

Carer Knowledge Exchange

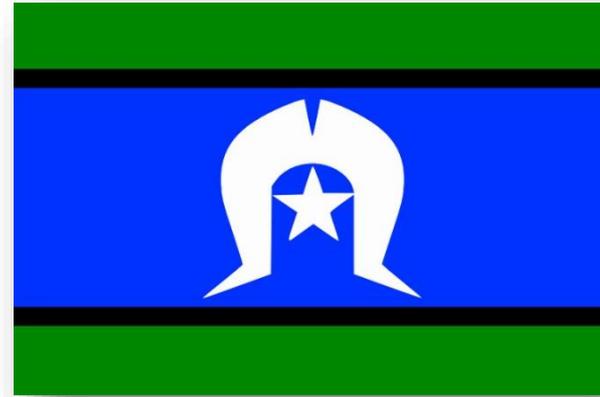
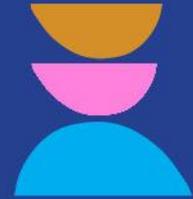
Bringing together carers, former carers, researchers, policy makers and practitioners to share their knowledge and learn from each other.

carerknowledgeexchange.admin@uts.edu.au

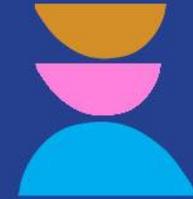
CONNECTING RESEARCH TO PRACTICE



Proudly supported
by the NSW Government



The Exchange team would like to acknowledge the Traditional Custodians of this Land. We would also like to pay respect to the Elders both past and present and extend that respect to other Aboriginal people present today.



About the Carer Knowledge Exchange

Connecting research to practice

The Carer Knowledge Exchange is a partnership project delivered by **Carers NSW** and the **Institute for Public Policy and Governance** at the University of Technology Sydney, proudly funded by the NSW Government. The project brings together carers, former carers, researchers, students, decision makers, professionals and service providers to share their knowledge about carers and learn from each other with the aim to improve outcomes for carers across Australia. It features an interactive digital platform and a range of events and opportunities. Find out more below.





What is the purpose of the Carer Knowledge Exchange?

The Carer Knowledge Exchange aims to provide a central platform for knowledge about carers to be shared and developed. We define 'knowledge' as a combination of research evidence, practice-based expertise, and lived experience.

The Carer Knowledge Exchange has been designed to:

- BUILD on the experience and expertise of both partner organisations to expand the carer evidence base
- TRANSLATE the carer evidence base for a range of audiences to improve carer-focused policy making and practice
- EXPAND researcher, sector and community awareness and use of the carer evidence base through better access to published research as well as engagement, networking, learning and collaboration opportunities

Our key priorities are:

- Putting carers at the centre: All our work is informed by carers' needs and experiences.
- Knowledge translation: Making useful, reliable evidence available to more people to improve outcomes for carers.
- Sector engagement: Actively connecting with a wide range of audiences to continually strengthen and expand the project.
- A focus on outcomes: Ensuring that our work is relevant, effective and ultimately improves life for carers.
- Open access to research: Providing research based information in accessible language and formats to include a wide audience.
- A partnership approach: Carers NSW and IPPG work together, and with other key stakeholders and advisory groups, to deliver the project.



The CKE addresses the NSW Carers Strategy, 2020-2030:

Priorities And Key Themes

-  **PRIORITY 1:** Carers have better access to information, services and supports
-  **PRIORITY 2:** Carers will be recognised, respected and empowered
-  **PRIORITY 3:** Carers have improved financial wellbeing and economic opportunities
-  **PRIORITY 4:** Carers have better health and wellbeing



Facts about carers

A carer is any individual who provides care and support to a family member, child or friend who lives with a disability, mental illness, alcohol or drug dependency, chronic condition, terminal illness or who is frail due to age. There are more than 2.65 million carers across Australia.

Many carers don't use the word 'carer' to describe themselves. However, each one of us is likely to become a carer for a family member or friend at some stage in our lives. Carers come from all walks of life, cultural backgrounds and age groups.

For many, caring is a 24 hour-a-day job with emotional, physical and financial impacts that can also affect their participation in employment, education and community activities.

* Australian Bureau of Statistics 2018 Survey of Disability, Ageing and Carers

** Deloitte Access Economics 2020 The value of informal care in 2020

*** Carers NSW 2020 National Carer Survey

1 in 10
Australians
are aged 25 years and under*

260,700
carers

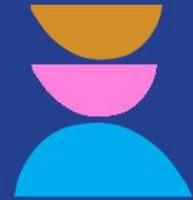
8
million
hours

is a carer*

of care are provided by Australian carers every week*

\$77.9 billion
is how much it would cost every year to replace carers**

1 in 3
carers are highly socially isolated***



CONNECTING RESEARCH to PRACTICE

LAUNCH of the CARER KNOWLEDGE EXCHANGE DIGITAL PLATFORM

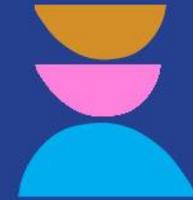




Carer Knowledge Exchange Research Library

The Carer Knowledge Exchange Research Library is a collection of recent Australian publications and other resources that contain reliable research about family and friend carers, including grey literature publications. It is constantly being added to, and users can submit their own research publications or suggest other resources via the digital platform.

Aside from functioning as a database for carer-related research, each publication features key research translation elements, making this knowledge accessible to all our key audiences. This offers researchers a chance to extend their reach and improve community engagement with this work.



Family perceptions of benefits and barriers to first episode psychosis carer group participation



Family perceptions of benefits and barriers to first episode psychosis carer group participation

Published Date: 12.3.2014

Author/ Author's

Melissa Petrakis, Julia Oxley, Hannah Bloom

Suggested citation (APA 7th edition)

Petrakis, M., Bloom, H., & Oxley, J. (2014). Family perceptions of benefits and barriers to first episode psychosis carer group participation. *Social Work in Mental Health*, 12(2), 99-116. <https://doi.org/10.1080/15332985.2013.836587>

Long Summary

This study evaluated an open-ended family group intervention within a public adult mental health service. Interviews were conducted with: (1) carers who continually attended; (2) carers who attended once only; (3) carers who never attended; (4) case managers and (5) early psychosis clinicians. Benefits to group participation included: reduced isolation, sense of collective experience, opportunity to feel heard, reduced stigma and shame, increased knowledge about mental illness, and enhanced skills in supporting the care recipient. Barriers included: competing family and work commitments, applicability to own experiences of caring, discomfort with social situations and revealing and hearing emotions, and a belief that experiences are private. While attending the group increased knowledge, the benefits most emphasized were in the social connection with other carers and sharing one's story in a safe and reassuring environment.

Key Messages for Carers

- Carers can learn what benefits can be gained from participating in group-based education and support programs
- Carers can gain insight into the many barriers carers may face to accessing group-based education and support programs

Key Messages for Policy Makers

- Policy makers or practitioners can learn what to include in programs to resource carers through education and support
- Policy makers and practitioners can learn what the strengths and limitations, barriers and opportunities are in such programs

View Publication

Theme: Developing skills and knowledge

Sub-theme: Group learning

FIRST-EPIISODE PSYCHOSIS

CARER EDUCATION



Carer Knowledge Exchange Events

- Delivery of three interactive webinars per year (February, August, November), designed to bring together carers, researchers, practitioners & policy makers to learn, connect and collaborate via presentations and facilitated discussion.
- An annual Research Incubator event (May), designed to identify gaps in knowledge, research, and policy to inform future research directions and policy development and implementation.
- These events are designed for anyone with an interest in connecting carer related research to practice, including carers and former carers; academic and not-for-profit researchers; research students with an interest in carers or associated fields; policy makers and practitioners; and people who receive care.



TRANSITIONS in the CARING ROLE

INSIGHTS from a REGIONAL COMMUNITY

TROUBLES with SCHOOL'S PERSPECTIVE
"THE BOYS DID THIS..."

CONDUCT LETTERS SUSPENSIONS

IF YOU'RE not HAPPY with what's GOING on

DEALING with the N.D.I.S.



the SHIFT at SCHOOL WORKING with their BEHAVIOURS and NOT on THEM

HAVE a PLAN B

SPEAK to your LOCAL M.P.



CARING for IDENTICAL TWIN SONS with LEVEL 3 NON-VERBAL AUTISM

STAY STRONG & PUSH for what YOUR CHILD NEEDS

IN-DEPTH CARER EXPERIENCES SHARED THROUGH SURVEY RESPONSES



PROSPECTS for LIFE AFTER CARING

LIVED DISCRIMINATION of LGBTQ+ CARERS make them MORE LIKELY to REMAIN HIDDEN CARERS

TRANSITIONS are MUCH MORE MESSY and FLUID

TAKING CONTROL TOOLKIT

EXISTING RESEARCH in PALLIATIVE CARE POINTS to

PARTICULAR BARRIERS for TRANS & GENDER DIVERSE PEOPLE

HIV & AIDS

BARRIERS ACCESSING SUPPORT

↓ LEVELS of SATISFACTION with SERVICES

↑ LEVELS of DISTRESS for SIGNIFICANT OTHERS / CARERS

TRANSITIONING OUT of CARING

HOW EXPERIENCES of CARING MIGHT END

"I'D LOVE to HAVE MY OWN LIFE AGAIN"

"CARE DOESN'T STOP, IT JUST CHANGES"

"WHAT if SOMETHING HAPPENED to ME?"

IT'S TIME for ME to SWITCH ROLES

ENDING my ROLE as a CARER

PRACTICAL, FINANCIAL & EMOTIONAL CONSIDERATIONS WHEN PLANNING for an END of LIFE in LGBTQ+ COMMUNITIES

FAILURE to CONSIDER NEEDS of LGBTQ+ CARERS & SUPPORT NETWORKS

the NEEDS of LGBTQ+ PEOPLE DIFFER:

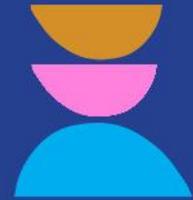
WHO we CONSIDER to be OUR FAMILY

MENTAL HEALTH & TRAUMA at HIGHER RATES

LGBTQ+ CARERS DENIED SUPPORT "you're NOT NEXT of KIN"

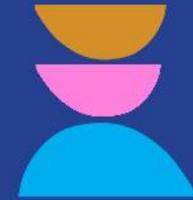
ACKNOWLEDGEMENT of STIGMA/DISCRIMINATION & TRAUMA

PEOPLE have a DESIRE to be TREATED with RESPECT with END of LIFE CHOICES



Communities of Practice

The CKE currently offers two communities of practice groups – **navigating systems** and **best practice to listen to carers, co-design and collaboration with lived experience** – participating in these workshops offers you the chance to make new connections, engage in networking activities, explore opportunities for collaboration, and provides opportunities for new knowledge and learning.



Meet Prudence, our Carer-in-Residence!

Seven years ago, my father was diagnosed with Early-onset Alzheimer's and everything in my life changed. I was 22 years old and at first had no idea what this meant for myself or my family. For the first few years his decline was not overly impactful, and I went about my life as usual, aware my father was unwell, but not completely understanding the implications this would have, for his life or for mine. I never envisioned that I would one day become my dad's carer, but a few years later I fell into the role, and it has been one of the most rewarding and challenging experiences of my life.

[Read more](#)





Policy makers and practitioners, the CKE offers you the opportunity to....

- access the latest carer related research
- listen to lived experience to inform your work
- connect with researchers and carers
- learn about developments in carer research
- make your grant applications more competitive
- add depth to your reports
- improve service design
- share case studies of best practice with researchers and other colleagues

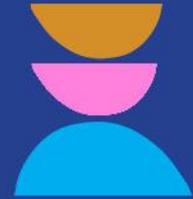


Research Incubator Event 2023

Making connections: Exploring carer health and wellbeing

- Tuesday 16 – Thursday 18 May 2023 (hybrid)
- Registration is free and opens soon – sign up to the CKE mailing list to be notified
- All sessions will be live streamed and recorded on Zoom to maximise participation

Tuesday 16 May 2023	Wednesday 17 May 2023	Thursday 18 May 2023
<p><u>Panel: Evidence-based carer health and wellbeing initiatives</u></p> <p>10:00am – 12:00pm (online)</p> <p><u>Spotlight series: short videos highlighting published and ongoing research and practice initiatives</u></p> <p>12:00pm – 12:30pm (online)</p>	<p><u>Spotlight series: short videos highlighting published and ongoing research and practice initiatives</u> 12:00pm – 12:30pm (online)</p> <p><u>Panel: Improving service literacy and service access</u></p> <p>1:15pm – 1:45pm (hybrid)</p> <p><u>Workshop: 'Connectedness and wellbeing'</u></p> <p>3:00 – 4:30pm (hybrid)</p>	<p><u>Spotlight series: short videos highlighting published and ongoing research and practice initiatives</u></p> <p>12:00pm – 12:30pm (online)</p> <p><u>Workshop: Measuring carer wellbeing in research and practice</u></p> <p>2:00 – 4:00pm (online)</p>



Any questions?

Please use this QR code to sign up to the Carer Knowledge Exchange.



Carer Knowledge Exchange

Register for updates @
<https://www.carerknowledgeexchange.com.au>

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