Innovation in Dementia care
– where are we headed?

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Outline: Current → Future

- Prevention
- Stigma
- Diagnosis
- Post-diagnosis
- Treatment
- Acute Care
- Community Care
- Residential Care
- BPSD
- Palliative Care
- Special issues
- Policy
- Research
- The future
Prevention - current

• 30% of risk for AD = modifiable environmental risk factors e.g. obesity, inactivity, diabetes, low education, hi BP, depression, smoking
• Delay onset by 2 years $\rightarrow$ 20% ↓ prevalence
• Better lifestyle may already be ↓ incidence (new cases) but this trumped by ageing popu
Prevention - current

• Low take-up of prevention by:
  – Community
  – GPs

• Research
  – Drugs for AD - antibodies (USA)
  – Lifestyle esp. vascular risks (Europe)

  • FINGER ✓
  • Pre-DIVA X
Prevention - future

• GPs/NPs advise on prevention strategies
  – ? funding model

• Successful drug for those at risk eg antibody
  – I/D risk, expense, accessibility, side effects

• Lifestyle changes
  – Diet, exercise, cognitive training

• Vascular risk factors
  • BP, cholesterol, diabetes
Internet based interventions

- HATICE - Europe
- Maintain Your Brain
  - NHMRC Dementia Research Team Grant RCT
  - 18,000 55-75 yo's over 4y
  - 4 modules: exercise, diet, cognitive training, depression
Stigma – current

• General
• Medical community
  – Prescribed disengagement (Swaffer)
• Self-stigma (Low LF et al)
• Campaigns: AA, advertisements
• Education programs: bank tellers, police, taxi drivers, ambulance .... → everyone
Stigma – films

On Golden Pond
Still Alice
Iris
The Iron Lady
Dementia Friendly Communities
De Hogeweyk
Stigma - future

• Positive ageing
• Achieve what cancer achieved
• Integrate not segregate
• Stigma free, dementia friendly community → dementia friendly country

Dementia-friendly community ... where people living with dementia are supported to live a high quality of life with meaning, purpose and value
Diagnosis - current

- Gap symptoms to diagnosis $\approx 2$ years
- GP diagnosis of mild dementia $\approx 50\%$
- Screening – controversial, not favoured
- Memory Clinics – systematic in Victoria only
  - Sporadic elsewhere
  - Cost-benefit?
- High tech diagnosis
  - MRI, CSF, glucose PET, genetics (Apo E)
  - Amyloid PET and Tau PET
Under-diagnosis in Indigenous, young onset dementia, non-English speaking, developing countries
A-beta and tau PET

Expensive, not very accessible, need?
Diagnosis - future

- GP/ Practice Nurse models
- Blood test for Alzheimer’s
- High tech developments – imaging, CSF
- Clearer indications of when
- Decrease in cost
- Genomics
Post-diagnosis - current

• Paucity of information
• Lack of referrals eg to AA
• Lack of lifestyle recommendations
• PWD = Non-person
• “Prescribed Disengagement” (Swaffer)
Post-diagnosis - future

• Remedy all of these
• Prescribed engagement
• Rehabilitation program cf stroke
  – Lifestyle – exercise, cognitive rehab, diet
  – Compensation strategies
  – Evaluation of these
Treatment - Current

- ChEIs and memantine
- Drug trials spend $$ billions, but 99%+ failure
- Trials moving to pre-symptomatic or very early dementia
- Little research in non-AD
- ?Relevance for late life dementia where more multiple pathologies AD + VaD + HS
- > Attention to vascular risk factors
Treatment - future

- Antibody or secretase inhibitor
- Other symptomatic treatments
- Combination therapy (cf leukaemia)
- Cost, access, practicality
- Delay onset or delay progression
- Pharmacogenomics
Community care - current

- MyAgedCare website
  - Good in theory; unwieldly forms, difficult
- CDC, concept attractive
  - but real choice? High % on admin cost?
- Community care
  - More flexible with 4 levels, but …
  - Long waits for ACAT and for services
  - Episodic, reactive
Dementia friendly communities

- De Hogeweyk Village
- The Eden Alternative
Community care - future

• Remedy website
• Community services to meet needs
• Real CDC, consumer holds budget?
• Key worker model for all ages
Acute Care - current

- 50% of all admissions through ED are > 65yo of whom 30%+ have cognitive impairment
- Delirium and dementia frequently undiagnosed
- Older people in ED with cognitive impairment and long bone # wait 2¼ hours for analgesia (compared to 41’ for younger person without cognitive impairment) (Fry, M. Int Psychoger 2015)
Acute Care - future

- Australian Commission on Safety and Quality in Health Care - mandatory screening
- Cognitive Impairment Identifier (M. Yates)
- Confused Hospitalised Older Persons Project (J. Close)
- Better & continuing nurse training
Residential Care – Current 1

• 2800 RACFs in Australia, 180,000 residents
• Ageing in place policy: high vs low care
• High rate of Res Care in Australia, economically unsustainable
• Funding models undergoing change – separating hotel from care costs
• Many excellent services, innovative, creative, hard working
• Only about half of new facilities embrace design recommendations
Residential Care – Current 2

- Need for services for YOD, CALD, LGBTIQ, Indigenous, other minority communities
- Lack of choice for rural communities
- System rewards disability, not re-ablement
- High levels of psychotropic medication, including antipsychotics
- PCC
- Group Homes – Australia, Netherlands
- Residential neighbourhoods - USA
Residential Care – future

- Economies of scale of large with benefits of small discrete units
- More tailored facilities
- Use of robots, assistive technology
- Arts Health Institute Concierge model
- Nurse Educators/ Champions – case based
- Regular multi-disciplinary team reviews
- Dedicated GPs (＆/or NPs)
BPSD - Current

- Nomenclature
- High rates in people with dementia
  - 90%+ in residential care
- High reliance on drug therapy
  - TGA, PBS rules on antipsychotics >12 w
- DBMAS/SBRT (now unified across Australia)
Seven-tiered model of management of behavioural and psychological symptoms of dementia (BPSD)

Tier 7: Dementia with extreme BPSD (e.g., physical violence)  
Prevalence: *  Rare†  
Management: In intensive specialist care unit

Tier 6: Dementia with very severe BPSD (e.g., physical aggression, severe depression, suicidal tendencies)  
Prevalence: <1%†  
Management: In psychogeriatric or neurobehavioural units

Tier 5: Dementia with severe BPSD (e.g., severe depression, psychosis, screaming, severe agitation)  
Prevalence: 10%†  
Management: In dementia-specific nursing homes, or by case management under a specialist team

Tier 4: Dementia with moderate BPSD (e.g., major depression, verbal aggression, psychosis, sexual disinhibition, wandering)  
Prevalence: 20%†  
Management: By specialist consultation in primary care

Tier 3: Dementia with mild BPSD (e.g., night-time disturbance, wandering, mild depression, apathy, repetitive questioning, shadowing)  
Prevalence: 30%†  
Management: By primary care workers

Tier 2: Dementia with no BPSD  
Prevalence: 40%‡  
Management: By selected prevention, through preventive or delaying interventions (not widely researched)

Tier 1: No dementia  
Management: Universal prevention, although specific strategies to prevent dementia remain unproven

* Prevalence is expressed as estimated percentage of people with dementia who currently fall into this category.  
† Estimate based on clinical observations. ‡ Estimate based on Lyketsos et al.²
BPSD - Current

- Models of care; guidelines eg DBMAS Guide, Triangle
- Lack of services for top of ▲
- Lack of allied health staff, eg psychologists, OTs, SWs
- Good evidence that PCC, 1-1 engagement, reduces agitation
- Lack of translation into practice
Behaviour Management
A Guide to Good Practice

Managing Behavioural and Psychological Symptoms of Dementia

DCRC DBMAS dementia behaviour management advisory service

Helping Australians with dementia, and their carers
BPSD - Future

• PCC → Business as Usual
• Behaviours maybe communication or symptoms
• PCE – following guidelines, consulting nursing staff and consumers, integrating into community, creative planning
• Handovers → multidisciplinary = opportunity for discussion, planning, education
• More nuanced use of psychotropic Rx, regular review, informed consent
Palliative Care - Current

• Advance Care Planning, Advance Care Directives

• Issues with access to palliative care at the end of life, under- and over-treatment of symptoms and complications, and inadequate policies and workforce to support quality care. (National Framework for Action on Dementia 2015 – 2019)
Palliative Care - future

- Coherent plan for services
- Training of staff
Policy - Current

- National Framework for Action on Dementia 2015-2019 – no implementation plan
- NSW Health Dementia Services Framework 2010-2015 – no approved implementation plan
- Victoria Action Plan on Dementia 2014-2018
  - Unable to be retrieved
- Queensland Health Dementia Framework 2010-14
- South Australia's dementia action plan 2009-2012
- Dementia Action Plan for WA 2003-2006
Policy - future

- Coordinated frameworks and implementation plans at state and national levels
- Proactive, continuous, contiguous
- Quality standards
- Dementia registry to monitor care, understand service use & natural history
Research - current

• 2014 Dementia Research Initiative $200m/ 5 years ✓
• NHMRC National Institute for Dementia Research ✓
• Funding = fraction of heart disease, diabetes, cancer despite dementia prevalence, cost and as a leading cause of disability and death
Research - future

• NNIDR beyond 2019?
• Knowledge Translation eg diagnosis, post-diagnosis, PCC
• Funding → Prevention, Care, Cure
• Capacity Building
• Multi-disciplinary and underfunded areas
  – Health economics, biostatistics, public health
Aspirations, trends, opportunities

- Ageing
- Baby boomers
- Export markets in Asia the most rapidly ageing part of the world
- Stigma-free, dementia-friendly communities
Thank you

DCRC: www.dementiaresearch.org.au
DOMS: www.dementia-assessment.com.au
CHeBA: www.cheba.unsw.edu.au
Behaviour guide: www.dementiaresearch.org.au
On App – type in “BPSD” in iPhone or Android
Or for carers “Care4Dementia”
Alzheimer’s Aust www.fightdementia.org.au

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