy for different situations.



Figure 5 - The least preferred room in Richards and McLaughlan’s study of homeliness in palliative care. Note the hospital-style furniture, linoleum flooring, visible medical equipment, and fluorescent lighting.



Figure 6 - The most preferred room picked by palliative care staff from a choice of 5 design styles. Note the use of wood, carpet, indirect lighting, a view of and direct access to a garden, a ‘normal’ bed and a lack of clinical medical equipment.

Richards and McLaughlan⁹⁸ found that defining homeliness is expressed by palliative care staff as spaces that are non-clinical, with timber cladding, carpeted flooring, ambient lighting and a view to and/or access to outdoors. These elements also apply to designs for respite care. Rooms that are warm, with “home-like décor”, chosen colour palettes and ordinary (non-clinical/hospital) beds. This is the opposite of institutional or clinical environments which, more often than not, have harsh fluorescent lighting, a lack of colour, clearly visible stainless steel and moulded plastic medical equipment, and clinical materials such as linoleum floors and walls.



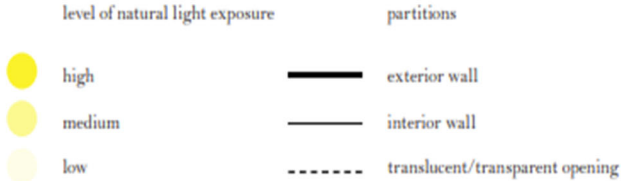
Figure 7 – Left: The living area at Maggie's West London showing the use of varied spaces, wood accents, colour, diffuse and natural lighting, views to the courtyard and opportunities for residents to be social or alone as needed in different capacities.

Figure 8 – Below: Whitehead's (2016) outline of part of the living area at Maggie's in West London illustrating the varied spaces and opportunities for privacy within a public area.

These home-like elements have been incorporated into the design of cancer care centres such as Maggie's Centres in the UK and elsewhere to great effect.⁹⁹ While every one of the 28 Maggie's Centres is architecturally different and unique, the architects are all given the same brief. This includes: the building must be designed to a domestic scale. It must be the antithesis of a hospital or clinical setting: no "closed doors implying secrets withheld, the endless corridors, the signposting, the artificial light".⁹⁹ At Maggie's there are no signs, even on the toilets (again, mimicking a home and not a clinical setting where signs are everywhere). There must be two toilets with washbasins in the public areas, at least one of which must be wheelchair friendly. They ask for three sitting rooms: large rooms for group relaxation activities such as yoga, meetings or lectures, close to the kitchen area, sound-proofed enough not to disturb the rest of the floor and capability to be private; medium-sized rooms for workshops, other sessions and capacity to be private; smaller sitting areas with the potential to be quiet counselling areas. They do not specify the



deconstructed plan



number of bedrooms, but their largest sitting room, and the kitchen and dining areas must accommodate 12 people at one sitting, and a sitting room that features a fireplace or stove that invokes cosiness and friendliness. Other spaces may include reflection spaces, an arts and crafts room, individual counselling spaces, an exercise room, a computer desk with two computers close to the office area, a

Figure 9 – Whitehead’s (2016) lobby design for Virginia Commonwealth University (VCU) Medical Centre “Nest – caring for the caregiver” featuring wood accents, comfortable furniture, splashes of colour, strong patterns and a wall of shelving for plants, books and personal



Figure 10 – Maggie’s Yorkshire, with the kitchen/dining at the heart of the organic-looking beech and cork ‘fins’. The use of multi-layers, indoor plants, large windows, diffused natural lighting and organic look contribute to public spaces that are inviting and gentle on the eye.



Figure 11 – Maggie's Tokyo, above, featuring single-level buildings linked with outdoor spaces and simple gardens which offer privacy from the outside world yet still allow for natural light and large windows facing the garden area.

Figure 12 – Maggie's Tokyo, uses natural wood, splashes of colour in the furniture, multiple sitting areas and views to the garden from every perspective.



library and a separate entrance/welcome area, friendly enough for newcomers to be able to stop and rest comfortably before proceeding.¹⁰⁰ Having a dedicated, welcoming entry space is vital to separate the outside world from the respite within the building. It allows clients, visitors and carers a moment to re-orient themselves to where they are and the purpose of their visit. This welcome space should flow from an outside entrance area that looks and feels like a home.

Integration and use of gardens is crucial in best practice design. Having a view of the natural world is considered very important and being able to open windows makes a big difference for client experience.¹⁰¹ Even just being able to hear birds through an open window improves client experience. What is most important, however, is access to nature.¹⁰²

Outcome measures of wellbeing in research on building and interior design for non-clinical therapeutic environments also includes elements such as easy orientation (easy wayfinding, easily accessible outdoor areas, awareness of time of day and season), placement of exits, rooms for common activities, and number and placement of bathrooms “to preserve, residents’ dignity and privacy”.^{103(p.397)}

Independence around bathing and toilet spaces is vital as bathing can be a particularly stressful experience for those needing and providing care. Bathrooms in public areas need to be places where residents and visitors can cry without being self-conscious,¹⁰⁴ so providing access to multiple toilet areas with discreet access is important. Providing various types of rooms (standard guest room with a small ensuite, and suites for families or couples including a kitchenette with dishwasher and fridge), living and separate sleeping rooms is also a design option.



Figure 13 – Above: A Ryder Architects design showing a bedroom with a set of doors opening to the outdoors and the other view to a shared, central lounge space. These single rooms include a sofa bed, a work desk, and an armchair. The exterior doors also allow for pet access, and visits during pandemic conditions. Photographs by Keith Hunter.⁷

Future-proofing

Part of that philosophy of care includes future-proofing. Climate change, which will inevitably result in more pandemics,^{14F¹⁰⁵} has created new considerations for design. Research of design experience during COVID-19 lockdowns has shown that having private rooms, with private bathrooms, and doors opening to private courtyard areas where family can visit easily during times of lockdown and negate viral loads in small or enclosed spaces¹⁰⁵ is a relatively achievable ideal. Part of the design challenge for access to external garden spaces for visitors is ensuring the landscaping allows them to access room verandas/areas without entering the building.

Regarding airconditioning, the use of ‘air curtains’ to mark doorways with pressured air is particularly useful for those with sight impairments and can help control interior temperatures.^{17F¹⁰⁶} Negative pressure rooms, necessary in clinical environments during the Coronavirus pandemic, can be created to avoid “recirculating unfiltered air”.^{18F¹⁰⁷} The quality of air filtration attached to heating/cooling systems should be considered. This will also be vital with an increase in extreme temperatures, bushfires and bushfire smoke over the coming decades. Engineering the whole space with the potential for additions including mechanical, personal space, smart house development etc. are some of the design elements that could also be considered.

System-level considerations

At a more systemic level, research is consistently finding that carers need to be encouraged and educated to seek respite to prevent burnout rather than to wait until burnout occurs.^{61,108} The use of

allied health care such as physiotherapy and occupational therapy can attenuate the risk of burnout. “A standardized needs assessment for caregivers could help policymakers and healthcare practitioners to identify caregiving” spouses “at risk of burnout and provide early intervention”.⁴⁷

Diagnostic tools

Diagnostic tools for burnout and bereavement have been shown to be useful in supporting and/or predicting the needs of carers at different points along the trajectory of chronic or life-limiting illness. A commonly used tool is the Maslach Burnout Inventory (MBI)¹⁰⁹(see Appendix 1) which can be adapted to use for unpaid caregivers. The MBI captures individual profiles using Likert scales to measure emotional exhaustion, depersonalization, personal accomplishment, levels of support, negative physical symptoms, as well as sociodemographic data.¹¹⁰ A notable finding of Kokurcan et al’s 2015 study of burnout profiles of caregivers using the MBI was that the lower the perception of social support held by caregivers, the higher the possibility is of caregiver burnout. It is imperative that simple, easy-to-use tools can be accessed and are utilized by health carers or other professional support personnel. Another such tool is the modified Bereavement Risk Index (BRI),¹¹¹ (see Appendix 2) which has proved to be reliable and simple to use. The Carer Support Needs Assessment Tool Intervention (CSNAT)¹¹² is another evidence-based assessment that can help carers (and health practitioners) determine and validate the needs of carers. A license to use the CSNAT is [available here](#).

Many measures that are used to assess the wellbeing of carers are standard tools to assess anxiety, stress, or depression in the general population and provide a basis for comparison between carers and non-carers before and after interventions. These include:

- [Carers Star™](#)
- Carers Assessment of Satisfaction index (CASI) (See Appendix 3)
- Carers Assessment of Managing Index (CAMI) (See Appendix 4)
- Positive and Negative Outcomes of Caring Scales Young carers (PANOC-Y20) (See Appendix 5)¹¹⁴

Referral systems

To support more systematic carer needs assessments, there is need for more overt referral systems.^{61,113} The needs of carers vary so greatly that every case must be assessed independently, depending on the age of the carer, their family relationship with the cared-for, their financial situation, whether they have supportive work or study arrangements, the cultural or ethnic background of the carer, their education level, the level of care they provide, the illness or disability of the family member and the point in the trajectory of that care provision. Referrals may then also vary from respite to education/training, counselling, support groups, practical help in the home, physical exercise or technological support.¹¹⁴

Marketing and information campaigns

Social inclusion in the form of recognition and respect, opportunities, and recognition can help improve the carer experience.¹¹⁵ There is potential for community-level social marketing campaigns in this space,¹¹⁶ promoting knowledge and behavioural change in service use for carers, the cared-for, and for health practitioners. There is also a supporting need for public awareness campaigns and social marketing to effectively address community knowledge gaps which enable carers to identify themselves and their needs.^{61,113} The importance of a non-clinical environment in respite care can make a profound

difference in providing support, hospitality and crucially, a willingness to accept respite services.^{117,118} It is also vital to have triage capacity and data capture ready at the point of contact with non-clinical respite facilities.

Cultural and linguistic diversity

Of the 850,000 carers in NSW, “around 1 in 5 were born in a country where English is not the main language, and around 1 in 10 speak a language other than English at home.”¹¹⁹ According to the Australian Bureau of Statistics (ABS), the top languages other than English spoken in the Queanbeyan-Palerang region are:

Language	Number	%
Macedonian	901	1.4
Punjabi	796	1.3
Italian	578	0.9
Nepali	544	0.9
Serbian	319	0.5

Consideration should be given to translating key information materials regarding the services offered into these languages. Translated materials should be used alongside culturally appropriate outreach, consultation and building respectful relationships.¹¹⁹ Working with community representatives is crucial to informing cultural and linguistically diverse communities. The information [here from Carers NSW](#) is very helpful with these challenges.

Data management

Booking systems must have the capacity to include waiting lists that can prioritise the need and availability of those seeking respite. Including categorizations of need (e.g. spousal carers who are the “most prone to negative consequences of a caring role”).^{120(p.11)} Intake forms could potentially be completed at an earlier time to lessen the stress of paperwork in times of need. Plans for regular respite could be arranged, where necessary and possible. Data gathering for regular evaluation of the service would include illness/prognosis, who is coming (if it is the patient coming alone, a nominated local carer must be nominated), religious affiliation, place of birth, length of stay, dietary needs etc.

A review of relative cost burdens to the community

According to the 2021 ABS Census, 12.2% of people in Queanbeyan-Palerang region “provided unpaid assistance to a person with a disability, health condition or due to old age”.¹²¹ Queanbeyan is home to about 4,500 unpaid carers.¹²² The overall replacement value of informal care in Australia in 2020 was \$77.9 billion^{23(p.iii)} (equivalent to 4% of gross domestic product and 54.4%^{23 (pp.22,23)} of the health and social work industry). Non-clinical respite can relieve approximately 50%¹²³ of the overall cost burden from public hospital admissions. The savings may be far higher, with Magill (2021) calculating “that the average cost of an acutely distressed person visiting” (non-clinical respite) “is approximately 10% of the

cost of them visiting an ED [Emergency Department] instead".^{2(p.36)} Despite knowing this, carers aged 18 to 60 are faced with few suitable options when it comes to respite services which places a heavy burden on the thousands of people in unpaid carer roles.

When looking for respite, a carer is most likely to find respite in Australia designed for aged care. Publicly available costs, therefore, are based on calculations for those receiving aged care pensions. Those who have an NDIS package also have the option of up to 14 days at a time, and up to 28 days short-term accommodation per year, of paid respite, the costs of which are covered by the scheme.¹²⁴ Costs will vary from provider to provider, place to place, depending on disability and illness levels.

For the many unpaid carers who do not have access to NDIS funding or are not eligible for aged care support, however, their options may seem bleak, depending on their GP or specialist's knowledge of social prescribing, and knowledge of the respite services available to them, particularly if the patient has specific needs. Bearing in mind that the annual replacement cost of informal care is estimated to be in excess of \$77 billion each year,²³ the below costs provide a general indication of the financial value either by averages or starting costs for carers who do not qualify for aged care or NDIS-funded packages.

Ambulance

As of 2022 in New South Wales a non-emergency road call-out (as opposed to helicopter or plane) for an Ambulance transfer comes with a call-out fee of \$407, plus an additional charge of \$3.67 per kilometre or part thereof.¹²⁵ The cost to the health consumer varies according to private health care cover and the state or Territory in which they live. The NSW Government subsidises 49% of ambulance costs.

Hospital

The Audit Office of NSW has calculated a one-night admission to a NSW hospital can cost from between \$1,100 to \$1850 for one night only,¹²⁶ while the Independent Health and Aged Care Pricing Authority (IHACPA) has calculated the average overall cost to a hospital of a stay for an admitted patient in an Australian hospital in 2019-2020 at \$5,335.¹²⁷ This is calculated as a "cost per National Weighted Activity Unit (NWAU)", which is a "measure of health service activity expressed as a common unit, against which the National Efficient Price (NEP) is paid".¹²⁸ This average is made across more than 80 public hospitals. It includes costs across every stage of the admission process from emergency presentation to admission and is weighted for clinical complexity.

The Commonwealth minimum benefit for shared room accommodation in a medical admission in 2022-23¹²⁹ starts at \$383 per 24 hours for 1-14 days and \$331 for 15+ days. This is a baseline costing that does not include specialist costs or interventions.

Other medical costs

Extra costs that can be incurred by either the health system or the health consumer include:

Outpatient visits

Average cost across states and territories per non-admitted service event in 2019/20 was \$337.¹³⁰

General Practitioner

In 2021-22, 49% of health consumers had an out-of-pocket cost for a follow-up appointment for a complex disorder in a private setting across Australia. Of those: Patients typically paid \$67, Medicare paid \$119.”¹³¹

Occupational therapist

In 2021-22, 38% of health consumers had out-of-pocket costs in a private setting across Australia. Of those: Patients typically paid \$103. Medicare paid \$77.¹³¹

Medical Oncology

In 2021-22, 14% of health consumers had out-of-pocket costs for a follow-up appointment for complex disorder in a private setting. Of those: Patients typically \$81. Medicare paid \$119.¹³¹

Nursing

Research into the economic value of end-of-life and palliative care interventions suggests that, overall, home-based care offers “substantial savings to the health system, including a decrease in total healthcare costs, resource use and improvement in patient and caregivers’ outcomes”.^{132,133, 134} For carers who are able to manage respite in their own homes, the costs of needing nursing care and other home help services can be prohibitively expensive .

While the average salary for agency nurses in Australia is \$52.91 per hour,¹³⁵ this is the lowest starting point and varies depending on the nurses’ expertise, the place, the shift (morning, evening, night, Saturday, Sunday, public holiday). The National Disability Insurance Scheme (NDIS) pricing arrangements start from \$89.17 per hour for a weekday, daytime shift nationally (or \$133.75 for a very remote posting), to \$204.70 per hour for a public holiday nationally (or \$307.05 for a very remote posting). However, there are 30 different item numbers for casual nursing costs per hour, each being paid differently according to the time of day and week and the type of nursing required.

Using the lowest of each of the NDIS-provided costings, an 8-hour weekday shift (\$89.17 per hour), 8-hour evening shift (\$121.79 per hour) and an 8-hour night shift (\$143.50 per hour) adds up to a starting point of \$2,680.08 for one 24-hour period. Very few unpaid carers would be able to privately manage these costs without NDIS funding.

Cost savings

The projected total operating costs of Respite Care for QBN is \$3,172 for a 24-hour period (based on the Respite for QBN Respite Budget Grant total of \$1,157,775.20 for one financial year). With its six double rooms, makes it a total cost of \$528.66 per room per 24-hour period. Considering a baseline cost for home nursing for one 24-hour period is \$2,680.08 (and this does not include the cost of the carer’s leave were they to give themselves a break outside the home).

Comparative costs	Cost	Saving
Hospital average stay	\$1475 (mean cost per night in NSW)	\$947
Ambulance trip	\$407 + \$3.67 p/km average 6km (\$22.20)=\$429.20	\$429.20
Home nursing	\$2680	\$2152
QBN Respite	\$528 (per night)	

Not only is respite saving the public health system money, beds and precious resources, but it is providing uncountable intangible benefits, quality of life and dignity for those navigating chronic and/or life-limiting illness.

A review of the more ‘intangible’ benefits of respite

The success of carer respite lies not just in financial cost saving, but in the ultimate goals, and then outcomes, for the carer and the cared-for. When reviewing the cost of intervention for carers, it is vital to understand that intervention for the carer “will impact the wellbeing and functioning of the other” (the patient).^{136(p.85)} When a life-limiting diagnosis is given, priorities change. Family carers take on varied levels of physical and emotional labour.⁴⁶ Being in a state of constant monitoring and surveillance is exhausting.⁶⁶ Depression, sleep deprivation, loss of social networks, frustration, inability to take any sort of break⁶⁶ all contribute to the burden of caregivers and can result in the carer’s own health suffering.

Family members use respite for many reasons. It can be used for carers to spend time with other family members, and to attend to their own health and other appointments.¹³⁷ It can be an important opportunity for carers to take the time to reconnect to other existing supports and friends, developing other social networks, and other supportive relationships outside the home and family environment. Maintaining those external relationships has been shown to help reduce the carer burden “after the respite has ended”.^{138(p.13)} Respite supports quality of life and dignity for patients during the journey of navigating life-limiting or chronic illness by increasing emotional wellbeing, improving physical health with healthy eating, reducing worry, increasing confidence and coping capacity, and it allows carers to think about their own futures and personal goals.¹³⁹ Having regular respite gives carers “something to look forward to and keep them going”.^{140(p.614)} Longer periods of time, particularly in non-clinical respite services, is “most associated with the recuperating and restoring of “batteries”.^{141(p.457)}

Research has repeatedly shown that respite provides carers with time for themselves and enables them to “manage their daily lives a little better”.^{141(p.451)} This relieves them of the responsibility and burden of their role, and in removing them from the physical space where caring generally occurs, allows them to cope better.¹⁴¹

Respite activities outside the house includes access to and immersion in nature. Even spending as little as “15 minutes spent in a natural environment can result in beneficial short-term effects on mental health, in particular for stress and anxiety”.^{146 (p.1855)} Research on spending time in nature has been shown, over the past couple of decades, to be remarkably beneficial to health and wellbeing.^{142,143,144,145} This can include improving sleep and lowering stress hormones,¹⁴⁶ access to a garden can improve

cognitive functions and even improve glucose levels for those with diabetes, and improvements for those with allergic conditions.¹⁴⁷

An analysis of Respite Care for QBN’s proposed respite facility

Respite Care for QBN’s proposed respite facility responds to the research and developments in end-of-life care. It aims to provide space and comfort; access to gardens, including large windows that open to the garden area; it includes shared, communal living spaces, nearby and easily accessible parking, and quiet wings for privacy and safety.

The centre will provide a space where carers can be relieved of their burden. They will receive the time and space to enable their own care provisions in a home-style situation in a modern design that incorporates much of the contemporary findings for best-practice respite design. However, there are some aspects that could be given further attention to enhance/increase benefits to carers and care recipients. Below is the current design for Respite Care for QBN.



Based on the evidence and best practice design for respite care, the current design for Respite Care for QBN might wish to consider the following areas:

General

- The current corridor design is reminiscent of aged care and clinical/hospital care designs. Softening the experience of that space could be done using materials, such as floating wood, laminate wood or engineered wood or bamboo flooring throughout the corridors and dining areas.
- Utilise the corridor wall space for artwork that can be viewed easily from standing and sitting (wheelchair) heights.
- All entrances and exits, and outdoor spaces, must be accessible for those with limited eyesight and people using wheelchairs.

Entry

The entry space could make or break a person's choice to stay. The entrance area is a space in which a newcomer can sit comfortably and "pause".⁹⁹ The newcomer should be able to "assess...the layout of the rest of the building", with a friend or relative.⁹⁹

"The entrance should be obvious, welcoming, and not intimidating, with a place to hang your coat and leave your broly. The door should not be draughty, so perhaps there should be a lobby."⁹⁹

In the current design for Respite Care for QBN, on entering, the visitor is faced with a corridor, three walls and a closet. While this affords privacy, it is not inviting and could potentially look more like a back entrance for workers than a front door inviting people to stay. Using the left-hand wall space as a feature that includes plants, mementos, books, other objects commonly found in people's homes (see Figure 5) and potentially a small, comfortable sofa against the opposite wall should space permit (or two separate, small armchairs), a comfortable space could be created. Another option would be to have glass doors in the left-hand wall in the entry, creating a kind of open mudroom/laundry area, such as would be found in a normal home. This would give a direct view of the living areas from the office space and allow the visitor to have a welcoming view of everyday living. Interior design experts will be able to advise further regarding details and possibilities for the space. Architects could advise further on whether adjusting the laundry space is possible and if there is space to increase the size of the entrance area to include comfortable seating.

Office

The current office design does not give the staff member the capacity to have any view of the common living areas. As there is no reception desk (and nor does there need to be), the office must be designed so that the staff member has a discrete view over the entrance area. The current design has the staff member's back to the entry way and their desk facing a wall. There must be sufficient space in the office for more than one workstation, should this be part of the service delivery design, with a phone, computer point, lighting and storage space for each computer space. There should also be room for printed information materials for regular replacement in the entry area.

Bedrooms

- Adjustments to bedrooms 1 and 4 to include two larger suites (including bathroom ensembles, a small living area and/or kitchenette) for couples, families with young children or other carer/patient relationships where two beds (the second of which may be a sofa-bed) may need to be utilised. Given the intended age range of 18 to 60, it is inevitable that clients with children will use respite—catering to the needs of their children to stay with/visit will help with uptake.
- All bedrooms to include glass doors that open on to the garden/outdoor area. This would include privacy screening (using suitable plants, for example) for each room. There is currently space and opportunity for this to be implemented in consultation with garden experts. This would contribute to future-proofing re outdoor access to families in future pandemics, provide secondary private spaces at little cost, and direct access to nature which would contribute to overall preventive health care, and improvement in health outcomes.
- If funding allows, bedrooms 2,3,5 and 6, to have small ensembles, some of which could be wheelchair and/or disability accessible. Given space restrictions, just a toilet/basin could be considered as an ensuite and keep bathing facilities more communal.

Lounge

- The division of the existing lounge space into two separate spaces goes some way to responding to best practice respite care design, however, there need to be more options for smaller, more private spaces, and consider whether you may wish to have a larger, separate meeting room that is separate to the existing living spaces. Ways that these could be included in the current design include:
 - o Divide one half of the existing lounge space into smaller, more private spaces using interior design, for example, using a dropped ceiling section in the interior corner, dividers, furniture, plants etc. to create two or three separate and varied spaces.

Garden

- Consider including a water feature (a feature fountain or some other kind of flowing water feature may be best considering safety implications for young children)
- Create spaces in the garden area that are protected from the elements and provide outdoor rest, comfort and privacy (two small pagodas with day beds or other reclining furniture for example) or somewhere to sit quietly and chat with a counsellor, friend or other resident.
- Include a sensory garden that considers smells at different times of year; sounds (long grasses/rustling in the wind etc.); colour at different times of years; a raised-bed kitchen garden area for those who need to touch the earth or for whom gardening is a way of relaxing.
- Consider the landscaping of multiple rooms/areas outside to break up the space and provide for more resting areas.
- Fruit trees and a mix of evergreen and deciduous trees should be planted. Careful consideration should be given to the mix of plants/trees to encourage as much bird life as possible.

Other

- Consider whether the architects would be able to incorporate a meeting room for formal or informal meetings/talks.

- Consider creating a space for arts and crafts either at the outer end of the dining area or extending the largest of the current storage areas next to bathroom 2. This could also serve as a play area should young children be visiting or staying with a parent.
- Consider including a computer space where people can either plug in their own laptops or permanent computers (and a printer) are placed for residents' use. This space should be within sight or easy communication distance of the office, if that is going to be the place where a staff member will usually be found.
- The kitchen should have two dishwashers and either one very large or two smaller fridges. The current design of the kitchen and dining areas is good, with space for 12 people and enough space for multiple people to be help themselves to tea or coffee or snacks etc.

Summary and recommendations

We present the review above as a guide to existing research on carer burden, the cost burden of carer burnout, best practice respite care and design, and the intangible benefits of respite. We include considerations that Respite Care for QBN should consider in terms of design. We understand that the design is limited by the block and its orientation, and by finances and time. Given that the build is in final approval stage through council we understand that modifying the physical structures may not be possible. As such, the focus for QBN should be on:

Design

- Those with lived experience must dictate design needs and advice on usage.
- Consideration should also be given to the design suggestions based on existing best practice and future-proofing.
- Interior design and styling should achieve a home-like environment using materials, colours and lighting.
- Open designs in living areas; private ensuites in bedrooms; glass doors in bedrooms to open directly to the garden area, and improvements to the entry design would add great benefits.
- Careful consideration should be given to getting best use of the outdoor garden areas and any possible minor changes to improve design for affect and to improve the client experience. This includes a water feature, private spaces, raised kitchen garden beds and sensory gardens.

Care

- Respite must cater to the needs of carers at varying points in their role.
- Those with heavier burdens can include spouses, employed people without support from their workplaces, those with little knowledge of the health system, men providing later stages of care and women who may need regular care.

Systems

- Carers lack information about respite options. When respite is available and known to carers, they are reluctant to utilize it due to internalized familial and societal expectations. With this in mind, tailored marketing and information campaigns for health consumers promoting greater awareness of the health risks and effects of caring must be developed, with data management in place for regular evaluation.

Respite Care for QBN's vision is to support carers by providing short-term residential care for people aged 18 to 60, living with a life-limiting or chronic illness. Objectives include providing a centre of excellence run by respected professionals; working with Commonwealth and NSW State governments, local businesses and the community, and supporting families of residents to "re-energise and continue their responsibilities" as carers.¹⁴⁸

Incorporating the knowledge and recommendations from the current literature and research into the system-wide approach of a dedicated non-clinical respite centre in Queanbeyan will contribute greatly to supporting the wellbeing of the unpaid carers.¹⁴⁹ currently living in the region. Supporting carers and relieving their burden of care is a significant financial cost saving to them and the public health system.

But the outcomes are not just about numbers and finance. Nor is living with, or being a carer for somebody with, a life-limiting or chronic illness just about managing medical care. Respite for carers in a non-clinical space provides a qualitative environment that results in deeply personal, life-altering experiences. Providing an accessible space that is capable of holding people who live with the enormity of managing potential or impending loss is incalculable. It is "...a social and interpersonal experience, and a focus on improving patient–family experiences is integral to practice and care".¹⁵⁰

Respite Care for QBN will be embedded in the local community so will be easily accessible to carers in Queanbeyan and the surrounding region. As it stands, the facility will ensure a well-earned break for carers and their loved ones. It will keep people out of hospital and take much-needed pressure and costs off the health system.

The research team is happy to talk through all these options with Respite Care for QBN and your architects, designers and landscapers if needed.

Appendix 1 Burnout inventory

1 of 3

Burnout Self-Test Maslach Burnout Inventory (MBI)

The Maslach Burnout Inventory (MBI) is the most commonly used tool to self-assess whether you might be at risk of burnout. To determine the risk of burnout, the MBI explores three components: exhaustion, depersonalization and personal achievement. While this tool may be useful, it must not be used as a scientific diagnostic technique, regardless of the results. The objective is simply to make you aware that anyone may be at risk of burnout.

For each question, indicate the score that corresponds to your response. Add up your score for each section and compare your results with the scoring results interpretation at the bottom of this document.

Questions:	Never	A Few Times per Year	Once a Month	A Few Times per Month	Once a Week	A Few Times per Week	Every Day
Section A:	0	1	2	3	4	5	6
I feel emotionally drained by my work.							
Working with people all day long requires a great deal of effort.							
I feel like my work is breaking me down.							
I feel frustrated by my work.							
I feel I work too hard at my job.							
It stresses me too much to work in direct contact with people.							
I feel like I'm at the end of my rope.							
Total score – SECTION A							

Questions:	Never	A Few Times per Year	Once a Month	A Few Times per Month	Once a Week	A Few Times per Week	Every Day
Section B:	0	1	2	3	4	5	6
I feel I look after certain patients/clients impersonally, as if they are objects.							
I feel tired when I get up in the morning and have to face another day at work.							
I have the impression that my patients/clients make me responsible for some of their problems.							
I am at the end of my patience at the end of my work day.							
I really don't care about what happens to some of my patients/clients.							
I have become more insensitive to people since I've been working.							
I'm afraid that this job is making me uncaring.							
Total score – SECTION B							

Questions:	Never	A Few Times per Year	Once a Month	A Few Times per Month	Once a Week	A Few Times per Week	Every Day
Section C:	0	1	2	3	4	5	6
I accomplish many worthwhile things in this job.							
I feel full of energy.							
I am easily able to understand what my patients/clients feel.							
I look after my patients'/clients' problems very effectively.							
In my work, I handle emotional problems very calmly.							
Through my work, I feel that I have a positive influence on people.							
I am easily able to create a relaxed atmosphere with my patients/clients.							
I feel refreshed when I have been close to my patients/clients at work.							
Total score – SECTION C							

SCORING RESULTS – INTERPRETATION

Section A: Burnout

Burnout (or depressive anxiety syndrome): Testifies to fatigue at the very idea of work, chronic fatigue, trouble sleeping, physical problems. For the MBI, as well as for most authors, "exhaustion would be the key component of the syndrome." Unlike depression, the problems disappear outside work.

- Total 17 or less: Low-level burnout
- Total between 18 and 29 inclusive: Moderate burnout
- Total over 30: High-level burnout

Section B: Depersonalization

"Depersonalization" (or loss of empathy): Rather a "dehumanization" in interpersonal relations. The notion of detachment is excessive, leading to cynicism with negative attitudes with regard to patients or colleagues, feeling of guilt, avoidance of social contacts and withdrawing into oneself. The professional blocks the empathy he can show to his patients and/or colleagues.

- Total 5 or less: Low-level burnout
- Total between 6 and 11 inclusive: Moderate burnout
- Total of 12 and greater: High-level burnout

Section C: Personal Achievement

The reduction of personal achievement: The individual assesses himself negatively, feels he is unable to move the situation forward. This component represents the demotivating effects of a difficult, repetitive situation leading to failure despite efforts. The person begins to doubt his genuine abilities to accomplish things. This aspect is a consequence of the first two.

- Total 33 or less: High-level burnout
- Total between 34 and 39 inclusive: Moderate burnout
- Total greater than 40: Low-level burnout

A high score in the first two sections and a low score in the last section may indicate burnout.

Note: Different people react to stress and burnout differently. This test is not intended to be a scientific analysis or assessment. The information is not designed to diagnose or treat your stress or symptoms of burnout. Consult your medical doctor, counselor or mental health professional if you feel that you need help regarding stress management or dealing with burnout.

C. Maslach, S.E. Jackson, M.P. Leiter (Eds.), Maslach Burnout Inventory manual (3rd ed.), Consulting Psychologists Press (1996)

Appendix 2 Bereavement risk index

Form 6: Modified bereavement risk index

Name of Resident: _____

Name of family carer: _____ Relationship to resident: _____

Contact details of family carer

Address: _____

Phone number: (H) _____ (W) _____ (M) _____

	Risk Factor		Score
1	Anger	None	1
		Mild irritation	2
		Moderate (occasional outbursts)	3
		Severe (spoiling relationships)	4
		Extreme (always bitter)	5
2	Self-reproach (self-blame/guilt, feeling bad and/or responsible for something)	None	1
		Mild (vague and general)	2
		Moderate (some clear self-reproach)	3
		Severe (preoccupied with self-blame)	4
		Extreme (major problem)	5
3	Current relationships	Close intimate relationship with another	1
		Warm, supportive family	2
		Family supportive but lives at a distance	3
		Doubtful (patient unsure whether family members are supportive or not)	4
		Unsupportive	5
4	How will key person cope?	Well (normal grief and recovery without help)	1
		Fair (probably get by without specialist help)	2
		Doubtful (may need specialist help)	3
		Badly (requires specialist help)*	4
		Very badly (requires urgent help)*	5
* Will be automatically referred to specialist bereavement support			Total Score

Low risk score (less than 7)

- Give a copy of the booklet – “Now What? Understanding Grief” (a copy is included in the PA Toolkit and can also be downloaded from the PA Toolkit website at www.caresearch.com.au/PAToolkit).

Moderate risk score (7-10)

- Give a copy of the booklet – “Now What? Understanding Grief”
- Suggest they may like to contact one of the support agencies listed in the booklet

High risk score (10 or more)

- Encourage the person to contact a health professional e.g. GP, psychologist, counselling service, or bereavement counsellor
- Give a copy of the booklet – “Now What? Understanding Grief”

Appendix 3 Carer's Assessment of Satisfaction index (CASI)

Carer's Assessment Of Satisfactions Index (CASI)

Caring is often a difficult and stressful task but for many carers there are also moments of personal satisfaction.

On the following pages are some statements which carers have made about those aspects of caring that they find satisfying. Please read each statement and then indicate how it applies to you.

Ratings:

- X This doesn't tend to apply in my situation.
 - This applies to me. I find it provides:
 - 0 No real satisfaction;
 - 1 quite a lot of satisfaction;
 - 2 a great deal of satisfaction.
1. Caring has allowed me to develop new skills and abilities.
 2. The person I care for is appreciative of what I do.
 3. Caring has brought me closer to the person I care for.
 4. It's good to see small improvements in the person I care for.
 5. I am able to help the person I care for reach their full potential.
 6. I am able to repay the kindness of the person I care for.
 7. Caring provides a challenging and stimulating job.
 8. Despite all the problems, the person I care for doesn't grumble or moan.
 9. It's nice to see the person I care for clean, comfortable and well turned out.
 10. Caring has enabled me to fulfil my sense of duty.
 11. I'm the sort of person who enjoys helping people.
 12. I get pleasure from seeing the person I care for happy.
 13. Knowing the person I care for the way I do means I can give better care than anyone else.

14. It helps to stop me from feeling guilty.
15. Caring has made me a better, less selfish person.
16. It's nice to feel appreciated by those family and friends I value.
17. Caring has strengthened close family ties and relationships.
18. It's good to help the person I care for overcome difficulties and problems.
19. It's nice when something I do gives the person I care for pleasure.
20. I am able to keep the person I care for out of an institution.
21. I feel that if the situation were reversed the person I care for would do the same for me.
22. I am able to ensure the person I care for is well fed and their needs tended to.
23. Caring has given me the chance to widen my interest and contacts.
24. Maintaining the dignity of the person I care for is important to me.
25. I am able to test myself out and overcome difficulties.
26. Caring is one way of showing my faith.
27. Caring has provided a purpose in life that I didn't have before.
28. At the end of the day I know I'll have done the best I could.
29. Caring is one way of expressing my love for the person I care for.
30. Caring makes me feel needed and wanted.

Appendix 4 Carer's Assessment of Managing Index (CAMI)

Carer's Assessment Of Managing Index (CAMI)

Ratings:

4. Very Helpful
3. Quite helpful
2. Not really helpful
1. I don't use this

Managing Events/Problem Solving

(Please circle the number that best describes your experience)

- | | | | | |
|---|---|---|---|---|
| 1. Finding out as much information as you can about the problem. | 1 | 2 | 3 | 4 |
| 2. Getting as much help as you can from professionals and other service providers. | 1 | 2 | 3 | 4 |
| 3. Talking over your problems with someone you trust. | 1 | 2 | 3 | 4 |
| 4. Relying on your own experience and the expertise you have built up. | 1 | 2 | 3 | 4 |
| 5. Keeping one step ahead of things by planning in advance. | 1 | 2 | 3 | 4 |
| 6. Establishing a regular routine and sticking to it. | 1 | 2 | 3 | 4 |
| 7. Establishing priorities and concentrating on them. | 1 | 2 | 3 | 4 |
| 8. Thinking about the problem and finding a way to overcome it. | 1 | 2 | 3 | 4 |
| 9. Altering your home environment to make things as easy as possible. | 1 | 2 | 3 | 4 |
| 10. Keeping the person you care for as active as possible. | 1 | 2 | 3 | 4 |
| 11. Trying out a number of solutions until you find one that works. | 1 | 2 | 3 | 4 |
| 12. Preventing problems before they happen. | 1 | 2 | 3 | 4 |
| 13. Getting as much practical help as you can from your family. | 1 | 2 | 3 | 4 |
| 14. Being firm and pointing out to the person you care for what you expect of them. | 1 | 2 | 3 | 4 |

Appendix 5 Positive and Negative Outcomes of Caring Scales Young carers (PANOC-Y20)

**Young
Carer
Hilfe**

Positive and Negative Outcomes of Caring (PANOC-YC20)

The Positive and Negative Outcomes of Caring (PANOC-YC20) is a questionnaire to be completed by young carers (a 20-item self-report measure) that can be used to provide an index (or score) of the subjective cognitive and emotional impact of caring in young people. Research and practice have identified that many young carers are significantly affected by their caring responsibilities both negatively and positively. For this reason, the PANOC-YC20 was designed to provide two scores. One score showing how much caring is experienced negatively and one showing how much caring is experienced positively.

Scoring

The PANOC-YC20 is a 20-item psychometric instrument designed to assess the positive and negative effects of caring activity. Each item is rated on a 3-point scale, 'Never', 'Some of the time', and 'A lot of the time'.

For scoring purposes:

'Never' = 0
'Some of the time' = 1
'A lot of the time' = 2

The PANOC-YC20 consists of two 10-item subscales: (1) positive responses, and (2) negative responses. Scores on both the subscales have a potential range of 0 to 20, with higher scores indicating greater positive and negative responses, respectively.

To calculate the positive response score: sum items 1, 2, 3, 4, 7, 8, 15, 18, 19, and 20.

To calculate the negative response score: sum items 5, 6, 9, 10, 11, 12, 13, 14, 16, & 17.

Interpretation of scores

Statistical analysis indicates that scores of less than 12 on the PANOC-YC20 positive scale and/or greater than 8 on the PANOC-YC20 negative scale may be indicative of concern (see Table 1). For example, this may indicate that the young person is suffering from emotional distress. In such circumstances practitioners will need to follow their usual working practices and procedures in terms of exploring the young person's feelings with them and their family and responding appropriately, perhaps in partnership with appropriate health or children's social care services.

**Table 1: Interpreting scores on the PANOC-YC20
Scores Interpretation**

Positive

0 No positive outcomes reported – potential for concern
1-12 Relatively few positive outcomes, potential for concern
13-20 Relatively high positive outcomes reported

Negative

0 No negative outcomes reported
1-8 Relatively few negative outcomes reported
9-20 Relatively high negative outcomes reported, potential for concern

Of most concern will be those young carers who score less than 12 on the positive scale AND greater than 8 on the negative scale. However, where there are serious concerns we recommend that the PANOC-YC20 be used as part of a fuller assessment process by qualified health and social care professionals.

Young Carer Hilfe

NAME..... DATE.....

Below are some things young carers like you have said about what it feels like to look after someone. Please read each statement and tick the box to show how often this is true for you. There are no right or wrong answers. We are just interested in what life is like for you because of caring. **Thank you.**

N e v e r	S o m e o f t h e t i m e	A l o t o f t h e t i m e
---------------------------	---	---

		0	1	2
1+	Because of caring I feel I am doing something good	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2+	Because of caring I feel that I am helping	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3+	Because of caring I feel closer to my family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4+	Because of caring I feel good about myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5-	Because of caring I have to do things that make me upset	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6-	Because of caring I feel stressed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7+	Because of caring I feel that I am learning useful things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8+	Because of caring my parents are proud of the kind of person I am	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9-	Because of caring I feel like running away	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10-	Because of caring I feel very lonely	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11-	Because of caring I feel like I can't cope	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12-	Because of caring I can't stop thinking about what I have to do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13-	Because of caring I feel so sad I can hardly stand it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14-	Because of caring I don't think I matter	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15+	Because of caring I like who I am	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16-	Because of caring life doesn't seem worth living	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17-	Because of caring I have trouble staying awake	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18+	Because of caring I feel I am better able to cope with problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19+	I feel good about helping	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20+	Because of caring I feel I am useful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

PANOC-YC20

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 Developed for Carers Trust by Young Carers International Research and Evaluation,
 School of Sociology and Social Policy, University of Nottingham, University Park, Nottingham NG7 2RD.

Die Instrumente inklusive Erklärung sind unter folgendem Link abrufbar <https://professionals.carers.org/young-carer-assessment-tools> (Stand Oktober 2019)

Appendix 6 About the research team

Associate Professor James Connor

Associate Professor James Connor has undertaken a range of project evaluations, research consultancies and research projects with Government Departments and Agencies (such as Defence, ATO, Home Affairs, IP Australia) and the private/not for profit sector (such as WADA, Sports Medicine Australia, Palliative Care ACT). He is an expert in understanding culture and advising on how change can be achieved with lasting impact. His specific expertise in the palliative care area includes published research on carer care burden, emotions and burn-out, and evaluation of palliative care respite service provision.

Dr Vanessa McDermott

Dr Vanessa McDermott specialises in research about corporate governance and organisational culture, and how organisations communicate and manage behaviour change initiatives. She has researched and led evaluations of organisational behaviour change programs in both the private and public sector. Dr McDermott has developed and led APS evaluations (e.g., in Defence, IP Australia, Department of Employment and Workplace Relations), including developing co-designed program logic and theory of change models, and tailored evaluation strategies. Vanessa is a skilled qualitative researcher including conducting focus groups and interviews, qualitative data analysis and reporting.

Dr Penelope Bergen

Dr Penelope Bergen is a post-doctoral research fellow at the UNSW Canberra School of Business. Her research focus is the relationship between human and organisational systems: Workplace cultures and their impact on policy outcomes and community development. Over the past two years she has been working in health policy and the health consumer research space, with a particular focus on health consumer co-design, and rural, regional and remote health access.

Research capability at UNSW Canberra

The School of Business is a supportive, stimulating and friendly environment focused on exploring the forces shaping modern organisations, economies and governments to create better understandings of how to work within them as managers, and how to lead the way for change. We recognise the complexity of organisational and social systems and value our interdisciplinary research approach as essential for the study of business issues in a changing and uncertain world. Our world-class research outputs include thought leadership in project management, risk management, governance, asset and logistics management, relationship management, accountability and business intelligence.

UNSW is a Go8 institution and the UNSW Canberra School of Business is an accredited member of [The Association to Advance Collegiate Schools of Business \(AACSB\) International](#). Our undergraduate and postgraduate students have access to the world-class academic expertise of our internationally recognised researchers and develop a sophisticated knowledge of strategy, leadership and other managerial concepts.

The School of Business develops exceptional managers across the public, private and not-for-profit sectors. Our graduates are equipped to excel in business areas such as people management, project management, acquisition and procurement and logistics. Our educational offerings uniquely cater to the

needs of our stakeholders and include the Master of Strategic People Management, Master of Sustainment Management, Doctor of Public Management as well as a suite of Professional Education programs, including executive education programs on Measurement and Reporting of WHS.

At UNSW Canberra, our mission is to create and disseminate applied business knowledge for the benefit of students, organisations and society. The School of Business develops leadership capabilities for Defence, the public sector, business, academia and the not-for-profit sector, with the capacity to succeed globally.

Our vision is to be recognised as a leading research-intensive business school renowned for its students and staff, teaching quality, relevance and innovation.

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