



# Exploring the needs of local family and friend carers in the ACT community

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Prepared by



for



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## ACT Carers Population

The 2018 ABS Survey of Disability, Ageing and Carers (SDAC) reported that there were approximately 50,200 carers in the ACT providing unpaid care to family members or friends who needed assistance with daily living due to a disability, chronic illness, mental illness, or frailty due to ageing (1). Of those providing care, 55% were female, with the majority of all carers aged between 35-64 years (1). It was found that 34% of ACT carers were primary carers, with this figure higher than that of the national average. In 2018, the most common type of informal care provided in the ACT was care for a partner (20,400 carers), a parent (19,800 carers), a child (14,000 carers), other relative (10,600) and, a friend or neighbour (7,500 carers).

A recent national report highlighted most hours of informal care are provided by primary carers, who are estimated to spend an average of 35 hours per week providing care (2). For primary carers, 28% spent more than 60 hours per week, while 25% spent between 1 and 9 hours per week undertaking caring duties (2). Research has demonstrated that wellbeing outcomes of carers were significantly poorer if they spent more than 30 hours a week engaged in caring (3), with a longer duration of caregiving being associated with a reduction in tangible support from others, along with increased carer burden (4).

Family and friend carers continue to provide informal care, despite the ongoing demands of the process. The three most common reasons noted in the SDAC for primary carers taking on a caring role were a sense of family responsibility (70%), emotional obligation (47%), and the belief they are able to provide better care than anybody else (46%) (1). For those caring for individuals aged 65 years and over, 35% said that no other friends or family were available to provide care compared with 29% of people caring for individuals aged less than 65 years of age (1). For primary carers aged less than 65 years old, 25% stated that the high cost of alternative care was a core reason why they continue to provide informal care (1).

Modelled estimates for carers in the ACT by age and geographical areas from 2018 indicated that Belconnen and Tuggeranong had the greatest number of carers, followed by Gungahlin and North Canberra. For most areas, 60% of carers aged were aged over 45 years, while carers in Gungahlin, Molonglo and Uriarra-Namadgi were likely to be younger (see Table 1).

**Table 1: Modelled estimates for carers in the ACT by age and geographical areas 2018 (ABS, 2018) (1)**

	Total	=<14	15-24	25-34	35-44	45-54	66-64	65+
<b>Belconnen</b>	11,669.00	186.00	799.00	1,291.00	1,840.00	2,326.00	2,336.00	2,877.00
<b>Canberra East</b>	189.00	1.00	4.00	19.00	21.00	42.00	54.00	45.00
<b>Gungahlin</b>	7,956.00	176.00	590.00	1,224.00	1,713.00	1,866.00	1,248.00	1,127.00
<b>Molonglo</b>	547.00	9.00	35.00	145.00	134.00	106.00	72.00	48.00
<b>North Canberra</b>	6,387.00	77.00	684.00	891.00	868.00	1,334.00	1,250.00	1,294.00
<b>South Canberra</b>	2,878.00	30.00	154.00	334.00	325.00	622.00	683.00	722.00
<b>Tuggeranong</b>	11,582.00	187.00	831.00	1,113.00	1,575.00	2,558.00	2,789.00	2,483.00
<b>Uriarra - Namadgi</b>	82.00	2.00	4.00	13.00	19.00	18.00	20.00	5.00
<b>Weston Creek</b>	2,866.00	42.00	145.00	206.00	382.00	602.00	602.00	881.00
<b>Woden Valley</b>	4,188.00	57.00	227.00	317.00	487.00	942.00	908.00	1,241.00

ACT carers provide care for individuals with a range of conditions and severity. Recent data from the NDIS noted there were almost 7,000 active participants in the ACT (5), with the most number of active participants aged between 7-14 years old, followed by those aged 0-6 years old and then aged 55-64 years old. The most common conditions for NDIS participants under the age of 25 years requiring care from an informal carer were autism, intellectual disability, developmental disability and cerebral palsy (5). However, for participants aged 25 years and over, the most common conditions was psychosocial disabilities, intellectual disability and physical disability (5). External to the NDIS, chronic conditions in the ACT have increased in both prevalence and complexity (6), which has led to an increase in the number of people providing unpaid care in the ACT. A carers wellbeing survey in regional Australia demonstrated that chronic illness, old-age related health problems and a permanent disability (including mental illness or dementia) were common conditions for people receiving care (3).

## Impacts of caring activities on carers

A longitudinal analysis of mental and general health status of unpaid carers in Australia demonstrated that this population had significant differences in mental and general health outcomes compared to noncarers (7). Locally, the ACT Public Dashboard for March 2019 highlights that in all age groups, informal carers had lower than desirable levels of social contact, hours of work and good health (5). Other significant 'wellbeing gap' between carers and non-carers included confidence in their future security, satisfaction with their standard of living, and satisfaction with what they were achieving in life (3). This reflects the broader literature regarding the impact of caring on the carer which has consistently shown that carers experience poorer mental and emotional wellbeing compared to non-carers, including weariness, resentment, depressions, poor self-efficacy, low life satisfaction and avoidant coping strategies (8-13). It has been shown that informal carers are likely to experience feelings of helplessness, loneliness, loss of control, uncertainty and being undervalued (14, 15).

Interestingly, the perception of carers about their caring roles can have significant impacts on their mental health. Carers with positive views and attitudes towards their caregiving have been shown to have lower levels of carer burden, higher levels of resourcefulness and better mental health (16). Carers self-awareness of their own limitations to provide care has been identified as a cause of emotional stress for a number of carers (17). In contrast, carers confidence in their ability to provide care was a predictor of lower carer burden and increase psychological health (18, 4).

## Carers' concerns with current services

Carers face a significant number of challenges when trying to access support services for themselves and the person(s) they care for. Below are some specific difficulties that carers encounter when accessing common schemes and services including NDIS, My Aged Care, health services and assessments for carers.

### NDIS

A 2018 evaluation of the NDIS was unable to find a statistically significant improvement in carer wellbeing with levels of reported carer wellbeing falling across the duration of the evaluation (19). It was found that carers of NDIS participants with mental/psychosocial disability have lower levels of wellbeing than the carers of NDIS participants with all other disability types, with carers reporting high levels of dissatisfaction with respite services and support networks (19). The evaluation highlighted the anxiety experienced by carers about the long-term sustainability of the NDIS, along

with the administrative burden of the system, which led to stress and negatively impacted on the wellbeing of some families (19). It was also highlighted in the same report that some NDIS participants were receiving less supports than prior to their participation in the NDIS, or were consistently having NDIS-funded supports reduced at review (19).

The 2020 National Carer Survey reported that in the ACT carers accessing NDIS and disability supports expressed great dissatisfaction in most criteria of carer's involvement and support, including whether carers were asked about their needs (58%), whether services meet the needs of carers (54%), break from providing care (49%), whether carers were provided with relevant information (45%), whether carers were enabled to stay in work (43%) and whether services were easy to organise (41%) (20). The most common challenges identified to access services included "difficult to find information" (29%), "takes too much time/energy to organise" (23%), "not enough funding" (21%), "long wait for service access" (16%) and "services not available locally" (15%) (20).

### My Aged Care and aged care services

The evaluation of Wave 3 of My Aged Care, found the overall satisfaction of carers for the scheme was considerably lower (58%) compared to that of clients (72%), with the proportion of very satisfied carers down significantly on Wave 2 (26%, compared to 37%) (21). Carers had generally low level of satisfaction for the information that they received about setting up Home Care Packages and had limited knowledge about new reforms(21).

The 2020 National Carer Survey reported that care experiences with aged care services in the ACT had areas for improvement, with more than 25% carers expressing dissatisfaction/ disagreement with: "whether carers asked about needs", "break from providing care", "enabled to stay in work", "meets carer's needs" and "easy to organise" (20). Major challenges identified by ACT carers to access services included "difficult to find information" (27%), "care recipient did not want services" (22%) and "long wait for service access" (23%) (20). Other challenges included long wait for assessment, too much time/ energy to organise, not enough funding, quality/safety concerns, services not available locally, costs of services being too high and care recipients not eligible for services (20).

### Mental health services

In 2020, the National Carers Survey reported that carers in the ACT were significantly dissatisfied with mental health services for most criteria of carer support and inclusion. Approximately 60% of carers were unhappy with not being asked about needs and services not being able to meet carer's needs (20). Approximately 55% of carers believed significant improvements were required in information provided, respite services and supports put in place to enable them to remain working (20). ACT carers identified a number of challenges when accessing mental health service were that services offered at a lower level than needed (24%), long wait-times (24%), information being difficult to find (20%) and services taking too much time to organise (16%) (20). Other challenges include cost/co-payment being too high, services not available locally, care recipient not eligible and a lack of culturally-appropriate services (20).

### Primary care, community health and hospital services

Carers in the ACT felt overlooked in primary care, with 59% of those surveyed reported that GPs did not enquire about their own needs as a carer and 40% reported GPs did not provide them with appropriate information (20). This trend was also reflected for hospital services, with 73% of carers reported that the hospital did not ask for their own needs as a carer and 41% reported that the hospital did not provide them with information (20). More broadly, approximately 55% of carers reported that options and facilities to support carers were insufficient (20).

Carers are involved in different activities when providing care, including but not limited to patient caregiving, information sharing, shared decision making and patient care transition (22). Given the important role carers play in the lives of the person they provide care for, improved communication between healthcare professionals and carers is required, including the acknowledgment of the role of carers and recognising their expertise can bring positive mental and physical health outcomes for both carers and patients in different care settings (23-25), agreed procedures to involve the carer in decision making (26).

### Carers assessment

Research has highlighted the need to regularly identify and assess the needs of carers to ensure appropriate support is provided to them as carers, as well as potentially prevent adverse outcomes, such as potential hospital admissions for the patient (27). The process of a preventative assessment could acknowledge the carer, their role and its challenges (28), which has been demonstrated to lower levels of early grief, better psychological and physical health of palliative carers (29). Currently, many assessments with carers are completed reactively, often due to crisis (30), are completed in an informal manner (30) and task-focused and not capture the affective dimensions of caring, the complexities of the care relationships, the meanings carers attach to their roles and how these might change over time (30). Practitioners have reported a number of barriers to conducting assessments with carers including; lack of perceived value of such assessments (30), concern in raising false expectations when identifying needs that cannot be met (31) and no separate record system, or payment items, for carers (31).

A more detailed description of the needs of carers of people with specific conditions, please see Appendix A.

## Exploring the needs of Carers in the ACT

### Methodology and Data Analysis

The Capital Health Network, ACT's Primary Health Network, worked in collaboration with Carers ACT to develop a mixed methods approach that aimed to better understand the needs of carers living in the ACT. This consisted of a broad community-based survey and focus groups. The target population for this was anyone who lives, works, or studies in the ACT who identified as a family and/or friend carer.

Informed by the literature as well as key gaps in local data identified by Carers ACT, a survey was developed to meet the identified aims. The survey consisted of a range of questions including demographics, current caregiving status, how caring is impacting their life as well as the Personal Wellbeing Index (PWI). The PWI is utilised by Carers ACT when assessing the needs of new carers who join their organisation. It is also a well validated tool that has been demonstrated to assess wellbeing in seven different quality of life domains, and scored between 0-100, with higher scores representing higher wellbeing (32). The survey had a free text question for participants to make any additional comments, as well as an invitation to participate in focus groups to discuss their caregiving experiences in more detail. The survey was developed as an online tool using the Survey Monkey platform and distributed via the Carers ACT database, Capital Health Network (CHN) newsletters and through a number of service providers commissioned through CHN.

Focus groups were designed based on the primary condition (as described by Carers ACT) of the care recipient, enabling carers to feel comfortable sharing stories with others who may have similar caring experiences as themselves. Individuals who nominated to participate in focus groups were

contacted and invited to participate in the appropriate group. With participants' permission, the focus groups were recorded for transcription purposes, and notes were taken during the discussion to supplement the transcripts.

Quantitative data collected from the survey was entered into appropriate statistical programs and a range of statistical analysis was completed, and the qualitative data from both the survey and focus groups was thematically analysed.

## Results

A total of 346 carers completed the survey. Of these, 79 indicated they were willing to take part in a focus group with CHN to discuss their caregiving experience further, to which 21 individuals participated.

### Demographics

Of the 346 survey respondents, the majority were female (82%), currently residing with the person(s) they care for (81%) and were providing care for more than 30 hours per week (46%). The average age of respondents was 61 years (ranging from 15-89 years). Approximately 13% of respondents spoke a language other than English at home, and 3% identified as are either Aboriginal and/or Torres Strait Islander. When asked what the primary condition was for the person they provide care for, chronic conditions was the most common response (23%), followed by dementia (16%), physical disability (14%), autism spectrum disorder (12%) and mental health (12%). A further 9% of survey participants said that they were providing care for other conditions, such as Parkinson's disease, cancers, and a range of comorbidities.

Most carers reported that they were providing care for a partner or spouse (40%) and a child (32%), with 21% were providing care for a parent. For partner/spouse carers, the most common conditions they were providing care for were chronic health conditions (38%), dementia (24%), physical disability (17%). More than half of the partner/spouse carers who responded, resided in either Belconnen (32%) or Tuggeranong (21%). Approximately 10% of partner/spouse carers reported residing in Gungahlin, South Canberra, North Canberra or Woden Valley, while only 5% reported living in the Molonglo Valley. For those who were providing care for their children, the most common conditions that they were providing care for were mental health (23%), autism spectrum disorder (22%) and physical disability (13%). Carers in this group reported residing in Belconnen (36%), Tuggeranong (20%), Gungahlin (15%) and Molonglo-Weston Creek (11%).

When asked about financial support, almost half (45%) of carers reported they did not receive financial support for themselves as carers and only 22% of carers stated that the person they provide care for, receives formal financial support from the government. Only 36% of carers noted that they were in some type of employment, with 14% employed full time, 16% part time and 6% working casually. It was also reported that 40% of carers had combined household income less than \$69,390 per year.

### Impact of caring and the Personal Wellbeing Index

The survey explored the views of carers on the way caring is impacting their life including health, wellbeing, stressors, support, services and interactions with health professionals (see Table 2). It was found that the majority of participants either agreed or significantly agreed that their caregiving responsibilities were negatively impacting their physical and mental health was being negatively impacted by their caregiving responsibilities and have caused financial stress in their household. While the majority of carers either agreed or significantly agreed that their caregiving responsibilities has caused them to feel isolated as well as a sense of burden, carers also reported a

high level of confidence in being able to support the person they care for, although there was a mixed response regarding access to supports to assist with caregiving. More than half of the respondents agreed they were satisfied with the level health professionals involved them in decision making, however there was not the same level of agreement relating to the belief that health professionals care about their health and wellbeing separately from the person they care for. There were also mixed responses regarding the quality of services accessed by respondents as well as the satisfaction regarding the level of gender inclusivity and/or cultural appropriateness of services.

**Table 2: Frequencies of carers views on how caring is impacting their life**

Variables	Significantly Disagree (%)	Disagree (%)	Neutral (%)	Agree (%)	Significantly Agree (%)
My physical health is being negatively impacted by my caregiving responsibilities	1.7	7.2	22.3	42.3	26.1
My mental health is being negatively impacted by my caregiving responsibilities	1.2	6.9	13.6	46.5	31.5
My caregiving responsibilities have caused financial stress in my household	5.5	21.1	23.1	29.2	20.8
I feel a sense of burden because of my caregiving responsibilities	4.6	9.5	19.4	38.4	27.7
I feel confident in supporting the person I provide care for	2.0	14.2	20.6	46.8	16.0
I feel isolated due to my caregiving responsibilities	3.8	16.5	25.1	31.8	22.5
I am able to access the support I need to assist me with by caregiving responsibilities	10.8	24.7	32.8	28.2	3.2
I am satisfied with the level health professionals involve me in decision making	6.4	13.9	27.2	42.0	9.3
Health professionals care about my health and wellbeing separately from the person that I care for	7.8	18.2	30.1	35.8	7.8
I am satisfied with the quality of services I am accessing	5.8	22.0	35.0	29.5	7.5
I am satisfied with the level of gender inclusivity and/or cultural appropriateness of services	11.0	7.8	47.4	31.8	0

The internal consistency of the PWI was calculated using Cronbach's alpha ( $\alpha = 0.93$ ) suggesting high levels of internal reliability of the instrument. The average PWI score across all carers was 56.4. This is more than 10 points below the average PWI score of carers across regional Australia in a 2016 survey (3). Among all carers, carers for people with autism reported the lowest scores in most items



of the PWI, followed by carers for mental health conditions. Greatest discrepancies from 'All Carers' average score are reflected in general life satisfaction, what they can achieve in life, personal relationship, personal safety, and future security.

**Table 3: Average scores for PWI domains of carers by primary conditions they provide care for**

	All Carers	Chronic conditions	Dementia	Physical disability	Autism	Mental health
Thinking about your own life and personal circumstances, how satisfied are you with your life as a whole?	53.4	51.9	58.8	51.0	51.7	49.5
How satisfied are you with your standard of living?	64.5	61.1	69.9	65.5	53.9	61.4
How satisfied are you with your health?	49.9	50.8	54.7	45.5	37.6	47.4
How satisfied are you with what you are achieving in life?	49.6	48.1	56.6	43.6	42.4	48.6
How satisfied are you with your personal relationships?	54.8	52.3	58.7	56.6	41.7	51.2
How satisfied are you with how safe you feel?	71.6	72.0	70.9	75.7	64.4	59.5
How satisfied are you with feeling part of your community?	54.4	54.9	61.2	59.8	36.6	52.4
How satisfied are you with your future security?	53.8	55	60.8	54.5	34.1	50.0

When exploring whether there was a relationship between PWI scores and views on how caring is impacting the carers' life, a significant negative correlation was found in all but two of the variables. The only items with no significant relationship were those focussed on confidence and gender/cultural inclusivity of services. This suggests that the level of confidence of a care to support the person they care for, and the level of satisfaction with level of gender inclusivity and/or cultural appropriateness of services, is not related to an individual's person wellbeing score.

All other items had a significant, negative correlation with PWI score. This demonstrates that those with lower PWI scores were significantly more likely to: agree their physical and mental health is being negatively impacted by their caregiving, agree that their caregiving has caused financial stress, feel a sense of burden, feel isolated, agree that they are less able to access supports needed to assist with their caregiving responsibilities, be satisfied that health professionals involve them in decision making or that health professionals care about their health and wellbeing separately from the person they care for, and, feel satisfied with the quality of services they are accessing.

Needs of carers for people with chronic conditions, dementia and frail age as primary conditions.

Carers in this group were generally older than carers of other primary conditions (mean age 64.5 years) and were more likely to be partner or spouse of the person they care providing care for. Approximately 32% reported they were still in some form of employment, 41% received some form of financial supports for being a carer and 42% had family combined income less than \$69,390 per year. PWI scores for this group were generally higher than the 'All Carers' average. Carers in this group also had manage multiple health issues as 77% of carers were providing care to a person with multiple co-morbidities. The variety of co-morbidities noted were broad and added a level of complexity to the type of care provided. Common co-morbidities mentioned were Dementia & cognitive/ behavioural problems, mental health conditions and other chronic illnesses.

The most common sources of stress reported by carers in this group were from: interactions with aged care services (including navigating the system and time delays to receive support packages), inconsistent quality and/or standard of services (e.g. constant changing of support staff and inconsistent quality from provider to provider), feeling uncertain about what to expect when accessing services and, significant administrative burden. Less common sources of stress also included a lack of skills and knowledge regarding how to provide appropriate practical care for the person that they care for (e.g. personal care, diet), how to manage the changing nature of the relationship with the person and what to expect as the condition(s) progress.

The long-term impacts of care responsibilities on financial situation were considered major stressors for carers in this group who are still working, leaving them feeling anxious and uncertain as to how they can cope when accident or crisis happen in the future. Support for carers who require intensive assistance for a short period is reported to be lacking, and others acknowledged the changes in their care responsibilities as the conditions progress, often happen gradually without them noticing, until they are overwhelmed and no longer able to cope.

*“Services don’t acknowledge the long-term financial impact caring for mum has for me. I’ll keep caring for her, or her health will deteriorate and that will affect my mental health if that happens. The sacrifice is that it could leave me homeless with children when she passes on, as it impacts the hours I can work and my ability to stay connected with being skilled and my community, that also impacts my mental health. Centrelink denied me carers assistance and disability assistance for my own health issues. Right now I’m trying to juggle what resources I do have to sustain being a carer, I’ll never be able to get that back to set myself up in the future.”*

**- Carer of a person with chronic conditions**

*“I am caring for my mother who has early signs of dementia. Her condition has gotten worse lately and I did not realise how much care responsibility has crept up. I may need to access help soon.”*

**- Carer of a person with dementia**

Mental health support was the most commonly reported expressed unmet need for this group, including support to cope with stress from care responsibilities, how to manage when the nature of relationship change, grief counselling and how to overcome social isolation. While there was acknowledgement that there was current counselling for carers provided via Carers ACT and that it was being utilised, it was highlighted that this support should be more tailored and practical for the carers’ situation than it is now. This would improve the perceived quality of the counselling service provided, as well as improving the likelihood of meeting the mental health needs of the carer.

*“Mental health support (psychologist) is crucial to maintaining my role as a carer”*

**- Carer of a person with chronic health conditions (neuropathic pain)**

*“My caring experience has been bumpy. One thing I did was get professional advice on how to work with other family members to build a better relationship with them. I doubted this would work, but I was given some simple strategies and they have worked.”*

**- Carer of a person of frail age**

Another need that was consistently raised in the focus groups was for a manual to navigate the aged care system that clearly indicates what supports are available, what they need to be able to access services and transparent service description. Courses on how to provide personal care for particular

conditions are mentioned frequently in both the survey and focus groups, with the aim to help educate and provide carers with strategies and tools to alleviate the stress on how to provide the level of care expected of them, and how to plan for future constructively.

*“Navigating the aged care system is very complicated and time consuming, for instance this is one of the reasons I have not accessed the carer allowance.”*

**- Carer of a person of frail age**

*“(There are) plenty of bodies to direct you to services, but no one to actually help complete the forms, deal with technology etc. Assumption seems to be that the carer is able to manage these areas even though I don’t have regular internet access, knowledge of technology etc and have my own pre-existing health issues.”*

**- Carer of a person with dementia**

Other expressed needs mentioned included such things as: relationship management support, support to navigate difficult conversation with the person they care for, practical tips to provide care, quality respite care, carers getaways, peer groups to network and share experiences, and supports for carers with full-time employment responsibilities. The need for peer support groups was dominant amongst carers for people with dementia, believing this would provide them with a social network and enable them to exchange experiences in providing care.

*“Hard to tailor needs to each case understandably but it would be fantastic to be able to leave your cared for person in their own environment with someone to stay over rather than a welfare visit.”*

**- Carer of a person of frail age**

*“Real pity Carers Assoc. doesn't provide away from home retreats or we don't seem to qualify for them. Govt. funding for this type of relief is the least the Govt. could do as well as make provisions for carers to receive targeted medical support by say special drop-in centres to compensate for the free (slave like) labour totally unfunded carers provide (otherwise caree would be in nursing home at cost to Govt).”*

**- Carer of a person with chronic conditions**

Needs of carers for people with autism, intellectual disabilities and mental health issues as primary conditions.

Carers in this group were generally younger (mean age of 54 years) and were more likely to be parents of children with conditions that require care. They were more likely to be working (50% compared to 36% of all carers), less likely to receive financial supports for being a carer (27% compared to 50% of all carers) and 35% have a combined family income less than 69,390 annually. PWI scores for this group were lower across all domains compared to other carers.

Carers for this group, regardless of whether the primary condition was autism, intellectual disability, or mental health, reported high levels of co-morbidities that include both mental and physical health conditions. Some of the more common co-morbidities were depression, anxiety, attention deficit hyperactivity disorder, obsessive compulsive disorder, oppositional defiant disorder and chronic pain. They are also more likely to have multiple care responsibilities, requiring them to provide care to more than one child, or to other family members.

The most commonly reported sources of stress were financial (particularly for carers feel trapped between care responsibility and their employment), interacting with the support system (including NDIS and Carers Gateway) and feeling deprived of personal life and career development prospects.

Many carers in this group reported that they feel extremely vulnerable against future risks as they have lost employment, have no savings or their savings were spent already due to caring responsibilities. Many in this group are more likely to have multiple care responsibilities than any other carers (e.g. having more than one child with mental health issues or intellectual disabilities), which exacerbates their stress.

*“It’s hard enough surviving with two children on the spectrum. Surviving as a single mum now, with zero training, zero job prospects due to being out of the workforce for so long and knowing I will be even poorer later on in life makes it hard to think about the future. I’m smart enough to earn HDs at uni but completely trapped and unable to access opportunities. It’s beyond frustrating.”*

**- Carer for a person with autism spectrum disorder as primary condition**

*“My main challenge is that I provide care for four people and if they all take it in turns to have crises I can just about manage it - but when they stack them and have concurrent crises (NDIS, Funding, health needs, personal issues, accommodation, sourcing new service providers, etc) it is more than I can really cope with.”*

**- Carer for a person with autism spectrum disorder as primary condition**

Another common sources of stress for carers in this group relates to the interaction with health and service professionals. Participants stated that they do not feel respected and are not included as part of, or consulted about, the care plan for the individual they look after. This places carers under significance stress as they feel disconnected with the care plan and do not know what is going to happen next as the condition(s) progress. Stress also comes from the unavailability of services for the person they care for in the ACT, such as the condition categorised as either being too hard, too complex, or too rare to treat, and the subsequent need to travel for specialist services. This then places additional stressors on the carer regarding finances, time away from work and/or other caring duties. Other sources of stress mentioned for this group were concerns about personal safety, no (appropriate) crisis support (e.g. for mental health escalation), poor follow-up and coordination of care due to high turn-over of staff, feeling isolated, lack of respite, no services or supports dedicated to carer’s needs and services not being gender-inclusive. Carers in this group also struggles with the education system regarding administrative processes, relationships with support professionals and willingness to provide alternative options for class or assessment work.

*“The lack of information from medical personnel etc when she is unwell because of her age is a real problem. It means I don’t know what I am dealing with. Is it safe for me to see her? Should I stay away? I feel scared when she is psychotic.”*

**- Carer of a person with mental health as primary condition**

*“Fundamentally, my son is a complex case who appears to have been relegated to the “too hard basket” by health professionals and disability service providers. Dad will do the job (while he is still alive).”*

**- Carer for a person with intellectual disability as primary condition**

*“School was not really equipped to support people with mental health issues and the suitable arrangements that work for person with mental health is very costly (I had to pay a lot of money for clinical psychologist to allow people with mental health issues to receive homeschooling).”*

**- Carer of a person with mental health as primary condition**

One major theme identified among carers for people with mental health conditions is issues with the carer assessment, as many carers did not meet the criteria to be recognised as a carer, even though they provide complex and high-level care for the person. They report that the current criteria for carers assessment focus disproportionately on physical disability and in-home functionality instead of social functioning, which leaves a significant number of carers in this cohort unable to access required support. Carers believed this placed them at increased risk of stressors and financial vulnerability, as they thought they had no other option but to pay to access private psychiatry or psychology services, while receiving no financial support. Additionally, many carers also felt forced to access these services interstate given the current mental health workforce issues in the ACT. Carers in this cohort also concerned about the discontinuity of support for themselves and the person they care for when the person reaches an age where they are no longer considered eligible to access services. This can leave the person vulnerable with no support during transition, or no suitable/ available support after the service ceased.

*“CentreLink assessment does not really capture all the aspect of mental health issues. Carers fall through the gaps as not being qualified as most of the criteria is about the ability to function in the home and physical function, rather than social capability.”*

**- Carer for a person with mental health as primary condition**

*“I wish there was more financial support available. My daughter cannot work or study but as she is under 22 she is not eligible for any support. Even though an adult, I have to pay for her medical costs including psychologist. I am unable to retire because of the financial burden.”*

**- Carer for a person with mental health as primary condition**

Other common expressed unmet needs in this group were relationship management, mental health supports that do not add more psychological workload for carers, grief counselling, better carer identification and recognition, support for carers (when the person they care for chooses not to participate in care), and future planning for themselves and the person they care for.

## Discussion and Recommendations

In collaboration with Carers ACT, the Capital Health Network, the ACT’s Primary Health Network, conducted a needs assessment to explore the needs of carers in the local community. This was completed through both a survey and a series of focus groups. A total of 346 local carers completed the survey, which asked questions about demographics, their caregiving status, the impact of caring on their life, and their wellbeing. A total of 21 carers participated in the focus groups, which allowed participants the opportunity to discuss in more detail, their caregiving experiences, and identify their needs.

The majority of survey participants were female, were the spouse/partner of the person they provided care for, resided with that person, provided more than 30 hours of care a week, and the primary condition of the person they provided care for was a chronic illness (which was not specified). However, carers of people with mental health issues or autism, were more likely to be the parent of that person. Many carers noted that the person they provided care for had multiple co-morbidities that also required their care.

Participants reported that their caring responsibilities were having a substantial impact on their lives. This ranged from mental and physical health to financial stressors, feeling isolated and the way they interacted with the health system. Many of these issues were also reflected in the focus groups and the qualitative responses in the survey. The PWI was also administered to participants. This index measures several domains relating to quality of life and provides an overall wellbeing score

out of 100. The average PWI score for carers in this survey was 56.4 – which is lower than other studies of Australian carers. Carers of people with autism or mental health issues as primary conditions, consistently scored lower across all domains of the PWI compared to other carers.

When exploring carers needs in more depth, it was found that carers of people with chronic conditions, dementia and frail age as the primary conditions, had major sources of stress relating to interactions with aged care services, inconsistent quality and/or standard of services, feeling uncertain about what to expect when accessing services and, significant administrative burden. Carers for people with autism and mental health issues as primary conditions identified major sources of stress as financial, interacting with the systems in place to provide support, and feeling deprived of their own personal life.

Key issues that were consistent across all carers were: that the person they care for often has multiple conditions that require care and support, caring places a significant financial burden on themselves and their household, high levels of difficulty navigating and managing the service that are designed to help, and the feeling that there are not enough supports in place to help the carers themselves as individuals, not just as a carer of someone who is unwell.

### Recommendations for Carers ACT

There are three main categories of potential strategies suggested by carers from the needs assessment. Providing resources to support carers providing care, adjustments to current programs/processes/staffing, and advocacy.

#### *Providing resources to support carers providing care*

##### **Understanding the nature of illness/disability**

An online course with resources and activities that carers can work through at their own pace that is tailored to the specifics of each illness or disability. This course would enhance understanding of the nature of disability or illness, how to maximise quality of life, practicalities that need to be considered, practical and scalable advice on how to best support carers, personal care procedures, how to plan for trajectory of disease progression, being equipped for crisis, communication and behaviour tips and strategies.

##### **Carers wellbeing**

Wider and more comprehensive provision of online courses that are tailored to different needs of carers. Ideally designed so that they can work through at their own pace, and with content that promotes self-management of mental health, relational well-being and emotional resilience through regulation strategies, stress-management, skills, and healthy communication strategies for stronger and improved relationships, cultivating beneficial personal habits and qualities, enhancing emotional intelligence, self-compassion, self-esteem and self-care practices, support for grief, etc. Whilst there are already online course offerings through the Carer's gateway, having a wider and more comprehensive selection that can provide more nuanced support for the specific groups (such as age group or life stage or living situation) within the carers cohort would be helpful.

##### **Service navigation support**

A manual or online webpage that helps with understanding the health service landscape related to specific illnesses/diseases would be of benefit. This would focus on enhancing understanding of relevant services and support navigation through a resource that is tailored for certain illness/disability types. It would outline such things as: suggested care coordination plans, translation of service eligibility, flow-charts of moving through different client needs and which providers can meet that need, how to plan in case of emergency or crisis, and a carer's dictionary of medical and service terms.

### **Financial support or giveaways for carers**

Continuing with existing supports and increasing where possible: free/discounted/coupons for supportive services: massage, in-house support (cleaning, maintenance, transport, replacement of household items), transport and accommodation

### *Adjustments to current programs/processes/staffing*

#### **Maintain frequent check-ins**

Regular reach outs and check-ins with carers who have not engaged with service for a period will allow Carers ACT to identify carers that may have dropped off engagement due to high caring responsibilities but still need support.

#### **Broader promotion of Carers Gateway**

Ensure wider advertising of the Carers Gateway, Carers ACT in general and available services/supports to ensure that carers from all demographics and areas of Canberra are aware of supports and services are available.

#### **Offer family/relationship counselling and practical strategy support**

Provide relationship/family counselling as well as individual counselling to support carers to improve relationships with care recipient. Within the individual counselling, offering both 'talk' therapy and targeted, practical strategy support to manage challenges.

#### **Offering social worker/third party/case management support**

A third-party professional that will come and assist carers communicate with their person who needs care to accept illness/disability and/or communication and transition support to outline how to move forward in way that best supports carers and family. Aspects of this role could be to provide support to Carers with paperwork, service recommendations and decision making would be helpful also, to the carers who require this service.

#### **Wide range of face to face, online supports, and carers getaways**

Continuing with providing a range of social supports both online and face-to-face and cater to a range of different hobbies, skill levels, preferences, and availabilities. The Carers Getaways provide a chance to get away and relax, so more available opportunities for carers to participate in these would be greatly appreciated. Peer support groups is another solution suggested by many carers to help them better achieve social life, feel less lonely in their care journey, and feel more confident in providing care thanks to experience exchange.

#### **Inclusive supports that are accessible for wide range of demographics, including minorities**

Enable supports to be accessible and appropriate from those from minority groups (CALD or LGBTIQ+ and for carers of all age groups). Consulting and collaborating with relevant community peak bodies on how to provide culturally appropriate and gender and sexuality affirming spaces and services could be a useful way to ensure effective approaches are utilised.

### *Advocacy*

#### **Better awareness of the role of carers and the impacts of caring on carers**

Having the roles and impacts of caring better understood by health professionals and services is important for carers to be able to receive supports for themselves, separate from the person that they care for. Carer's rights and expertise need to be recognised by services involved for carers to feel respected, be able to advocate for the right supports and be prepared for the future. It is also important to advocate for the rights and appropriate supports for non-primary carers (e.g. siblings) and recognise the impact that caring role of family member may have on them.

### **Service provision/integration**

Advocacy for a more streamlined process in support services (e.g. Centre Link, My Aged Care, NDIS and Carers Gateway) to reduce mental health burdens for carers is suggested in all focus groups. Packages offered should also be more flexible to allow carers to tailor to the care needs of the person they are providing care for. There should be better consistency in service quality and staffing i.e. through more thorough training and better staff retention strategies, to minimise administrative burden for carers and risks of negative outcomes for clients. Service affordability, reduced wait-times and increased integration are important areas that need immediate improvements to alleviate carer's stress. Advocacy for normalisation of disability/chronic health problems/mental through media, events, campaigns are helpful to create a better-supported and inclusive environment for both carers and the person that they care for.

### **Carer specific supports**

Some specific and practical areas that carers suggested need more advocacy supports are financial support through increase in carers payments, subsidised bills/services, emergency crisis service specific to carers that is not having to call '000', better support for young carers in school, and better carer identification process (e.g. more comprehensive assessment criteria that do not let carers fall through the gaps like in the case of carers for people with mental health conditions). There needs to be multiple service points to identify carers beside Centrelink. The following settings were recommended by the literature to be potential points for identification to occur (60):

- Primary care – specifically GP practices,
- Public and private assessment services,
- Formal Admission to a specialist public or private mental health service,
- Formal discharge from a service,
- Continuing care in both the public and private sectors.

### **Conclusions**

This needs assessment demonstrated that the needs identified in the local ACT community were consistent with those identified in the literature. Carers must juggle multiple responsibilities as an individual, but also as a provider of care to family or friends – the majority of whom have multiple co-morbidities. It was seen that irrespective of the primary condition of the person receiving care, carers faced similar stressors regarding finances, system navigation and the need for mental health support. The honest and candid responses of carer participants in this needs assessment were instrumental in providing the recommendations to Carers ACT regarding providing resources to support carers providing care, adjustments to current programs/processes/staffing, and advocacy. This report highlights while there are gaps in the system for carers, they are a resilient, hopeful cohort who deserve the care and support to continue the important work that they do within the community.



## Appendix A: Carers subgroup needs analysis

A desk top review was conducted to further identify the needs in each sub-group of carers. Carers at different stages in life require different supports to adapt to their changing social, health and emotional needs. Specific conditions also require different care regimes and support services. For that reason, we conducted a subgroup needs analysis based on carer's demographic qualities and the conditions that they provide care for to assist in service designed that best tailored to the needs of carers.

### Young carers and young adult carers

There were around 7,300 young carers (carers less than 15 years old) and young adult carers (carers aged 15-24 years old) in the ACT in 2018 (1). Research shows that the range of caring activities that young carers and young adult carers deliver include providing/contributing to household income, household chores and other same tasks as paid and trained health and social care practitioners, although they are unpaid and untrained (33).

Young people who care are disadvantaged, and restricted in their opportunities; those from single-parent and single-child families, and dealing with more stigmatised and debilitating problems were most severely impacted by caring (33). In general, young carers are exposed to numerous health and wellbeing risks and spend much more time spent for caring due to the lack of knowledge about the medical diagnosis and lack of training (33). They can also feel invisible and unacknowledged as caregivers (33). Young carers and young adult carers may experience various economic and social disadvantages and difficulties, including restricted educational opportunities and employment, difficulties in meeting the demands on them in university education, reduced social capital, and experience of stigma leading to secrecy and social withdrawal (33). Level of well-being of young carers may also be influenced by the high chance that they got bullied at schools (33). Taking caring responsibilities early in life transgresses the accepted social norms regarding the relationship between a young person and his or her parent, which may affect their development, sense of self, social integration, or interaction with their peers (33, 34). However, young carers still experienced some positives from caregiving, including increasing maturity, closer relationships with parents, the feeling of being well prepared for life, and the ability to foster qualities of compassion and empathy (33).

There are a number of needs for young carers identified in the literature, including, the need for interventions or programmes that assist young carers to access education, training and employment, through expanded respite and other supports (35) as well as those able to assist young carers to engage in mindfulness practices – that may increase the range and use of coping skills through improved self-awareness and reflection (36). It has also be recognised that there is a greater need for support and understanding from education and health professionals for young people with caring responsibilities to better engage with education (36).

Despite the numbers of young carers in the community, there are many challenges that they face when accessing services, including being ineligible for financial assistance (e.g. financial assistance) (36), difficulty attending support sessions or appointments often due to their dual role as a carer and a student (34) and finally, issues with role identity, that is, not identifying themselves as carers for fear of losing their self-identity and drawing unnecessary attention to themselves (34)

### Older carers

Around 11,100 older people in the ACT were carers in 2018 (1). Nationally, about 19.5% provided care for grandchildren only, 8.7% provided regular care for a sick or disabled relative or friend, and 4.2% provided care for both grandchildren and sick or disabled relatives or friends (defined here as

grandparent carers) (37). Older carers are often frail and have their own health conditions to manage and at higher risk of decreased health-related quality of life, a significantly lower sense of coherence and higher role strain (4, 27). Ability to physically provide care decreased as they aged (4). Data from wave 2 of the PATH Through Life Study surveying 2,222 adults aged 64-69 years conducted in Canberra and Queanbeyan, Australia reported carers to have significantly poorer mental health than non-caregivers, poorer physical health, greater financial stress, greater responsibility for household tasks, and more conflict and less social support from their family and spouse (38). Analysis showed that the poorer mental health of caregivers reflected elevated rates of their own physical impairment, a lack of social support and greater conflict (38).

Older carers concern about the future are particularly important for older carers of adult children with disabilities and people with dementia because they expect to be outlived by their care recipients (39). Other necessary supports for older carers have been identified in *Carers of people with dementia*, *Carers of people with heart failure*, *Carers of patients with chronic conditions* and *Carers of people in palliative care*..

### Aboriginal and Torres Strait Islander carers

Among the states and territories, the proportion of Indigenous people with one or more selected chronic conditions in the ACT was the second highest in Australia in 2018-19 (57%) (40). Recent data from the 2018-19 National Aboriginal and Torres Strait Islander Health Survey states the most common chronic health problems among Indigenous populations were mental and behavioural conditions, asthma, ear/hearing problems and back problems (40). The gaps between Indigenous and non-Indigenous populations in the ACT in terms of asthma, mental and behavioural conditions were most significant, with the rates of Indigenous populations being about twice as much as those of non-Indigenous (40). Stress reported by carers often centred around their child's behavioural problems. Ongoing aggressive behaviour, even by very young children, challenged caregiving and caused injury to carers and siblings (41). These disparities affect Aboriginal and Torres Strait Islander carers who are more likely to be an unpaid carer for a person with a disability than non-Indigenous Australians (42). The impact of caring is more pronounced for Aboriginal and Torres Strait Islander carers and their communities due to the high levels of socioeconomic and health disadvantage (43).

Many Aboriginal and Torres Strait Islander people with disabilities engage in interventions from multiple government and non-government agencies with mixed success (44). Due to issues with access, transport and location of services, many families missed scheduled appointments, resulting in being labelled as "difficult to engage" and therefore impacting their ability to continue to gain support (44). Due to the importance of community and social support networks, relocating to be closer to service networks, even temporarily, is not considered beneficial for the carer or the person receiving care (41). Supports to address the barriers of low income and lack of transport are needed to make services more accessible for Aboriginal and Torres Strait Islander families.

Caregiving in Aboriginal and Torres Strait Islanders families is considered a family obligation and part of the culture (41). The term 'carer' may not resonate with the community, thus this cohort may not identify as carers despite significant care responsibilities (41). The differences in defining and conceptualising disability and other culturally inappropriate features of services are major barriers for Aboriginal and Torres Strait Islander people to access services (44). Generational trauma and historical mistrust of government institutions are also important barriers to be addressed (44).

### Culturally and linguistically diverse carers

Several carers who did not speak English as their first language reported that language was a significant barrier to accessing help (45). They reported to be often ignored at medical and support consultations, with little consideration given to their views, and Information about the patient was

frequently not shared with them (45). The language barrier also prevented some carers from accessing basic support such as assistance completing benefit forms, with many health services often unable to provide these carers with an interpreter, which perpetuated their feelings of marginalisation (45).

### Carers for people identified as LGBTIQ and carers identified as LGBTIQ

LGBTIQ caregivers, compared with non-caregivers, experience significantly higher levels of depression, disability, victimization, discrimination, and stress, placing them at heightened risk of poor health and quality of life (46). These social experiences impact upon the ability to provide or receive care in addition to stress that may arise from the provision of care and the care relationship (47). High rates of exposure to stressful events increase the risk of carers developing common mental illnesses of anxiety or depression, physical injuries, and physical health problems (47).

It has been documented in the literature that LGBTIQ+ carers and carers for people identified as LGBTIQ+ need supports that include an understanding of additional complexities, especially when mental health recovery in the LGBTIQ+ community may have many complexities, assistance in locating LGBTIQ+ friendly services and a non-discriminatory approach that demonstrated understanding of the context of fear, discrimination, vulnerabilities, and risks, that recognized gender diversity, and that did not assume all people are heterosexual (47). Carers wanted staff to ask how a person identified, to use gender-neutral forms, and to acknowledge relationships (47).

### Carers of older people

In Australia in 2018, only 27% of carers of older Australians reported to be satisfied with the quality of assistance received, 43% were satisfied with the range of organised services, while 33% did not know the range of services available (1). The most prevalent types of unmet needs identified for this group included financial (18%), physical (13%), and emotional support (12%), as well as additional respite care and support to improve carer health (12%).

In a 2015 study of unmet support needs of carers of older Australians, the majority of carers for older people were female, aged 45-75 years, were spouse carers and living with the care recipient, and not currently in the workforce (48). Approximately 93% had been providing care between 1 to 10 years and 57% received no formal care assistance (48). Among this group of carers, approximately one-third of those with any unmet support needs were in psychological distress (31%), compared with 17% of those with no unmet needs (48). Psychological distress was highest among females, those from a non- English speaking background, younger carers and those with lower levels of education (48). Carers with a care recipient who has dementia as their primary condition were at an almost two-fold risk of distress compared to those caring for a person without dementia (48). The number of health conditions of the carer is also strongly associated with the odds of psychological distress (48).

It has been identified that carers for older people need individually tailored services that address to specific illnesses or conditions of the care recipient, and be provided with situational management skills allowing the carer to feel they have more control and subsequently benefitting their well-being (17)

### Carers of people in palliative care

As people approach the end-of-life, those who care for them can incur increasing needs putting them at risk of physical strain and psychological distress; affecting their ability to care and their own health and well-being (14). Providing physical care (e.g. heavy lifting), lack of sleep, bureaucracy type issues and complicated medication regimes can lead to increasing fatigue for palliative carers (49).

The literature has identified a range of needs for carers of people in palliative care by palliative carers, including a description of palliative care, prognosis and treatment of the condition, pain and medication management, what to do in an emergency and nutrition (14, 50).

### Carers for people with disability

Around 80,000 people in the ACT live with a disability and 25,800 persons with profound or severe core activity limitation (1). The number of people with disabilities has increased significantly from 62,000 people in 2015 (1). According to Deloitte 2020, about 44% of primary carers spend more than 60 hours per week caring for individuals that have profoundly restricted core activity, compared to 39% who spend less than 10 hours per week caring for someone with mildly restricted core activity (2).

### Intellectual disability

Carers of people with intellectual disability were more likely to be struggling financially and have a high caring load, which were related to lower well-being (51). Carers of people with intellectual disability express uncertainty and fear about the future, including financial concerns, fear of inappropriate and what will happen when they are no longer able to provide care (52, 53). By mid-life, parents of people with intellectual disability had poorer health and mental health compared to other age groups (54, 52).

There is a significant gap in services supporting people with intellectual disability. In Australia in 2018, 52% of people with Autism Spectrum Disorders reported that their needs were not fully met (1). The need most likely not to be met was cognitive or emotional tasks (401%), followed by household chores (37%) and communication (34 %) (1). Quality care was hindered when providers find it challenging to communicate with people intellectual disability and do not know what to expect from informal carers (55).

A study has found that the most common coping style that carers for people with intellectual disability and psychiatric illness employed was religious coping (52). The use of positive reinterpretation and growth can help this group of carers lower levels of depression and stress symptoms (52). Other studies have shown that carers for people with intellectual disability require supports to address challenges regarding the changing nature of their child's condition (as they age), managing challenging behaviours, planning for the future, and preparing for the separation (56, 57, 53). Open communication and better info regarding diagnoses, procedures and medication regimes, potential side effects of medication, what to do in response to side effects, and lack of information about the dosing and duration of medication are required (45).

Concerns regarding quality and appropriateness of services and poor therapeutic relationship are featured in many studies (58-60, 56). Mental health services (including inpatient, outpatient and community services) were viewed as the least helpful, while specialist and disability services were reported as the most helpful (60). A study conducted in Australia about satisfaction of carers with support services showed mixed ratings were reported with psychological services (60). Finances, lack of insurance, lack of transportation, lack of knowledge (about the sorts of help available, system navigation and ability to question clinical decisions), lack of trust in care providers and not being taken seriously were the biggest barriers to help seeking (45, 59).

### Physical disability

To carers for people with physical disability, the provision of equipment to improve their child's mobility, respite care or transport to enable school attendance is helpful (61). Health care and social service providers should consider the functional impairment of each child when designing stress

reduction interventions for their caregivers (62). The scope and targets of social services and stigma reduction programs by the government should include caregivers and family members (62).

### Carers of patients with chronic conditions

#### Chronic Obstructive Pulmonary Disease (COPD)

COPD is a relatively unpredictable long-term illness with evident emotional consequences, creating challenges for carers (28). The role increases quantitatively (i.e. the number of hours caring) but also, in its complexity (28). The trajectory of the caring role in COPD is hard to predict which makes timely and repeated identification and response to unmet carer needs essential (28). Other needs include strategies to help carers manage the caring role and to manage feelings of helplessness and powerlessness, knowledge and strategies to support the patient, information about the future course of the illness, symptom control, emotional support for their patient (28). Support with knowing what to expect in the future and advance care planning are needed (28).

#### Multiple Sclerosis

The progression of MS and accumulated caring tasks caused certain interruptions in carers' employment and lifestyle (63). The unpredictable nature of MS was another challenge that MS carers found hard to deal with during their caring experiences, which also leads to uncertainty and anxiety towards future planning for carers themselves (64). Carers found it difficult and stressful to deal with the care-recipients physical, cognitive, behavioural and emotional problems (64). The literature has found that this group of carers require a number of supports including emotional and psychoeducational supports from health professionals (64) and programs that support joint participation of people with MS together with their caregivers in physical activity (65)

Many carers of people with MS note that one of the main challenges is when patients have difficulties accepting their diagnosis and adjusting to their disabilities. When this occurs, individuals with MS often only wanted assistance from their usual informal carer, rejecting help from others, placing increase stressors on the preferred carer to manage their role (64).

#### Co-morbidities

Co-morbidities often cause increasing difficulties/complications for care-recipients and as a consequence, increase their dependency on the carer, resulting in caregiving becoming more burdensome, requiring constant vigilance of multiple conditions, placing an increasingly high demands on carers' time (66). Carers described the challenges of receiving services from multiple providers and being 'bounced' between services which are misaligned with care-recipients' individual needs (66). Additionally, due to poor communication and coordination between different health care teams, information that carers did receive was sometimes contradictory, resulting in confusion (66). Coordination could be improved if clinicians dealt with care-recipients as a whole individual, taking into account their unique combination of conditions and how best to care for them holistically (66). Having a combined service for the multiple conditions and a designated professional coordinating all care-recipients' care (66).

#### Dementia

In Australia in 2018, the most common disabilities older people with dementia had include memory problems or periods of confusion (72%), restrictions in physical activities (66%), mental illness (54.9%) and chronic or recurring pain or discomfort (43%) (1). Carers are required to make decisions on behalf of the person they provide care for, which can be extremely challenging to justify care goal decisions for advance care planning whilst experiencing anticipatory grief for their loss (9). The challenges carers have to face when providing care for people with dementia are the complexity of the diseases, memory impairment, resistance to care, communication difficulties, presence of co-

morbidities of care recipients, role reversal, functional disabilities lead to carer burden (9). Additionally, approximately one third of family members caring for people with dementia report the care recipient has acted abusively towards them, which increases carer stress (67).

Carers said that they need sensitive and timely information about the natural progression of dementia, including family carer education of the dementia trajectory, symptoms, prognosis, social functioning, and impacts (9, 68, 69). A model of changing care goals and priorities reflecting the changing significance of care goals at different dementia stages, appropriate treatment options, how to care for someone with this condition (e.g. medication management and self-management), better support for uncommon dementia, how to communicate with the person with dementia to promote conversations about end of life and shared decision-making are needed (9, 70-72).

### Heart failure

Heart failure is a complex cardiac syndrome prevalent in an older population (73). Caring for heart failure patients through the disease trajectory presents physical and emotional challenges for informal carers (74). With a high prevalence of heart failure in people aged above 75 years, a consequence is that many of the carers are elderly themselves and therefore have their own health problems (75). Carers who perceived they had less control showed greater anxiety and poorer mental health (76). Supports to deal with patients' behavioural problems, managing dietary needs, monitoring signs and symptoms, obtaining health information from health-care providers and emotional support are needed (77).

### Carers of people with mental health issues

A 2016 University of Queensland Carer Survey reported that carers of people with mental health conditions were more likely than carers of people with physical conditions to provide emotional support to their care recipient and less likely to assist with practical tasks and activities of daily living (78). It has been demonstrated that people who are a carer for someone with mental health issues are more likely to be out of the work force, and those who were working, were more likely to work fewer than 16 hours per week and in lower skilled occupations (79). Approximately 26% of primary mental health carers had reduced their working hours to care, and a further 26% stopped working altogether (79). In Australia in 2012, primary carers of people with mental illness were significantly more likely to have a disability themselves, with around one-third of primary carers having a disability (37%), compared with 16% of people living in households who were not in a caring role (80).

Limited understanding and knowledge of mental illness and services can further contribute to carers' excessive stress levels (10). Caring during crisis was described as a terrifying experience not just because of the aggression but also because of the perception of abandonment by professionals (81). Inconsistent experiences with crisis response services and fragmented responses cause carers stress due to the uncertainty about the supports they can receive each time (82).

Studies have shown that carers of people with mental health conditions need interventions and support options addressing the challenging interpersonal dynamic of the caring relationship, the burden of caring and impaired carer wellbeing (83). Additionally, there is a need for increased involvement of carers in the treatment plan and crisis response, when the person they care for is experiencing psychosis and mental health crisis (84), including the provision of relevant information to carers, including general mental health knowledge and information on their relative's specific mental health status (84).

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