Dementia beyond Disease:

Enhancing Well-Being

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Seminar

Alzheimer Society—Faroe Islands

9 & 10 October 2023

Welcome and Introductions

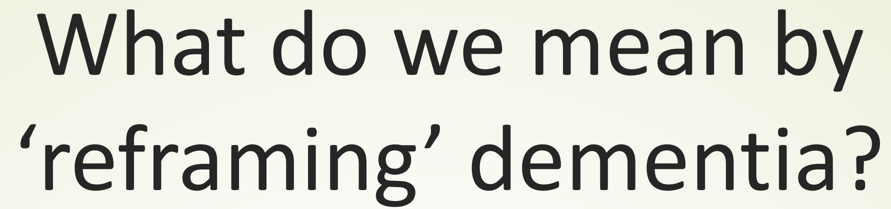
Al Power and Jessica Luh Kim

Opening Exercise

Perspectives

'The only true voyage of discovery . . . would be not to visit strange lands, but to possess other eyes, to behold the universe through the eyes of another, of a hundred others, to behold the hundred universes that each of them beholds, that each of them is . . .'

- Marcel Proust



What do we mean by ‘reframing’ dementia?

- We do not invent anything new
- We do not deny the existence of brain disease or injury
- We learn to look at the condition through ‘different eyes’, and expand our view beyond narrow structures, rules and approaches
- We emphasise the importance of learning from people living with the condition and trying to appreciate each person’s unique perspective
- In doing so, we can find new solutions for living better, *AND*
- At the same time, our insights will challenge many long-held views about dementia and supporting people who live with the diagnosis

- I will share some information that is agreed upon by most specialists in dementia
- I will tell you when I am sharing an idea of mine that challenges or diverges from the ‘conventional wisdom’ of more traditional approaches, *and*
- I will support my views with evidence and/or specific examples

My story:

- Private practice in internal medicine
- Switch to geriatrics and residential care
- Involvement with transformational movements (The Eden Alternative, The Green House Project, and Pioneer Network)
- Criticising the use of antipsychotic drugs in dementia
- Applying transformational concepts to our view and support of people living with dementia
- Career change to education and consulting work

What is Dementia?

- **What we know:**

- Dementia is a *syndrome* with over 100 causes
- Brain changes identified as 'Alzheimer's' are seen most often
- There are problems with several types of thinking, and they are permanent and severe enough to affect daily life
- Dementia is progressive in most people and death often occurs due to complications of dementia
- There is currently no way to cure, reverse, or stop the progression of dementia
- BUT there are many things we can do to live more fully with the diagnosis

What (in my opinion) we still *don't* know about dementia:

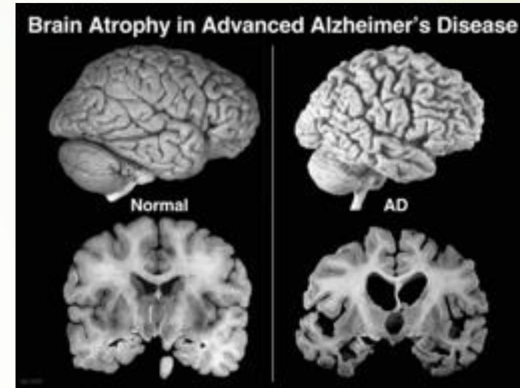
- The causes of Alzheimer's
- If Alzheimer's is truly a single 'disease'
- What role amyloid plays (vs. many other abnormalities)
- Whether reducing amyloid is beneficial
- How 'Mild Cognitive Impairment' is related to dementia
- Why we spend so much money on trying to find a cure while spending so little on addressing the many underlying risk factors

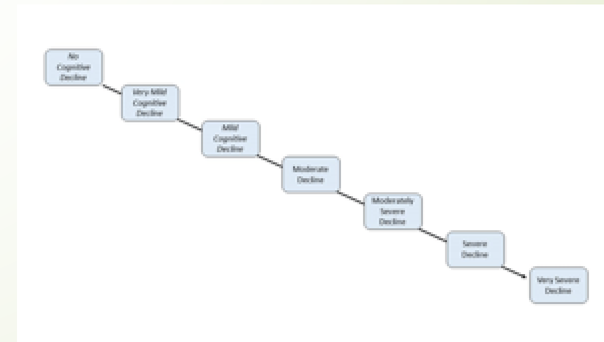
What medical questions do you have about dementia?

The result of all these questions

- The brain is incredibly complex (100 trillion nerve connections!)
- People are complex and unique too
- None of the above medical information tells us about the ***person***, or about their strengths
- None of the above truly helps us to help people to live better ***today***; and that is the primary role of those of us who are not doing drug research!
- Furthermore, a narrow biomedical view of dementia has many deleterious effects on people living with the diagnosis

The Biomedical Model of Dementia





Fallout from a Narrow Biomedical View

Myths & Stigma

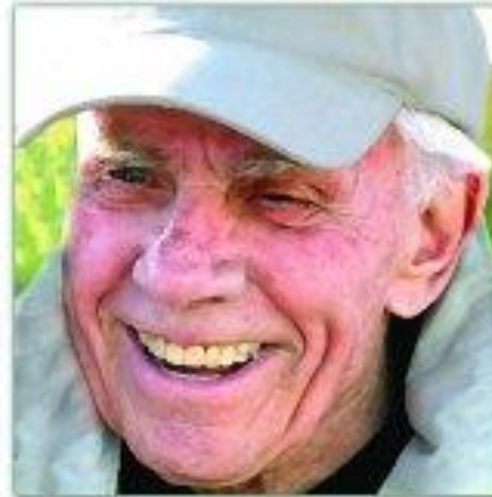
Looking to pills for well-being

Disempowerment

'Dementia Care'

'BPSD'

Example of stigma: Ed Voris' story

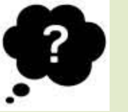


Biggest Danger of Stigma → Self-Fulfilling Prophecies

Kate Swaffer

The problems with cognitive scores and staging systems

- They reduce people to a number



- Is a person with dementia just their cognitive score? Are you just your school grade average??

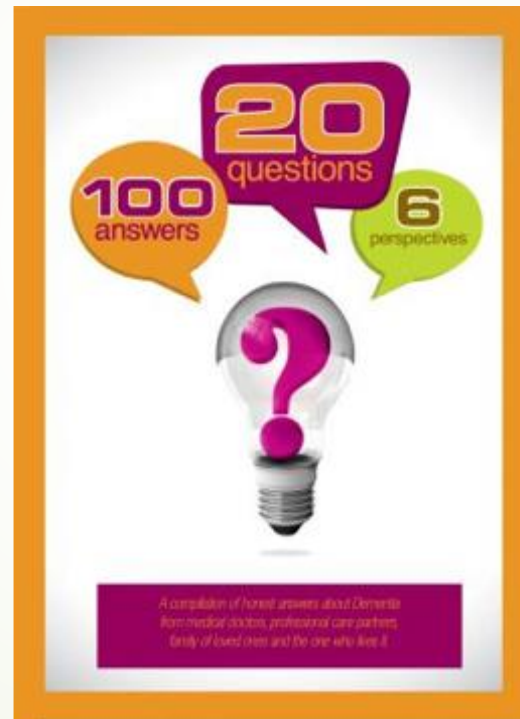
- They 'pigeonhole' and stereotype people
- They do not recognise many intact strengths and characteristics of people
- They sell people short
- They lead to unhelpful practices

- Should you only live with other people who had the same school grades? Should you only be offered activities with those people, and will you all like doing the same things??

Myths and stereotypes

- People with dementia cannot make decisions
- People with dementia cannot learn or grow
- People with dementia become like children again, and we must ‘parent’ our parents
- People with dementia are fading away

Are people with dementia fading away???



Steven Sabat, PhD (DAI webinar, 2015)

Abilities often preserved into advanced dementia

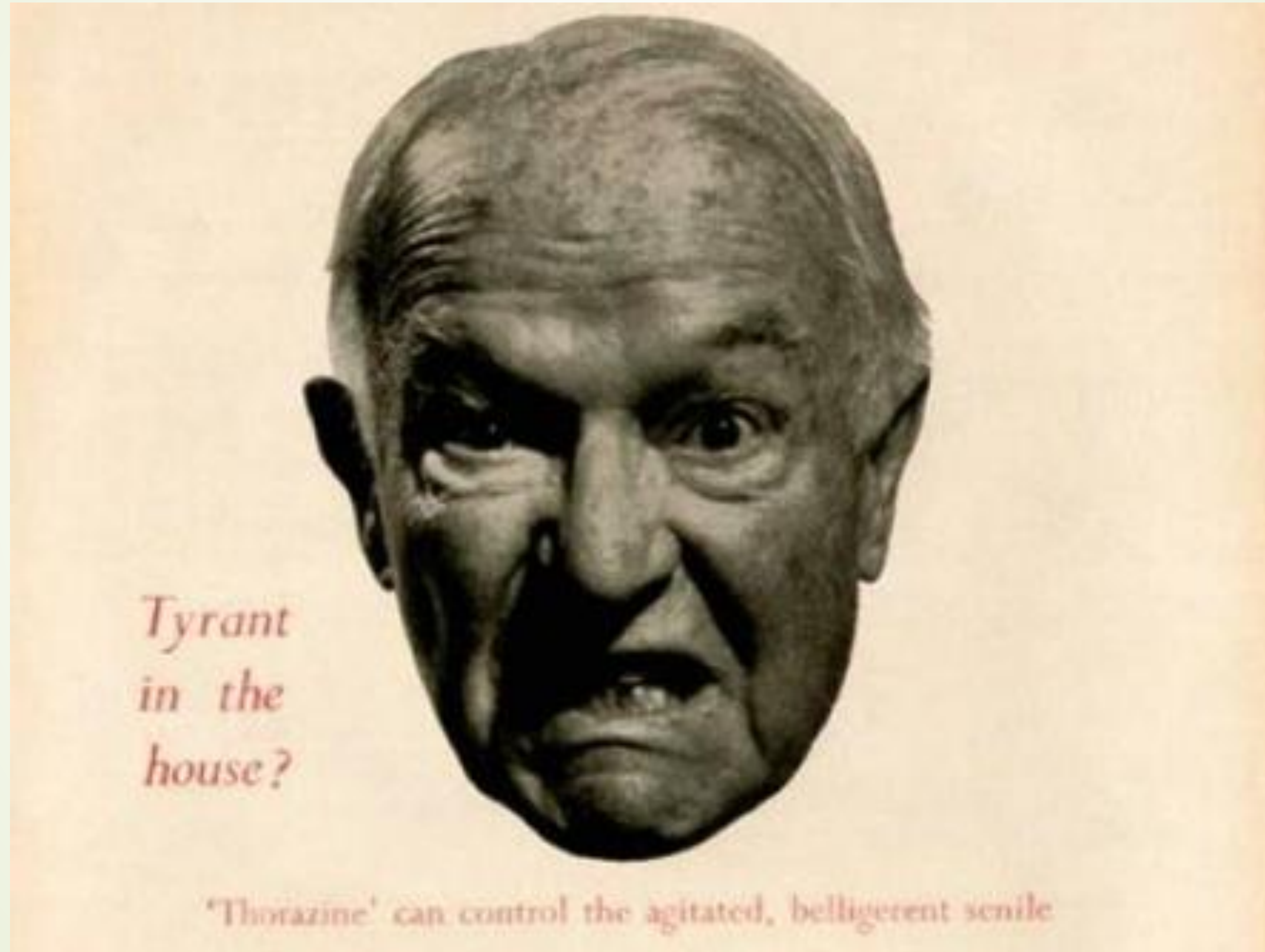
- Experiencing pride and maintaining dignity (as well as experiencing shame and embarrassment)
- Feeling concern for others
- Communicating feelings with assistance from a facilitator or by using nonverbal aids
- Maintaining self-esteem
- Manifesting spiritual awareness

- Learn new information—implicitly and explicitly
- Access memories and language with the proper stimuli (music, art, etc.)
- Read a book to a child
- Sing and play music
- Create art
- Teach a recipe
- Create stories (e.g., TimeSlips)

And…many people with dementia can…

- Teach others about what it is like to have dementia
- Give input into care plans
- Advise on dementia education programs
- Give input into design and renovations
- Lead and engage in peer conversations
- Survey care homes through ‘other eyes’ (Agnes Houston)
- Participate in volunteerism
- Etc., etc., etc.

Reframing ‘Behaviours’



Do We Hold People Living with Dementia to a Higher Emotional Standard than Ourselves??

You and I	People with Dementia
Walk, explore, do our ‘steps’, or just get bored and leave	‘Wander’, ‘elope’, or ‘exit-seek’
Get restless when forced into others’ rhythms	‘Sundown’
Shop in bulk	‘Hoard’
Get angry, sad, anxious or frustrated	Exhibit ‘challenging behaviours’
Don’t like being locked up, bossed around or touched by strangers	Are ‘resistive’, 'agitated’, or ‘aggressive’

The Problem with ‘BPSD’

(‘Behavioural and Psychological Symptoms of Dementia’)

- Attributes people’s expressions to brain disease
- Ignores relational, environmental and historical contexts
- Pathologises normal expressions
- Creates a slippery slope to drug use
- Does not explain how drug use has been successfully eliminated in many care homes
- Misapplies psychiatric labels, such as psychosis, delusions and hallucinations
- Has led to inappropriate drug approvals in many countries

Is Dementia Really the ***Root*** *Cause* of the Person's Actions??

- Note: The brain changes are very real! People can especially experience difficulties with:

  - Retrieval of information and memories
  - Verbal communication
  - Coping skills and 'social filters'
  - Executive function

- As a result, the changes of dementia can ***modify*** a person's response to a situation, but that is very different from saying that brain disease is the ***root cause***

Words and Actions May Represent:

- Unmet needs **/** Challenges to well-being*
- Sensory challenges*
- New communication pathways*
- Expressions of agency*
- New ways of interpreting and problem solving*
- Response to physical or relational aspects of environment*
- May be perfectly normal reactions, considering the circumstances!*

(*NO medication—*or* 'non-pharmacological intervention'—will help these!)

The Story of Ray

What medication would have helped Ray???

A few more examples

- Trying to exit a living area is ***not*** abnormal. What is abnormal is locking people in and not letting them leave!
- Resisting being undressed by someone you don't recognise is ***not*** abnormal! (What would *you* do??)
- Wanting to do things your way, at your pace, or on your terms is ***not*** abnormal!
- Being angry if you've expressed a concern to someone and they try to correct you, distract you, redirect you or lie to you is ***not*** abnormal!

Or, to put it musically…

https://www.youtube.com/watch?v=eiolJQ4Kgws

1) Antipsychotics are largely ineffective and potentially dangerous
2) In fact, there is no biochemical rationale for using antipsychotics other than sedation, (including Lewy body dementia)

BUT…

Antipsychotics are *not* the root problem!

*The **real** problem is the idea that people need a pill!*

Checking the Cows
Why 'Nonpharmacological Interventions' Do not Work!

The typical 'nonpharmacological intervention' is an attempt to provide person-centred care with a biomedical mindset

- Reactive, not proactive
- Discrete activities, often without underlying meaning for the individual
- Not person-directed
- Not tied into domains of well-being
- Treated like doses of pills
- ***Superimposed upon the usual care environment***

Shifting Paradigms:
How would ***you*** respond if you were told:

- 'Over 90% of people living with dementia will experience a BPSD during the course of their illness'.

VS

- 'Over 90% of people living will dementia will find themselves in a situation in which their well-being is not adequately supported'.

Take a break!

What questions do you have so far?

My Key Message

Set aside systems and rules about dementia pathologies, stages or living environments.

The most important factor is the ***overall mindset*** we adopt.

A new approach rests upon Three Pillars

- ‘Experiential model of dementia’
- Well-being as a primary outcome
- Transformation of the care environment

A New Definition of dementia

‘Dementia is a shift in the way people experience the world around them’.

Where This ‘Road’ Leads…

- From fatal disease to changing abilities
- From psychotropic medications to ‘ramps’
- A path to continued growth
- An acceptance of a ‘new normal’
- A directive to help fulfill universal human needs
- A challenge to our interpretations of distress
- A challenge to many of our long-accepted care practices
- A radical re-shifting of ‘expertise’

Exploring Well-being

Question:

*What gives **you** a sense of well-being?*

Well-Being Framework

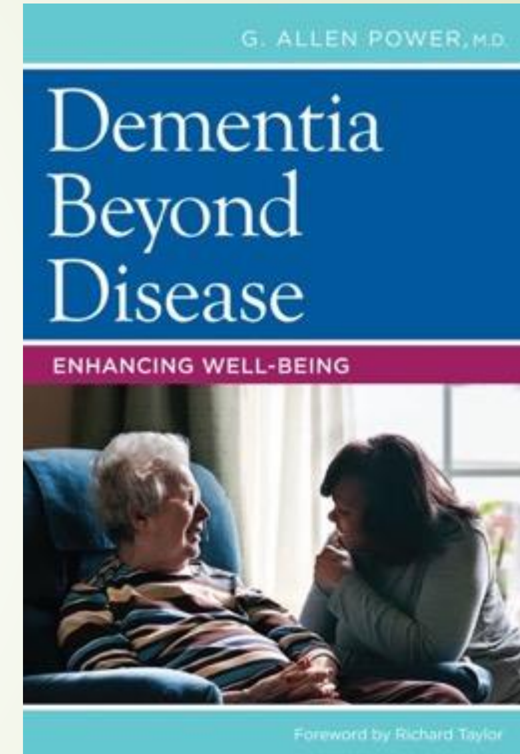
Focusing on Enhancing Well-Being

'Well-being is a much larger idea than either quality of life or customer satisfaction. It is based on a holistic understanding of human needs and capacities. Well-being is elusive, highly subjective, and the most valuable of all human possessions'.

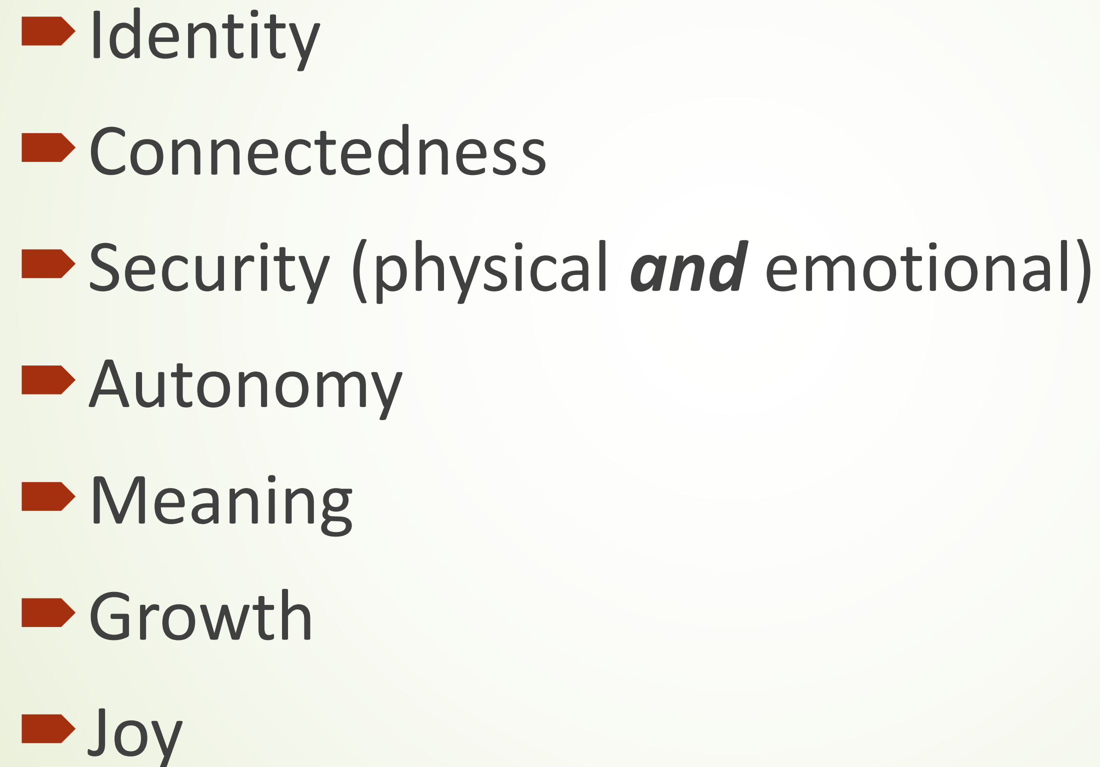
- Dr. Bill Thomas

One framework for viewing well-being

Well-being pyramid from *Dementia Beyond Disease: Enhancing Well-Being*, by G. Allen Power. Published by Health Professions Press. Copyright © 2017



In Faroese:



- Identity
- Connectedness
- Security (physical ***and*** emotional)
- Autonomy
- Meaning
- Growth
- Joy

Discuss with a Friend

What Gives You a Sense of Well-Being?

Identity:

Connectedness:

Security:

Autonomy:

Meaning:

Growth:

Joy:

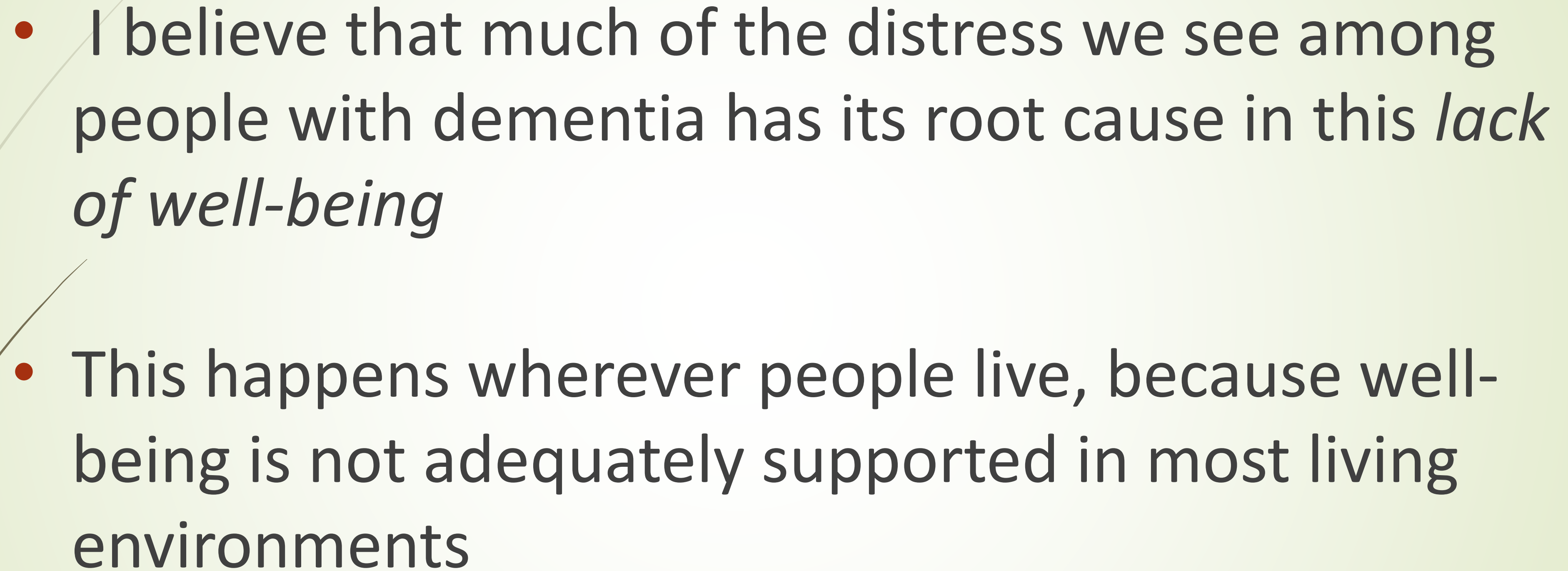
- **Find** a partner.
- In your pairs, you will **interview** each other.
- You will **ask** your partner “*What gives you a sense of well-being?*”.
- **Answers** must relate to each of the 7 domains of well-being.
- Please **document** the answers on the provided form.
- You have **5 mins** per interview.

‘When we change the way we look at things, the things we look at change’.
Wayne Dyer

Why Use a Well-Being Approach?

- Well-being needs are universal, regardless of age, culture, nationality, faith tradition or the presence/absence of illness
- People who are chronically ill or have dementia have difficulty maintaining their own well-being without assistance
- Most carers do not learn about well-being, and therefore are unaware of the need to to actively support it, and…
- Furthermore, many of our usual daily operations and interactions may even *worsen* people's well-being

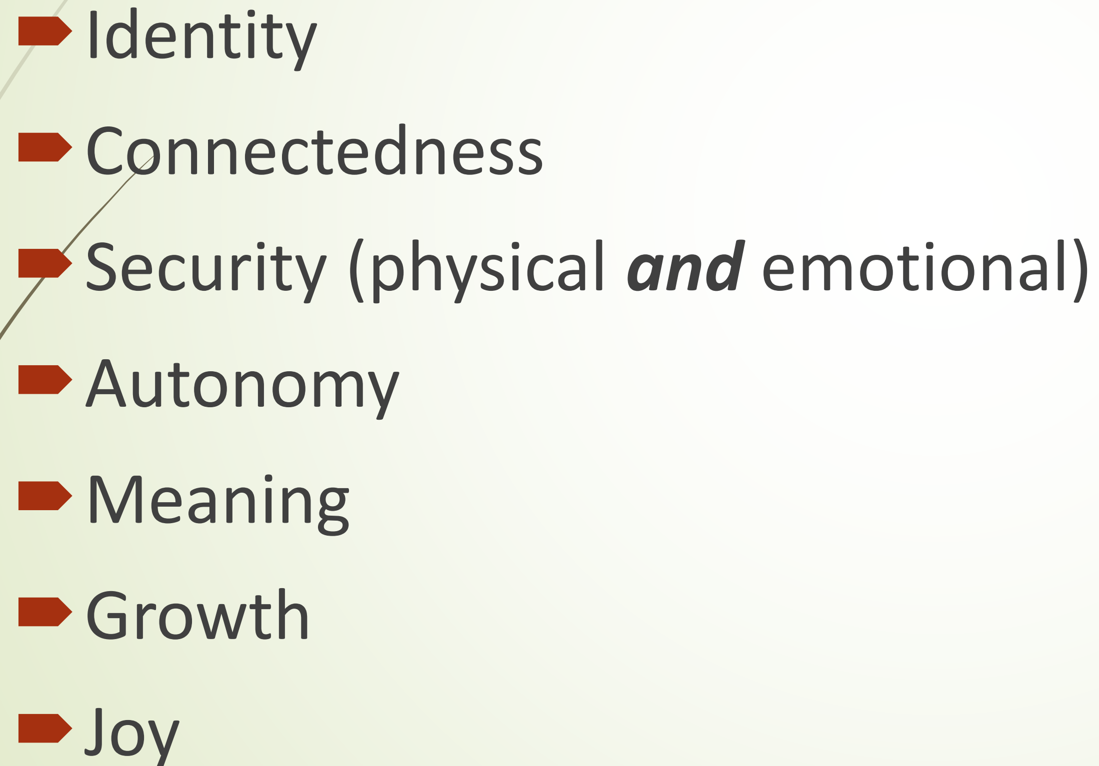
Therefore…


I believe that much of the distress we see among people with dementia has its root cause in this *lack of well-being*
This happens wherever people live, because well-being is not adequately supported in most living environments

The ‘Punchline’…

- *What if most of the hard-to-understand distress that we see is related to the erosion of one or more aspects of the person’s well-being??*
- Well-being is a need that transcends all ages, abilities, and cultures, and yet…
- There is ***no*** professional training program that teaches about well-being and how to operationalise it…
- *So… is it any surprise that people we care for have ongoing distress, even though we have ‘done everything we can think of’ to solve it???*

A strengths-based framework



- Identity
- Connectedness
- Security (physical ***and*** emotional)
- Autonomy
- Meaning
- Growth
- Joy

- When gathering information upon moving in
- At routine care plans
- At case conferences held due to distress or other concerns
- At daily shift huddles
- In the community for any professional, family care partner or any worker in a public area who is trying to understand a person in distress

Advantages of a well-being focus

- It is *proactive* and *strengths-based*
- It can be helpful regardless of a person's diagnosis or level of ability
- It provides *resilience and reserve* for people who live with chronic conditions or in challenging situations

What a well-being approach is NOT:

- It is ***NOT****: Only reacting to distress in the moment or providing a temporary intervention to calm someone.*

- *It* ***IS****: A series of supports that are implemented 24/7 to build an environment supportive of the well-being domains.*

Walkaround activity

What are some ways that we might *proactively* support each domain of well-being for people living with dementia?

An example of a ‘ramp to well-being’: Improving our Communication Skills

Good Communication

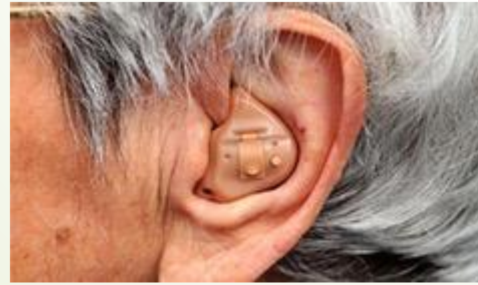
Is

Empowerment!!!

First Steps…

- Re-establish the relationship

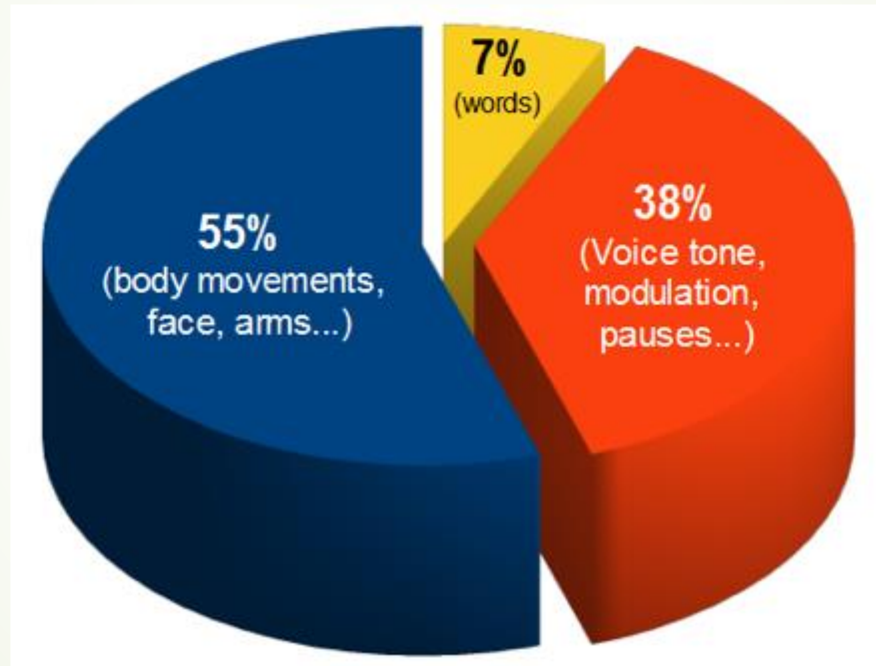
- Optimise comfort, hearing, and vision



3 Reasons to sit down…

Presence (consapevolezza)

Body language



Mehrabian, A. *Silent Messages.* c.1972 Wadsworth Publishing (now Cengage).

The ‘verbal-nonverbal connection’

Speaking

- Slowly and clearly, mirror pace of person
- Do not ‘talk down’ or patronise
- Do not address like a child
- Be genuine
- Enunciate consonants if hard of hearing—don’t speak too loudly
- Speak as you would to any other person

Christine Bryden

Dancing with Dementia

'As we become more emotional and less cognitive, it's the way you talk to us, not what you say, that we will remember.

'We know the feeling, but we don't know the plot. Your smile, your laugh, and your touch are what we will connect with'.

- Mindfulness
- Focus on the person
- Open, accepting presence, body language
- Pay attention to the person's emotional content and body language
- Always validate feelings
- Watch for 'embodied expressions' of choice

Other communication tips

- Give people enough time to speak
- Don’t cut them off, but do help fill in ideas and confirm understanding
- Rephrase questions to help get people ‘unstuck’
- Speak to the underlying feelings
- **‘Speak like a sports interviewer’**

What questions, comments, or stories do you have, related to what we discussed this morning?

Vælgagnist!

Transformational Models of Care

Transformation

- **Personal**: Both *intra-personal* (how we see people living with dementia) and *inter-personal* (how we interact with and support them).
- **Physical:** Living environments that support the values of home and support the domains of well-being.
- **Operational:** How decisions are made that affect people with dementia, fostering empowerment, how communication occurs, and conflict is resolved, creation of care partnerships, job descriptions and performance measures, etc., etc.

#
Some Examples of Operational Transformation

- Consistent staff assignments
- Flexible wake-up times and breakfasts
- ‘Household’ staffing model with versatile workers
- Resident input into daily routines, activities, renovations, hiring

- Smaller is better ('Size is more important than décor'—Emi Kiyota, PhD)
- Variety of levels of engagement
- Privacy
- Access to the outdoors and natural light
- Attention to lighting, sound, flooring, colour and contrast
- Wayfinding cues
- 'Would we do this at home?'

Zimmerman, et al.

(*JAMDA*, 25 January 2021)

- Studied the Green House model in US
- *Significantly lower* COVID cases *and* mortality, compared to both small and large traditional homes
- Beneficial factors include small households, private rooms with *en suite* baths, consistent staffing and low agency use, versatile staffing, access to outdoors, flexible gathering spaces, etc.

New environmental guide

https://the-ria.ca/wp-content/uploads/2021/11/Supporting-comfort-and-belonging-for-people-living-with-dementia-RIA-Resource-FNL-2.pdf

- Follows a more enlightened view of dementia
- To be used by staff and residents, not just architects and leaders
- Looks not just at physical features, but operational, interpersonal, sensory changes, well-being domains, etc.
- Can be used to look at the living area for all, ***or*** to investigate one individual person's distress
- Can be broken into sections for huddles etc.; includes action planning sections

Understanding distress: Consider three 'audits'

Medical Audit (not always necessary)

Environmental Audit

**Experiential Audit (Well-Being Approach)*

When to consider a medical evaluation?

- There is an expression that is very unusual for the person
- There is an expression in conjunction with physical signs or symptoms (low-grade fever, grimacing, change in breathing, etc.)
- There is any suggestion of discomfort
- A person is a bit more *lethargic* than usual

- Pain
- Infection
- Drug reaction
- Other medical illnesses (heart failure, abdominal problems, etc.)

Physical Discomfort

- Does not have to be due to severe pain or injury
- May be seen during personal care or movement, and/or after periods of immobility
- May be more prevalent later in the day
- Can see recent falls or signs of injury

Physical Discomfort (cont.)

- Untreated pain can be a cause of delirium
- Can be related to medication side effects
- Can be related to bowel/bladder needs
- Many people, even with advanced cognitive changes, can still answer when asked about pain
- If unable to answer, use an observational scale such as PAINAD

Pain Assessment in Advanced Dementia Scale (PAINAD)

Behavior	0	1	2	Score
Breathing Independent of vocalization	• Normal	• Occasional labored breathing • Short period of hyperventilation	• Noisy labored breathing • Long period of hyperventilation • Cheyne-Stokes respirations	
Negative vocalization	• None	• Occasional moan or groan • Low-level speech with a negative or disapproving quality	• Repeated troubled calling out • Loud moaning or groaning • Crying	
Facial expression	• Smiling or inexpressive	• Sad • Frightened • Frown	• Facial grimacing	
Body language	• Relaxed	• Tense • Distressed pacing • Fidgeting	• Rigid • Fists clenched • Knees pulled up • Pulling or pushing away • Striking out	
Consolability	• No need to console	• Distracted or reassured by voice or touch	• Unable to console, distract, or reassure	
			TOTAL SCORE	

(Warden et al., 2003)

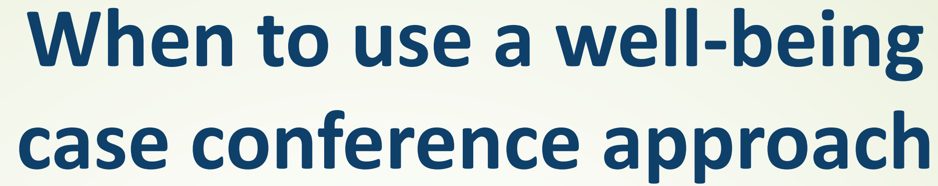
Sourc[illegible]t and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. *J Am Med Dir Assoc,* 4(1), 9-15.

Environment

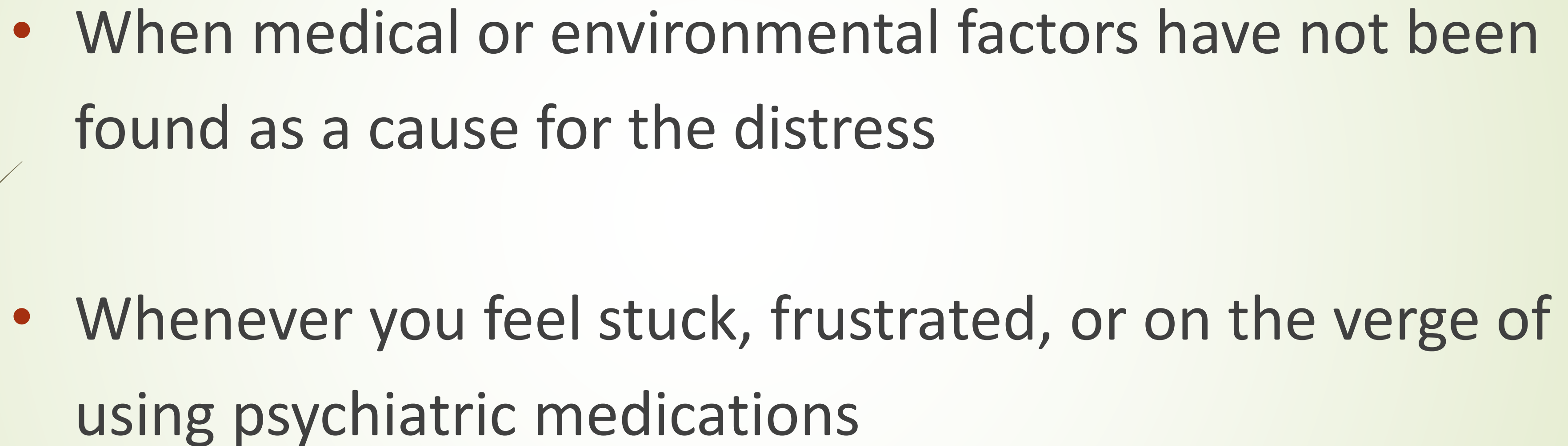
- Over- or under-stimulation
- Bowel bladder issues
- Hunger/thirst
- Environmental sounds
- Heat/Cold
- Interactions with others
- Getting ‘stuck’

The Well-Being Case Conference Approach to Distress (Power, 2014)

People who wonder whether the glass is half empty or half full miss the point. The glass is refillable.



When to use a well-being case conference approach



- When medical or environmental factors have not been found as a cause for the distress
- Whenever you feel stuck, frustrated, or on the verge of using psychiatric medications

How do we measure well-being in a case conference?

- First, speak to the person to see if they can give input
- Look at each domain of well-being as a drinking glass ranging from empty to full
- Try to look through the person's eyes, see what they see and feel what they feel, *without judgment*
- Estimate as a group how full each glass is currently for the person, from 0 – 100% (*if* the person is not able to tell you themselves)
- Draw a corresponding level on the glass to get a picture of each domain

The Well-Being Approach using Daily Shift Huddles

J. Carson /

Step 1: Assess Resident's Well-Being

- **Huddle 1 / Day 1**: Assess a specific resident's well-being
- **Huddle 2 / Day 2:** Discuss what's working well to support well-being

Step 2: Share Ideas for Improvement and Develop a Well-Being Plan

- **Huddle 3 / Day 3**: Review Huddles 1 and 2 and share ideas for how to better support well-being
- **Huddle 4 / Day 4**: Open discussion; work collaboratively to develop a proactive well-being plan
- As appropriate, **discuss well-being plan with resident and family member(s)**; then finalise, share with team, and **take action!**

Step 3: Reflect on the Well-Being Plan

- **Huddle 5**: How well is the plan working and what adjustments might be needed to achieve the best outcome?

The Key (and it is not easy)…

Turn your backs on the 'behaviour' and build the 'ramps' to well-being!

Source: Public Health Sudbury & Districts www.phsd.ca

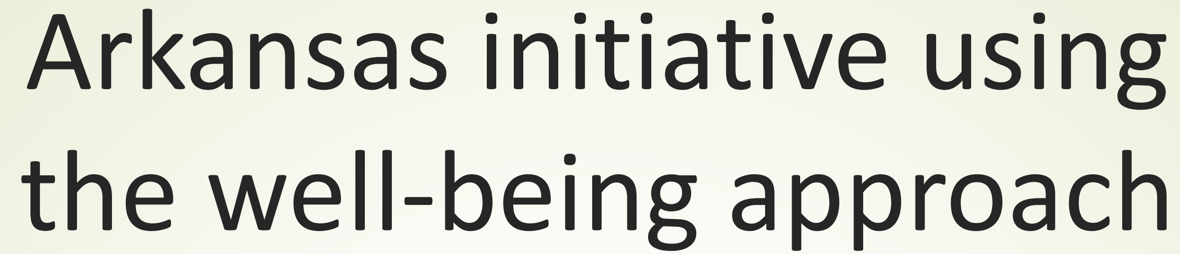
Let’s try it!

Case Discussion using the Well-Being Approach

Pause

True Stories…

Angela Norman, D-NP



- Instructional seminars and in-home coaching
- Well-being domains used proactively in care plans, as well as case conferences
- Hotline for challenging situations
- Antipsychotics cut 50% to an **average of 6.7% across 92 care homes in 2 years**, from 2017-2019
- ***No*** increase during the pandemic
- **Discharges to acute Geri-psych units cut by 74%**

Only ‘semantics’??

- US National Institute of Ageing $11.2M grant to five centres to administer electroconvulsive therapy (ECT) to people living with dementia with ‘severe BPSD’
- ECT is a highly invasive procedure; data on long-term safety in people with pre-existing dementia is not known
- Subjects were chosen from Geri-psych units

But… what if those people had lived in Arkansas??

Questions about the Well-Being Approach??

‘Sundowning’ and ‘Psychosis’

To see these differently, we must recognise that the person’s brain is *very active and engaged*, assessing the environment, making sense and problem solving as well as able.

‘Sundown Syndrome’

- As with the BPSD argument, consider the changes of dementia as modulators, rather than the root cause
- I make attendees ‘sundown’ in my day-long seminars all the time (some of you may be doing so now, and it’s not even 1300!)
- Being forced into others’ rhythms and needing to concentrate for long periods without rest can cause mental fatigue, which along with dementia, increases the risk of confusion and distress
- Environmental, operational and interpersonal triggers can also confuse those who struggle to hold onto a sense of time

Two examples of "sundown cures"

- Beatitudes campus, Phoenix, AZ: Removing triggers and 'rest as needed' policy
- Enhanced Support Neighborhood at Erin Mills Lodge, Mississauga, ON (opened 2021 to decompress acute care system of its most 'challenging' residents): effects of 12-hour shifts (7-7)

‘Psychosis’

- The Experiential model of dementia contends that most ‘hallucinations’ and ‘delusions’ are misdiagnosed and instead are the brain’s way of understanding the world, while compromised by:

  - limited information

  - language barriers

  - hyperattention to nonverbal cues, and/or

  - reactions to imposed operational challenges.

- As such, these are not truly psychosis, biochemically or phenomenologically
- Dementia is virtually always a condition of brain dopamine depletion (unless we are prescribing it for Parkinsonian forms). Therefore, dopamine blockage has no rationale.

‘Psychosis’, (cont.)

- At least one noted neurologist supported this view, saying that many of the ‘hallucinations’ of dementia are ‘embedded in a complex matrix of sensory deceptions, confusion, disorientation, and delusions.’ (Sacks, *Hallucinations*, 2012).
- In Lewy body dementia, the the visual cortex is damaged, causing various visual phenomena. Once again, this is not true psychosis and not amenable to dopamine blockade.
- But even the notion of ‘delusions’ can be largely refuted with an empathic application of the well-being approach.

Al's *Wheel of Fortune* explanation of 'delusions'

(now being taught at UC-Irvine gerontology classes)

Wheel of Fortune

- Imagine a board with this puzzle:

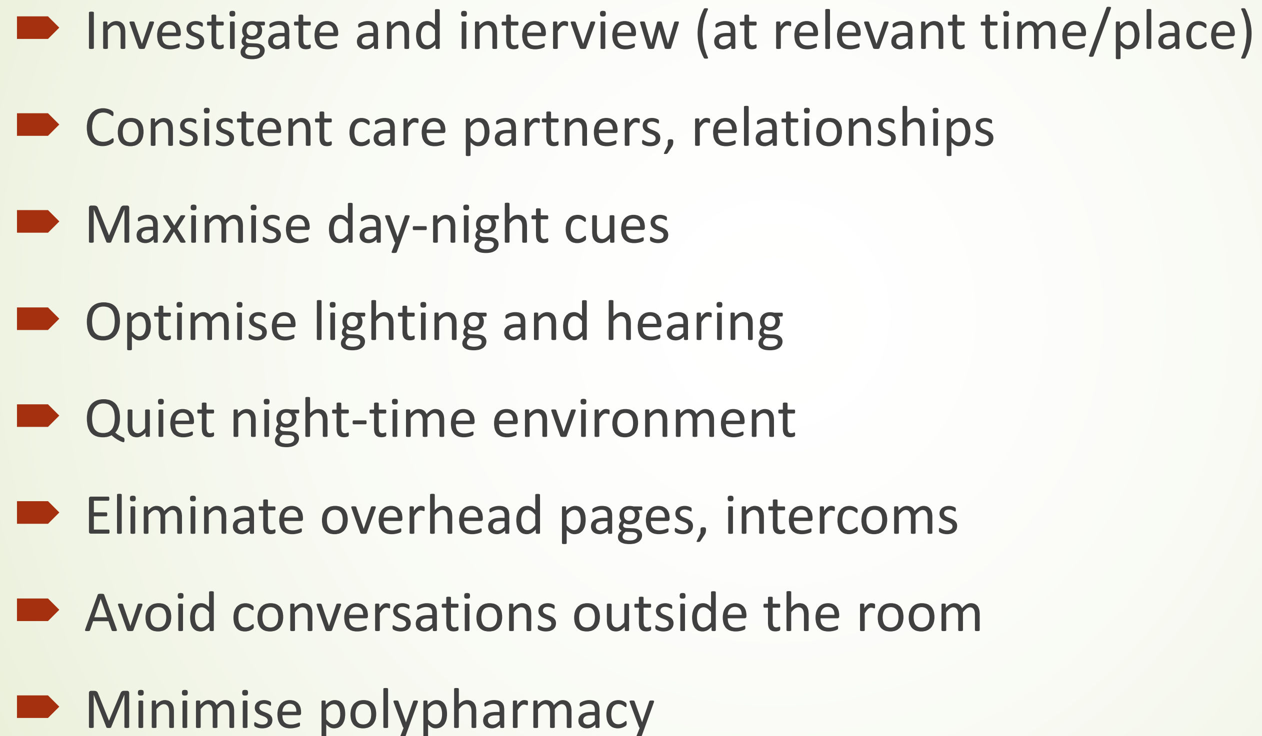
  S _ _ _ _ _ _ OF L _ _ _ _ _ _ Y

- A relaxed contestant may solve it immediately ('Statue of Liberty'), but one who is nervous and less able to work it out on the spot out might say, 'Stacks of Laundry' or 'States of Lunacy'. Those are incorrect (and rather humorous), but *not* delusional.
- Risperidone will not help the contestant solve the puzzle!!
- With dementia, people are trying to fill in gaps in memory/information as best they can, using environmental cues. They often come to a different conclusion. That is not the same as a delusion.

Exercise:
Don't jump to conclusions about those delusions!

- ‘They don’t like me here’
- ’Someone stole my purse’
- ‘I hear voices at night’
- ‘My children will be home from school soon’
- ‘I was raped’
- ‘They are poisoning the food’

A few non-pharmacological approaches


Investigate and interview (at relevant time/place)
Consistent care partners, relationships
Maximise day-night cues
Optimise lighting and hearing
Quiet night-time environment
Eliminate overhead pages, intercoms
Avoid conversations outside the room
Minimise polypharmacy

Are you caring for your *own* well-being?

Action Planning time

Hard to get fruit – 1 year

er to reach (6 mos.)

Low hanging fruit (3 mos.)

Harvested fruit (Now)

Closing learning circle

‘We need to see the “humanness” in people with dementia. I believe that as people progress with dementia, their humanity *increases*’. -- Richard Taylor, PhD

Thank you!
Questions?