



Acknowledgement of Country

We acknowledge the traditional owners of the lands in which we live and work, and pay our respect to Elders past, present and emerging.

We also acknowledge the Stolen Generation, past and present, and their families.

CULTURE COMMUNITY COUNTRY FAMILY CONNECTION

KINDNESS, COMPASSION

LIVING WELL AGEING WELL

RESPECT FOR ELDER

ENGAGEMENT, TRUST, HEALTH LITERACY

SEEN, HEARD, RESPECTED, VALUED

WHOLE PERSON, WHOLE OF LIFE

GETTING HEALTH CARE

HIGH QUALITY HEALTH CARE, EVIDENCE-BASED GUIDELINES

FAIRNESS, EQUITY, EVERYONE

DTA Webinar Series

Webinar 5 - Health and Wellbeing of Carers for People with Cognitive Impairment and Dementia

Roslyn Malay and Dr Wendy Allan



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Aims of the Let's CHAT Dementia project

To increase:

- health service and community awareness of Cognitive Impairment / Dementia
- health service knowledge about, and skills for, preventing, detecting and managing CI/D
- detection rates of CI/D

To maximise:

- care of people with CI/D
- carer health and wellbeing





Let's CHAT Implementation best-practice dementia care

To Let's CHAT Webinars:

1. GP webinar
2. Detection of Cognitive Impairment and Dementia
3. Health Care for People Living with Cognitive Impairment and Dementia
4. Health Promotion and Prevention
5. **Health and Wellbeing of Carers of People with Cognitive Impairment and Dementia**
6. Planning, Decision-making and End-of-life Care

Resources

- *Best Practice Guide to Cognitive Impairment and Dementia Care for Aboriginal and Torres Strait Islander People in Primary Care*
- *Summary Guide*



Key messages from Webinar 4: Prevention & Health Promotion for Cognitive Impairment & Dementia

- ***Living well*** supports ***ageing well***
- There are ***many protective factors*** that can increase cognitive reserve
- ***Many*** risk factors for cognitive impairment and dementia are ***modifiable risk factors***
- Primary health care has a large role to play in ***promoting brain health*** across the life course.





Webinar 5 Overview

What is a carer?

Caring for an Aboriginal or Torres Strait Islander person with cognitive impairment or dementia

Why it's important to look after carers and what that might involve



Webinar 5 Learning Objectives

At the end of this
webinar, you
should be able to:

Recognise the value of **identifying, educating and supporting** distressed carers.

Understand the importance of **regular assessment** of carer health and wellbeing.

To use **culturally appropriate or adapted** tools to assess carer health.

Recognise the importance of linking carers with appropriate **support services** in a timely manner.

To be aware of elder abuse and that prevention and response is found in the community

Carer

- A person who gives someone **regular and ongoing** care and support.
- Often **without being paid or underpaid**.
- Could be a family member, a partner, a friend, or a community member.
- In contrast “*care worker, formal carer or agency carer*” refers to a paid care worker employed to give care to an (most likely) unknown person or people.

*The focus of this workshop is on **carers** not care aids/care workers/formal carers.*

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Someone with dementia may

Lost	Go for a walk and get lost,
Worry	Feel worried and frustrated but not know why,
Disconnected	Not want to engage with family or community,
Poor sleep	Have disrupted sleep,
Self-care	Have trouble with self care,
Toilet	Have trouble managing going to the toilet,
Mood	Get cranky and say things they wouldn't have said before
Forget	Forget things they have already said,
Daily Living	Have trouble shopping, paying bills, cooking or even remembering to eat.

Challenges Carers Face

- Caring demands are high and may intensify.
- Carers commonly experience chronic grief.
- Carers also experience frustration, fatigue, social isolation, and financial pressure.
- Missing work and school.
- Carers often have ill health themselves.
- A carer might be untrained and may not understand the disease.
- A carer may become the proxy decision maker.

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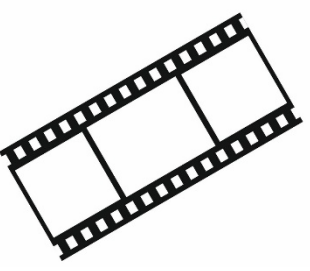
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You're Not Alone: Discussing Dementia



Elder abuse

- Evidence suggests Elder abuse is on the increase
- Financial abuse is most commonly reported
- Elders may feel shame and keep the abuse hidden



Artist: Natasha Short.

Resource: Kimberley Community Legal Services: no more humbug

Source: Government of South Australia: Elder Abuse and people from an Aboriginal background





Response

- Often the keys to prevent and respond to Elder abuse are found within the community.
- Getting help and support of trusted and respected family members or community is important.
- A partnership model is more effective and culturally safe

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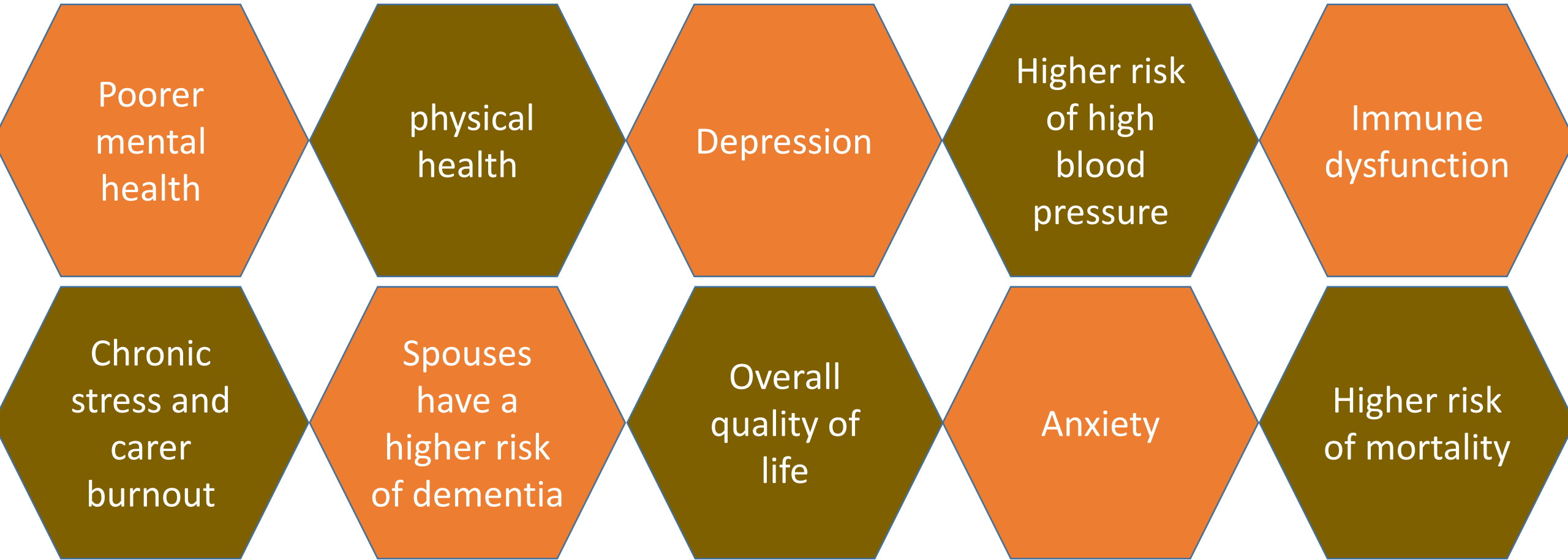
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Common Carer Health Issues



References:

- Fredman L et al. *Study of Osteoporotic Fractures. Mortality associated with caregiving, general stress, and caregiving-related stress in elderly women: Results of caregiver-study of osteoporotic fractures. Journal of the American Geriatrics Society.* 2010 May;58(5):937-43
- LoGiudice D, et al. *The well-being of carers of older aboriginal people living in the Kimberley Region of remote Western Australia: empowerment, depression, and carer burden. Journal of Applied Gerontology.* 2021 Jul;40(7):693-702.
- Livingstone et al. *Dementia prevention intervention and care: 2020 report of the lancet commission.* The Lancet. 2020 Aug 8;396(10248):413-46
- Schulz R and Beach SR. *Caregiving as a risk factor for mortality: the Caregiver Health Effects Study.* Jama, 1999, vol. 282, no 23, p. 2215-2219.

Culture and Care

- Strong family support systems are valuable
- Caring responsibilities may be shared.
- Older people may not access services that are not culturally safe.
- Carers may look after other people in addition.
- Aboriginal carers in communities are often young.
- Carers may have complex health needs.
- Older people may not want to be looked after by their children or by family members.

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4.1 Case Study: Aunty Molly

- We have met Aunty Molly, a 68-year-old lady living with her son Frank, in the earlier webinars .
- Aunty Molly was diagnosed with Alzheimer's Disease 2 years ago. She often repeats herself and her family report that she misplaces items and then accuses her family.
- She sometimes has episodes of urinary incontinence especially at night, and also has osteoporosis and severe osteoarthritis.
- She wakes up at 3am thinking it is time to go to the shops and the art centre where she is very involved.



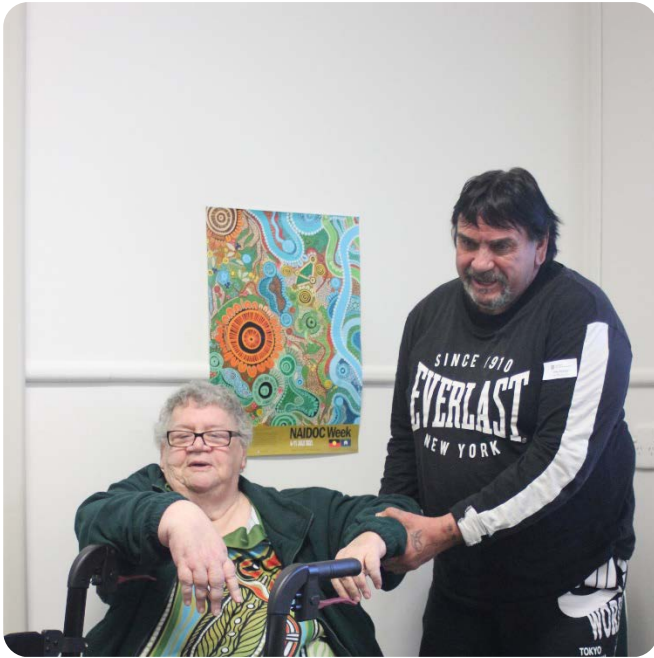
4.1 Case Study: Aunty Molly



What are the issues
(impact) that Aunty Molly
faces?

How would you help
(response) Aunty
Molly?

Person	Impact	Response
Aunty Molly	Health needs and expression of unmet needs (Disrupted sleep)	Regular general primary care – assess pain, medication review etc.
	Personal care	Home care support
	Missed appointments	Home care support/inform carer of appointment times/health service supports (reminders)/ organise transport
	General health and wellbeing /complex health needs	Regular primary care/Geriatrician referral
	Social wellbeing	Social supports – cultural centre



4.2 Case Study: Frank and Family

- Aunt Molly's son Frank is having a regular health check for his diabetes and tells you "he is at the end of his tether caring for his mother".
- He can't understand how his mother can accuse her family of stealing things. Frank is finding it hard to sleep because he is woken up at times. He also worries how he is going to continue caring for her mother
- Frank has taken time off work to care for Molly though has no leave left.

4.2 Case Study: Frank and Family



What are the issues faced by Frank and his Family?

How would you help Frank and his family?

Person	Impact	Response
Frank	Complex health needs	Regular primary health care /mental health care plans
	Competing care commitments	Home care support/respite/support from other family or the community
	Time /work	Home care support/respite
	Social isolation/impact on relationship	Respite / education of family and friends about disease progression & responsive behaviours
	Managing expression of unmet needs	Education about responsive behaviours /education about disease progression
	Disrupted sleep	Respite /managing the sleep patterns
	Stress / grief	Counselling /health service mental health

Why is it important to care for the carer?

Reducing carer burnout

- Improved quality of life and health outcomes for the carers, person with CI/D, their family and the community.
- Lowering residential aged care admissions.
- Reduces the likelihood of Elder abuse.
- The person with CI/D can stay at home for longer.
- People with dementia can stay on Country and in the community for longer.

REFERENCE: Guterman EL, Allen IE, Josephson SA, et al. Association between caregiver depression and emergency department use among patients with dementia. JAMA Neurol 2019; 76: 1166–73

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Identifying Carer Burden: Clinical Recommendations

- Recognition of carer-related needs:
- Use of culturally appropriate/adapted tools to regularly assess health and well being e.g. anxiety and depression
- Regular general primary health care
- Age-appropriate screening for dementia risk factors and case finding for cognitive impairment.

Best Practice Guide to Cognitive Impairment and Dementia Care for Aboriginal and Torres Strait Islander Peoples attending primary care

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GP Management Plan Recommendations - Carers of people with CI/Dementia

CHRONIC DISEASE MANAGEMENT – Carers of people with cognitive impairment/dementia. Recommended elements for a GP Management Plan			
Health issues / care needs / relevant conditions	How often	Treatment and services, including actions to be taken by the patient	Arrangements for providing treatment/services (eg. who, where, details, etc)
Healthy lifestyle advice: <ul style="list-style-type: none">• alcohol intake• healthy diet• healthy weight• smoking cessation• safe driving• cognitive activity	Opportunistic	Provide advice including patient information resources for a healthy lifestyle and potential of cognitive impairment/dementia, such as diet, exercise, cognitive activities, sleep, social activities, support groups, etc.	GP/Physio/GP
State including quality of life, anxiety and depression	6-12 months	Questions about Depression/anxiety. Consider R-10 measurement/SDS/PAS or equivalent	GP/Physio/GP/Mental health professionals/ Psychologists
Medication review	6-12 months	Identify anticholinergic load, including antipsychotics, antidepressants, anticholinergics, sedatives	GP
Hearing	Annual	Ear check	GP/Physio/GP/Audiologist
Blindness	Annual	Refer to audiology annually if hearing impairment identified. Otherwise, 5 yearly	GP/Physio/GP/Audiologist
Planning	6-12 months	Clarify who is involved in decision making, Schedule medical decision making reviews, consider need for power of attorney for financial and other affairs, consider advanced care plan, ask the doctor managing process for health and financial affairs in place and functioning	Consider care conference. Consider family meeting
Social factors	6-12 months	Social isolation, housing, financial issues, informal/formal supports, how often do they access these supports? How do carers manage this ongoing care requirement? Consider carer/undercarer disease	GP/Physio/GP/Social worker
Optimal management of related chronic diseases	12 months, dependent on disease & severity	Consider carer/undercarer disease	Refer to practice protocols for chronic disease management
Vaccinations	Annual	Influenza vaccine annually. Pneumococcal (Once 10Y, every 5 years)	GP/Physio/GP

This GP management plan outlines common care needs and recommended treatments and services directed towards carers of patients with mild cognitive impairment or dementia in general practice.

Best-practice guide to cognitive impairment and dementia care

Carer support, What works?

- Support and services to help look after the person with dementia
- Support and services to look after the carers
- Health service programs that are tailored to needs
- Increasing carer knowledge about Dementia
- Culturally appropriate care that is community-based

References:

LoGiudice D, et al. *The well-being of carers of older aboriginal people living in the Kimberley Region of remote Western Australia: empowerment, depression, and carer burden. Journal of Applied Gerontology.* 2021 Jul;40(7):693-702.

Livingstone et al. *Dementia prevention intervention and care: 2020 report of the lancet commission.* The Lancet. 2020 Aug 8;396(10248):413-46



Connecting carers with support & payments services

- Caring for Spirit: Caring for a person with Dementia
- Dementia Australia: The National Dementia Helpline; Advice and counselling; Carer Education and Support Program.
- Centrelink- carers payment
- Carers Australia
- NDIS
- Carer Gateway Australia
- Dementia Support Australia – resources BPSD
- My Aged Care and local support services e.g meals delivery , ACAT
- Local counseling services
- Local respite services – day programs or residential care

Resources for Family Carers



Communication tips

- Reduce background noise eg, radio, TV, conversations
- Treat with respect and dignity
- Always introduce yourself
- Give the person your full attention
- Speak clearly, using short simple sentences
- Be relaxed and friendly
- Offer encouragement
- Avoid arguments
- If the person is agitated, angry or stressed, try again later





Key Messages from Webinar 5: Health and Wellbeing of Carers for People with Cognitive Impairment and Dementia

- Looking after the **health and wellbeing** of carers is an important part of dementia care.
- Supporting carers' health improves **QoL and health outcomes** for:
 - the carer.
 - person with cognitive impairment & dementia, their family and community
- It is important that health service staff can **effectively identify, educate** and support carers.
- Connecting carers with **culturally safe services**.



Thank you!



Questions?



Resources

- Caring for Spirit: caring for a person with dementia <https://caringforspirit.neura.edu.au/research/caring-for-a-person-with-dementia/>
- Aboriginal Health and Medical Research Council - <https://www.ahmrc.org.au/resource/deadly-tips-to-stress-less/>
- Dementia Australia - <https://www.dementia.org.au/support/family-and-carers>
- Dementia Support Australia –
 - Family Carers Guide to Dealing with Dementia <https://dementia.com.au/resources/library/behaviour/family-carers-guide-dealing-with-dementia-behaviours.html>
 - Dementia Support Australia Library <https://dementia.com.au/resources/library>
 - Dementia Things To Do – Activity Resource for Carers: [https://dementia.com.au/downloads/dementia/Resources-Library/Aboriginal-Torres-Strait-Islanders/Dementia things to do Activity resource for carers.pdf](https://dementia.com.au/downloads/dementia/Resources-Library/Aboriginal-Torres-Strait-Islanders/Dementia%20things%20to%20do%20Activity%20resource%20for%20carers.pdf)
- Dementia Centre For Research Collaboration - Posters for Remote Aboriginal Communities – Behaviours and Psychological Symptoms associated with Dementia <https://dementiaresearch.org.au/resources/bpsdposters-aboriginal/>
- Dementia Australia Help Sheets <https://www.dementia.org.au/resources/help-sheets>
- Carers Australia <https://www.carersaustralia.com.au/>
- Aboriginal Home Care. NSW only. <https://www.australianunity.com.au/assisted-living/aboriginal-home-care>
- My Aged Care <https://www.myagedcare.gov.au/support-aboriginal-and-torres-strait-islander-people>
- KICA-Dep, Available from: <https://www.aboriginalageingwellresearch.com/>

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Stay in touch

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Dr Wendy Allan w.allan@neura.edu.au

Artwork- Trek of hope for dementia

Artist – Mary Jane Page

To access the story connected to the artwork visit

<http://ageingbycaring.com.au/wordpress/wp-content/uploads/2011/06/postcard-final-portrait-2-020712.pdf>



Next webinar 9th March 2022

Webinar 6

Planning, Decision-making and End-of-life Care for People with Dementia

Presenters: Diane Cadet-James and Christine Howard



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References

Arkles R, Jackson Pulver L, Robertson H, Draper B, Chalkley S, Broe A. Ageing, cognition and dementia in Australian Aboriginal and Torres Strait Islander peoples: a life cycle approach.

Fredman L, Cauley JA, Hochberg M, Ensrud KE, Doros G, Study of Osteoporotic Fractures. Mortality associated with caregiving, general stress, and caregiving-related stress in elderly women: Results of caregiver-study of osteoporotic fractures. Journal of the American Geriatrics Society. 2010 May;58(5):937-43.

Guterman EL, Allen IE, Josephson SA, et al. Association between caregiver depression and emergency department use among patients with dementia. JAMA Neurol 2019; 76: 1166–73

Livingston G, Huntley J, Sommerlad A, Ames D, Ballard C, Banerjee S, Brayne C, Burns A, Cohen-Mansfield J, Cooper C, Costafreda SG. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. The Lancet. 2020 Aug 8;396(10248):413-46.

LoGiudice D, Josif CM, Malay R, Hyde Z, Haswell M, Lindeman MA, Etherton-Beer C, Atkinson D, Bessarab D, Flicker L, Smith K. The well-being of carers of older aboriginal people living in the Kimberley Region of remote Western Australia: empowerment, depression, and carer burden. Journal of Applied Gerontology. 2021 Jul;40(7):693-702.

Schulz R, Beach SR. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. Jama. 1999 Dec 15;282(23):2215-9.

Government of South Australia: Elder abuse and people from an Aboriginal background

<https://www.sahealth.sa.gov.au/wps/wcm/connect/99a36f004a1d6bf1b48bf490d529bdaa/Elder+abuse+-+People+from+an+Aboriginal+background.pdf?MOD=AJPERES&CACHEID=ROOTWORKSPACE-99a36f004a1d6bf1b48bf490d529bdaa-nwKIAz4>

Best Practice Guide to Cognitive Impairment and Dementia Care for Aboriginal and Torres Strait Islander Peoples Attending Primary Care

<https://www.racgp.org.au/FSDEDEV/media/documents/Clinical%20Resources/Guidelines/Best-practice-guide.pdf>

Kimberley Community Legal Services: no more humbug <https://www.kcls.org.au/no-more-humbug-1>

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