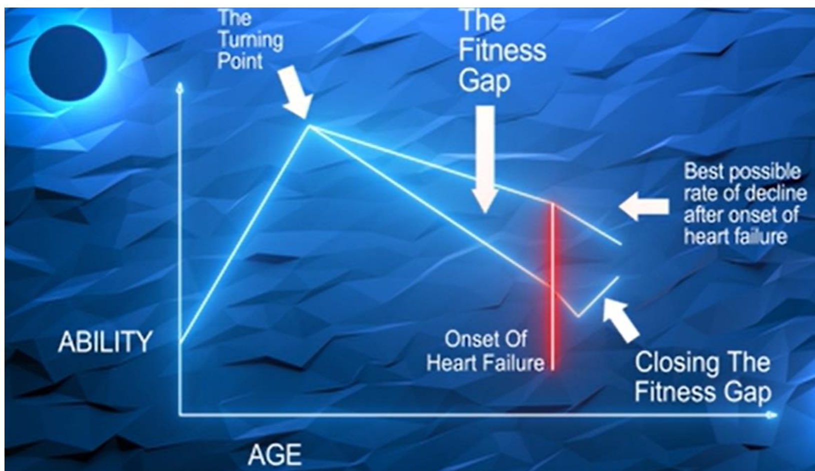
Paul Cadger

Living Well with Dementia and Promoting Independence

1

- **What does <u>living well</u> mean for you?**
- **Is it the same as person next to you?**

What would your **plan** be, so you live well to your retirement?, to your 70s, 80s and 90s?



Learning with experts; Live longer better
rfwellbeing@gmail.com
(Rachel Faulkner)

2

2

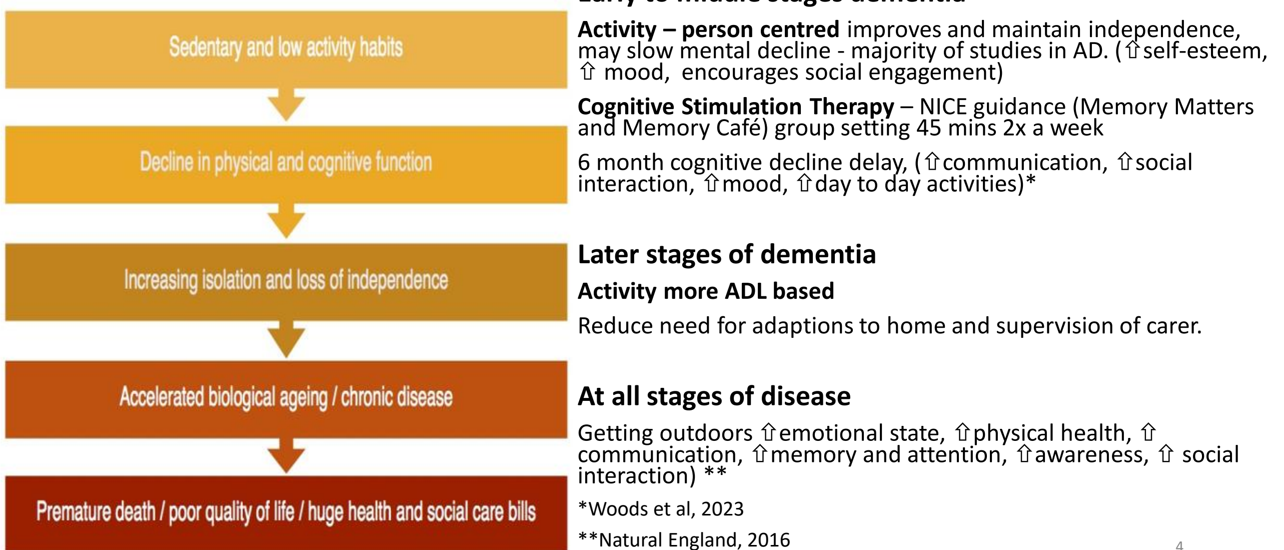
Purpose

https://app.frame.io/presentations/de3a95c8-1a60-4171-b5ca-c906b79ce344

3

3

Activities



Early to middle stages dementia

Activity – person centred improves and maintain independence, may slow mental decline - majority of studies in AD. (⇧self-esteem, ⇧ mood, encourages social engagement)

Cognitive Stimulation Therapy – NICE guidance (Memory Matters and Memory Café) group setting 45 mins 2x a week

6 month cognitive decline delay, (⇧communication, ⇧social interaction, ⇧mood, ⇧day to day activities)*

Later stages of dementia

Activity more ADL based

Reduce need for adaptions to home and supervision of carer.

At all stages of disease

Getting outdoors ⇧emotional state, ⇧physical health, ⇧ communication, ⇧memory and attention, ⇧awareness, ⇧ social interaction) **

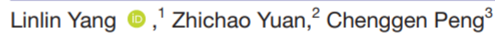
*Woods et al, 2023

**Natural England, 2016

4

4

Effects of aerobic exercise on cognitive function and quality of life in patients with Alzheimer's disease: a systematic review and meta-analysis



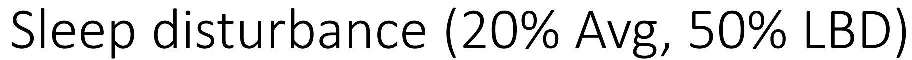
- Exercise classed as either resistance, aerobic or mixed vs stretching/usual – no cognitive training element or anaerobic
- Alzheimer's disease all stages but not other sub-types of dementia

> 16 weeks (3x week, 30-50mins) Improved cognition (MMSE) and Quality of life

5

6

Sleep disturbance (20% Avg, 50% LBD)



- Little to no evidence for medication to improve, Z drugs ⇧ harm
- Cochrane review 19 studies of non-pharm approaches to sleep (Wilfling et al, 2023) all low evidence quality, not conclusive, many have multiple components so difficult to isolate intervention that works
  - Positive effect physical activity, social activity and carer interventions (training) ⇧ nocturnal sleep (overall) ↓ night time awakenings

Barriers to living well

Only 20% of PLwD stated dementia as a barrier, whereas 83% of carers

Transport

Cost

Inadequate support (getting there, facilities and participation)

Risk aversion – Falls, Missing (Herbert protocol)

A lack of awareness of PLwD needs

Adaptive aids

What examples of adaptive aids could be used to increase or maintain independence?

- Telecare - portable alarms GPS, fixed position alarms (doorways), movement pressure sensors, life line, pill dispensers, smoke and fire alarms
- Daily Living – walking sticks, grab rails, bath boards shower seat, clocks with day and time, large button phones, digital pictures and name display, white board/diary, clothing / shoes buttons-velcro
- Smart phone/tablets - alarm clock, notes/reminders, games, reminiscing aids, voice controlled assistants
- Nutrition - contrasting crockery, eating at familiar time, cultural foods, eating by hand, eating in groups, engage in preparation of food/eating,

No evidence to recommend specific technologies for PLwD (Livingston et al 2024), Tech should supplement not replace face to face interventions to avoid isolation

Adapting environments

Association of Dementia Studies/ Kingsfund - Is your _____ Dementia friendly?

Care Home, Housing, Garden, Ward, Hospital or Health Centre

https://ext-webapp-01.worc.ac.uk/kings_fund

7 main themes interaction/purpose, well-being, eating and drinking, mobility, continence and hygiene, orientation, calm and safe

NHS Wolverhampton – NO STUMBLES

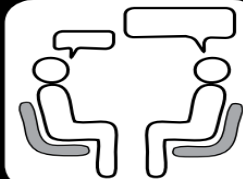
University of Newcastle Australia – HomeFAST (Falls and Accident Screening Tool)

Housing – Interaction and purpose

1 The environment promotes meaningful interaction and purposeful activity between residents, their families and staff

Rationale

Uncared for and unwelcoming spaces can cause anxiety and provoke concerns about the quality of service in both residents and their relatives. In communal areas the arrangement of furniture will give clues as to the function of the space. There should be a choice of seating, including chairs with arms; and arranging chairs in clusters will encourage conversation. People with dementia are adults with a lifetime of experience and so communal activities should be carefully and deliberately chosen to reflect the age of the residents, their culture and individual interests.



Questions

Please score each answer from 1 – 5
(1=barely met, 5=totally met)

- **A** Does the approach to the housing development look and feel welcoming? ☐
- **B** Is the entrance obvious and the doorbell/entry phone easy to use? ☐
- **C** Does the development give a good first impression i.e. does it look clean, tidy and cared for? ☐
- **D** Are there communal social areas such as sitting and dining rooms and gardens/outside spaces? ☐
- **E** Are the chairs in communal areas arranged in small clusters to encourage conversation? ☐
- **F** Does the furniture contrast with the walls and floors and is there a choice of seating e.g. single chairs and settees? ☐
- **G** Does the environment in the communal areas support residents to engage independently in activities of daily living e.g. clear signage to the laundry and/or external drying area? ☐
- **H** Do communal areas enable individual and group engagement in age and culturally appropriate activities e.g. space for activities other than watching TV? ☐

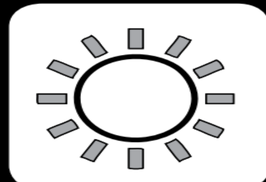
11

Housing – Well-being

2 The environment promotes well-being

Rationale

Older people need higher light levels and people with dementia may interpret shadows or dark areas on the floor as holes and try to step over them. Stripes or strong patterns on flooring, walls or furniture could be confusing and disorientating. Appropriate light levels can help promote normal patterns of waking and sleeping. Views of nature and spending time outdoors are essential to well-being. Dementia is a terminal illness and research indicates that people prefer to die in places and amongst people that are familiar to them.



Questions

Please score each answer from 1 – 5
(1=barely met, 5=totally met)

- **A** Is there good natural light in communal areas, hallways, kitchens, bedrooms? ☐
- **B** Is the level of light comfortable and appropriate for what residents want to do in the space and can it be adjusted? ☐
- **C** Do the light switches contrast with their surrounds/the walls so that they are easy to see? ☐
- **D** Is the lighting and natural light from windows even e.g. without pools of light and/or dark areas, stripes or shadows? ☐
- **E** Is the lighting designed to support normal sleep and wake patterns e.g. can bedrooms be made completely dark using black out curtains/blinds? ☐
- **F** Are links to and views of nature maximised e.g. by having low windows, using natural materials and colours? ☐
- **G** Is there accommodation available for relatives to stay overnight if needed? ☐
- **H** Have sheltered seating areas and points of interest been provided in the outside space? ☐
- **I** Is planting non-toxic and has it been chosen to offer variety throughout the year? ☐

12

Housing – Eating and Drinking

3 The environment encourages eating and drinking

Rationale

Open shelves/glass fronted cupboards or labels/pictures on cupboard doors will help residents remember what goes where. Having a choice of where to eat, e.g. with others or by themselves, may encourage people to eat and drink. For people with dementia, table cloths, crockery, cutlery and drinking glasses should be chosen with care to look familiar (beakers and specially shaped plates may not be recognised) and to offer a colour contrast from the food or drink because people may not be able to see white food that is presented on a white plate.

Questions

Please score each answer from 1 - 5
(1=barely met, 5=totally met)

- **A** Are the fixtures and fittings e.g. hobs, ovens, kettles and fridges of traditional design and easy to use? ☐
- **B** Are all appliances fully visible i.e. not hidden behind cupboard doors? ☐
- **C** Are kitchen taps, sinks and plugs of a traditional design? ☐
- **D** Are there open shelves/glass fronted cabinets in the kitchen? ☐
- **E** Are there sufficient cupboards to prevent clutter? ☐
- **F** Does the layout of the flat/house enable enough space for a traditional table and chairs? ☐
- **G** Are communal dining areas domestic in scale? ☐
- **H** Is there enough space and chairs in communal dining areas for visitors to sit in to help with eating and drinking and/or eat alongside the residents? ☐

13

13

Housing – Mobility

4 The environment promotes mobility

Rationale

Being able to walk independently is important. Safety can be enhanced by providing handrails and small seating areas where people can rest in corridors and outside spaces. People with dementia may interpret shiny floors as being wet and/or slippery. Strong colour contrasts in flooring, paving, threshold strips or floor mats should be avoided as they may be interpreted as something to step over. Speckles in flooring could look like pieces of litter. Interesting artworks will encourage mobility as well as helping people find their way around.

Questions

Please score each answer from 1 - 5
(1=barely met, 5=totally met)

- **A** Is there space to walk around independently both inside and outside the development? ☐
- **B** Is the flooring matt rather than shiny and of a consistent colour i.e. does not have speckles, pebble effects or stripes? Is the flooring in a colour that contrasts with the walls and furniture? ☐
- **C** Are the handrails in a colour that contrasts with the walls and can they be grasped properly? ☐
- **D** Are there small seating areas for people to rest along corridors and outside? ☐
- **E** Are there age appropriate points of interest and way finding clues throughout the development e.g. different colours or artworks on each floor or residential block? ☐
- **F** Are lifts easy to find and do they have large control buttons? ☐
- **G** Have the outside areas been designed to encourage engagement and activity e.g. circular/returning pathways, raised flower beds, a clothesline? ☐
- **H** Are dead ends avoided by putting a chair or an artwork at the end of a corridor? ☐

14

14

Housing – Continence and hygiene

5 The environment promotes continence and personal hygiene

Rationale

Not being able to find the toilet provokes anxiety and using the same signs and door colours to denote all toilets in communal areas will help people find them more easily. Ensuring good colour contrast on sanitary fittings will make toilets and basins easier to see and use. Traditional and familiar designs will help ease anxiety and promote self-care. Being plunged into darkness if sensor lights go out while washing or sitting on the toilet can be very frightening. Badly placed mirrors can increase disorientation. Pictures of people or reflections in a mirror may cause people to think there is someone else in the bathroom with them.

Questions

Please score each answer from 1 - 5
(1=barely met, 5=totally met)

- **A** Is the door to the toilet easily identifiable e.g. is it painted a distinctive colour? ☐
- **B** Are the toilet seats, flush handles and rails in a colour that contrasts with the toilet/bathroom walls and floor? ☐
- **C** Are the taps clearly marked as hot and cold and are they, the toilet flushes, bath and shower controls of familiar design? ☐
- **D** Do residents have access to an assisted shower/ bathroom big enough to allow space for a wheelchair and carers to assist with the door closed? ☐
- **E** If sensor lights have been installed do they allow sufficient time for completion of toileting or washing? ☐
- **F** Are there open shelves/glass fronted cabinets in the bathrooms so that self-care items can be easily found? ☐
- **G** Are mirrors carefully placed to avoid disorientation and can they be covered if required? ☐

15

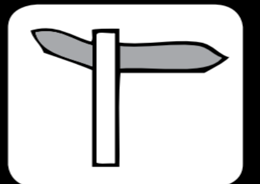
15

Housing – Orientation

6 The environment promotes orientation

Rationale

People with dementia rely heavily on what they can actually see to help them find their way around. They are likely to become agitated in unfamiliar surroundings. Providing visual clues and prompts, including accent colours and artworks, and providing clocks and calendars will help with orientation. Signs should be mounted on the door to which they refer. Directional signage may be required if a location such as the dining room is not obvious. Signs using both pictures and text need to be placed at a height where they can easily be seen. Strong realistic patterns of e.g. flowers and fruit may be misinterpreted. Life size images e.g., of trains and installations such as indoor bus stops are likely to further disorientate people with dementia



Questions

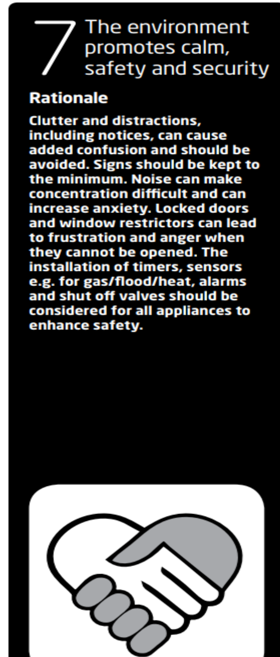
Please score each answer from 1 - 5
(1=barely met, 5=totally met)

- **A** Are there good sight lines inside the flats/ houses e.g. can the toilet door be seen easily from the sitting room? ☐
- **B** Do doors have a clear or transparent vision panel to show where they lead to? ☐
- **C** Is it easy to navigate between the communal areas e.g. can the dining room be seen clearly from the lounge areas? ☐
- **D** Are signs of a good size and of a contrasting colour so as to be seen easily? ☐
- **E** Are signs placed at key decision points to assist navigation through the building? ☐
- **F** Do signs e.g. for communal areas use both pictures and words and are they hung at a height (approximately 4 foot/1.2m) that makes viewing them easy? ☐
- **G** Are pictures/objects and/or colours used to help people find their way around? ☐
- **H** Are individual's front doors personalised e.g. through the use of names, numbers or colours? ☐
- **I** Have strong patterns been avoided e.g. in wall coverings, furnishings and flooring? ☐
- **J** Are large faced clocks, a calendar and orientation board easily visible in communal areas? ☐

16

16

Housing – Safety and security



Questions

Please score each answer from 1 - 5
(1=barely met, 5=totally met)

- **A** Are houses/flats big enough for residents to have their own furniture and personal possessions? ☐
- **B** In communal areas are notices kept to a minimum to avoid distraction and confusion and are spaces kept clutter free? ☐
- **C** Have noise absorbent surfaces been used e.g. on floors and ceilings, to aid noise reduction? ☐
- **D** Is background noise kept to a minimum including doorbells and alarm systems? ☐
- **E** Are doors to exits clearly marked but 'staff only' areas, disguised e.g. by painting the doors and door handles in the same colours as the walls/ having no architrave/ continuing the handrail and skirting across the door? ☐
- **F** Are the emergency cords clearly distinguishable from lighting cords in all rooms? ☐
- **G** Has the installation of timers, sensors and shut off valves been considered? ☐
- **H** Are all hazardous liquids and solids e.g. cleaning materials, in the communal areas locked away? ☐

Driving, a barrier to diagnosis

- 1 in 3 PLwD legally continue to drive, but as disease progresses a time will come to stop. Due to safety and the complex tasks involved with driving.
- Once diagnosed with dementia, person has a legal requirement to inform the DVLA and car insurance provider promptly – voided if not informed. GP can follow-up if concern
- DVLA will ask PLwD to complete a questionnaire and DVLA will ask for medical reports from GP, DVLA will review information and either;
  - Renew (annually)
  - Revoke licence
  - Ask for more information
  - Request on road driving assessment – the PCDP or GP are able to refer to Cornwall Mobility for Ax for free test or £175

Depression and anxiety – more common in early stages

Talking therapies (CBT)

Reminiscence and life story work

Stay active

Talking to friends and family

Health diet

Reduce alcohol and caffeine intake

Anti-depressants – no more effective than placebo in PLwD.

Meta-analysis <20,000 carers - 31% prevalence depression among family carers of PLwD

Collins R, N., and Kishita N., (2020) prevalence of depression and burden among informal care-givers of people with dementia. A meta-analysis. Aging and Society https://doi.org/10.1017/S0144686X19000527

19

Culture and Spiritual

Dementia does not discriminate

- Significant part of a person's identity
- Considering food and drink (institutions need to adapt to maintain adequate nutrition)
- Identify religious and cultural occasions
- Support pre-existing community cultural ties and beliefs
- Bond may have been already created with religious leader (possibility of bringing faith home)
- Form part of person centred activities

20

20

Sex and Intimacy

Older people are not asexual - Part of society when homosexuality legalised (1967), know of famous figures Lily Savage (1997).

Important aspect of many people's lives (self-esteem, confidence, stress relief and emotional bond).

Sex or intimacy may change with dementia (less rationale/intellectual more emotional/feelings) a diagnosis can help understand changes.

Challenges; incorrectly identifying partner, new partners, ending relationships, apathy

Both partners need to consent, dementia does not automatically mean a person lacks consent

Challenging sexual behaviour – share concerns, distraction techniques, minimise opportunity (gender opposite sexual attraction, encourage independence and privacy) consider what the triggers might be to reduce incidences (hot environment, personal care)

https://www.alzheimers.org.uk/get-support/daily-living/sex-intimacy-dementia#content-start
https://www.micra.manchester.ac.uk/research/pastprojects/opus/

21

21

HOW WOULD REDUCE RISK OF FALLS AND FATIGUE?

Falls are usually multifactorial in origin;

- Continence
- Cognition
- Foot inspection and footwear
- History (doing what, when, any prior signs)
- Medication
- Strength, balance, joint range of movement
- Vision
- Environment

Fatigue (Mental/Physical)

- Education (activity, sleep/rest, triggers)
- Pacing
- Breathing techniques
- Guided (by them) activity/exercise
- Organise work/living space

For both falls and fatigue signpost via GP (Care Home/Domiciliary) or refer via single point of access (CFT/RCHT)
https://forms.office.com/Pages/ResponsePage.aspx?id=sITDN7CF9UeyIge0jXdO4yLILELGL-1Fu3YMVUeVt8tUMEkzVIJLWVIYTjdJRUIIWVZKSTdJWDUxWSQIQCN0PWcu

22

Thank you

References

Alzheimer's Society (2018) bookcase analogy available at https://www.youtube.com/watch?v=WQ9uSR22qkI accessed on 18th January 2023
Alzheimer's Society, How does dementia affect sex and intimacy? Available at https://www.alzheimers.org.uk/get-support/daily-living/sex-intimacy-dementia#content-start Accessed on 18th January 2023
Association of Dementia Studies (2020) Environment Assessment Tools available at https://ext-webapp-01.worc.ac.uk/kings_fund Accessed 18th September 2022
Learning with experts (2023) Preventing and coping with disease available at https://www.learningwithexperts.com/classrooms/12210/lessons/736 accessed on 28th June 2023
Learning with experts (2023) The importance of purpose and planning available at https://app.frame.io/presentations/de3a95c8-1a60-4171-b5ca-c906b79ce344 accessed on 28th June 2023
Livingston et al (2024) Dementia prevention, intervention, and care: 2024 report of the Lancet standing Commission Lancet vol 404 issue 10452 pg. 572-628
Metropolitan Police (2023)Herbert Protocol available at https://www.met.police.uk/SysSiteAssets/media/downloads/central/advice/herbert-protocol/herbert-protocol-form.pdf Accessed on 6th July 2023
Natural England (2016) Is it nice outside? - Consulting people living with dementia and their carers about engaging with the natural environment available at https://publications.naturalengland.org.uk/publication/5910641209507840 accessed 10th July 2023
Woods et al (2023) Cognitive Stimulation to improve cognitive functioning in people with dementia. Available at https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD005562.pub3/full accessed on 10th July 2023

Any questions?

paul.cadger@nhs.net