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Webinar

Supporting families of people living with dementia

Wednesday, 3rd May 2017

“Working together. Working better.”

Supported by The Royal Australian College of General Practitioners, the Australian Psychological Society, the Australian College of Mental Health Nurses and The Royal Australian and New Zealand College of Psychiatrists

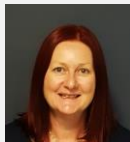
This webinar is presented by



Tonight's panel



Prof Dimity Pond
General Practitioner



Dr Alison Argo
Geropsychologist



Ms Alissa Westphal
Occupational
Therapist



**A/ Prof Stephen
Macfarlane**
Psychiatrist

Facilitator



Dr Konrad Kangru
General Practitioner

Ground Rules



To help ensure everyone has the opportunity to gain the most from the live webinar, we ask that all participants consider the following ground rules:

- **Be respectful of other participants and panellists.** Behave as you would in a face-to-face activity.
- You may interact with each other and the panel by using the **participant chat box**. As a courtesy to other participants and the panel, keep your comments on topic. Please note that if you post your technical issues in the participant chat box you may not be responded to.
- For help with your technical issues, click the **Technical Support FAQ tab** at the top of the webinar room. If you still require support, call the Redback Help Desk on 1800 291 863. If there is a significant issue affecting the overall delivery of the webinar, you will be alerted via an announcement.
- Your feedback is important. Please **complete the feedback survey** which will appear on your screen when the webinar finishes.

Learning Outcomes



Through an exploration of dementia, the webinar will provide participants with the opportunity to:

- Identify challenges, tips and strategies for building appropriate referral pathways and implementing a collaborative response to assist families caring for people living with dementia
- Implement key principles of providing appropriate therapies and communication approaches that families can engage with to support their family member who is experiencing dementia
- Describe the general principles of providing a safe and supportive environment for families that are providing care for people living with dementia, including self-care.

General Practitioner Perspective



Impact of dementia caring

- Depression – up to 30%
- Other stress related psychiatric disorders
- Reduced quality of life
- Fear for the future
- Lack time for themselves and their own social life
- Feel they have lost control of their lives
- Practical hardships eg financial hardship

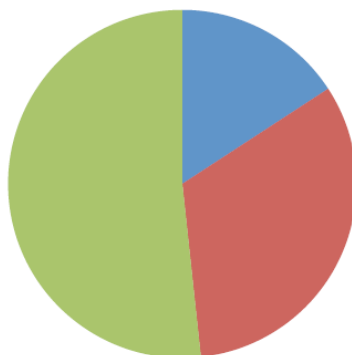


Dimity Pond

General Practitioner Perspective



How has caring affected your mental health?



- My mental health has been positively affected by caring
- My mental health has not changed as a result of caring
- My mental health has been negatively affected by caring

<http://www.carersnsw.org.au/Assets/Files/2012%20Carer%20Survey%20Report%20final%5B1%5D.pdf>



Dimity Pond

General Practitioner Perspective



Caregiver burden scale

- Do you feel that your relative asks for more help than he or she needs?
- Do you feel that because of the time you spend with your relative you do not have enough time to care for yourself?
- Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?
- Do you feel embarrassed over your relatives behaviour?



Dimity Pond

General Practitioner Perspective



Carer burden

- Do you feel angry when you are around your relative?
- Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?
- Are you afraid about what the future holds for your relative?
- Do you feel your relative is dependent on you?
- Do you feel strained when you are around your relative?



Dimity Pond

General Practitioner Perspective



Caregiver burden scale

- <http://www.ftlda.org/wp-content/uploads/2011/12/FTLDA-CARGIVER-BURDEN-SCALE.pdf>

Adapted from Zarit et al Gerontologist 1980;20:649-55. 22 items



Dimity Pond

General Practitioner Perspective



Assessment and management of physical and mental health problems in the carer

- Ask for symptoms of depression, anxiety, insomnia, financial stress etc. and review these
- Check on social life (what is being given up, how can the carer get out?), family relationships
- Reinforce self care strategies (nutrition, exercise, medications, check-ups including routine specialist and allied health appointments)



Dimity Pond

General Practitioner Perspective



What carers may require

- Education about dementia
- Practical strategies for management
- Assessment and management of physical and emotional problems in themselves
- Assistance with respite, plan move to residential care when appropriate
- Sources of support services and legal advice



Dimity Pond

General Practitioner Perspective



Psychological approaches

- Cognitive behavioural therapy:
 - Reduces burden of care
 - Delays institutionalisation and improves survival
 - Improves skills in managing patient behavioural problems



Dimity Pond

Geropsychologist perspective



Diagnosis: Carer burnout

Signs & Symptoms

- Extreme tiredness
- Poor sleep
- “Trapped”
- Crying
- “Snappy”
- Fractured relationships
- Resentful feelings
- Frustration and anger
- Reduced concentration
- Making errors
- Neglecting health & hobbies

Impact (in no particular order)

- Serious implications for her
 - Mental health
 - Physical health
 - Social relationships
- Putting her most important relationships at risk
- Reduced ability to provide adequate care for person with dementia
- Reduced ability to work effectively, risking job status



Alison Argo

Geropsychologist perspective

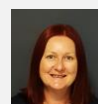


Treatment

- Identified need for multi-modal input to address:
 1. Practical supports to reduce workload and exhaustion
 2. Education on self cares
 3. Therapeutic input to assist with emotional processing
 4. Education on dementia behaviour management techniques

Often these treatment targets need to occur simultaneously....without adding to stress and burnout!!!

- While treatment is focused on the carer, all input requires dual advocacy for Maureen and for her father Malcolm.
- Treatment requires providing support and education to Maureen in her role as carer of someone with dementia, not just Maureen in isolation.
- It requires thorough knowledge of dementia symptoms and behaviours (for each type of dementia), risk mitigation, prognosis and future planning, decision-making capacity and pathways, community supports and aged care resources.



Alison Argo

Geropsychologist perspective



Treatment – Practical Supports

- Establish who is making decisions. Given Malcolm's moderate cognitive deficits it is likely he requires assisted decision-making and/or substitute decision-making.
- If the person with dementia lacks insight, establishing decision-making capacity becomes a very large issue.
- Assistance to establish a proper level of community support (current level grossly inadequate) via MAC, ACAT, Level 4 package, carer support agencies, dementia agencies.
- Given his level of symptoms, daily supports recommended.
- Ongoing medical reviews and screening essential (educate re risks of delirium, deficiencies and sensory deficits).
- Once immediate needs addressed and risks reduced; future planning needs to occur.



Alison Argo

Geropsychologist perspective



Treatment – Self Care

- Challenge the concept of 'self last' and promote 'self first'; immediate family second
- Educate on carer burnout and the evidence on health outcomes if left untreated
 - Physiological limitations and consequences
- Validate choices, validate workload, validate sanity, validate worth, validate failures
- Self care recommendations need to be individually tailored – not one size fits all
- Pamphlets and brochures are NOT ok. Burnt out carers are too tired, we're not!



Alison Argo

Geropsychologist perspective



Treatments

Emotional Processing

- Grief & loss
- Dying with dignity
- Guilt
- Divided loyalties
- Love : Reframe their values and efforts in terms of love and commitment, external to their current exhaustion
- Gently, gently. Until practical supports are increased, carers are often too exhausted for it to be safe or wise to broach these issues

Dementia education incl. BPSD

(Behaviours and Psychological Symptoms of Dementia)

- Basic dementia symptoms
- Often carers are already 'experts' in dealing with these behaviours... but
- Fine tuning techniques often results in a reduction of BPSD and increase in well-being for both carer and the person with dementia.
- Task Breakdown
- Non-verbal communication
- Re-direction
- Environment



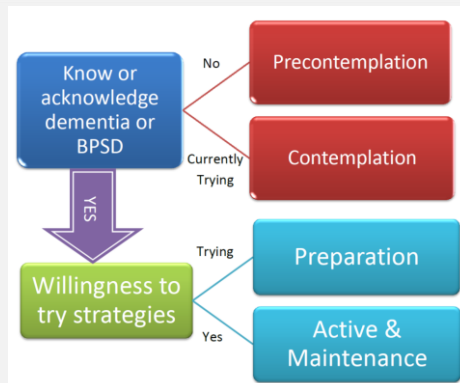
Alison Argo

Occupational Therapist perspective



Carer focussed:

- Issues & priorities
- Strengths & abilities
- Role as carer & readiness for change¹
 - Willingness to try strategies
 - Past successes?
- Self-care
- Resources & supports
 - Family or shared approach
 - Anne's visits?
- Communication & phone calls



Alissa Westphal

¹ Gitlin & Corcoran (2005); Gitlin & Rose (2014)

Occupational Therapist perspective

Malcolm focussed:

- Incontinence issues – Are there functional causes?
 - Task analysis/breakdown
 - Environment
- Daily engagement
 - What are his interests & abilities?
 - How does he spend his time?
 - What opportunities are available?
- Environment
 - How does it shape, support or hinder?
- Are there any safety or risk issues?

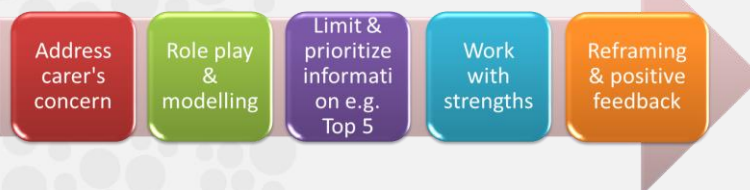


Alissa Westphal

Occupational Therapist perspective

Responses

- Highly achievable strategies first
- Modify expectations & tasks
- Shared care & schedule
- Relaxation, mindfulness, aromatherapy
- Physical activity
- ↑Supports e.g. in home respite, activity groups
- Communication & approach



Alissa Westphal

Occupational Therapist perspective

Responses

- Direct/encourage engagement
 - Use abilities
 - Provide structure & prompts e.g. schedule
 - Familiar & achievable e.g. chores
 - Modify or simplify e.g. repetition
 - Pace engagement e.g. rest & relaxation
- Technology
 - Video calls, pill dispensers
- Environment
 - Modify e.g. Signs, cues, orientation, optimise stimuli, lighting

What's on Today?	
7:30	Wake up
8:00	Breakfast
8:30	Shower or wash & dress
9:00	Read the newspaper
9:30	Fold the laundry
10:00	Morning tea
10:30	Collect the mail
11:00	Take a walk in the garden



Psychiatrist perspective

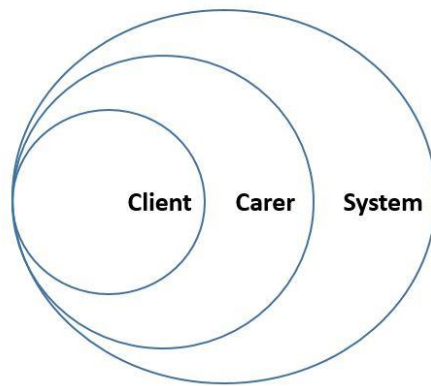
Issues

- Mild-moderate dementia (MMSE 23, MOCA 18)
- Anxiety (likely contingent on poor memory/orientation)
- Carer burnout
 - time commitment
 - distance
 - complex family needs of her own
 - disagreement with siblings regarding care needs
 - likely depressed
 - conflicting needs



Stephen Macfarlane

Psychiatrist perspective



Levels of Intervention



Stephen Macfarlane

Psychiatrist perspective

Potential for Intervention (1)

- Medical review (Malcolm)
 - Continence (GP/nurse/clinic/specialist)
 - Cognition
 - Anxiety
- Medical review (Maureen)
 - Assess/treat underlying depression
 - Management of sleep disturbance



Stephen Macfarlane

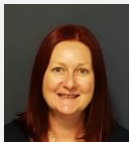
Psychiatrist perspective

Potential for Intervention (2)

- “What would you wish for?”
- Increased supports
 - My Aged Care referral
 - Package
 - Respite approval
 - Husband’s willingness/capacity to help currently unexplored
 - Financial advice
 - (DHS free financial information service)
 - Carer allowance



Stephen Macfarlane



Q&A session

Thank you for your participation



- Please ensure you complete the *exit survey* before you log out (it will appear on your screen after the session closes)
- Certificates of Attendance for this webinar will be issued within two weeks
- Each participant will be sent a link to the online resources associated with this webinar within two weeks
- Our next webinar, **Collaborative mental health care to support adults on the autism spectrum**, will be held on Monday, 5th June 2017.

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**Thank you for your contribution
and participation**

Good evening