

Consumer direction and dementia in the community



home**care**today

Your resource hub for new ideas
and choices in home care

Your areas of interest

- ① Evidence from international experience that informs practice in Australia
- ① Evidence about effective partnerships with and support for families
- ① Particular challenges encountered by consumers with younger onset dementia
- ① The role of assistive technology in providing effective support




Overview

1. Introduction to CDC and dementia
2. The impact of perceptions of dementia
3. Skills for supporting consumer direction
4. Challenges
5. Considerations for service providers

Before we begin

- ⦿ Everyone living with dementia is unique.
- ⦿ Each family is unique.
- ⦿ People with dementia will surprise you.

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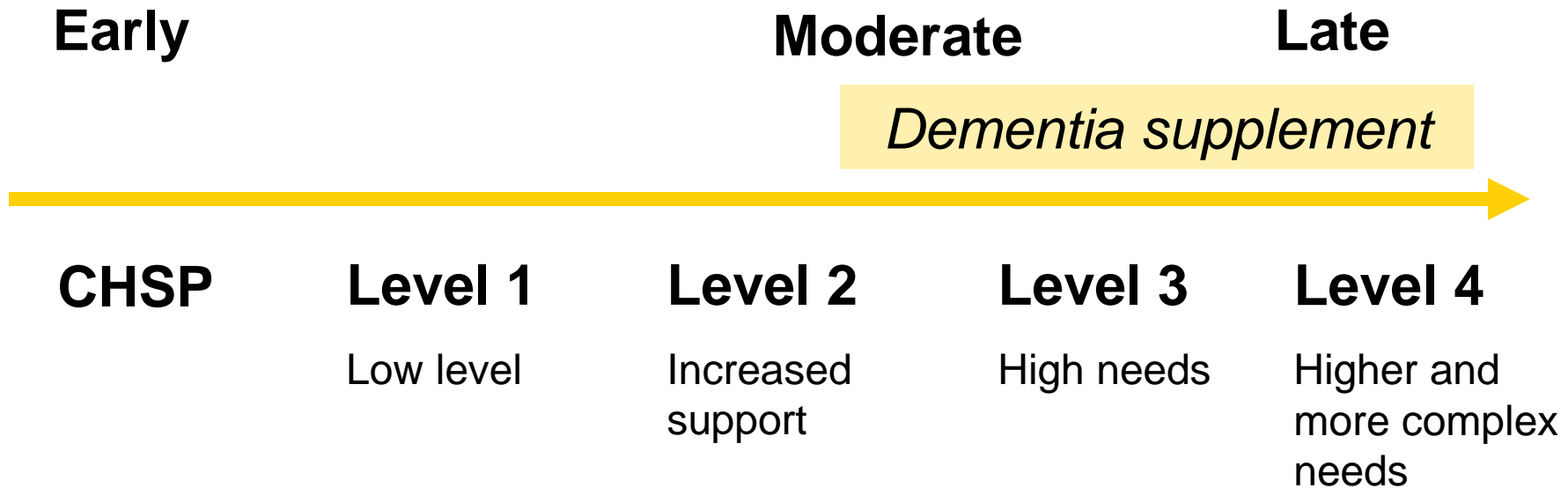
Part 1:

Introduction to CDC and dementia

Dementia statistics

- 413, 106 Australians living with dementia (Est. 166% increase by 2056)
- Younger Onset Dementia: approximately 25,938 under 65 have dementia
- Carers: Estimated 1.2 million people are involved with the care of a person with dementia (2016)
- People from culturally and linguistically diverse backgrounds: 2010- 35, 000 to 2050-120,000 (Est. 242% increase)

Dementia's progression



The Dementia Supplement

- ⦿ moderate to severe dementia
- ⦿ support for additional costs
- ⦿ available in all levels
- ⦿ assessment required

12% of packages include a dementia supplement

Chat room

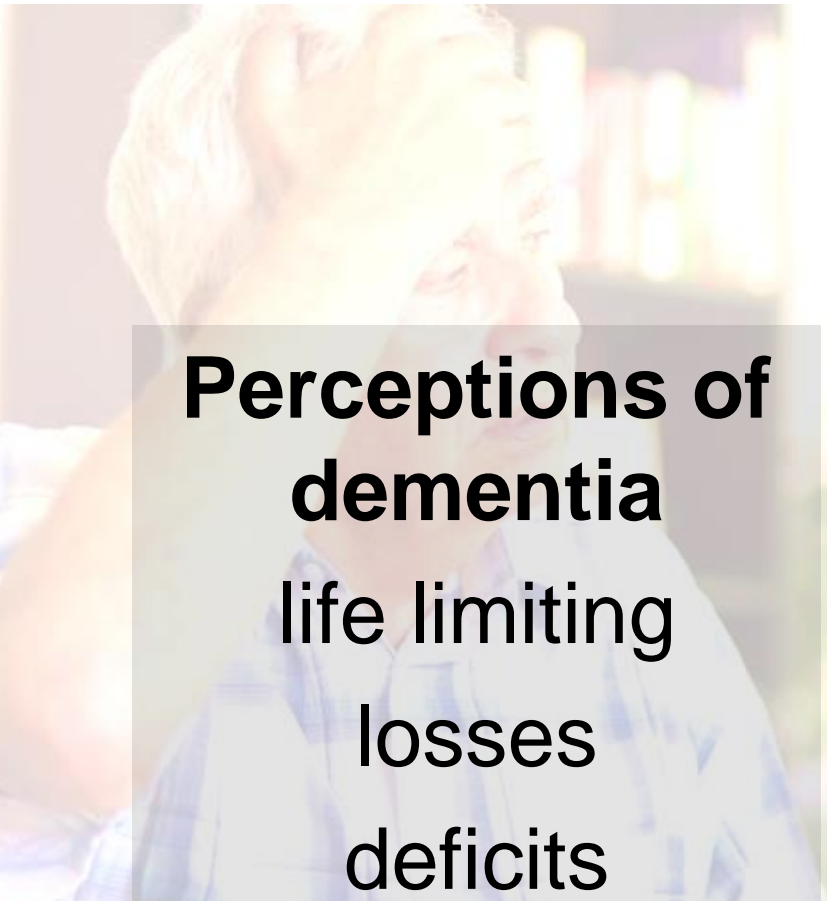
What percentage of the packages provided by your service include a dementia supplement?

Dementia and consumer direction


Key findings from overseas

- ⦿ limited research
- ⦿ increasing trend for consumers to want more control
- ⦿ integrated approaches
 - ⦿ case management
 - ⦿ integrated services
 - ⦿ CDC

Dementia and CDC in the community



**Perceptions of
dementia
life limiting
losses
deficits**



**CDC
choice
reablement**

A signpost with three directional signs. The signpost is a vertical metal pole with a decorative finial at the top. Three arrow-shaped signs are attached to the pole. The top sign points left and says 'THIS WAY'. The middle sign points right and says 'THAT WAY'. The bottom sign points left and says 'ANOTHER WAY'. The background is a bright blue sky with soft, white clouds.

THIS WAY

THAT WAY

ANOTHER WAY

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Part 2:

**Perceptions of dementia and
the impact on relationships,
opportunities and support**

Defining dementia

Dementia is a syndrome in which there is deterioration in memory, thinking, behaviour and the ability to perform everyday activities.

Dementia is caused by a variety of diseases and injuries that primarily or secondarily affect the brain, such as Alzheimer's disease or stroke.

WHO 2016

Common forms

- ⦿ Alzheimer's disease (60–70%)
- ⦿ Vascular dementia
- ⦿ Lewy body disease
- ⦿ Fronto-temporal dementia
- ⦿ Mixed conditions

In future you will see dementia referred to under the umbrella of neurocognitive disorders.

Alternative perceptions of dementia

Prescribed
disengagement TM

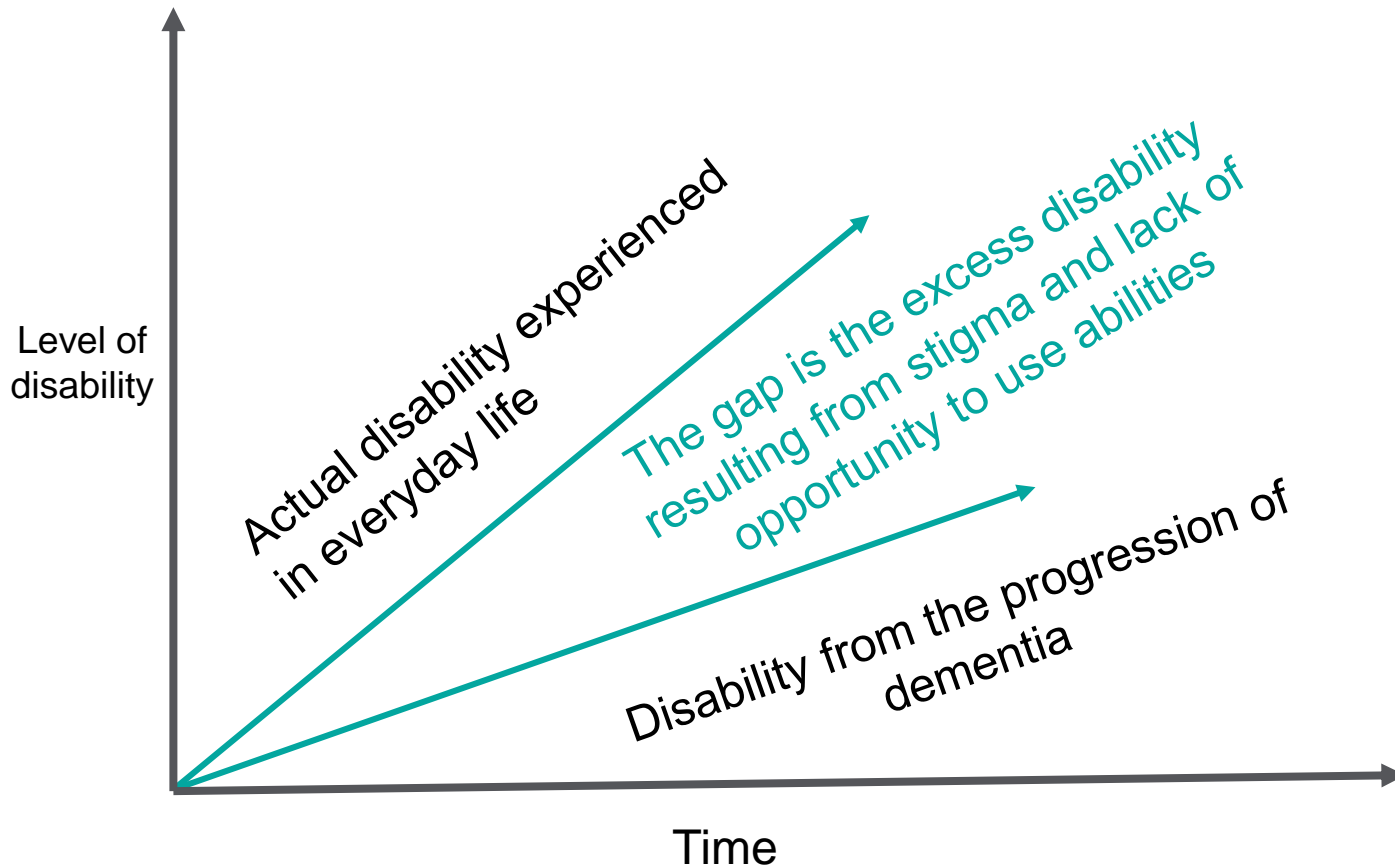
Kate Swaffer, Nominee for 2017
Australian of the Year

Swaffer, 2015

‘Dementia is a shift in the
way a person experiences
the world around him/her’

Dr Al Power, 2014

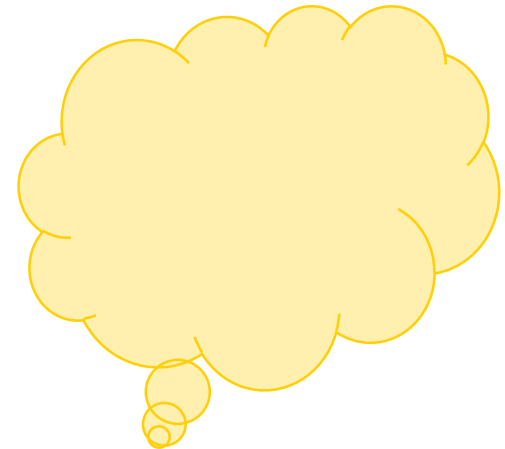
Reduce excess disability



What do I focus on?

Chat room

- ⦿ symptoms, deficits and problems?
- ⦿ caring for the person?
- ⦿ what the person can still do?
- ⦿ supporting the person to function at their highest possible level?



Factors influencing life with dementia

personality

significant life events

relationship with families and carers

communication

physical and emotional environment

co-existing health conditions



Consumers' perceptions of quality

- ⦿ autonomy
- ⦿ individuality
- ⦿ interpersonal relationships
- ⦿ consistency of care providers
- ⦿ choices at end of life

Good dementia practice supports wellbeing



support participation in meaningful everyday activities

encourage decision-making and autonomy where possible

work collaboratively with caregivers

ensure consistent, familiar staff

support the whole person

focus on abilities

provide cognitive supports

support relationships

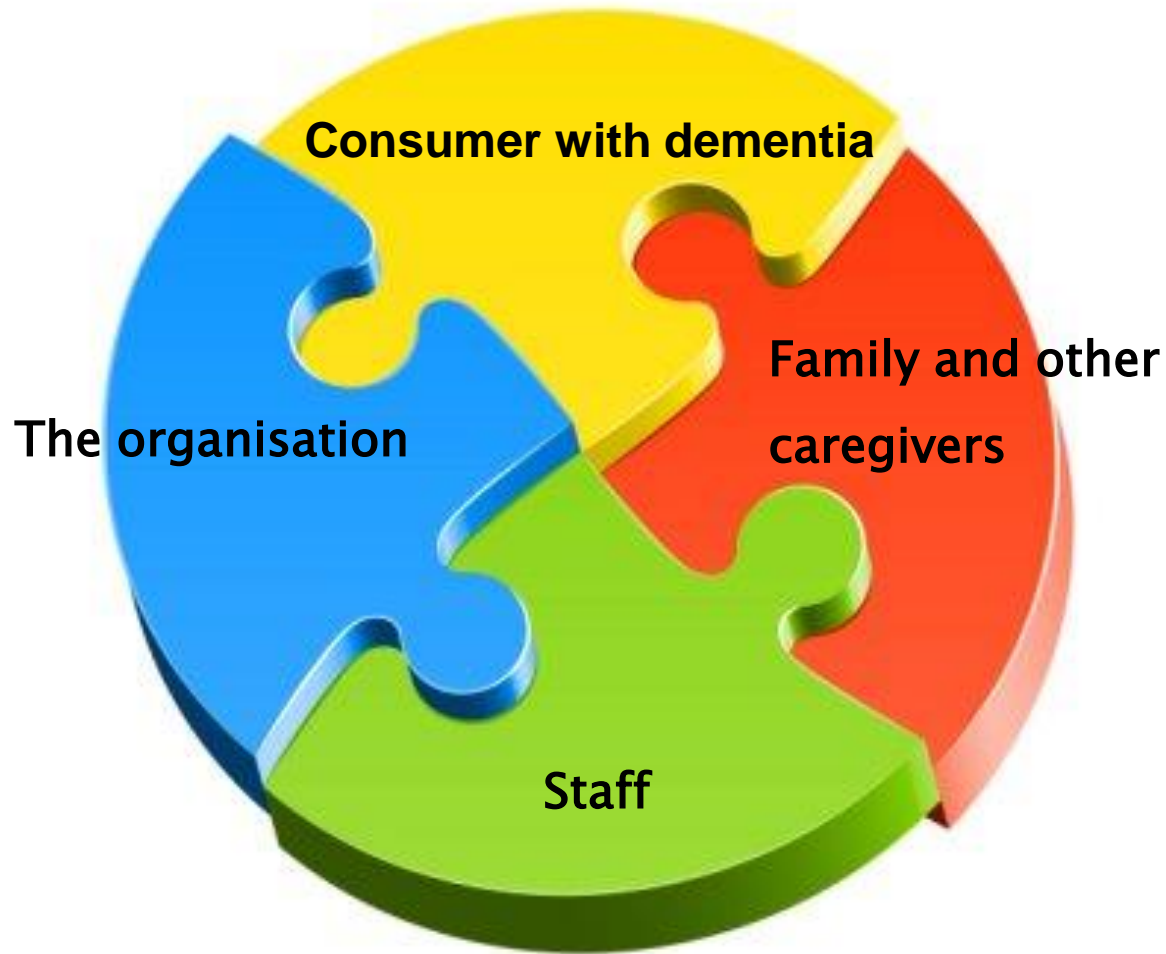
‘Quality of care without quality of life is pointless’ Fox 2007

Dignity in Care Principles

1. Zero tolerance of all forms of abuse.
2. Support people with the same respect you would want for yourself or a member of your family.
3. Treat each person as an individual by offering personalised service.
4. Enable people to maintain the maximum possible level of independence, choice and control.
5. Listen and support people to express their needs and wants.
6. Respect people's privacy.
7. Ensure people feel able to complain without fear of retribution.
8. Engage with family members and carers as care partners.
9. Assist people to maintain confidence and a positive self-esteem.
10. Act to alleviate people's loneliness and isolation.

Relationship Centred Care

We're all in this together



Moving from

Doing for

Problems and deficits

Restricting choices

Taking over

We are the experts

Moving to

Doing with

What the person can still do

Increasing opportunities

Working in partnership

Consumers with dementia are the experts in their lives

Potential benefits of good dementia practice for service providers

- ⦿ Increased consumer satisfaction
- ⦿ Decrease in consumers' negative responses
- ⦿ More rewarding work for staff
- ⦿ Decreased staff turnover
- ⦿ Positive reputation

CDC principles

- ⦿ More choice and flexibility
- ⦿ Support to access information and make informed decisions
- ⦿ A partnership approach
- ⦿ Wellness and reablement
- ⦿ Greater transparency

Chat room

In what practical ways have you applied the principles of CDC in your service for consumers with dementia?

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Part 3:

**Skills for dementia and
consumer direction in the
community**

Establishing connections

Communicating effectively

use a variety of visual prompts as required

use active listening to ensure you understand

break complex communication into small steps

allow time for responses

make sure the person can see your face

keep body language open and friendly

address the person by their preferred title

converse at the same physical level

speak slowly and clearly

Establishing connections

Case study

At 47, John was diagnosed with fronto-temporal dementia. He was dismissed from his position as CEO of a multinational company. Following the breakdown of his marriage, John went to live with Marj, his 80 year old mother. John's short-term memory is good but he has difficulty finding words and expressing ideas during conversation. Marj is very keen for John to resume playing his guitar and to mix with other younger people. You are working with John and Marj to develop John's care plan.

Chat room

What approaches would you use to effectively communicate with John?

Establishing connections

Know the person behind the dementia

what brings comfort?

what is likely to cause
upset?

important goals – ‘I
would if I could’

likes and dislikes

daily routines

support needs

proud achievements

abilities



what makes their day

religious and cultural
beliefs and traditions

hobbies and interests
past and present

key aspects of work
history

conversation starters

people who are
important in their life

Establishing connections

Consumers from culturally and linguistically diverse backgrounds

- ⦿ perceptions of dementia
- ⦿ regression
- ⦿ availability of culturally appropriate services
- ⦿ ongoing access to bilingual professional and direct care staff

Dementia and decision-making

Benefits of inclusion

Inclusion

- ⦿ identity
- ⦿ well-being
- ⦿ quality of life
- ⦿ prevent excess disability

Exclusion

- ⦿ depression
- ⦿ frustration
- ⦿ anger
- ⦿ exacerbate disability

Dementia and decision-making

The spectrum

- ⦿ people with mild to moderate dementia can actively participate in decision-making
- ⦿ decision-making isn't all or nothing – it is spread across a continuum
- ⦿ focus on empowering participation regardless of cognitive function

Dementia and decision-making

Types of decisions

- ⦿ autonomous
- ⦿ delegated
- ⦿ shared
- ⦿ non-involvement

Dementia and decision-making

Challenges for service providers

- ⦿ balancing vulnerability and autonomy
- ⦿ establishing capacity
- ⦿ clarifying expectations
- ⦿ providing sufficient information but not overwhelming
- ⦿ resolving conflict about whose needs are being met

Chat room

Are there any other challenges you have experienced related to consumers' participation in decision-making?

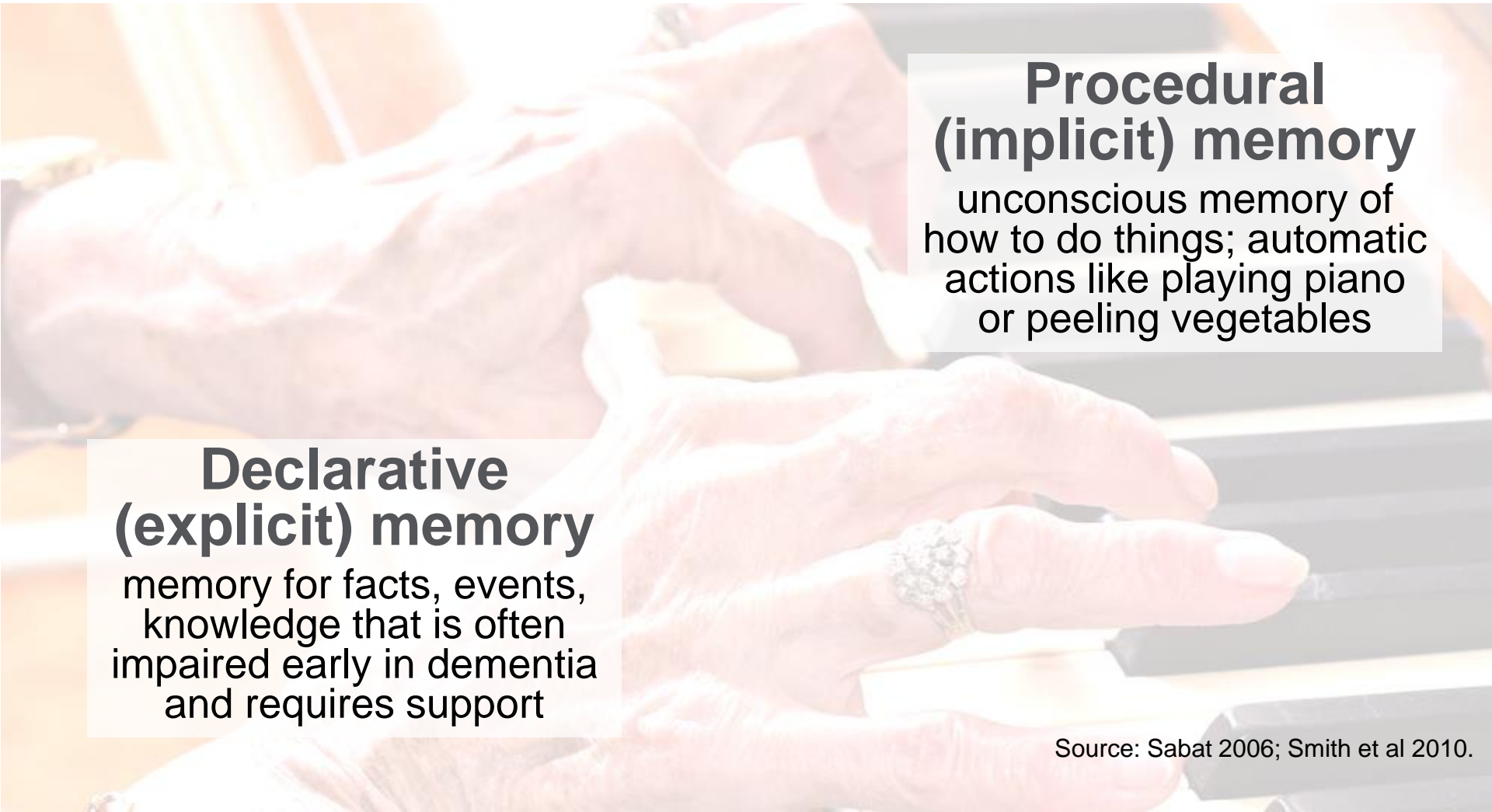
Focus on abilities

Benefits

- ⦿ maintenance of skills
- ⦿ enhanced self-esteem
- ⦿ support to lead meaningful everyday lives
- ⦿ connections with others

Focus on abilities

Areas of memory



Procedural (implicit) memory

unconscious memory of how to do things; automatic actions like playing piano or peeling vegetables

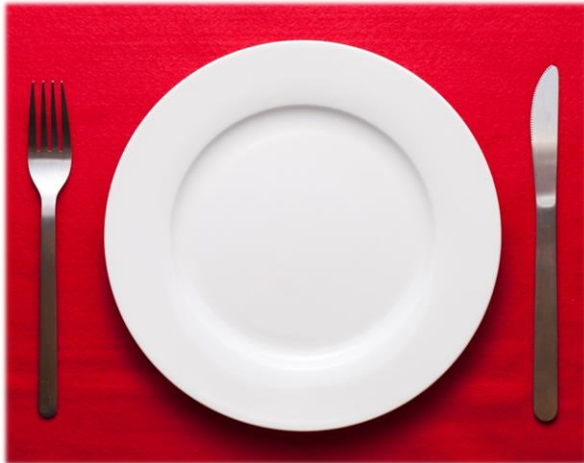
Declarative (explicit) memory

memory for facts, events, knowledge that is often impaired early in dementia and requires support

Focus on abilities

Supporting declarative memory

Colour contrasts



Signage to assist with orientation, way finding and activities of daily living



Focus on abilities

Supporting disability with assistive technology

- ⦿ Multiple options
- ⦿ Tailored to changing needs
- ⦿ Privacy, cost, reliability, substitutes
 - ⦿ Dementia Enabling Environments
 - ⦿ BaptistCare NSW
 - ⦿ Alzheimer's Australia Vic
 - ⦿ Independent Living Centres

Focus on abilities

A framework for identifying abilities

Sensory abilities

smell
taste
touch
hearing
vision

Thinking abilities

reading
counting
matching
sorting

Social abilities

conversation
humour
listening
leading a group

Motor abilities

carry
scoop
pour
use tools

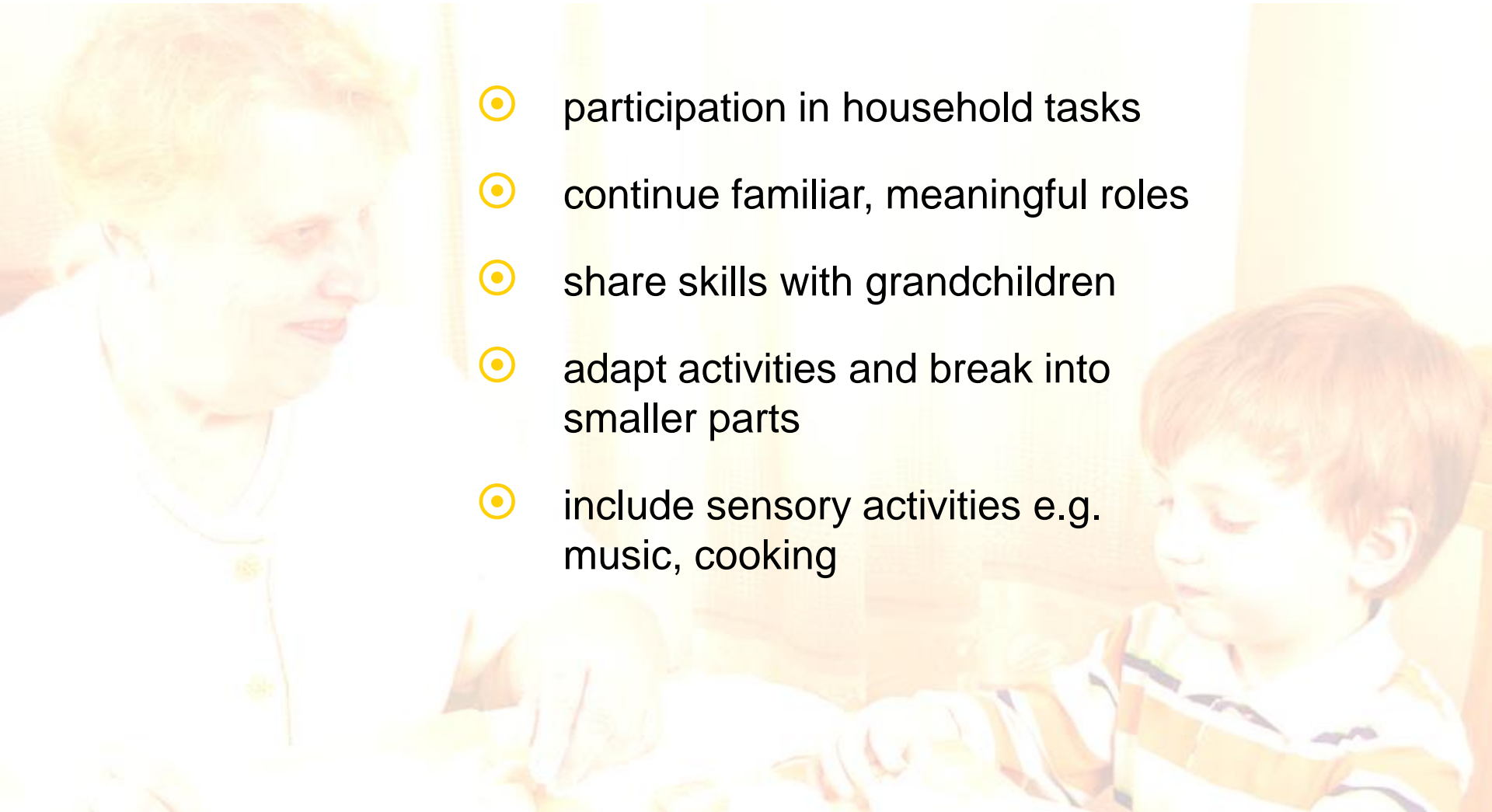
Focus on abilities

Identify abilities

- ⦿ Observe the person while they participate in everyday tasks such as having morning tea and socialising with family and friends.
- ⦿ Invite the person to assist with a task such as making a cup of tea.
- ⦿ Invite the person to undertake a task independently .
- ⦿ Ask the family carer what the person is still able to do.

Focus on abilities

Abilities in action at home

- 
- ⦿ participation in household tasks
 - ⦿ continue familiar, meaningful roles
 - ⦿ share skills with grandchildren
 - ⦿ adapt activities and break into smaller parts
 - ⦿ include sensory activities e.g. music, cooking

Focus on abilities

Abilities in action in centre-based respite

- ⦿ know your consumers – interests and abilities
- ⦿ invite consumers to be involved in planning activities
- ⦿ encourage consumers to adopt regular roles e.g. handing out name tags, setting tables, preparing morning tea
- ⦿ provide choices e.g. create small group activities based on consumers' shared interests and abilities
- ⦿ develop intergenerational activities through partnerships with schools and playgroups
- ⦿ establish activity areas e.g. sorting, putting, puzzles
- ⦿ establish reading groups
- ⦿ start a choir

Focus on abilities

Abilities in late dementia

**Engagement through
the senses**



Focus on abilities

Reablement



- ⦿ ‘Reablement involves time-limited interventions that are targeted towards a person’s specific goal or desired outcome to adapt to some functional loss, or regain confidence and capacity to resume activities.’ Dept Social Services 2015
- ⦿ Requires supportive physical environment
- ⦿ Common outcomes - greater independence, enhanced self-esteem and quality of life

Focus on abilities

Case study

Norm has been approved for a level 4 package. He recently returned home from hospital following a severe chest infection.

Norm lives with his daughter Sue who is concerned that since his return, her father is able to walk only a few steps. Sue is keen that Norm's mobility improve.

Walking in the garden and visits to the nursery with Sue for morning tea had previously been an important part of Norm's life.

discussion

What ideas do you have to reable Norm's mobility?

Focus on abilities

- ⦿ provides opportunities for broadening consumers' experiences
- ⦿ maintains current abilities longer
- ⦿ participation in part of an activity is preferable to no participation

Partnerships with family

Changes for family caregivers

- ⦿ **emotional** – grief, guilt, frustration, bewilderment
- ⦿ **physical** – fatigue, increased infections, injuries
- ⦿ **social** – increased isolation from friends and family
- ⦿ **routine of daily life** – changing roles; reduced flexibility
- ⦿ **financial** – increased care expenses and decreased income earning capacity
- ⦿ **the ‘sandwich’ generation** – balancing the needs of elderly parents and demands of own family

Partnerships with family

Each family is unique

- ⦿ knowledge of dementia
- ⦿ health of primary carer
- ⦿ extended family support
- ⦿ dynamics
- ⦿ approaches to problem solving
- ⦿ available resources

Partnerships with family

CDC and challenges for families

- ① **feeling overwhelmed** – new system, people, procedures, information overload
- ① **identifying creative solutions** to achieving quality everyday life
- ① **balancing** core needs and brokerage

Partnerships with families

- ⦿ Leadership, vision, systems and practice that support partnerships
- ⦿ Effective ongoing 2-way communication
 - ⦿ Establish connections, ask good questions, listen
 - ⦿ Manage expectations
 - ⦿ Establish on-going engagement e.g. focus groups, surveys, advisory group
 - ⦿ Feedback from staff 'on the ground'
- ⦿ Flexibility and openness

Partnerships with family

Evidence about supporting families

- ⦿ multi-component, tailored and integrated services
- ⦿ education about dementia, includes the person with dementia, relevant to the particular issues and context
- ⦿ coaching
- ⦿ respite
- ⦿ support to retain social connections

Chat room

What specific strategies have helped you develop effective partnerships with families?

Partnerships with family

Factors leading to residential care

- ⦿ primary carer's failing health
- ⦿ critical event e.g. fall, severe infection
- ⦿ behavioural issues e.g. wandering, severe aggression
- ⦿ incontinence
- ⦿ other health conditions

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Part 4:

Challenges

Challenges

Younger onset dementia

- ⦿ Refers to people under 65 years diagnosed or exhibiting symptoms of dementia – sometimes 30s or 40s
- ⦿ Diagnosis
- ⦿ Career
- ⦿ Relationships
- ⦿ Lack of appropriate services

Challenges

Supporting people with YOD

- ⦿ Know the person behind their dementia – abilities, interests, what makes their day, goals
- ⦿ Focus on abilities while providing support
- ⦿ Be creative and flexible
- ⦿ Tailor education and support to the needs of the family including the children
- ⦿ Link with other services and resources
 - ⦿ Alzheimer's Australia, National Younger Onset Key Worker Program
 - ⦿ Councils, respite services
 - ⦿ Support groups

Challenges

Living alone with dementia

Concerns...

- ⦿ Safety
- ⦿ Nutrition
- ⦿ Self-care
- ⦿ Isolation
- ⦿ Financial management

Challenges

Living alone with dementia

Suggestions for support

- ⦿ Accept a higher level of risk
- ⦿ Involve family, friends, neighbours, community members
- ⦿ Support social connections
- ⦿ Modify the environment
- ⦿ Implement prompts to support declarative memory
- ⦿ Work with established routines
- ⦿ ID when going out
- ⦿ Work closely with ACAS

Challenges

Concern about risk



conflict with carers

litigation

loss of reputation

**loss of professional
registration**



concern about harm

duty of care

**personal and company
liability**

Challenges

Concern about risk ..some considerations

- ⦿ life is a risk
- ⦿ perceptions vary... fun or risk?
- ⦿ 'risk' is broader than physical harm e.g. depression, frustration, loss of skills
- ⦿ there will be risks with the safe option too

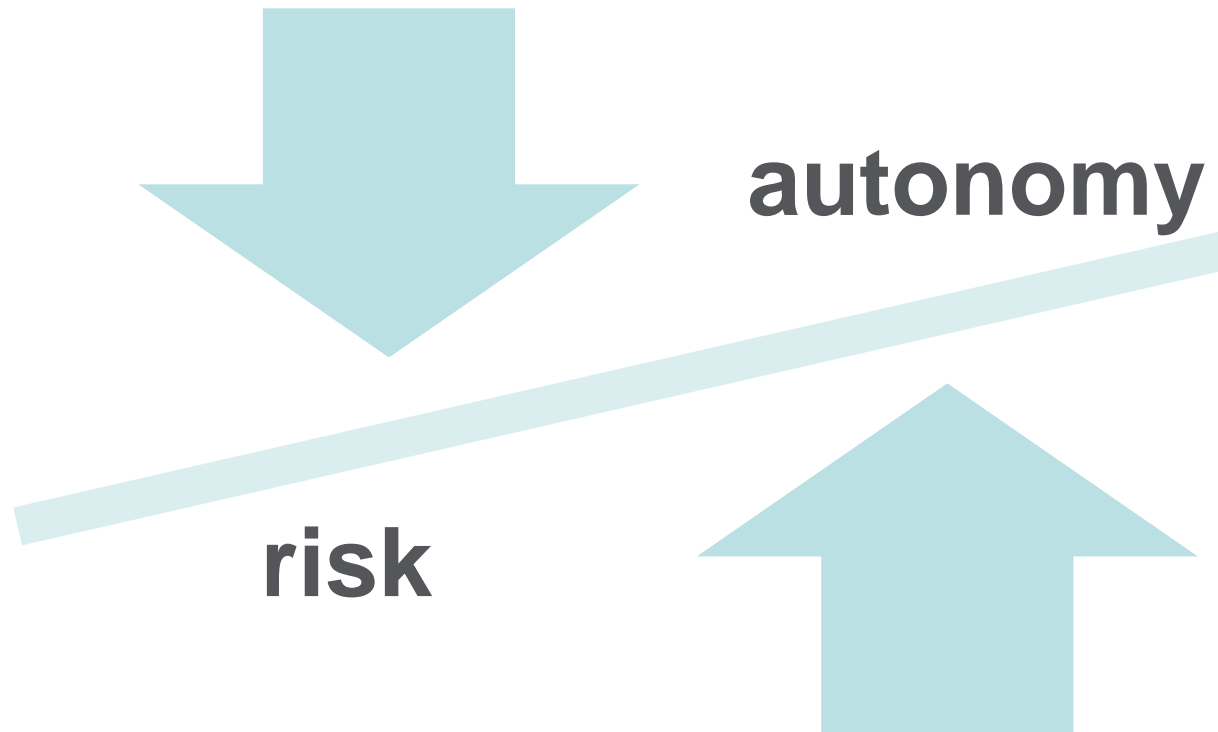
Challenges

Concern about risk

- ⦿ knowing the person's capacity for decision-making
- ⦿ abilities change over time
- ⦿ carers' different perspectives
- ⦿ risk-averse organisational culture
- ⦿ knowing what's possible

Challenges

Concern about risk



Challenges

Positive risk-taking

- ⦿ Know the person – abilities, what's important, attitude to risk, capacity to understand consequences
- ⦿ Involve all those who will be reasonably affected by the decision
- ⦿ Establish a framework for decision-making
- ⦿ Document shared decisions and observations
- ⦿ Encourage a supportive (not blaming) culture
- ⦿ Be flexible
- ⦿ Build capacity
- ⦿ Mitigate risks

Chat room

How does your organisation balance concern about risk with support for consumers' autonomy?

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Part 5:

Considerations for service providers

Resources

Education

- ⦿ University of Tasmania
Understanding Dementia - free
online 9 week course (MOOC); other
dementia courses
- ⦿ University of Wollongong: Graduate
Certificate in Dementia Care; Master
of Science (Dementia Care)
- ⦿ Dementia Training Australia
- ⦿ Hammond Care
- ⦿ Alzheimer's Australia
- ⦿ Meaningful Living for Elders
www.meaningfulliving.com.au

Carers

- ⦿ Carers Australia 1800 242 636
- ⦿ Alzheimer's Australia Helpline 1800
100 500

Other

- ⦿ Dementia Behaviour Management
Advisory Service (DBMAS) 1800 699
799
- ⦿ National Cross Cultural Dementia
Network (NCCDN)

nccdn@alzheimers.org.au; 08 8372 2140

Specialised dementia consultancy service



For service providers

Support to develop effective model of dementia practice

Dementia training for staff including music in social groups and at home

For families at home

Tailored dementia education

Personalised music

Creation of life stories

Phone Trudy Neal: 0415 959 260

Email: trudy@meaningfulliving.com.au

Web: www.meaningfulliving.com.au

Summary

- ✓ We're still finding our way
- ✓ Leadership, policies and systems support good dementia practice and CDC.
- ✓ Focus on what consumers can do and provide appropriate support
- ✓ Work in partnerships with families
- ✓ Staff have knowledge, skills and attitudes to support good dementia practice and consumer direction in the community.

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