



Caring for a person with a life-limiting illness

Scoping Project

'We're all on different paths but we're on the same journey.'
– Focus group participant

August 2016

ABOUT CARERS VICTORIA

Carers Victoria is the state-wide peak organisation representing people who provide unpaid care. We represent more than 700,000 family carers across Victoria including people caring for ageing parents, children with disabilities, and partners with chronic or mental illness. Carers Victoria is a member of the National Network of Carers Associations, and the Victorian Carer Services Network. Carers Victoria is a non-profit association which relies on public and private sector support to fulfil its mission with and on behalf of carers. Carers Victoria is a membership based organisation. Our members are primarily family carers, who play an important role in informing our work, contributing to advocacy and strategic aims, and distributing information more widely to other carers.

This report was prepared for the Loddon Mallee Regional Palliative Care Consortium (LMRPCC) by Carer Consultation Coordinator Margaret Boulos and Senior Policy Advisor Anne Muldowney, Carers Victoria. Funding to undertake the scoping of a potential Loddon Mallee Regional Palliative Care Carers Support Network was provided to the Consortium by Carer Support Services in Bendigo.

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EXECUTIVE SUMMARY

In 2015 the Loddon Mallee Regional Palliative Care Consortium (LMRPCC) made the decision to undertake a scoping study to assess the need for a regional program that connects and supports people caring for someone with a life-limiting illness throughout their journey. The Consortium contracted Carers Victoria to undertake the project. The purpose of this report is to summarise the findings gained through consulting carers using qualitative data collection methods.

The primary objective of the scoping study was to determine whether carers would perceive benefit in a regional-based network connecting individuals in similar contexts. A secondary objective of the study was to contextualise this perceived benefit by understanding the lived experience of people caring for someone with a life-limiting illness in the Loddon Mallee region. As such, we discuss the day-to-day challenges of caring roles including access to services for themselves, transport, time and money spent caring and the informal supports they may use.

Carers Victoria designed two methods to collect the data: a survey and focus group discussion. Two separate surveys targeted previous and current carers and were made available through the popular web-based survey mechanism SurveyMonkey®.

The scope of the report is to discuss the results of an online survey promoted to individuals living in the Loddon Mallee or accessing medical services in the region between March and May in 2016. People in the region who had experience of, or were currently caring for someone with a life-limiting illness as a family member, friend or neighbour – not as a paid worker – were able to complete the survey. There were no age limits on respondents. Comments made during two focus group discussions held in Bendigo (May 2016) and Swan Hill (June 2016) are also included.

The results of the scoping study indicate participants perceive a benefit in the development of a region-based network connecting people with past or present experience of caring for someone with a life-limiting illness to support carers by connecting them together, particularly in ways that facilitate face-to-face interaction. In addition to this, most respondents also perceive they have received an emotional and/or practical benefit from interacting with other carers. Participants also responded enthusiastically about the need for other activities such as workshops and information about available resources. There was more uncertainty that the experience of some participants could be a possible benefit to other carers and this suggests that a network would require professional facilitation which guides carers.

RECOMMENDATIONS

Based on the results of this small study, the following recommendations are made:

1. The sustainable development of a region-based network connecting individuals caring for a friend or relative with a life limiting illness.
2. Ongoing facilitation of the network to introduce new members and support existing ones.
3. Workshops and events to connect carers regarding palliative care, grief, self-care, financial and legal issues.
4. Significant level of integration between services that support the patient such as GP clinics or palliative care services in the region or Melbourne.
5. The distribution of information provided at times the carer, not the professional, deems appropriate.
6. Professionals to follow up with carers about the information provided and if they need any referrals.
7. Other services and supports provided at times the carer deems appropriate including out of hours services via telephone or face to face.
8. Ongoing professional and peer support after the caring role ends.

AIMS AND OBJECTIVES

The aim of the scoping study was to determine whether current and former carers of people with life-limiting illnesses consider there is a need for, and perceive benefits of, participation in a regional palliative care carers' network. If a benefit was perceived, participants were also asked to indicate their interest in a range of events that could assist them in their journey and/or to meet other carers in the region.

Carers Victoria aimed to scope the met and unmet needs of carers of people with a life-limiting illness during and after their caring role by contextualising these responses with insight into the lived experience of carers of people with a life-limiting illness. The survey questions were informed by the research question: how do people report the lived experience of caring for someone with a life-limiting illness? The survey posed questions about the person for whom they cared, the caring role, supports and services for the carer, the emotional impact of caring and demographic characteristics of the carer and person receiving care.

SURVEY METHODOLOGY

Two qualitative methods were used to collect the data from carers in the Loddon Mallee Region, a survey and focus group discussion. These methods were chosen because they provided a way of sampling carers in the region in a cost and time effective way. The online survey enabled carers who live in remote or isolated areas of the region to answer questions at their own pace and their own convenience. By providing the option of filling in a hard copy, the inclusion of carers who do not use or have access to the internet due to cost or technical difficulties was facilitated. The focus group discussions involved a more wide-ranging discussion about the context of caring for someone with a life-limiting illness such as the presence/absence of family members and other informal supports.

COHORTS

In order to engage carers on different parts of the caring journey, the project team identified two cohort labels to broadly reflect the experiences of carers looking after someone with a life-limiting illness: previous and current carers. These are broad categories and reflect a common perception that the term 'previous carer' would refer to a carer whose relative or friend had died. The term current carer would refer to people whose friend or family member is still living. However, during the course of the project we understood that a number of carers whose relative or friend were diagnosed with dementia and living in a residential facility had completed the 'previous carer' survey. We recognise individuals can be in caring relationships irrespective of living arrangements and having a friend or relative live in a residential care facility brings with it its unique issues and challenges.

Carers Victoria designed two surveys to target previous and current carers. Separating the two cohorts helped to streamline the survey and avoid changing tenses in each sentence. In addition to this, it enabled the development of specific questions to each cohort. For example, the previous carers were questioned about bereavement counselling and life after the death of their relative or friend. There were 66 questions in the previous carer survey and 62 questions in the current carer survey.

DATA COLLECTION METHODS

This project employed a purposive sampling strategy which aimed at the selection of participants with lived experience of caring for someone with a life-limiting illness. This strategy related directly to the purpose and rationale of scoping the relevance of a region-specific palliative care carer service including a regional peer network.

The two surveys were available on SurveyMonkey® between March 2016 and May 2016. Individuals who preferred a hard copy were able to request this by phone call to Consortium Manager Susan Morgan. Completed surveys were returned to Carers Victoria Carer Consultations Coordinator Margaret Boulos at Carers Victoria to ensure their anonymity.

The first focus group was held in Bendigo on 19 May and the second focus group was held in Swan Hill on 14 June 2016.

The Loddon Mallee covers 26 per cent of the state of Victoria. Choosing the locations of the two focus groups was based on capturing different experiences of living in the region. For example, Bendigo is a large regional centre with a population of approximately 104,425 people. The town has an inpatient hospice unit and day hospice as well as a large hospital. It is likely to attract people from around the region. Swan Hill is a smaller rural town with a population of approximately 21,595 people. The town has a small hospital and some local residents have collectively raised funds and advocated for a local hospice with both inpatient and day services. Swan Hill was also selected as it was assumed that it would also provide a greater opportunity for people located on rural properties to feed into the results.

SAMPLING

The aims and objectives of the research did not require participants to be screened out on the basis of their gender, age, cultural or religious background. Indeed, we hoped to examine the diversity of carers in the region and demographic questions were developed to capture a range of cultural backgrounds, genders and sexual orientations.

There were compulsory questions respondents were required to answer which would determine their eligibility to continue to the full survey.

These were:

1. Do you live in the Loddon Mallee Region? (YES/NO) (All carers)
2. Do you currently look after (or help look after) someone with a life-limiting illness? (YES/NO) (Current carers) OR Have you had the experience of looking after (or helping to look after) someone with a life-limiting illness? (Previous carers)
3. Which of the following best describes your caring role? (Answering b or c would automatically disqualify the respondent).
 - a) I care/d for the person as a spouse/partner, family member, friend or neighbour
 - b) I care/d for the person as a paid worker
 - c) I care/d for the person as a formal volunteer

As the study aimed to broadly understand the lived experience of carers looking after someone with a life-limiting illness for whom members of the Consortium might provide palliative care services and supports, it was necessary for the carer to live in the region at least for the duration of caring for the person.

Carers Victoria promoted the survey via its social media and electronic channels. This included a personalised electronic direct mail (EDM) to Carers Victoria members living in the region who had consented to be contacted for research purposes.

In addition, organisations within Carers Victoria's network forwarded weblinks to interested stakeholders. Staff at the LMRPCC also promoted the survey through emails to previous and current carers and posted signage in the respite centre in Bendigo and throughout the

Primary Health Network. Nurses working within palliative care teams helped to identify potential participants who may not be suitable for a group discussion because their experience of caring had been particularly traumatic.

The sample is not representative of all carers in the Loddon Mallee in strict statistical terms since random sampling was not possible. It is important to keep in mind there might be some selection bias in the sample because carers who have responded to the survey might be more inclined to answer these types of questions due, for example, to their socioeconomic and cultural backgrounds.

ETHICS

An application was submitted to the Bendigo Health Care Group Human Research Ethics Committee which was granted on 6 May 2016.

Potential participants were advised there were no costs associated with participating in the project and they would not be paid. Following National guidelines related to the ethical conduct of research, it was decided focus group participants were to be compensated with a gift-card of \$20. The LMRPCC facilitated access to respite facilities and provided food and drinks during and after the discussion. Palliative care nurses were available on the day of the focus group if any participant felt they needed to speak to someone about their feelings. Susan Morgan and Margaret Boulos called each participant one week after the focus group discussion to check on their wellbeing. No gift card was offered to survey respondents.

BACKGROUND

The Loddon Mallee Region is one of nine Department of Health regions covering north western Victoria. The vast region is bounded by the South Australian border to the north west; the Murray River to the north and the Macedon Ranges to the south east. The Loddon Mallee region covers an area of 58,961 square kilometres and includes ten local government areas; Macedon Ranges, Mount Alexander, Central Goldfields, Campaspe, Gannawarra, Loddon and Buloke; Greater Bendigo; Swan Hill and Mildura.¹



Figure 1. Loddon Mallee Region

The Loddon Mallee region has a population of approximately 318,077 people which is 5.8 per cent of the Victorian population. The number of people aged 75 and over is 24715 which is similar to the Victorian average. The main population centres in the region are the Greater Bendigo Region 104, 425, Mildura 53,046 and the Campaspe area 38,688. The region has approximately 31,651 carers which is 10.3 per cent of the population compared with the state average of 9.25 per cent. The region has largest proportion of people who identify as Aboriginal or Torres Strait Islander in Victoria.

CARING FOR A PERSON WITH A LIFE-LIMITING ILLNESS

Caring for someone diagnosed with a life-limiting illness presents specific challenges and rewards.

¹ 'Loddon Mallee Region – Department of Health and Human Services, Victoria, Australia' (Health.vic.gov.au, 2016), www.health.vic.gov.au/regions/loddonmallee, accessed 20 July 2016

The term life-limiting illness is used to describe illnesses where it is expected that death will be a direct consequence of the specified illness.

Such illnesses may include, but are not limited to:

- cancer
- heart disease
- chronic obstructive pulmonary disease
- dementia
- heart failure
- neurodegenerative disease
- chronic liver disease, and
- renal disease.

Each diagnosis will be characterised by different trajectories in the typical patterns of illness leading to death. There can be a short period of evident decline (mostly cancer), long-term limitation with intermittent serious episodes (for example heart and lung failure) and prolonged decline (for example, stroke, frailty and dementia). A trajectory to death for people diagnosed with dementia is characterised by slow progressive decline with potential difficulty in recognising the dying phase.² For each trajectory, periods of decline for the dying person are matched by periods of increased intensity of caring and the need for constant adjustment (Carers Victoria 2015).

Informal caregivers – family and friends of people with life-limiting illnesses are the largest sector of Australia's health workforce.³ However, the economic and social contribution the sector makes is both unacknowledged and poorly understood largely because of social expectations regarding reciprocity and caregiving between family members particularly for women.⁴ A result of the hidden nature of caring is that the needs of carers often go unmet.⁵

Supporting the complex needs of carers is important because having the opportunity for informal care at home is essential for the person with life-limiting illness to be able to spend the end of their life at home. However, 'the consequences for carers of providing

The care provided by families is conservatively estimated to be worth \$60.3 billion. This calculation is based on the 2.8 million carers in Australia in 2015 multiplied by an average of 673 hours per year or 13 hours per week per carer (1.9 billion hours in total). The high cost takes into account the amount needed to replace family carers with formal supports in the wider community.¹

² C. Stirling et al. 'A tool to aid talking about dementia and dying – Development and evaluation', *The Australian Journal of Nursing Practice, Scholarship and Research*, vol. 21, no. 4, 2014.

³ D.C. Currow et al. 'Palliative caregivers who would not take on the caring role again', *Journal of Pain and Symptom Management*, vol. 41, no. 4, 2011:

⁴ J.M. Lewis, et al. 'A social capital framework for palliative care: supporting health and well-being for people with life limiting illness and their carers through social relations and networks', *Journal of Pain and Symptom Management*, vol. 45, no. 1, 2013.

⁵ J.P. Rosenberg et al. 'Informal caring networks for people at end of life: building social capital in Australian communities', *Health Sociology Review*, vol. 24 no. 1, 2015.

EoLC [end of life care] include adverse physical, social and psychological effects with stress, poor mental health, sleep disruption, fatigue, family and social isolation all noted as significant burdens'.⁶ Caring can often lead to social isolation.⁷

The impact on individuals who provide care for people with a life-limiting illness in rural and regional settings is often exacerbated by the mere fact of their residential location. Living in remote and regional Australia invariably means a choice of fewer services, longer waiting lists and travel to metropolitan centres for medical treatment. For carers it can also mean social isolation from a) their everyday social circle if and when travel to a metropolitan centre is necessary and b) separation or disconnect from the professionals with whom they have connected whilst the person has received medical treatment in the metropolitan centre. Palliative Care Australia (2004) found it is common for carers in rural and regional areas to only find out about financial assistance to meet travel costs once treatment has ended or they have reached a financial crisis.⁸

In April 2015 the Victorian Auditor General's Office (VAGO) reported on their audit of the Department of Health and Human Services (DHHS) Strategic Directions and care in four public palliative care services. VAGO made 12 recommendations to address the major issues identified in the audit. Section four deals with support for carers and concludes in spite of the significant strain borne by carers and families; support for them in their caring role remains inadequate. Improving access to services such as respite and psychosocial support for carers of people with a terminal illness remains a major priority.⁹

Initiatives related to the development, implementation and evaluation of broadly-termed carer interventions are necessarily built on evidence from rigorous research. However, such efforts can be hampered by 'difficulties such as recruiting patients, reaching sample target numbers, high attrition rates, rapidly changing clinical situations, limited survival times, ethical dilemmas and the gatekeeping exercised by professionals (i.e. reluctance to contribute patients for research studies)'.¹⁰ Research into these areas is important in order for palliative care services to provide 'mechanisms of support for patients and informal carers [that] focus on strategies for recognising strengths and resilience building capacity and coping'.¹¹

RESPONDENTS

In total, 62 previous and current carers attempted the survey. Thirteen respondents did not answer more than 50 per cent of the survey questions and none of their answers are included in the results discussed in this Report. Four respondents were disqualified from the survey because they did not live in the region or they were paid workers.

Of the remaining 45 respondents, 24 were previous carers and 21 were current carers. It is also important to note three carers completed the 'previous carer survey' despite their relative or friend living in full time residential care. These respondents still provided significant care but identified as previous carers. For this reason, the entire survey was not applicable to their situation which they indicated at specific questions.

⁶ *ibid.*

⁷ Lewis et al., *loc cit.*

⁸ Palliative Care Australia (2004) 'The hardest thing we have ever done – the social impact of caring for terminally ill people in Australia': Full report of the National Inquiry into the Social Impact of caring for terminally ill people, 2004.

⁹ Victorian Auditor-General) 'Palliative Care Report', Melbourne, 2015.

¹⁰ Palliative Care Australia, *loc. cit.*, p. 33.

¹¹ Lewis et al, *loc. cit.* p. 97

In addition to the categories listed in the table below, carers who responded to the survey were caring for people with a range of life-limiting illnesses. For the combined cohorts, cancer was the predominant category (18), followed by dementia (13). Other conditions reported included: Parkinson's disease, Bipolar disorder and anorexia, diabetes, frontal lobe brain tumor, short gut volvulus requiring TPN, stroke survivor, Huntington's disease, stroke bleed to the brain, multiple systems atrophy, metabolic/neurological disease, massive stroke, malabsorption and short gut syndrome, colostomy, acute renal failure, depression and chronic pain syndrome.

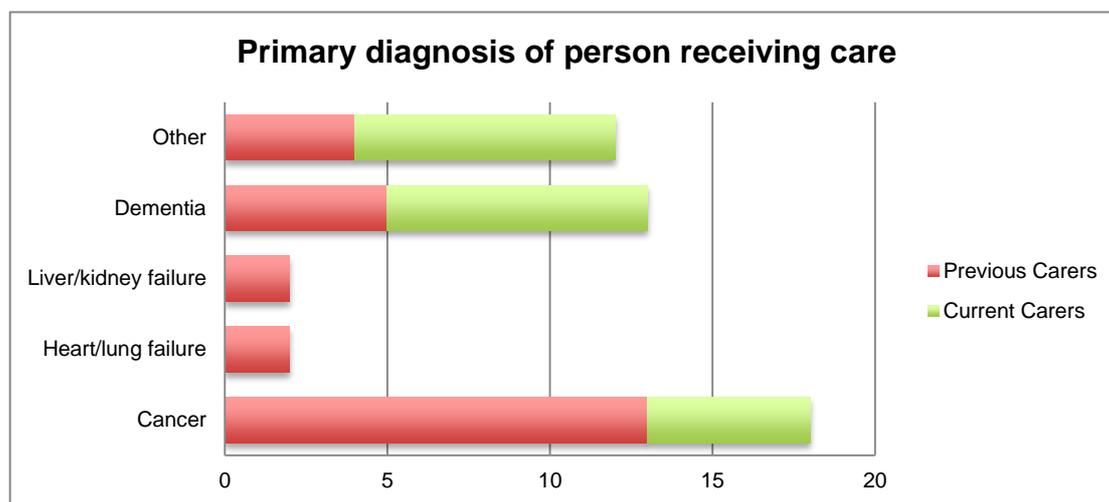


Figure 2. Primary diagnosis of person receiving care.

The next table shows 18 out of 24 people were able to pass away in the place of their choice. The responses show dying at home is a desired preference but is not the only preference: hospitals and hospices were also considered appropriate places of death.

Our very small dataset shows that individuals' preferences and actual events are different to average Australian preferences. For instance, 29 per cent of the cohort reported their relative or friend passing away at home, compared with evidence showing only 16 per cent of Australians die at home despite 'most healthy Australians...nominating [dying at home] home as their preference'.¹² 17 per cent of the cohort reported their relative or friend died in a hospice compared with 20 per cent of Australians dying in a hospice. 54 per cent of Australians die in hospitals while 25 per cent of this cohort reported their relative or friend died in hospital.¹³

¹² Commonwealth of Australia, *Supporting Australians to Live Well at the End of Life – National Palliative Care Strategy 2010* (Commonwealth of Australia 2010), [www.health.gov.au/internet/main/publishing.nsf/Content/EF57056BDB047E2FCA257BF000206168/\\$File/NationalPalliativeCareStrategy.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/EF57056BDB047E2FCA257BF000206168/$File/NationalPalliativeCareStrategy.pdf).

¹³ In community health services 'residential care' is considered as the person's home, so the data should show that 42 per cent of the cohort had died at home because that is where the person lived at the time of their death.

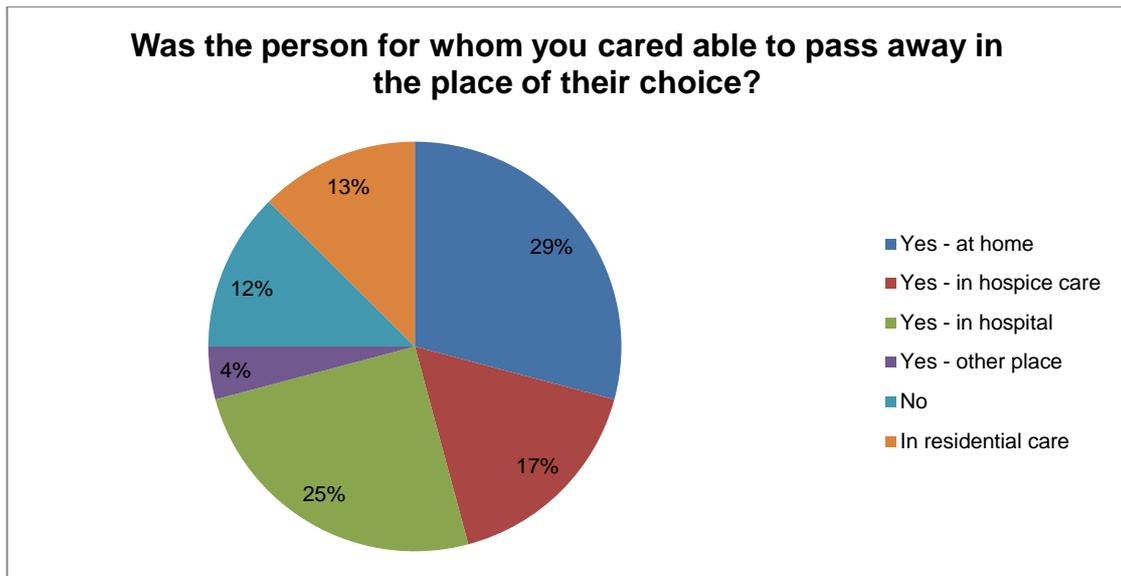


Figure 3. What the person able to pass away in the place of their choice?

The respondents in this study reported a range of reasons for their relative or friend being unable to pass away in the place of choice, including: the patient 'deteriorating too quickly and...it was too painful to travel from Melbourne to home in Mildura.' Another carer reported being burnt out and her adult daughter, who had been diagnosed with Bi-Polar Disorder (BPD) and Anorexia, had a VCAT-appointed administrator¹⁴ decide the options were to stay in hospital or go to a nursing home.

Another carer provided insight into her husband's dying while in the advance stages of dementia:

'As an Alzheimer's sufferer my husband was never able to agree that there was anything wrong with him, although in the last ten months of his life it was necessary for him to be in an aged care facility. He died in that facility which would not have been his preference had he had full mental capacity.'

There is another side to the question of place of death that is indeed critical to broader policy regarding end of life choices. This is highlighted in the following quote from a focus group participant:

'I've resented I haven't had a choice...[My husband] says he wants to die at home but I don't think I want him to. But I don't get to have a say. His parents are old and he said instead of them going into care they should come and live with us and I was aghast! What about me?! I actually said no way... I feel like I'm often asked to do things I don't want to do, by my husband and nurses. The assumption is you're always there, you're happy to do that.'

This quote which shows the presumption dying at home is best for the patient returns us to the point that informal caregivers are the largest part of the Australia's health workforce¹⁵ and the facilitation of the patient's wishes may come at the cost of family members' own:

¹⁴ We have directly quoted the respondent, however, this may be more widely known as VCAT-appointed Guardian.

¹⁵ Currow et al., loc. cit.

'You [the carer] only exist to this person [the relative or friend] for the trip home. You only count for the trip home.'

RELATIONSHIPS

The most common relationship between carers and the person with a life-limiting illness is/was spousal with 31 carers defining their relationship as such. Other respondents cared for their children (2), siblings (1), parents (7), parent-in-laws (2), friend or neighbour (1). One respondent provided no response to this question.

18 respondents were in a care relationship prior to diagnosis of life-limiting illness while 27 were not.

For around half of respondents (23), caring for a person with a life-limiting illness occurred concurrently with other duties and responsibilities such as caring for other people, animals or crops. Nineteen respondents reported they were not caring for others at the time. Despite other responsibilities, 25 respondents reported nothing affected their ability to care for the person in the way they would prefer.

The factors which influenced the carers' ability to look after the person in the way the carers would prefer included work commitments (7) caring for others (8) and their own health needs (9). Carers reported health issues emerged from prolonged or intensive caring such as physical exhaustion and mental stress. As one carer wrote:

'I became totally exhausted when [my husband] was in extreme pain and I had no sleep for four days. I was scared I would give him the wrong drugs.'

One way to measure the caring role being something over and beyond normal duties of a parent or spouse is the number of hours carers spend providing assistance. As the table below shows, many respondents reported they spent a significant proportion of their day caring for the person with a life-limiting illness. In addition to the 18 carers who selected 'More than 70 hours per week', eight carers who selected 'Other/hard to say' reported they cared on a 24/7 basis. When the person with a life-limiting illness moves into residential care the time spent on caring does not necessarily significantly diminish. The following carer's response demonstrates the time commitment remains high:

'I visit[ed] him every day for four years, to help feed and encourage his mental ability.'

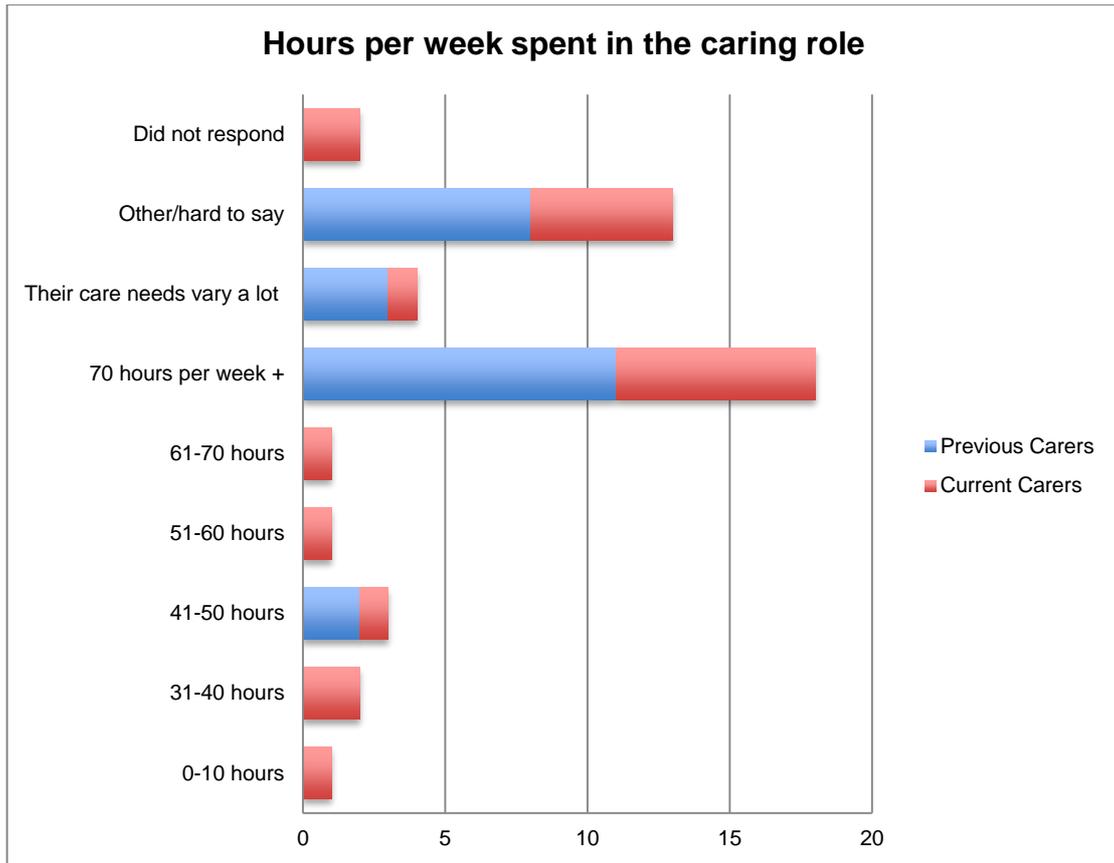


Figure 4. Hours per week spent in caring role. ¹⁶

Further analysis shows spousal relationships demanded the most hours of carers with 18 reporting their caring roles involved spending more than 70 hours per week or 24/7 care of their spouse or partner. This corresponds with data from Australian Bureau of Statistics (ABS) survey of Disability, Ageing and Carers in 2012 which shows on average partners often provide more than 40 hours of care or more a week. Six of the participants who reported they were caring for their parents said they spent from 30 to more than 70 hours per week providing care.¹⁷

The significant time commitment required of carers in this project is also borne out by numbers showing the incidents of shared caring. 17 respondents reported they were/are the only person who cares for the person with a life-limiting illness; 16 respondents reported they were/are the main carer but others provide care on an episodic basis and 12 reported others provide/d care on a regular basis.

Focus group participants also discussed having sole responsibility as a carer. Carers of spouses with dementia in particular consistently reported a lack of informal support and contact. It was suggested this could be due to the unpredictable nature of the individual's behaviour (shouting in the supermarket or making claims of unseen mortal danger) in addition to the regressive nature of the behaviour (holding hands in a directive way, aggressive behaviour):

¹⁶ We did not ask respondents how long they had been caring in addition to the hours spent providing care. We understand some caring relationships in the context of life limiting illness can be a short duration but high intensity and vice versa. It would have been difficult to contain the data given the degree of trajectories in this context.

¹⁷ Australian Bureau of Statistics 'Disability, Ageing and Carers, Australia: Summary of Findings', Canberra, 2012.

'I was in the supermarket with my husband one day and he began screaming out 'help' at the top of his voice. People would just scatter, sometimes I'd get my son on the phone and he's got this way of saying, can you see any danger at the moment, I think everything's fine. I'd get to the cashier who'd say 'how's your day been?' And I was like, didn't you hear the screaming? Nobody came and asked 'is there anything we can do?' You tend to start staying at home.'

Other participants in focus group discussions added:

'You're very much alone.'

'Your friends just disappear.'

'I couldn't rely on the daughter because things would happen in the middle of the night. The two boys had their own lives, couldn't stand to see their mother the way she was so I never bothered.'

'They can't face it or they move on with their lives.'

'Maybe in the beginning, when you first get the diagnosis they're like oh it's really awful. But then you might call them and they say we're just going on holiday, we'll catch up afterward, but it doesn't happen.'

'Your family is all too busy. Basically you're on your own.'

'My children have helped out. They've wiped their dad's bottom but that's not pleasant. They shouldn't have to do that.'

'[My wife] asks where everybody is. She was involved in quite a few community things but since she's been in hospital she asks, what have I done, why do they hate me?'

'I always got told off by my family because I was always late, and they would say oh tell her to get here half an hour earlier [than others] because she's always late and since my husband's died, I haven't been late. But I would put him into the car and he'd be sick or he would wet himself and we'd be delayed and I'd say you guys have got no idea, all you can do is sit there and say you're late. Well let's swap for a day and let's see if you're on time.'

'Some days the lady next door who's in her 80s – she had her husband in the extended care unit before he passed away – she would come and sit with her for a couple of hours. Otherwise our daughter might come around for five minutes but it wasn't organised. She was always busy doing what she had to do.'

The amount of time spent caring for the person with a life-limiting illness is an important issue when examining demographic characteristics of carers in this Project. 39 carers were female while five were male. The overwhelming majority of people receiving care were male (33), with a smaller number of females (10); two respondents did not answer this question.

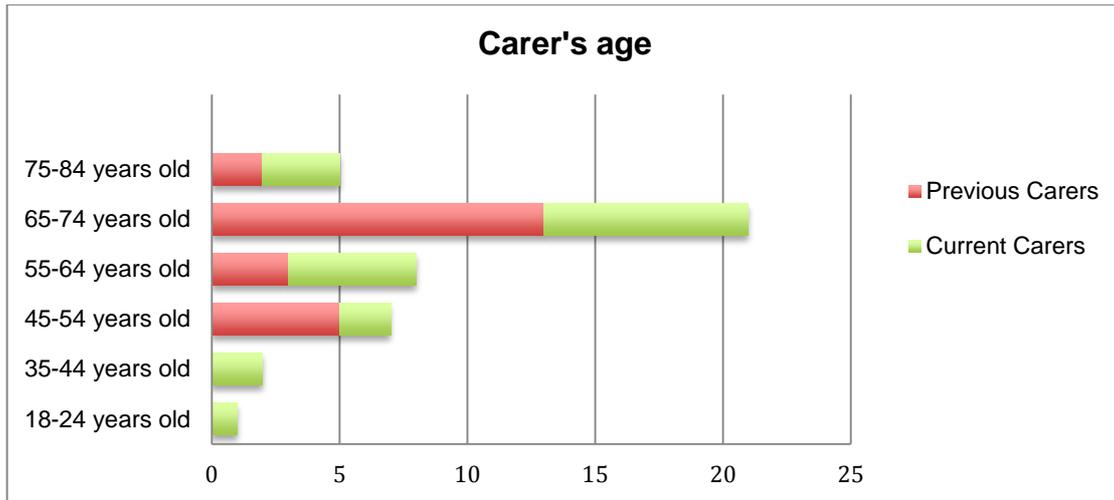


Figure 5. Carer's age.

While the most predominant age range for current and previous carers is 65–74 years, the chart demonstrates caring for someone with a life-limiting illness can happen at any time in an individual's life. The age of carers in the two cohorts is comparable with other carers in the Loddon Mallee and Victoria more broadly.

As the table below shows 21 respondents aged between 65–74 years represented approximately half of the overall sample. In comparison to broader regional demographics, 18 per cent of all carers are in this age range live in the Loddon Mallee region indicating people looking after a friend or relative with a life-limiting illness are likely to be older than carers looking after a person with a disability, mental illness or frail aged. As with other carers in the Loddon Mallee most 'end of life' carers were aged between 20 and 64, compared with 74 per cent of carers in the Loddon Mallee in this age range (28).¹⁸

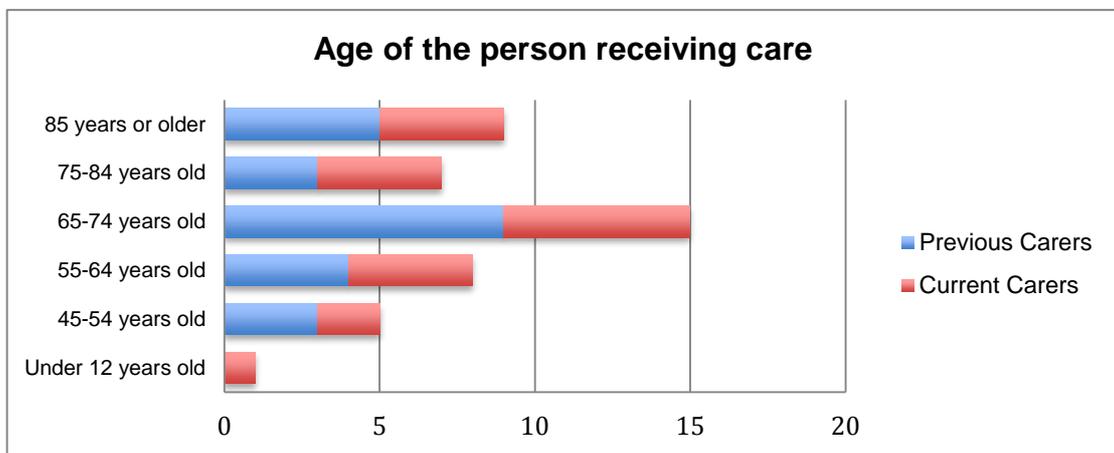


Figure 6. Age of person receiving care.

Given the age range of most carers who responded to this study, not surprisingly, many carers were retired (19) while five were employed full time and 11 were employed part time. Within Victoria, carers are more likely to not be in the labour force than non-carers (43.2 per

¹⁸ *ibid.*

cent compared with 30.7 per cent) and non-carers are more likely to be in full time employment (44 per cent) compared with carers (31 per cent).¹⁹

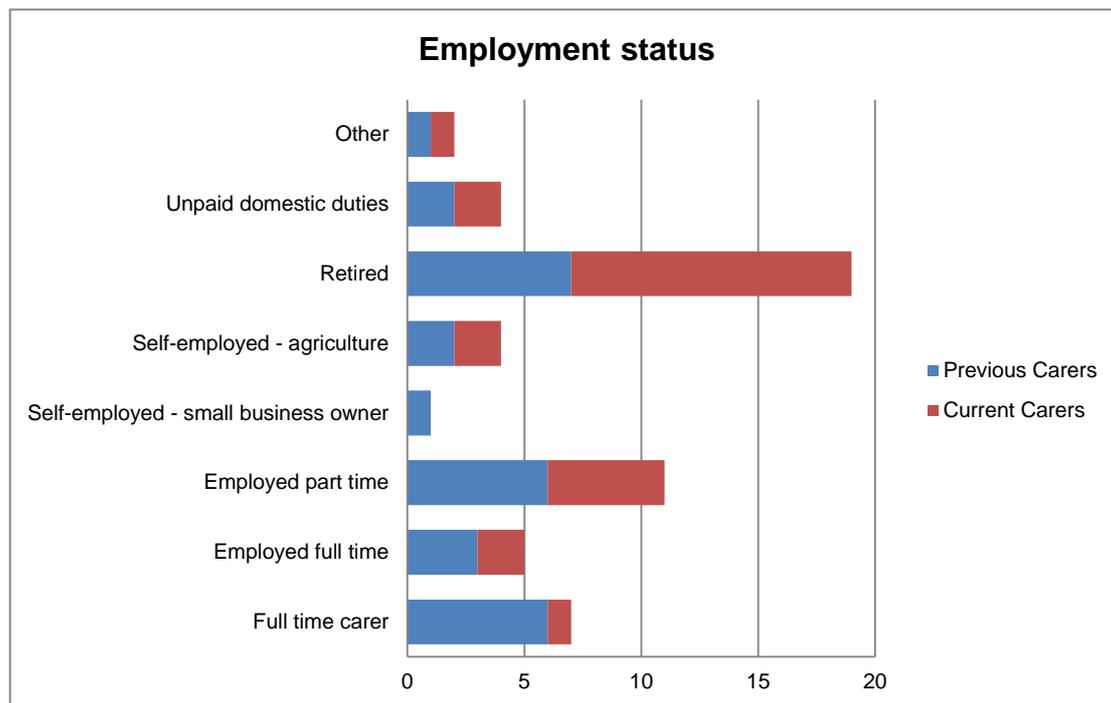


Figure 7. Employment status.²⁰

The impact of caring on an individual's social and economic status can be significant. Often, these impacts occur when caring is prolonged and occur when the carer is working age. Tellingly, carers experience lower than average rates of employment and are more likely to live in households with lower than average gross incomes. Indeed, carers are over-represented in the lower weekly income deciles and under-represented in the higher deciles. Income inequality is likely to be related to the reduced hours of employment carers work due to their caring responsibilities. For those carers who were employed or studying at the time of taking up the caring role, their responsibilities did impact on them. 14 carers stopped working because of their caring responsibilities while four had reduced the amount of hours they worked because of their caring responsibilities.

Reasons for reducing or stopping work to provide care are varied. On the one hand, the health system assumes availability of unpaid care – when discharge guidelines are followed closely or patients are sent home as soon as the procedure is complete – that the carer must accommodate or else witness their relative or friend in a difficult situation. On the other hand, broader economic structures such as liability law may prescribe personal care workers to specific duties which can be considered inadequate by family members; these include occupational health and safety guidelines that limit physical contact and time spent with the patient. This carer reports a major factor in her decision to reduce her working hours to part time was in large part based on the fact the formal caring system was inadequate for her family:

¹⁹ *ibid.*

²⁰ The term former carer refers to a person who is recognised as a primary carer and receives income-replacement from the Federal Government because these duties preclude them from paid employment or study opportunities.

'I went from full time to two days a week because I just couldn't get the carers. I've had 22 years of carers which has been a nightmare. They sent me a carer who said they've got a carers certificate. And they said can you show me how to do a shower? I've never done a shower. I've had so many carers I've had to train in my home before I could leave them alone with my husband.'

The Productivity Commission (2015) has identified two main reasons for involuntary retirement. One was an employee's own ill health and the second was a spouse or family member required care. For men this has been identified as largely their own ill health that resulted in retirement and for women it was the ill health and caring requirements of another.²¹

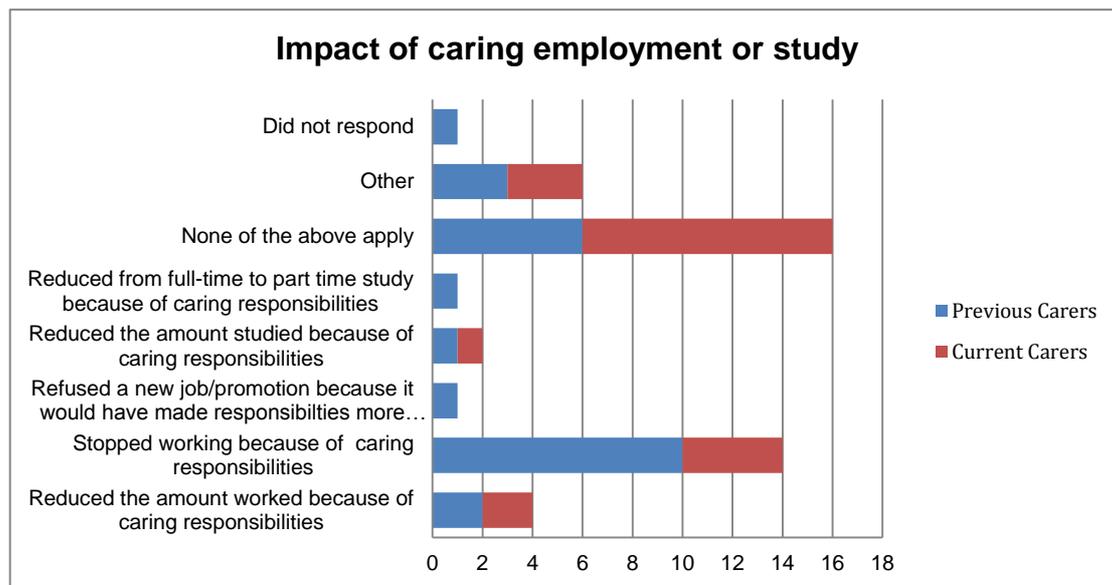


Figure 8. Caring role impact on employment and/or study.

Retirement from employment is presumed to be a time of increased leisure, however, this does not necessarily mean retirees are idle. One carer explained her caring responsibilities were becoming increasingly difficult to manage alongside her duties on over 10 committees; such involvement in her community was a strong part of her identity, however, her husband's high care needs meant she was not able to physically and emotionally sustain herself. With assistance from a counsellor, she made the decision to resign from the majority of her committee duties to continue in her caring role and attend to her own health.

Another carer talked about his daily routine and the voluntary work he undertook as the president of the local RSL. External duties in retirement gave him a semblance of respite from his caring role and provided an element of continuity after his wife passed away:

'I didn't have time off. Getting up, getting brekkie ready for her, then the showering, getting her comfortable, then my brekkie. Then we'd have a light lunch. After that you do the housework during the day. Then being president of the RSL I've got to go down, so I make sure she's comfortable. You have to come home at a certain time get tea ready because she was a person who had to have her vegies at least every second day. She was a good cook and I tried to be like her. I don't know if I'm a good cook like she was but I get by anyway.'

²¹ Productivity Commission, 'Superannuation Policy for Post-Retirement, Commission Research Paper', Canberra, 2015.

SUPPORT FOR A CARER NETWORK

The following section will discuss the perceived benefit of a regional network and other activities targeted at carers' needs. 30 carers from both cohorts responded they would join a region based network connecting carers looking after someone with a life-limiting illness; 13 indicated they would not join a network and two respondents did not specify. These responses are a positive indication that a means of connecting carers is important.

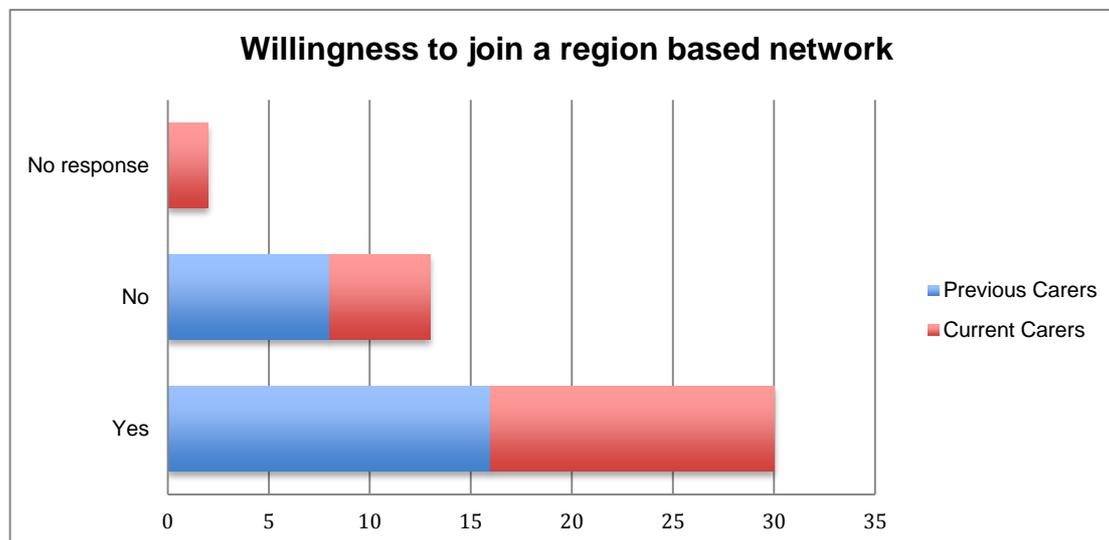


Figure 9. Willingness to join a region based network.

During further discussion in focus groups, participants identified the following features were important to establishing a peer-based support network:

'If you could help someone else; this point in time I would say yes. Previously to now I would have said no. Now there's the realisation, even though my husband has been sick many times and has been on the brink of death. The expectation was always short term. In my own studies, I've seen the stats on kidney failure, it's usually 12 months. It's like end dates keep passing, we're getting up to two years. The ship's further out to sea and I really need to pace myself because it could be much longer than anyone expects.'

'I really do feel you need that face to face contact. It's easy to talk to someone you've developed a friendship with to talk on the phone. I meet some lovely people that I talked to for ages before I knew what they looked like. I feel you do need to get together sometimes.'

'I needed the bereavement group through the hard time, it was a bit of talking, neutral. I went to it for a few months. It was a good transition. It was a little group, the feeling of people in my shoes.'

'It has to be with an emphasis that they're [the support] not coming for you [the carer] to entertain them. Don't rush around beforehand, don't bake a cake. I just walk in; if there's a mess, then there's a mess; if you don't have a cup of tea, then there's no cup of tea. I think as long as it's not putting more stress on [the carer].'

'The emotions that you go through are very similar. There's a sympathetic ear there; you might have had a good week but then the following week I could be a bucket of misery. No one judges.'

'I found that people say I'll come round and have a coffee with you but you never see it. Must be some sort of a stigma to go and see people. I don't know what the answer would be. You can't grab people by the hand and say I really need to talk to someone.'

One of the reasons participants were enthusiastic about the development of a network of carers was the ability to talk to someone who had a similar experience, where shorthand could be used and the relative anonymity of the relationships actually fostered an intimacy where carers can share their frustrations about their role and experiences:

'Best counsellor I ever had. She'd been a carer and she really knew where I was coming from.'

'You can be honest to a point with your kids but then you still try to protect them. You only go so far. Even with friends, I've got a great support base with friends and I can go round and be incredibly angry, be in tears and beside myself and I've even gone over there and said if he's gonna die then he might as well get it over and done with because I'm over this. You can feel pretty awful saying this. They're pretty good about accepting that with no judgement to a point.'

'Sometimes you need an outsider; you don't need someone who's close to you.'

'Your friends have a different life to what you have. They go on holidays, we don't go on holidays.'

'When it first happened [husband had a stroke] I pushed people away, you've got to cope, you've got to do it but then later you break down and you need that help. Someone who you can ring, she'd come and have coffee with me – or a gin and tonic – or a Bundy and coke. You need a person out there to say you're not coping, this is what we're going to do.'

Respondents were asked what kinds of activities they perceived as beneficial for people looking after someone with a life-limiting illness. The most popular resources that could be offered were 'information about resources' (34), 'individual face to face support' (32) and forms about services for carers' (29), while 'education' more generally and 'workshops about palliative care, grief, self-care, financial or legal issues' were also popular (27). These supports were perceived as most beneficial during the caring role. After the caring role ended, 'individual face to face support' (7), 'group face to face meetings' (5), 'workshops about palliative care, grief, self-care, financial or legal issues' (5) and 'information about resources' were desired. In comparison with other supports **during the caring role**, there was considerably less demand for online services that connected carers through text-based (14) or video chat platforms such as Skype, Viber or Facetime (10). The least applicable services for both cohorts were 'services for specific communities...' (13) and 'an online support group using video chat platforms' (13).²²

²² The fact services for specific communities were not applicable is clearly linked to the fact 99 per cent of the cohort identified as Australians with Anglo-Saxon or Celtic heritage who were heterosexual and spoke no language in addition to English. These demographic characteristics are reflected in ABS data, most recently the 2011 census which showed the most dominant cultural ancestry of residents was Great Britain and Ireland while Mildura and Swan Hill recorded approximately 5 per cent of its population with Italian ancestry.
http://www.censusdata.abs.gov.au/census_services/getproduct/census/2011/quickstat/UCL214018?opendocument&navpos=220

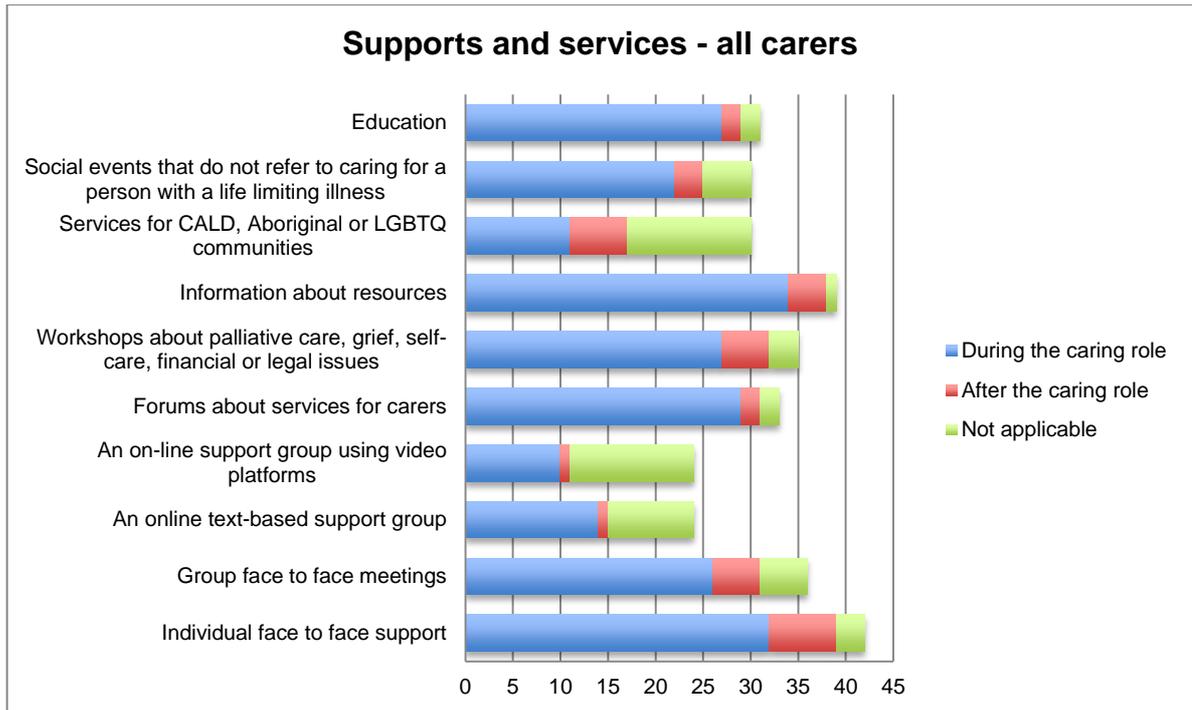


Figure 10. Supports and services – all carers.

'Maybe if there could be a carer's pack upon diagnosis. When you've got your head around what we've just told you today, have numbers for people to call when they've read the information.'

'I get this envelope of brochures from carer support services and I sat down and read them all and I just thought this is ridiculous. Vision Australia had the same information in a folder – the aims, what we can do, simple paragraphs, it was much, much better at getting the information across.'

As a way of developing a stronger rationale for the establishment of carer-specific services that is largely based on peer support and interaction, the survey also posed questions about the perceived benefit of interaction amongst carers. A large portion of the two cohorts reported that they perceived both an emotional (32) and practical (33) benefit from interacting with people who have their own experience of caring for someone with a life-limiting illness. Eight respondents reported they had not received an emotional benefit and five reported they had not experienced a practical benefit from interacting with other carers. However, when asked if their own experience could benefit others, there was more uncertainty. This question was posed to scope the possibility of survey respondents feeling comfortable or confident in 'completing the circle' of mentoring; that is, if they perceived an ability to *give as well as receive*. 25 carers responded that their experience could be a potential support to others in the same situation and a further 19 responded this was a *possibility*. No respondents reported this was an entirely non-viable proposition.

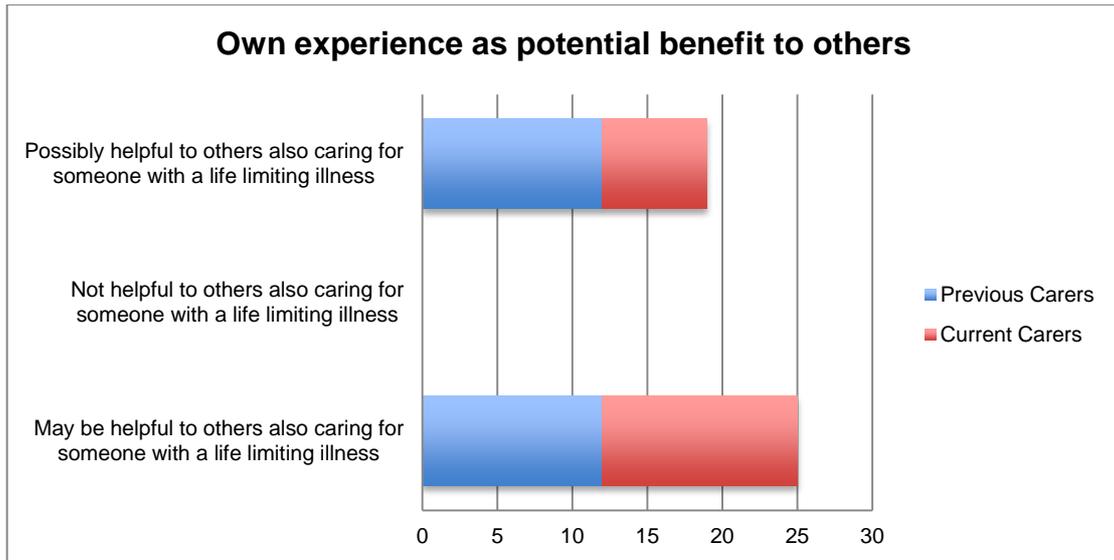


Figure 11. Own experiences as potential benefit to others.

When considered in light of the comments made below, previous carers may be likely to require coaching or mentoring in order to confidently engage with other carers:

‘Stroke support used to have a weekend away. It was fabulous because everyone was in the same boat, knew what having a stroke meant. People would say I’m outside and I might not hear him in the house but then another person would suggest remote control doorbells which go 100 metres. We’d share little things people had picked up to make things better. And it was really good for people who’d just had a stroke cos they could look at people and say they’re 10 years down the track.’

‘I found definitely cos we had a support group for me it was being able to join up with other people and feel safe that people understood we’re all on the same journey. We could cry together and laugh together and for me, because I think for a long, long time I hid so much from so many people who have these throw away lines showing they don’t understand – why are you now leading your husband by the hand?’

‘This [talking with other carers] is such good therapy.’

‘This is the best thing about our group. We have the tears and humour – it’s recognition.’

‘The biggest problem we have is not to do with travel, it’s people having the time and energy to come on the day.’



Figure 12. Ease to meet people who can share their own experience of caring.

CARING RESPONSIBILITIES

A person's ability to join a regional network and/or workshops related to their caring role is directly related to both the number of hours spent caring (discussed above) and the scope of their caring role. The physical nature of caring is an important factor in the carer's own ability to sustain themselves and protect their health. Respondents to this survey reported they undertook a range of duties and responsibilities for and on behalf of the relative or friend. These responses go beyond narrow understandings of caring as merely 'personal care' and provide a nuanced insight into caring roles.

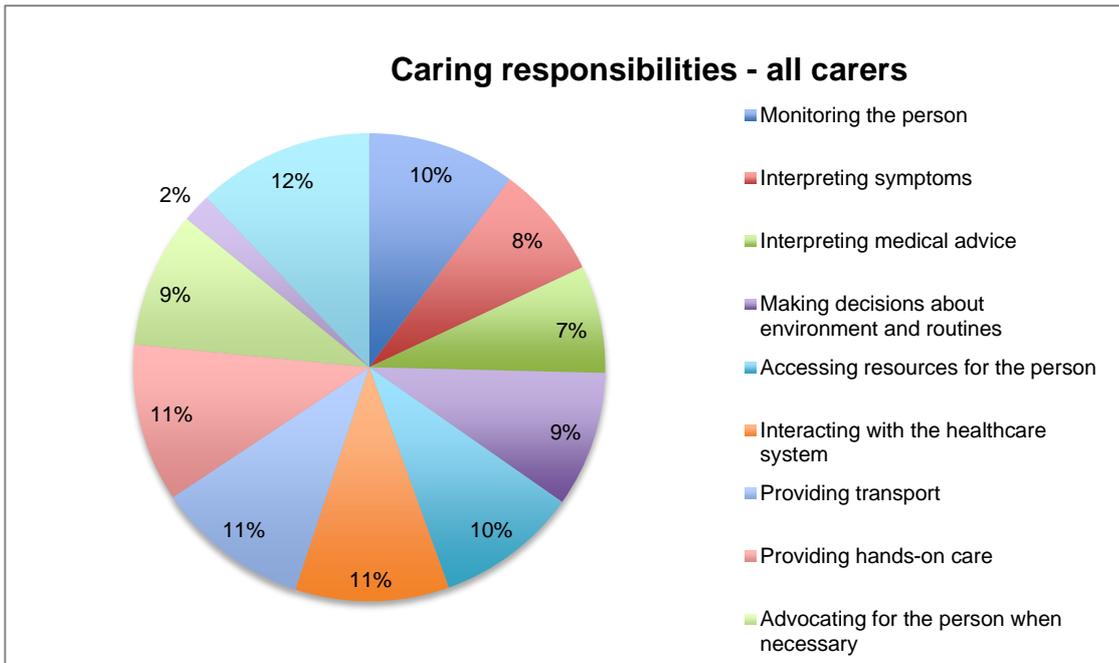


Figure 13. Caring responsibilities – all carers

This data corresponds with information published by the ABS which shows carers provide support and assistance in a range of activities such as self-care, mobility, communication, cognitive or emotional tasks, health care, reading or writing tasks, transport, household chores, property maintenance and meal preparation.²³

The types of caring duties are especially important in the context of professional assistance that was available to people with life-limiting illnesses and by consequence, their carers. Over half of the respondents to this survey reported their respective relative or friend were recipients of palliative care services. More previous carers (16) than current carers (5) reported the person for whom they were caring had received palliative care services. However, overall 25 carers reported their relative or friend was not or had not received palliative care services. This may reflect a rather common problem in the broader healthcare sector where patients are often referred to palliative care services only after any curative treatment options are exhausted (in a linear fashion), or patients and/or families refuse palliative care services because there are negative connotations to the treatment:

'She was very brave, probably two and a half years between being diagnosed and passing away...Didn't really get respite; we had very early on involvement in palliative care. That was the daunting part because we said she's only got lung cancer.'

'Even at our hospital, the palliative wing, it's known as the death room.'

In light of the variability of services available to people caring for someone with a life-limiting illness, it was important to explore what services currently exist for carers, which ones they have used, those they believe to be helpful or unhelpful, those they do not know about or those they are aware of but are not available in their area. This last category is very important in the context of regional Victoria where some services are likely to be scarce.

The table below shows previous carers' experiences and preferences. The most used services were GPs, information from websites and books, carer support staff (one-to-one case management) as well as carer support groups, education and training such as learning to provide medical care for the patient or one's own self-care, and a counsellor. The least used services were community and/or culturally specific services i.e. for people from culturally and linguistically diverse backgrounds, Aboriginal or LGBTIQ communities, art therapy and psychiatry. The most helpful services were the carer's GP and information from websites and books. The least helpful service was financial assistance/advice from Centrelink (5). One carer who attended a focus group reported she received a letter informing her Carer Allowance had been cancelled a week after her husband had begun living in a residential care facility (she continued to care for him in many ways including extensive daily visits).

²³ Australian Bureau of Statistics, loc. cit.

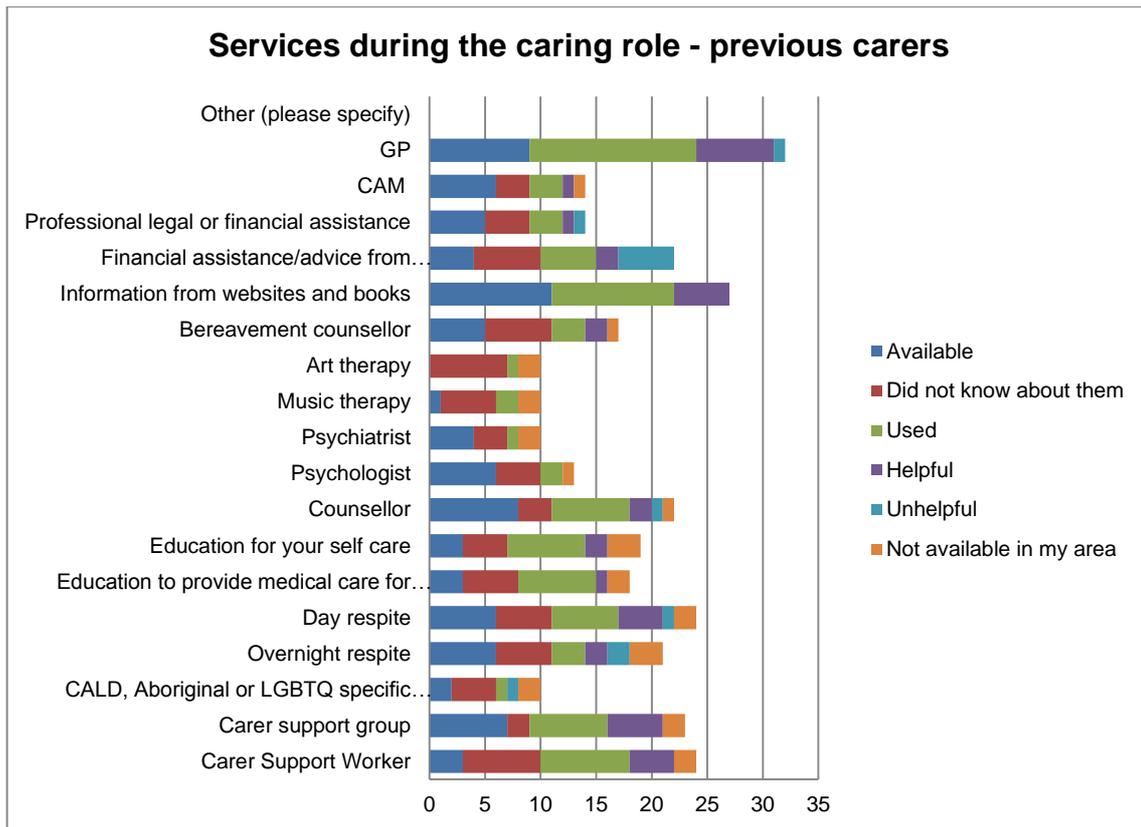


Figure 14. Services during the caring role – previous carers.

As the table above shows, carers reported many services were not available in their area. In specific regard to more regional or remote carers in this cohort (in the postcode areas 3525, 3585, 3480, 3500, 3475, 3585, 3485, 3579, 3584, 3597 and 3585), carers reported a range of services were not available in their area such as a carer support group, specific services for people from CALD, LGBTQ or ATSI communities, overnight respite, day respite, carer support worker, education to provide medical care to the patient, education for oneself, psychologist, psychiatrist, music therapy, art therapy and bereavement counsellor.

Participants in the Swan Hill focus group were all previous carers predominantly living in Swan Hill with one participant joining from Birchip. They all reported on the experience of living four hours away from specialist care in Melbourne or two hours from Bendigo's hospice or other services:

'We could afford to pay for accommodation. When my husband was in the hospice in Bendigo it was costing me \$600–700 per night to feed the kids and keep them in their hotels.'

'We had to go to emergency one time and then my husband was admitted. And I'm like where am I going to stay? [One of hospital administrators told me the accommodation for patients' families run by] Rotary House gives first preference to the families of patients with cancer. And I'm thinking, right now what's the difference between my husband and a cancer patient? And there isn't one. And I'm tossing up if I should just drive home but then there's the petrol cost and the food cost. Yes you can claim it back but there's a lot of work you have to do.'

'It's even worse when they fly you to Melbourne and then they tell you to go home [to Swan Hill] and you've got no car, no wheelchair, nothing. And my husband's lying in the bed and I'm like no we can't! I had to argue the point, we've got no wheelchair. They wouldn't fly him home because it cost too much. We flew down in 45 mins but it took us over six hours to get home because the guy got lost in Bendigo. My husband had to lie on this trolley he kept

falling off. The second time he got flown to Melbourne I actually drove in our wheelchair accessible car and his wheelchair so we had a way to get home.'

'When you're in the land of not [financial hardship], it's like hang on, you have to count your pennies and sometimes they don't stretch and your priority is always the person that you're caring for.'

'We were a little bit isolated in the hospice in Bendigo. One kid was back and then they all sort of come and I thought for my husband, he was away from his brothers and it was an emotional time. It would be a five hour round trip in a day, can't expect people to do that.'

'If we didn't pay for private health insurance money wouldn't be an issue but can we afford not to have private health insurance? No. So you're between a rock and a hard place. So you go to a private hospital and pathology charges you more, then the anaesthetist charges you more, then the doctor charges you more then there's no social worker, and there's no something else because there's this perception you've got private health insurance you can afford it.'

'We went to a hospital in Melbourne [from Swan Hill] and the accommodation was booked out by people who lived in Dandenong.'

Respondents were also asked when such supports or services could be most helpful to them in their caring role. Respondents in the previous carer cohort indicated it was their medical professionals they found most helpful at the time curative treatment ceased or life-limiting illness was diagnosed with GPs (5), specialist physicians (5) and palliative care nurses (4) scoring the highest. GPs (14) as well as informal supports like family, friends and neighbours (14) were most helpful at any time during the caring role; bereavement counsellors (5) and/or general counsellors (4) were most helpful immediately after the caring role ends and in the year after the caring role ends. These results indicate the carers' emphasis is predominantly on the person with the life-limiting illness and as the illness progresses, the importance of their social context re-emerges and ultimately the carer's own emotional state can be tended to once the patient has passed away.

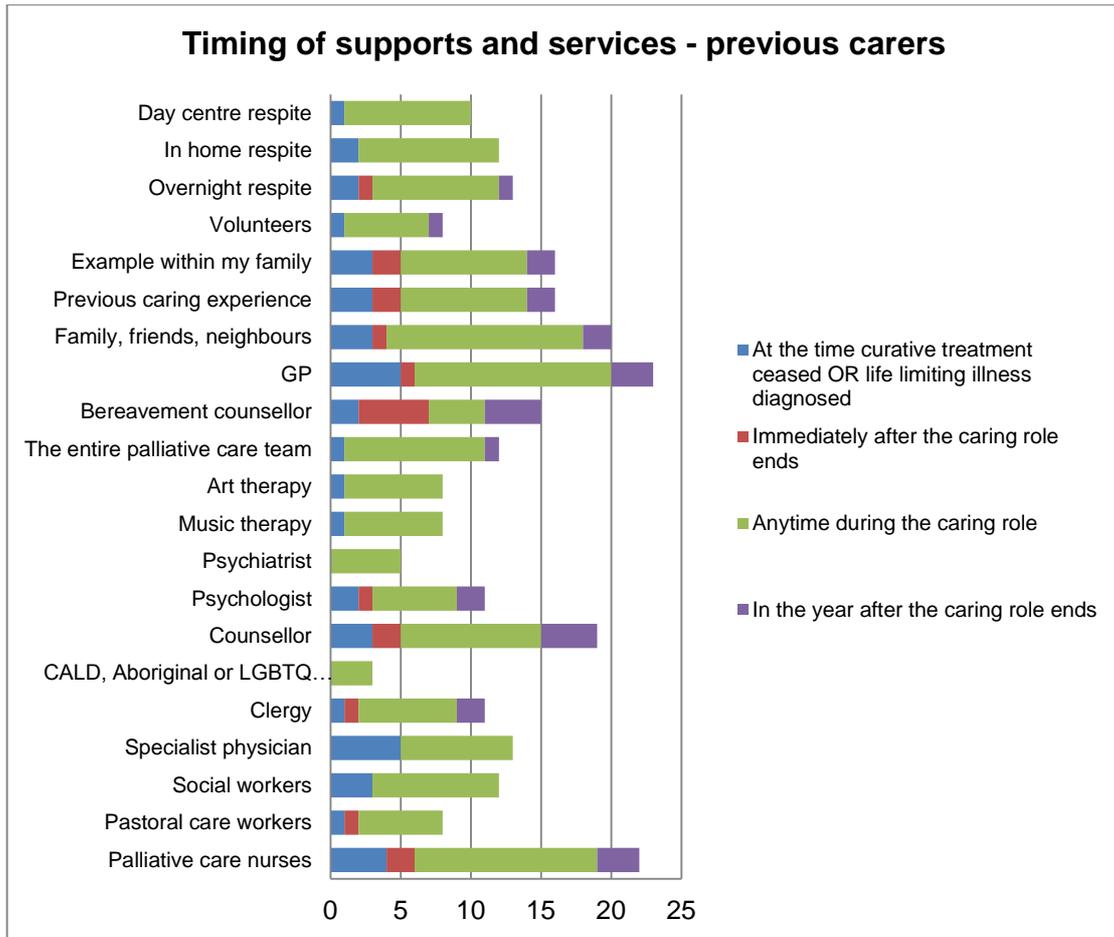


Figure 15. Timing of support and services – previous carers.

When asked what improvements could be made to the service landscape in which they cared, respondents indicated there was a range of formal and informal supports they preferred. The most popular potential resource (15 previous carers) was the option of the patient being cared for by professionals (in home or hospital) when their care needs become too much with which to cope. This is recognition by participants that caring in the context of life limiting illnesses may be ultimately too complex to be managed at an individual level and in one’s home. The expectation that one’s wife or husband, child or parent can adequately attend to the high-level medical care, emotional and spiritual needs in addition to completing everyday tasks and dealing with the impact on themselves is unrealistic at best.²⁴ However, every situation is unique and the patient’s need for supports should be assessed in conjunction with the carer’s own needs and resources.

²⁴ This is not meant to suggest carers are inot competent but to recognise they are not specialist clinicians or experts in grief management and moreover, applying such skills can be difficult when caring for someone they know as health professionals with informal caring roles can attest. Indeed, in more ideal circumstances, caring roles would be part of a holistic care team – an important informal support within a larger network of formal care professionals serving the patient.

Indeed, it is particularly telling the second most popular supports carers needed were emotional support from other carers *and* professionals. This result shows in the absence of healthcare infrastructure that adequately supports caring roles, the emotional challenges of providing care to a relative or friend with a life limiting illness are high; carers with experience recognise peer and professional supports ought to focus on the emotional, not just on technical aspects of health care. Emotional support from a professional may be obtained if an increase in visits from palliative care nurses was implemented. However, we should not ignore the data shows the services most used - GPs and information from websites and books – could also be utilised to provide emotional support in a familiar setting.

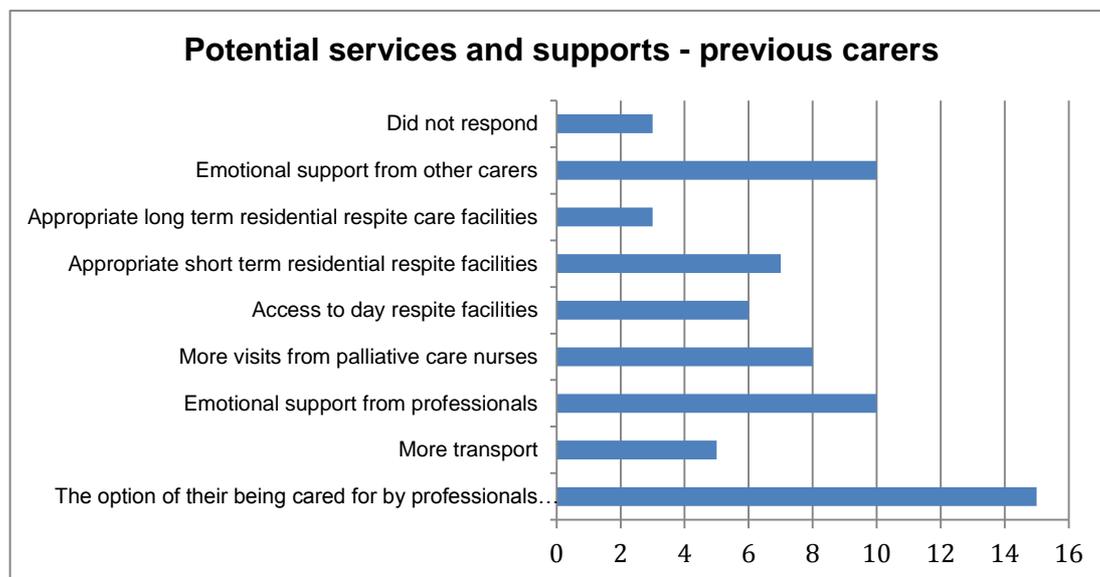


Figure 16. Potential services and supports – previous carers.

The two carers who are quoted below demonstrate the continued need for respite options to be available for both health and emotional reasons:

'My husband was 24 hour care and he couldn't be left alone. There is a huge demand for emergency respite in Swan Hill. At one point I had to discharge myself from intensive care with chest pains to go home and look after my partner because the carers were knocking off at certain time. I think it's a definite need for Swan Hill.'

'And I was given the advice, make sure you book ahead for respite so you've got these times to aim for so I started to do that. How many times I'd get up in the morning and think I just don't know how I can put one foot in front of the other and think it's all right, in a couple more weeks, just a couple more weeks [there will be respite] then many times it would be a week before [the booking] I'd get a phone call, just letting you know that bed's not available now, we're not doing respite anymore. We've actually taken it over for a full time bed so sorry about that. And your world just crashes because you've been hanging on, just another day, just another day...you're told to take care for yourself, but if the system isn't supporting you, it's not that we don't want a break. We want to know somebody is going to look after our loved one so that we know they're safe, cared for so we can find equilibrium again.'

CURRENT CARERS

Individuals in the current carer cohort responded to similar questions about the services that might assist them in their caring roles. Carers in this cohort were asked about grief counselling rather than bereavement counselling. The most **used** resource for current carers in this project was their GP (10) and 8 carers indicated their GPs were also the most **helpful** support. Carer support groups were the second most **used** resource for this cohort (8) and 8

respondents also indicated their support group was **helpful**. Respondents also indicated art and music therapy were not in their areas and/or they did not know about them. Similarly to the cohort of previous carers, financial assistance/advice from Centrelink was also the least helpful resource:

'But with Centrelink my mum had bowel cancer and my dad couldn't get the allowance; they kept saying she wasn't going to die, she didn't need a carer. The doctors wouldn't say she was going to die. It was the same with my brother who had cancer. He couldn't get his life insurance paid out because his doctors wouldn't confirm he would die from it.'

'Doctors don't want to say, they're [the patient is] going to die.'

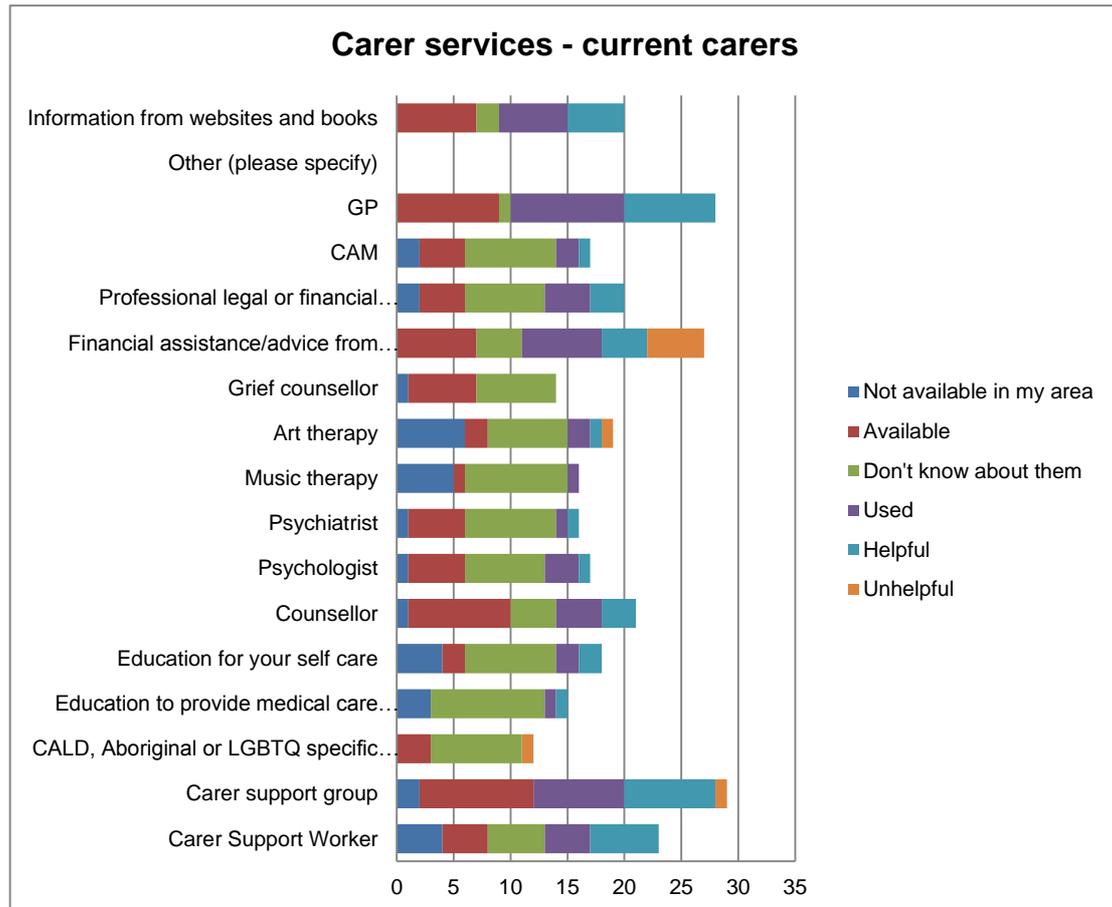


Figure 17. Services during the caring role – current carers.

The responses of this cohort indicate something different to the cohort of previous carers. Current carers show a preference for the same mix of formal and informal supports throughout the caring journey, such as palliative care nurses, GPs, families, friends and neighbours and counsellors. Current carers indicated the service they needed at the time curative treatment ceased or life-limiting illness diagnosed were palliative care nurses (3) family, friends and neighbours (2) and counsellors (2). This cohort again preferred family, friends, and neighbours (14) over any other services at any time during the caring role. However, out of home respite (12), GPs (11), social workers (10) and pastoral care workers (8) were also valued at this time. It was also anticipated the services needed immediately after the caring role ended would be professionals who aimed at helping carers address their grief and loss, such as grief counsellor (4), counsellor (4) and GPs (4). Interestingly, palliative care nurses were also preferred at this time (4) and in the year after the caring role ended (2), perhaps pointing to the carer's preference for continuity with formal supports: palliative care

nurses are likely to understand the context of the carer's situation and would have known and provided end of life care for their relative or friend.

This table shows carers reported the following services were not available in their area: complementary therapy, financial and legal planning from a professional, grief counsellor, art therapy, music therapy, psychiatrist, psychologist, counsellor, education and training for self-care, as well as to provide medical care for the patient, carer support groups and carer support workers. Two carers who live in the vicinity of Koondrook and Yambuna commented the services lacking their areas included carer support worker (one-to-one), education and training such as learning to provide medical care for the patient, education and training for carers' self care, grief counsellor, music therapy, art therapy, financial and legal planning from an accountant or legal representative and complementary or alternative therapy.²⁵

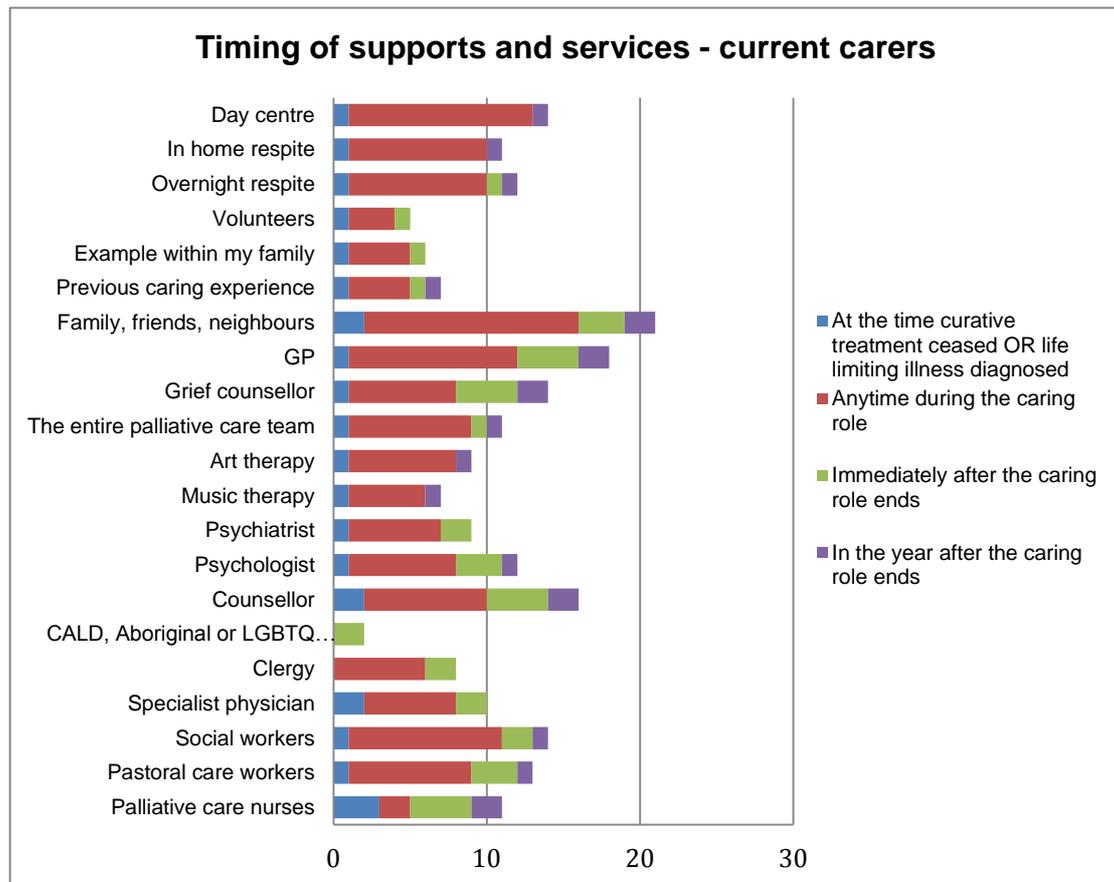


Figure 18. Timing of supports and services – current carers.

Respondents in this cohort expressed similar preferences to previous carers. The most popular potential resource (14 carers) was the option of the patient being cared for by professionals (in home or hospital) when their caring needs become too much to cope with. This is followed by appropriate short term residential respite and emotional support from other carers. By selecting these supports, carers were mindful of the accumulative impact caring will have on themselves and were seeking to sustain themselves with short-term respite and emotional support.

²⁵ Further exploration of postcodes within the 'Loddon' part of the region was not made on the basis that travel to Bendigo and/or Melbourne could be reasonable.

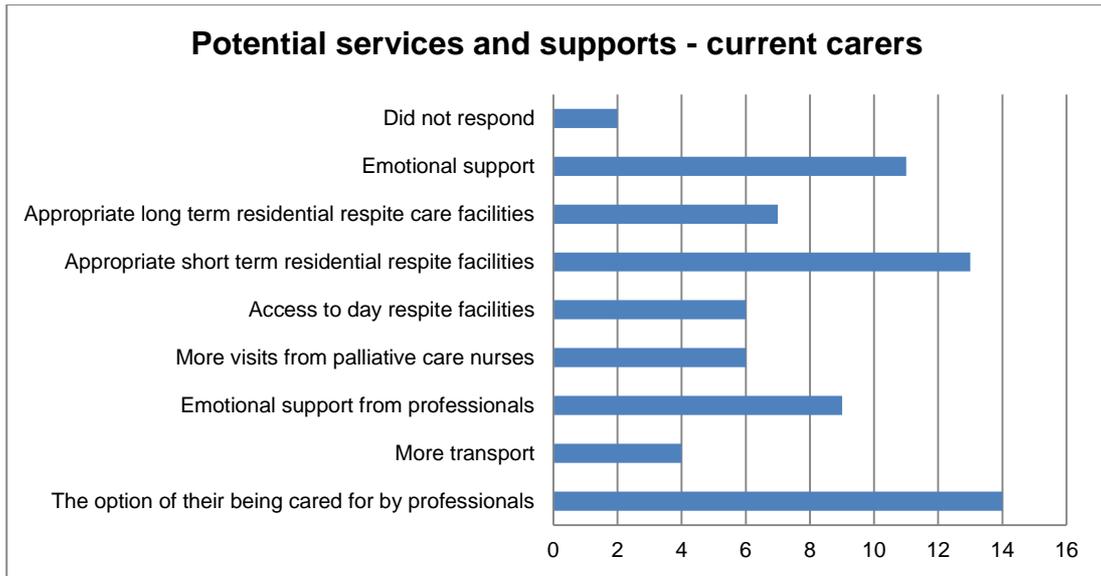


Figure 19. Potential services and supports – current carers.

THE COMPLEXITY OF CARING

Carers were asked to report the emotional effects of caring on themselves and other people in their informal networks. An enduring representation of carers is that they are overburdened, passive and disempowered; however, challenges to this paradigm are evident in service models such as strengths-based approaches which view service recipients as resourceful and resilient in adverse circumstances. This is why the survey also posed questions about positive aspects of the caring role. The responses illustrate the significant impact individuals in this context faced were emotionally (39) and physically (33) challenging, as well as leading to poorer quality of life (26) and being socially isolating (30). However, carers also reported it was a time of learning new skills (25) and satisfying to care for the person during this time (31). Two carers provided very different comments about their experience as a carer for someone with a life-limiting illness:

'Would do it again – no regrets.'

'I felt a failure when it came time to put him in aged care as he deteriorated – people judged me.'

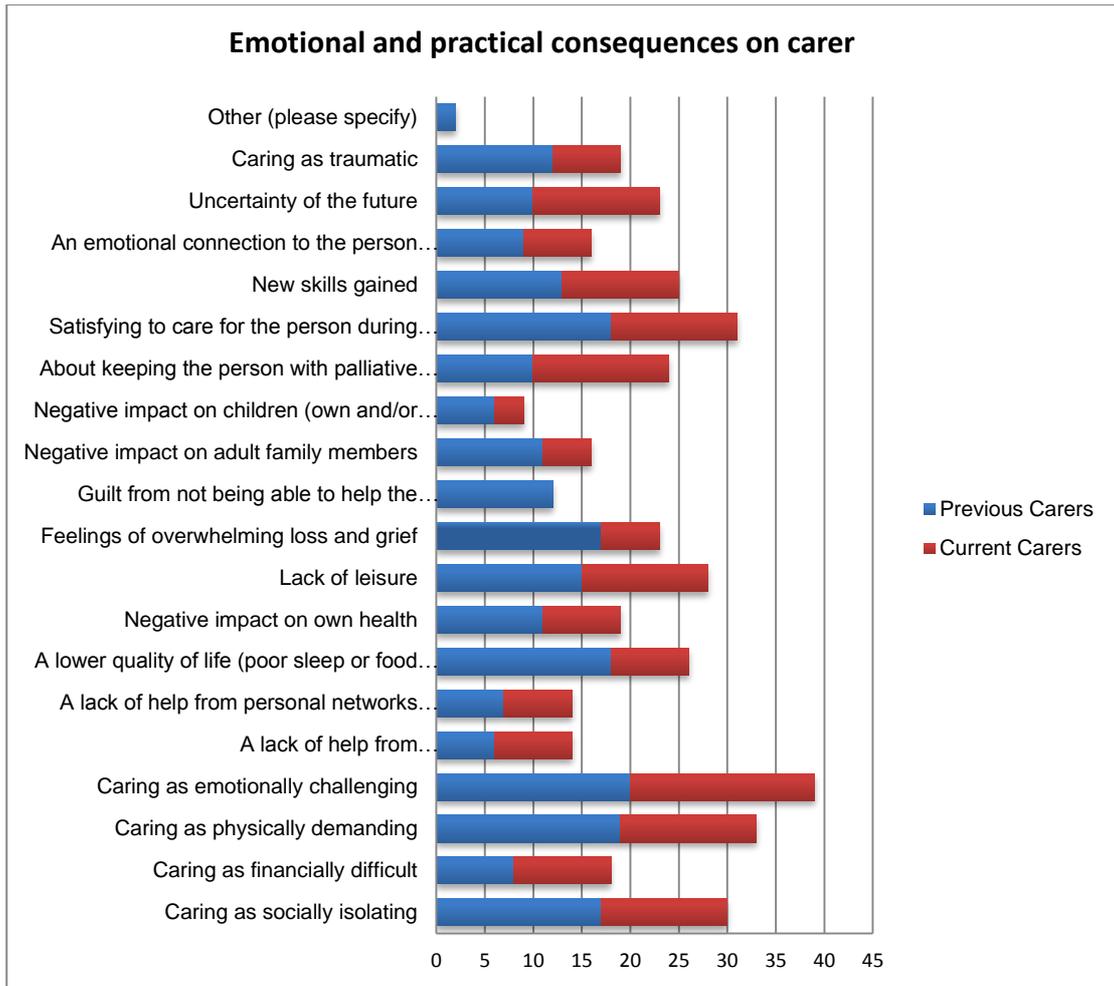


Figure 20. Emotional and practical consequences on carer.

CONCLUSION

This Report has discussed the results of a small study related to the support needs of people caring for someone with a life-limiting illness in the Loddon Mallee region. This report contains data collected from a small sample between March and June 2016. Because of the small sample and the non-randomised nature of sampling, the insights gained from project cannot be generalised to the broader population. Further research is required in order for generalisable conclusions to be made.

The purpose of the Report is to show within the sample there was strong support for and perceived benefit from the development of a regional network to connect carers to each other for emotional support and information sharing. However, participants also indicated they needed other supports such as educational workshops and services that facilitate the sustainable care of the person until their death. These include access to planned and emergency respite, effective relay of information, integration between healthcare professionals that facilitate referrals, as well as financial assistance from the community.

On the cover of this report, a carer is quoted 'We're all on different paths but we're on the same journey'. The metaphor of a journey, moving from one place to another is a powerful and effective way of summing up the aspirations of people caring for a relative or friend with a life-limiting illness. It is well documented that caring in any circumstance can be socially isolating and characterised by an urgent and often desperate need to access supports and services. Peer and professional support that assists people holistically – tending to medical, emotional, social, financial and legal issues in a sensitive and responsive way can make the journey more sustainable.

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