When caring ends:
Understanding and supporting
informal care trajectories

ARC Linkage Project Launch and Research Agenda

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Acknowledgements

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1 Understanding Trajectories out of Caring

Over 2.65 million Australians are reported to provide informal, unpaid, care to a family member or friend who lives with a disability, long-term health condition, terminal illness, or frailty[1]. At some point, all caring relationships will inevitably come to an end. Research has documented the impacts and 'aftereffects' of caring for carers themselves. But how carers experience trajectories out of caring are not well understood. In this research program we aim to generate a knowledge base on how, why, when, and for whom caring ends. This includes the various social and economic factors that can shape experiences before, during, and after caring. Our research will examine trajectories out of caring across a range of care relationships, life stages and contexts, foregrounding the voices and experiences of carers themselves. In doing so we aim to inform improvements in the delivery and provision of support and entitlements, help carers plan and prepare for sustainable futures, and improve recognition and visibility of current and former carers.

What is a care ending?

Every carer's trajectory inevitably entails an ending. Here, we use 'care endings' as a term to describe the full range of contexts and experiences in trajectories from the 'active' phase of caring to the 'post-caring' period[2]. Research has identified various pathways out of caring – for example, relinquishing full-time care when the care recipient is admitted into supported accommodation; when the care recipient's condition improves; or when a carer

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[1] ABS (2019) Disability, ageing and carers, Australia: summary of findings, 2018, https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/2018

[2] Kirby, E., et al. (2022). (How) Will it end? A qualitative analysis of free-text survey data on informal care endings. International Journal of Care and Caring, 6(4): 604-20.

becomes bereaved[3,4,5,6]. A care ending may be the transition from full-time caring to less intensive but continuing care relationships, where caring responsibilities gradually decrease. Or a care ending may happen more abruptly, following a definitive event. Pathways out of caring are not always clear or concrete. They can involve ongoing commitment or duties, and connection to a carer identity[4,7].

All trajectories out of caring require carers to adapt, to transition, and to negotiate this pathway to the next chapter of life. Sometimes a care ending may reflect a lack of choice or autonomy – for example where care needs increase to a point where formal care is required. Sometimes carers may have concerns around the quality of alternative caring options, while others worry about what will happen to the person they care for, or themselves, after caring ends[2]. A considerable proportion of carers will experience forms of burden and suffering through trajectories out of caring. The health and social impacts that people experienced by former carers are wide-ranging, including poor health, loneliness, limited employment opportunities, and financial precarity. Yet, support for former carers is lacking and policy, services, or entitlements are more focused on current carers, rather than those 'post-caregiving'. As such, there is an urgent need to recognise the ways in which care endings are experienced to understand how to better support and prepare carers for life beyond caring.

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[3] Davies, S., & Nolan, M. (2004) 'Making the move': relatives' experiences of the transition to a care home. Health & Social Care in the Community, 12(6): 517-26.
[4] Cavaye, J. & Watts, J. (2016) Former carers: issues from the literature. Families, Relationships & Societies, 7(1): 1410-57.
[5] Watts, J., & Cavaye, J. (2018) Being a former carer: impacts on health and wellbeing. Illness, Crisis & Loss, 26(4): 330-45.
[6] Larkin, M., & Milne, A. (2021) Knowledge generation and former carers: reflections and ways forward. Families, Relationships & Societies, 10(2): 287-302.
[7] Molyneaux, V., et al. (2011) Reconsidering the term 'carer': a critique of the universal adoption of the term 'carer'. Ageing & Society, 31(3): 422-37.

1.1   Approach to understanding how caring ends: Pilot Study

In July to November 2022, the research team, in collaboration with Carers NSW, conducted a pilot research study. We wanted to find out more about how to better support and prepare carers for life beyond caring. Our pilot study comprised qualitative focus group discussions with carer representatives and front-line carer support staff, from NSW, Australia. This method allowed for in-depth exploration of real-world views and experiences, to generate discussion on important topics and issues that require research, policy, and practice attention. By hearing the perspectives of those with first-hand experience as carers (n= 10) or those working to support carers (n=6), we can develop ideas, in association with existing research, to establish a research agenda that will guide our overall research program.

We conducted four focus groups, one with young carers, two with current and former carers, and one with professional carer support staff. Of the carers, 3 identified as current carers, 5 as former carers, and 2 as both current and former. Participants were recruited via carer networks, via email flyer, targeted email, or telephone call. The focus groups were conducted online, using Zoom video software, and lasted approximately 90 minutes. A focus group guide was used to facilitate discussion allowing flexibility to discuss topics deemed relevant by participants. With participants' consent, data were digitally audio-recorded, transcribed verbatim, and then coded individually by two researchers, using thematic analysis (where we identified patterns in the data, developed themes that encompassed experiences among participants, and considered outlier cases[8]). From this analysis, we identified a series of key focus areas related to trajectories out of caring, outlined below. Each of the areas is accompanied by excerpts from the focus groups and a visualisation developed by a professional designer who worked with the research team to depict participants' discussions. Once these visuals were drafted, the research team consulted four of the carer representatives who participated in the focus groups, to talk about the visuals, make sure they reflected carer experiences, and were tweaked according to carers' feedback and suggestions.

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[8] Green, J. et al. (2007) Generating best evidence from qualitative research: the role of data analysis. Australia & New Zealand Journal of Public Health, 31(6): 545-50.

2   Key focus areas

2.1   Financial and work impacts

All participants noted the financial and work challenges expected or experienced following a caring role. Participants worried about how to re-enter the labour market, often after significant time caring (according to the National Carers Survey, the average time spent in a caring role is almost 13 years[9]). Some felt they were 'behind' in their career or had missed out on work opportunities such as promotions; as a result, carers felt pressure to 're-skill' or 'up-skill' after their caring ended to make ends meet. Fears about financial precarity were exacerbated by the need to reduce paid work to manage caring, with less opportunity to build savings or superannuation. As a means to ensure financial stability, participants expressed a need to secure paid employment after caring ended, but managing this transition was difficult and carers did not feel well-supported.

> *There needs to be a transition program that says 'you've just come out of caring we'll still support you and you can go and look for work'… it's very hard to live on a pension with the cost of living so high. Why are we always forgotten?*

In terms of employment after caring ended, some carers wanted to pursue paid work that mobilised the skills they had gained as a carer, while others wanted to join workforces far removed from the caring professions.

> *I know there are programs, but a lot are about using your carer skills to get back into the workforce. A lot of carers don't want to go into providing care. I do a job that has nothing to do with care.*

Gender and age also shaped perspectives on financial and work impacts, reflecting socio-cultural norms that caring is a highly feminised role that can leave women disproportionately vulnerable to financial insecurity after caring ends[2,6,10]. Older carers also felt financially precarious given their limited retirement funds.

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[9] Carers NSW (2022) National Carer Survey Highlights. https://www.carersnsw.org.au/uploads/main/Files/3.Resources/Policy-Research/Carer-Survey/2022_National_Carer_Survey_National_Highlights.pdf
[10] Ehrlich, U., et al. (2020) What comes after caring? The impact of family care on women's employment. Journal of Family Issues, 41(9): 1387-419.

When Caring Ends — Financial & Work Impacts

2.2   Social and Cultural Expectations

Experiences of how caring ends are shaped by social and cultural norms, values, and expectations which impact upon people's capacity to sustain caring, or to pursue meaningful life beyond caring. Some felt greater expectations, a sense of duty, or obligation to continue caring; *'you should, you better, you must'.*

No one ever asked me if I wanted to be a carer, they just assumed I would do it, or, I had to try to pick up the pieces of systems not working.

I've looked at moving out, at going away on a holiday. But then I feel guilty. I get jealous of my brother because he was able to move out, to go away every week and I'm just stuck.

Social constructs of care as a 'labour of love', marital vows that include 'in sickness and in health', 'til death do us part', and social norms related to filial piety and intra-family solidarity all play into expectations of care[2,11,12]. As a result, some care endings can be uncomfortable or taboo, even considered social unacceptable. Social expectations around care endings can be intensified by the lack of perceived suitable care alternatives.

We're expected to take care of our elders at home. So, there is some kind of guilt and taboo or 'what are our friends and family gonna say', kind of thing.

Family expectations, including related to gender, age, and culture, also impact on a carer's capacity for respite, or opportunities outside of caring.

I've realised that I probably would have been given more opportunity to go out and have a bit of respite if it weren't for this cultural expectation to always be there, always care. Taking a break or leaving means you don't love them.

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[11] Egdell, V. (2013) Who cares? Managing obligation and responsibility across the changing landscapes of informal dementia care. Ageing & Society, 33(5): 888-907.

[12] Keating, N., et al. (2019) Life course trajectories of family care, International Journal of Care and Caring. 3(2): 147-63.

WHEN CARING ENDS
SOCIAL & CULTURAL EXPECTATIONS

SOCIAL

THERE'S JUDGEMENTS COMMUNITY PUTS ON A CARER IF THEY STEP AWAY

I FELT A SOCIETAL ≡ PUSH TO CARE FOR MY MUM & EVEN DAD

EVEN THOUGH GIVEN UP MY RELATIONSHIPS & CAREER, THERE'S STILL A SOCIETAL & FAMILY VOICE SAYING YOU SHOULD LOOK AFTER THEM

THERE'S A CULTURAL EXPECTATION TO ALWAYS BE THERE TO CARE

THERE'S NOT MUCH OPPORTUNITY FOR RESPITE. TAKING A BREAK OR LEAVING MEANS YOU DON'T LOVE.

CULTURAL

WHAT ARE OUR FRIENDS & FAMILY GOING TO SAY?

I GET JEALOUS OF MY BROTHER. HE WAS ABLE TO MOVE OUT... I'M STUCK

WE'RE EXPECTED TO TAKE CARE OF GRANDPARENTS AT HOME IN CHINESE CULTURE

IT'S KIND OF TABOO

THERE'S A RESPONSIBILITY MY MALE SIBLINGS & COUSINS DON'T GET!

PUTTING GRANDMA INTO AGED CARE, THERE'S GUILT, ESPECIALLY CULTURALLY

I FEEL GUILTY GOING AWAY FOR A WEEKS HOLIDAY

BEING THE OLDEST DAUGHTER, IT'S EXPECTED YOU CARE & BE A GOOD ROLE MODEL

GENDER

2.3 Young carer perspectives

Transitions out of a caring role can be challenging for young carers, who tend who experience higher levels of psychological distress, social isolation and financial distress compared to other carers[13] The young carers in our study identified a range of issues in navigating life in and beyond the caring role. Financial and work-related precarity heavily featured the discussion. Participants felt that they could not rely on family for support or financial assistance, particularly relative to their peers. They also noted the pressure of expectation that they would return to caring in circumstances where they might be needed in the future.

I know that my friends, if they need something, their parents will just pitch in, like… "I'll give you 100 bucks like this week", and stuff like that. I can't ask my mum for that.

The young carer participants struggled to be taken seriously as 'carers' compared to other young people who were building career opportunities. One participant said that people did not understand caring to be '*a real adult job*'. Employment or studying needed to be fit in around caring duties; feeling like they could not prioritise their own future opportunities was a concern, as was the pressure to do 'everything':

I look back and I go, what the hell was I doing? I'm really proud of myself. But I know at that time I thought I needed to do more and more to prove to myself that I can keep up with everyone else as well as being a carer.

The young carer participants also highlighted issues of recognition and visibility of caring in the community more broadly. The felt stigmatised as 'drop outs', despite the significance of their caring duties and skills. They also felt social pressure to 'be young', and this was most evident in trajectories out of caring: young carers felt like they had fallen behind their peers in terms of work and family life, whilst also less able to 'enjoy their youth'. Instead, the idea of life 'post-caring' was filled with questions and uncertainties.

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[13] Addo, I., et al. (2021) Young carers in Australia: Understanding experiences of caring and support-seeking behaviour. Australian Social Work. Doi: 10.1080/0312407X.2021.1971271

WHEN CARING ENDS
YOUNG CARER PERSPECTIVES

WE'VE MISSED OUT ON SKILLS THAT WE NEED NOW

INSECURITY

DO I KEEP STUDYING AT UNI?

FEAR OF WHAT'S NEXT...

WHERE DO I GO?

I COULDN'T ASK MOM & DAD FOR HELP BECAUSE THEY ARE UNWELL

I MISSED OUT ON A LOT OF SCHOOL DUE TO THE CARING ROLE

AM I HOMELESS AFTER THIS?

I HAVE SKILLS PEERS MY SAME AGE WOULDN'T HAVE LIKE MANAGING THE HOUSE

I'M NOT LIKE MY PEERS...

IT WOULD BE NICE TO HAVE SOMEONE TO CARE FOR US

NAVIGATING ONE'S FUTURE...

BIG QUESTIONS

IT CAN BE DIFFICULT TO BRING UP STUFF THAT IS HAPPENING

BUILD MY LIFE?

HOW DO I FIND MY OWN INDIVIDUAL IDENTITY?

STRESSES & CHALLENGES ASSOCIATED WITH EVERYDAY CARING

JUGGLING TO KEEP UP WITH BEING A YOUNG PERSON

I'M YOUNG & WANTING TO WORK OVERSEAS ONE DAY

WHAT AM I GOING TO DO NEXT?

I FEEL GUILTY JUST RESEARCHING COS I SHOULD BE HERE FOR MY FAMILY

2.4 Recognition and visibility

There were many experiences of a lack of recognition and visibility discussed in the focus groups. Several participants felt invisible as carers, and this lack of recognition shaped their transitions out of caring.

> *If you could just click your fingers and change the world, you could change people's perceptions, what would you have the governments and society, the community, your peers kind of recognise about caring? That we exist, full stop. That we're here, actually see us.*

Some participants also felt that the skills developed in their caring roles were not recognised or valued in society. This made trajectories out of caring difficult.

> *I was applying for homes to move into. It was so difficult because they would ask 'what's your tenancy history?' I don't have one, but as a carer I've had to manage a household, finances, responsibilities, retirement, and superannuation – this should make me an ideal tenant.*

Former carers tend to be less well-reflected in policy, and service support and entitlements focus primarily on 'active' current carers[6,14]. Unsurprisingly, participants spoke with concern and resentment about the lack of dedicated support for former carers, stating that they felt *'very much forgotten',* or that *'it would be nice if we could be considered valid enough to get support'.* One participant said that they felt '*cut off'*, and that '*the time that carers have the most pressing need for support is when they are no longer carers'.* These and other concerns draw attention to the potential for carers to experience loneliness and social isolation, and highlight the importance of focused attention on improving mechanisms of support whereby carers can feel recognised and valued, as they move out of their caring role.

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[14] Orzeck, P., & Silverman, M. (2008) Recognizing post-caregiving as part of the caregiving career: implications for practice. Journal of Social Work Practice, 22(2): 211–20.

WHEN CARING ENDS
LACK OF RECOGNITION & VISIBILITY

SERVICE &
COMMITMENT

OUR FORGOTTEN HEROS
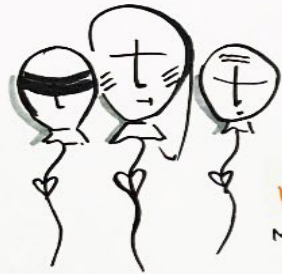
WE EXIST
MILLIONS OF US
ACTUALLY
SEE US

WHEN OUR
CARING ROLE
ENDS...
WE ARE CUT OFF

I FELT
INVISIBLE
AS A CARER
BUT AS A FORMER CARER,
I HAD NO IDEA
HOW MUCH MORE
INVISIBLE I COULD GET

CARERS

HOW DO WE
RECOGNISE &
ACKNOWLEDGE
CARERS
CONTRIBUTION
TO OUR SOCIETY ?

LACK OF EMOTIONAL
SUPPORT

RECOGNISE INFORMAL
CARE

NO RECOGNITION
OF THE ROLE
FOR THE LAST
10 YEARS

YOU NORMALLY GET A
LETTER FROM
GOVERNMENT SERVICES
TO SAY
YOU'VE BEEN TERMINATED

2.5 Ongoing roles and impacts

For some participants, caring came to an end abruptly and was marked by an event (such as a person moving to another region for ongoing care, or a person's death). In these circumstances carers often had little time to prepare for a new 'post-caring' identity. For others, endings were more '*ambiguous*' and '*complicated*'. For example, in circumstances like the one explained below:

> *When my child gets quite well, then my caring role finishes. But then when they get unwell the role comes back. It's not something that's sort of final, it's something that sort of quite ambiguous, and it's something that changes depending on the relationship.*

Trajectories out of caring are often not linear, clear-cut, or straightforward: they can involve ongoing commitment, duties, and ongoing carer identity[6,7,15].

> *Because Mum is moving into permanent care, I don't get that [government support] package. Even though I'm still providing her emotional support, support with all the administrative stuff … It's a lot, it's really time consuming, helping mum to navigate those systems. It's transitioning the role and there's still support I need…*

As the 'work' of caring recedes, the emotional aspects of being a carer may endure. Several participants referred to caring as an ingrained part of their identity that could never simply 'end'. For these participants, caring was an important part of their identity.

> *That's who I am. I have grown with this. So I don't know how you could stop [being a carer].*

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[15] Cavaye, J. (2006) Hidden Carers, *Vol 3*. Edinburgh: Dunedin Academic Press.

WHEN CARING ENDS
ONGOING ROLES & IMPACTS

I MOVED AWAY FROM **HOME** BUT MY **CARER ROLE HASN'T ENDED**

I'M STILL PROVIDING **EMOTIONAL** SUPPORT & **MENTAL HEALTH SUPPORT**

CARE ENDINGS DON'T HAVE A **FINALITY**, WHEN MY SON GETS UNWELL, THE **CARER ROLE** COMES BACK.

IMPACTS CAN BE **ONGOING**...
2 DAYS LATER
1 YEAR LATER
10 YEARS LATER

CARER IDENTITY DOESN'T SEEM TO **END**

THE WAY OF BEING CONTINUES & AFFECTS OTHER RELATIONSHIPS

I ACT AS A CARER TO **MY FRIENDS** & IN **RELATIONSHIPS**

IT'S NOT REALLY **MY ROLE** BUT I DON'T REALLY **KNOW WHAT** ELSE TO DO

I'M FINDING I'M CARING **FOR MY PARTNER** WHEN THEY DON'T NEED THAT **CARE**

IT'S A KIND OF **IDENTITY CRISIS**

2.6   Identity, loss, and hope

A key aspect of trajectories out of caring was the complex balance of experiences of loss and hope amidst shifting identity. All participants talked about the need to make sense of changing relationships and expectations, and how challenging this could be. As we have also explored in previous research[2], some participants worried about the future, but understood that an end to their caring role was inevitable:

> *I'm sad and I'm scared about the thought of not being my child's carer anymore. I understand it needs to happen, and it will happen and that's great, that's healthy, that's normal. But it's going to be a huge loss… most of my identity is as a carer. I'm proud of it. I think I've done a great job. And I've built my jobs around caring. So I'll also have to adjust…*

In this way, transitions out of caring entailed several forms of loss: of self, of identity, of a loved one, of a role. This has been described as a 'post-caring void'[16]. For some, experiences of loss were exacerbated by a lack of preparation or anticipation, especially in relation to support and counselling around grief.

> *Nobody prepares you for the carer ending process and you're kind of left in the lurch like this about finding grief processes, counselling services or support groups on your own terms.*

At the same time, feelings of hope and hopefulness were present across the focus groups. Carers maintained a sense of hope – for their own future and opportunities, and for those of the people they care for. Participants talked about the importance for carers to be determined, resilient, optimistic, and flexible, and that developing these traits helped them through and beyond their care ending. So was the need to adjust to different and new day-to-day priorities and activities.

> *I've noticed there's that sudden... Like I wouldn't say freedom, but I do have a little bit of extra time. And so it's just reestablishing what that time is and what I can do with that time. And that's been… it's been interesting. It's been great.*

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[16] Larkin, M. (2009) Life after caring: the post-caring experiences of former carers. The British Journal of Social Work, 39(6): 1026-42.

WHEN CARING ENDS
IDENTITY, LOSS & HOPE

HOW DO I ADJUST?

HOW DO I MOVE OUT OF A CARING ROLE?

HOPE FOR THE FUTURE?

NO-ONE PREPARES YOU

THERE WASN'T MUCH IN TERMS OF SUPPORT

A LOT OF SERVICES STOP WHEN YOU CEASE TO BE A CARER

FORMER CARER

POST-CARE VOID

WE DIDN'T RECEIVE ANY INFORMATION AFTERWARDS

MY SON GOT AN NDIS PACKAGE BUT WHAT SUPPORTS ARE AVAILABLE TO ME?

MULTI-FACETED LOSS

CONSUMED IN CARING ROLE

LOSS OF LOVED ONE

YOU'RE IN LIMBO

IT'S LIKE YOU ARE DROPPED ... THERE'S NO SUPPORT FOR ME... AS A CARER...

IDENTITY AS A CARER

SELF & LIFE

BECOME SO ISOLATED, ALONE

LEFT FINDING GRIEF PROCESSES COUNSELLING OR SUPPORT GROUPS ON OWN TERMS

LOST TOUCH WITH FRIENDS, INTERESTS, WORK

MENTAL HEALTH IS VERY VULNERABLE

I DON'T KNOW WHO TO ASK

WHAT AM I GOING TO DO WITH MY TIME?

2.7 Ideas for a Better Future

Thinking about the future raised a range of questions: *What happens next? Will they be ok? Am I homeless after this? Where do I go? Who will make sure they are looked after? What happens to me?* There was a sense of uncertainty about the future, yet most participants described how they understood that change (and adapting to change) was a core part of the caring experience. For example, several participants stressed the importance of preparation:

> *I'm now using my previous experience of care ending to set myself up for an easier time when my current caring role ends. It's going to happen at some point, it's something we can plan for, so let's plan for it. It might be an awful time, but let's make it a little bit less awful.*

Participants offered several ideas for how to improve trajectories out of caring. For some, a better future involved support to help carers return to everyday life 'pre-caring' (e.g., work and social life). For others, feeling supported to try new things was important. Ideas for a better future for carers were often intimately tied to better futures for care recipients. Feeling confident that future care needs would be met, and that there were viable quality care options to turn to, was key. Improving support systems and services to help carers through the 'post-caring void' was also talked about frequently. Experiences of feeling '*left to flounder*' prompted several suggestions where existing services could improve their awareness of trajectories out of caring.

> *In the care ending process you're left in the lurch, you need space and support to find out about grief processes, counselling services or support groups on your own terms.*

Having more opportunities to talk about how caring ends, with families and friends, and with other carers with lived experience, was suggested. As was more focus in government services on 'futures planning' and support. Participants suggested service support and activities such as a helpline for carers who need help to plan, community mentoring, online resources tailored for trajectories out of caring, workforce re-entry support specifically for former carers, and a dedicated transition program. Finally, the importance of policy that reflects the needs of former carers was raised by several participants.

WHEN CARING ENDS
IDEAS FOR A BETTER FUTURE

MENTOR

DOULA FOR END OF CARING

SOMEONE THERE FOR YOU

TEACH PEOPLE HOW TO BE GOOD INDIVIDUALS

INFO ON IMPORTANCE OF SELF-CARE

A NUMBER TO CALL SPECIALISED IN CARER TRANSITIONS OUT OF CARING

THANK YOU for your CARING SERVICE

SUPPORT WORKERS FOR A SHORT TIME LIKE NDIS RECIPIENTS

POLICIES & SERVICES COLLABORATING

NDIS > CENTRELINK > HOUSING

DEDICATED TRANSITION TEAM

WORKFORCE RE-ENTRY PACKAGES

PLANNING WILLS & END OF LIFE

FINDING A HOME

SKILLS TO PIECE YOUR LIFE TOGETHER

INCLUDING RELATIONSHIPS

MENTAL HEALTH SUPPORT

SUPPORT HUBS INFO & EDUCATION

GRIEF SUPPORT

$ FINANCIAL PLANNING

MENTOR PROGRAMS

FUTURE PLANNING

ACCESSIBLE RESOURCES IN DIFFERENT LANGUAGES

3 Next Steps

3.1 Launching our new 3-year research project

As we have shown above, our pilot study has highlighted a range of priorities for further research to help better understand and improve support for carers before, during, and after their caring ends.

We are excited to launch our new 3-year project, funded by the Australian Research Council, and in partnership with Carers NSW and Carers Victoria. This project will build the required evidence base on which to develop and respond to these research priorities. Our research will use a combination of methods to foreground carers' voices, while also engaging with a range of stakeholders across the government and not-for-profit sectors. The mixed-methods research design brings together statistical analysis of the National Carers Survey, in-depth qualitative interviews with current carers, workshops with former carers, and focus groups with key stakeholders. These methods will provide unprecedented access to experiences of care endings, over time and across contexts of relationships, conditions, and service settings, generating important foundational evidence.

Our research has three parts:

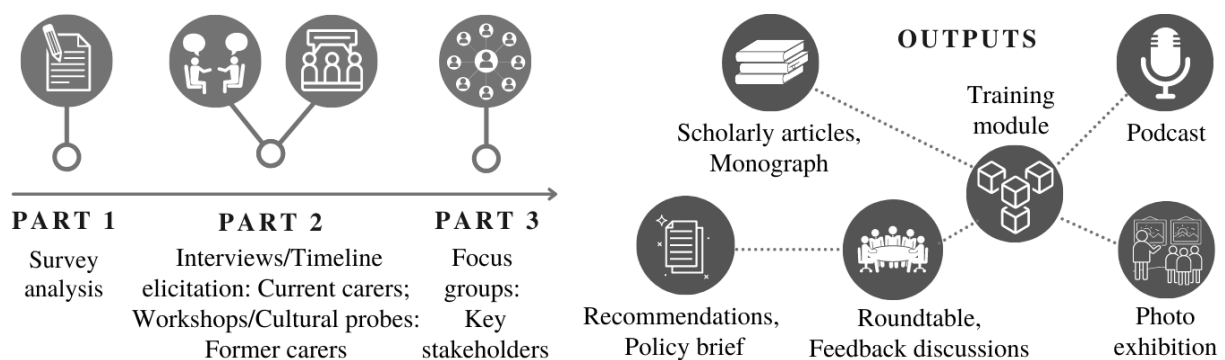### Part 1: The socio-demographic correlates of care endings

In Part 1, we will analyse data from the National Carers Survey, to understand the opportunities and challenges faced by carers before, during, and after their caring ends. This includes thinking about how to improve carers experiences of work, relationships, and social participation. We will examine how individual socio-demographic contexts impact upon these perspectives and experiences.

Part 2: The meanings and experiences of care endings

In Part 2, we want to understand how carers experience and make sense of their trajectories out of caring, including: carers' strategies for sustaining and/or ending caring, carer's experiences of loss, and carers' experiences of support. We will how social and cultural expectations shape pathways out of caring. We will also look at how former carers experience life beyond their caring role.

Part 3: Supporting trajectories out of caring

In Part 3, we will focus on how to support trajectories out of caring, across sectors and services. We will hold focus group discussions with key professional stakeholders and carer representatives, to think about what improvements can and should be made, and how to achieve these improvements. We will include perspectives from a range of organisations that support carers (e.g., support and advocacy services, healthcare, housing, family support, social care). Key to this is generating knowledge on how care endings are understood within current policy and practice.

PART 1
Survey analysis

PART 2
Interviews/Timeline elicitation: Current carers; Workshops/Cultural probes: Former carers

PART 3
Focus groups: Key stakeholders

OUTPUTS

Scholarly articles, Monograph

Training module

Podcast

Recommendations, Policy brief

Roundtable, Feedback discussions

Photo exhibition

3.2   What's next?

Over the coming months, we will begin to recruit participants for our research. This includes carers at all stages of their caring journey. We will advertise for volunteers (who will be compensated for their time) via our partners, Carers NSW and Carers Victoria – project flyers and announcements will be circulated through their memberships and mailing lists.

Our research will produce a range of outputs, including public-facing events and resources, as well as academic work. We will hold Roundtables and Feedback Sessions with carers, and public sector and industry stakeholders. We also develop Policy Briefs and Recommendations, that will help advocate for improvements to policy and support services. We will also develop a suite of resources to help support trajectories out of caring, including an online training module, and podcast.

In this project, we aim to improve the lives of carers, and help to normalise talking about, and preparing for, caring to come to an end. We understand how hard carers work to sustain their caring, and the value carers bring to our communities. Learning from the experiences of carers – who have developed skills, capacities and insights that remain under-recognised or undervalued – is of considerable benefit in informing responses to care needs in the future, including ensuring that recipients of care, wherever relevant, remain well-supported.