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Employing the Need-Driven Dementia Behaviour Model (NDB) and Person-Centred Care (PCC) to improve care and well-being for persons with dementia

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Evidence-based models of care

…bring a message of HOPE amidst the devastating effects of dementia.

Outline of presentation

A. Explore quality of life factors most important to the person with dementia
B. Understand behaviour as communicating needs and feelings
C. Use case studies to apply the NDB model in order to understand the factors causing agitation, apathy and aggression
D. Identify how to apply Person-Centred Care to avoid and reduce need-driven behaviour

What matters most to the person with dementia?

A sense of security-feeling safe
A sense of continuity- experiencing links between the past, present and the future
A sense of belonging- having a "place"
A sense of purpose- having direction
A sense of fulfilment- feeling of getting somewhere meaningful
A sense of significance- feeling you matter

(Kitwood 1993/7; Eales, Keating & Damsma 2001; Clarke, Hanson & Ros 2003; Hubbard 2002)

Impact of dementia on achieving quality of life

- multitude losses are occurring-cognitive, emotional, social, physical
- loss is characterised by disconnectedness in self-perception, awareness and response
- loss of self-perception can lead to disorientation, apprehension, distress, anxiety, depression, ambivalence, elation, withdrawal, perseveration
- these expressions are often labelled 'Behavioural & Psychological Symptoms of Dementia' (BPSD)
- quality of life suffers if the BPSD label negatively influences care and therapy delivery

What type of behaviours are referred to as BPSD?

ANXIETY

Generalised anxiety disorder

Repeated questions about forthcoming event

Fear of being left alone

Pacing

Wringing of hands, figeting

Chanting

AGITATION

Verbally NON-aggressive

- Negativism
- Chanting
- Repetitive vocalisation
- Constant interruptions
- Constant requests for attention/help

Verbally aggressive

Screaming
Cursing
Temper outbursts
Socially inappropriate comments

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Aggression

1. Physically NON- aggressive	2. Physically Aggressive
General restlessness	Hitting
Repetitive mannerisms	Pushing
Pacing	Scratching
Hiding objects	Grabbing
Inappropriate handling	Kicking
Shadowing	Biting
Escaping protected environment	Spitting
Inappropriate dressing /undressing	

Disinhibition Syndrome

- Impulsive and inappropriate behaviour
- Emotional instability
- Poor insight and judgement

DISINHIBITION

Crying	Euphoria
Aggression	Sexual behaviour
Wandering	Intrusiveness

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DEPRESSION	APATHY
• Self-pity	No interest
• Rejection sensitivity	Withdrawal
• Psychomotor disturbance	Passive
• Not engaging with others/activity	

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Why do persons with dementia display these behaviours?

- Neurological impairment (decrease of chemical activity and brain tissue loss in cortex, basal ganglia and brainstem)
- Poor health
- Poor physical fitness
- Life history of unique experiences/ situations and their impact
- Personality
- Social psychology of the environment

(Kitwood 1993, 1995)

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The A B C of Behaviour

A = Antecedant (trigger)

Every behaviour-positive or negative-is triggered by something-biological, physical, emotional, social

B = Behaviour

Any action is a behaviour

C = Consequence (aftermath)

If a behaviour continues or accelerates there will be a consequence which reinforces the behaviour

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What theories/models can we use to understand and avoid, or reduce, some of these behaviours?

- Need-driven Dementia-compromised Behaviour (NDB) Model
  (Algase et.al. 1996)
- Socio-psychological Theory of Personhood in Dementia
  (Kitwood, 1997a)

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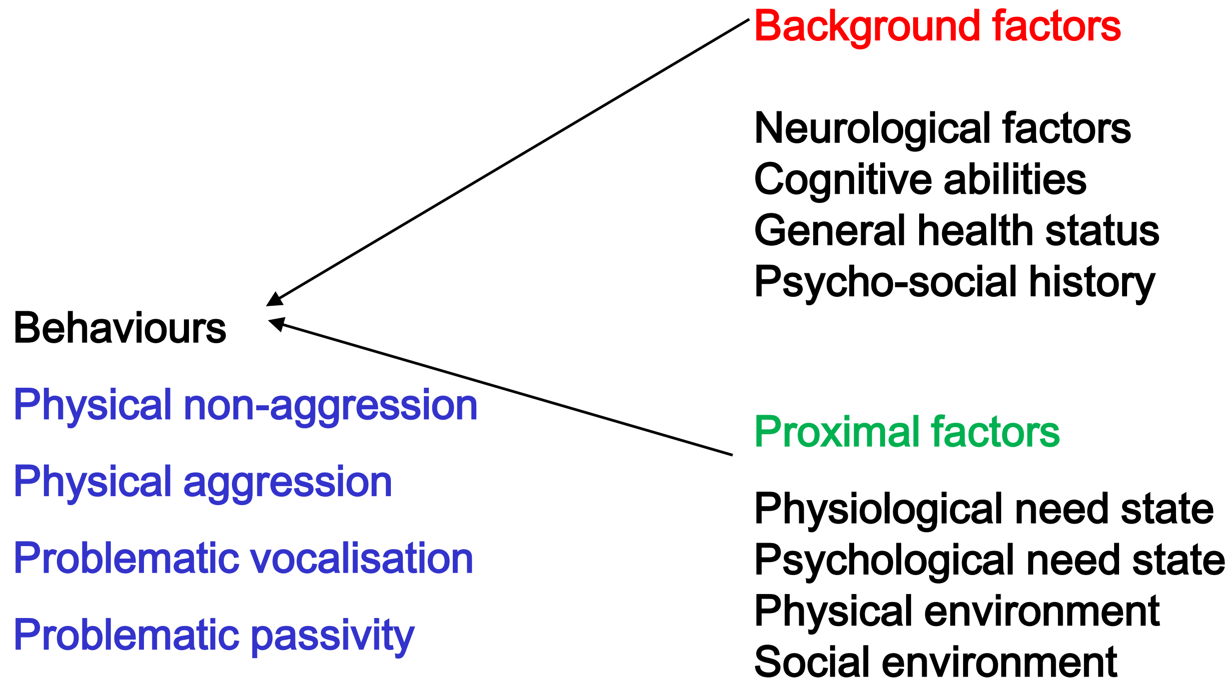
Need Driven Behavioural (NDB)Model



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How does the NDB model help us think about dementia and behaviour?

- **Background factors are characterized as the more enduring characteristics of persons with dementia that place them at risk for dementia behaviors (personality, culture, genetic conditions).**

- **Proximal factors are the more changeable, contextual factors that precipitate dementia behaviors in at-risk individuals (health state, environment, context).**

- **Background and proximal factors dynamically interact with one another.**

- **Some background factors have a direct influence on behavioral symptoms, independent of proximal factors. Other background factors mediate the response to proximal factors to produce behavioral symptoms.**

Penrod, Fang, Kolanowski & Fick. (2007) Reframing Person-Centered Nursing Care for Persons With Dementia. *Research and Theory for Nursing Practice.* 21(1):57-72.

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Socio-Psychological Theory of Personhood in Dementia (SPTPD) Kitwood (1997)

- Derived from Carl Roger's Person-Centred Therapy, where the client is provided with unconditional positive regard in all therapeutic encounters with the therapist
- The distinctive psychosocial environment surrounding the person can lead to disintegration of the person as a whole (ie. personhood can be lost)
- Personhood involves feelings, action, belonging, attachment to others, identity, and achieving one's potential
- If quality of the care and the care environment is not good at a psychological level most persons with dementia will move downwards into some stage of enduring ill-being
- The main goal is to support personhood in dementia

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How do we use the SPTPD model to avoid/reduce need-driven behaviour?

Our primary aim in care and therapy is to promote and support personhood:

- ✓ Attachment- bonds with others in immediate environment as well as from the past
- ✓ Inclusion- group membership & acceptance
- ✓ Comfort-sense of security, warmth, strength
- ✓ Occupation- meaningful activity that utilizes and supports all existing strengths
- ✓ Identity- continuity with the past, present and future

How can the psycho-social environment support personhood?

The care and therapy environment needs to feel:

- ✓ Safe & secure
- ✓ Comfortable and familiar
- ✓ Closeness to trusted others
- ✓ Free from frightening and unknown stimulation
- ✓ Abundant with interesting and recognisable stimulation
- ✓ Accessible for wandering & exploring & personal interaction, and for privacy
- ✓ Linked to wider community happenings and people

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What are identified deficits in organisational structures, funding , resources and policies that reduce opportunities to support personhood?

- Non-individualised care
- Un-skilled dementia trained staff
- Little access to specialist dementia services and therapists
- Task-oriented care driven by organisational schedules
- Little education and poor knowledge of how to support individual personhood
- Use of physical and chemical restraint to reduce behaviour
- Resident distress, injuries, falls, hospitalisation, reduction in function, cognition and well-being
- Staff burden , stress and high turnover

How is behaviour often being addressed in health and aged care settings?

- Staff **DISTRACT** and/or **IGNORE** behaviour and/or the person.
- Staff do not **ENGAGE** with the person's feelings and needs.
- **Care practices contribute to** the person's distress and subsequent behaviours.
- **Care environment** often gives rise to the person's distress and behaviour
- Staff make insufficient attempts to draw on the **persons unique profile, or get to know the person well enough,** to plan and monitor treatment, care and leisure activities that the person actually engages in, benefits from and enjoys

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How can we employ the NDB and PSTPD models to understand and address need-driven behaviour?

Four case studies will be considered to identify the triggers for NDB and the approaches that might be employed to reduce them, while supporting well-being.

1. Mrs Olive Beach (apathy)
2. Ms Edna Nabakov (agitation)
3. Mr Sunny Matsanaga (risky wandering)
4. Mr Con Soulos (aggression)

Case Study 1 - Mrs. Olive Beach displays apathetic behaviour

Olive Beach moved to the aged care home 6 months ago following a stroke which left her unable to walk, use the right side of her body, speak clearly, and self-care.

She has become socially withdrawn, unhappy, critical of staff, resistant when care and social activities are offered, and lost the desire to eat

She constantly talks about wanting to be left alone and occasionally, to let her die.

Is Olive depressed? How can staff reduce Olive's apathy and improve her well-being?

What can staff do to try to help Olive?

1. Ask Olive not to talk about death?
2. Ignore any mention of death
3. Turn the subject to something more cheerful?
4. Remind Olive she has a loving family, friends, a lot to live for?
5. Try to distract her with activities or care?

None of these strategies will help Olive to express her feelings, acknowledge her personhood, take her situation seriously, or give her any sense of hope for a brighter future

Case Study 2- Ms Edna Nabakov- displays agitated behaviour

- Ms. Edna Nabokov is known to be difficult, often agitated and sometimes aggressive
- Edna has been sitting at the dining table on her own for several hours and continuously rubbing the table top with her fingertips and flicking imaginary objects away with the back of her hand, while muttering to herself.
- Staff ignore this behaviour and leave her alone, except when she gets up and goes into other residents' rooms and touches things on their walls.
- Some of the residents get angry with Edna

What can we do to stop Edna doing this and upsetting other residents?

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What can staff do to stop Edna constantly rubbing her fingers and entering other resident's rooms and touching their objects?

1. Ignore the behaviour
2. Give her other activities to do that she enjoys, undertake some personal care, sit her down with others, or a give her a drink and snack?
3. Try to get Edna away from other residents' rooms, or steer her towards rooms where residents do not mind her touching things?
4. Frequently remind her that her fingers will get sore, and other residents' rooms are out of bounds?

None of these approaches will identify what Edna is trying to convey, satisfy her need, stop the behaviour, or get her to engage in an alternative activity for any length of time

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Case Study 3: Mr Sunny Matsanaga- risky wandering behaviour

- Mr. Sunny Matsanaga was admitted to the medical ward with an open pressure ulcer on both buttocks. He has dementia and is frail, but is still mobile.
- Sunny usually walks to the toilet, but the nurse uses a lifter to transfer him from the bed to move him to the bathroom. He is wearing only a hospital gown, open at the back.
- He has been in the lifter for at least 10 minutes while the nurse waits for assistance. Sunny is getting agitated calling out for help to get down, but the nurse makes no attempt to communicate with him. Eventually another nurse comes to help by which time Ted has opened his bowel onto the floor.
- The first nurse demands in an aggressive tone of voice "Sunny. why can't you do that in the toilet when you are supposed to. I don't have time for this." She says to her colleague, "It's worse than working in childcare."
- Later in the morning, security staff return Sunny after they find him wandering in the hospital grounds. They report that Sunny says he has to get out of this prison as he is being treated badly and is afraid of the guards.

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How can staff prevent Sunny from engaging in risky wandering behaviour?

1. Tell him he needs to stay in the ward to keep safe?
2. Admonish him for leaving?
3. Ask all staff to keep a close eye on him?
4. Put up signs asking all staff and visitors to not let him out of the ward?
5. Ask his relatives to keep watch and to explain to him that he must not to leave the ward?

None of these actions will meet Sunny's needs, help Sunny to feel safe and secure, or stop Sunny wandering from the ward if he feels unsafe

Case Study 4: Mr Con Soulos
Aggressive behaviour

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- Mr Con Soulos has reluctantly been transferred to his new "office" accommodation and is having trouble settling in because the staff are strangers and intrude on his space
- Con who was previously the Australian CEO of a large multinational company guards his office, refusing staff entry
- Con attacks residents who come near his "office" and attacks staff who try to provide personal care, especially the younger ones whom he believes have no manners, are bossy and exert their right to undress him
- Staff are afraid for the other residents' safety so they keep residents away from Con's end of the corridor and warn visitors of his aggression
- The staff are also afraid of Con's anger and aggression and they tend to avoid him. Con's care needs are being neglected and he often looks dishevelled
- Con is so debilitated by his need to remain vigilant against staff he is losing weight and in a constant state of anxiety

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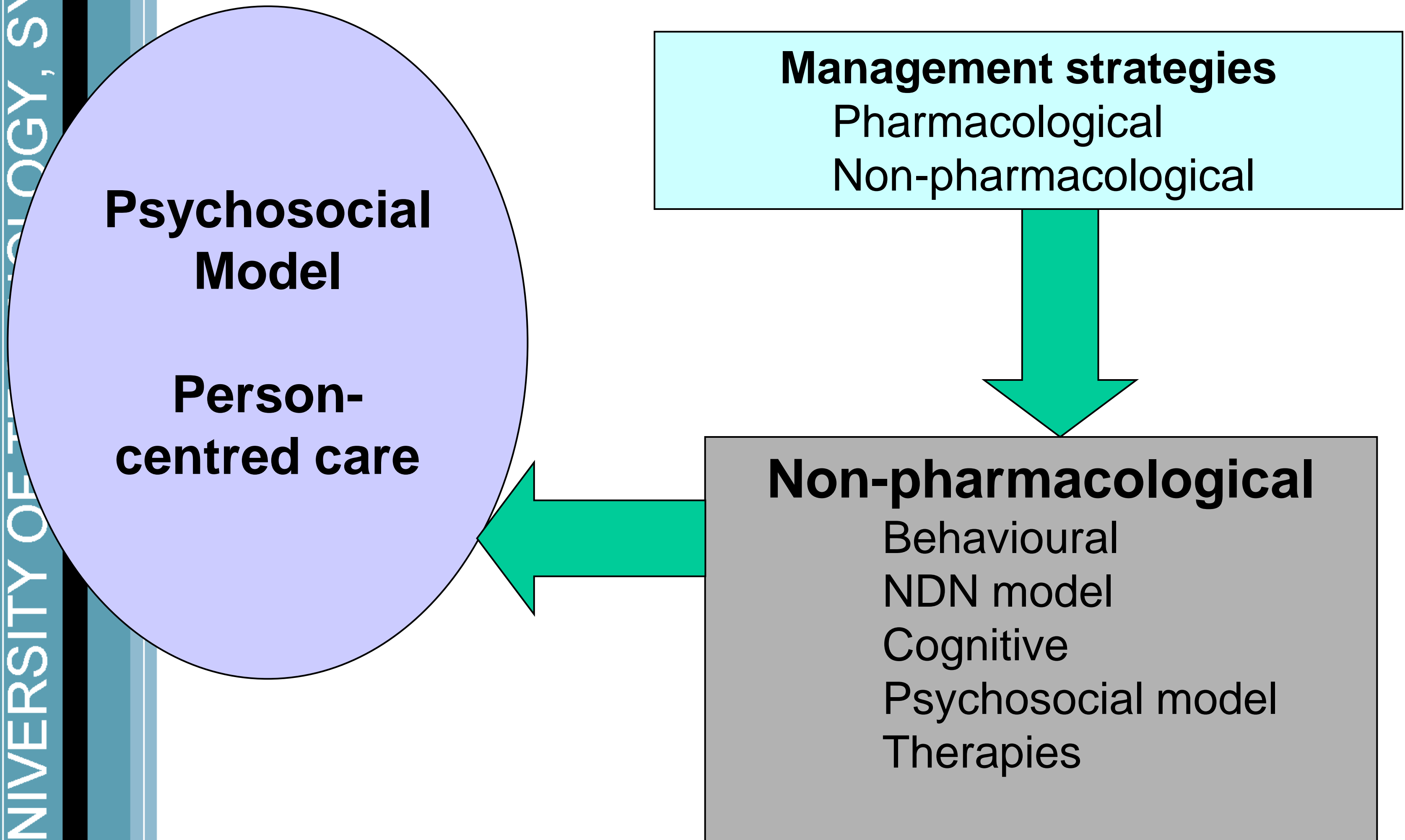
How can staff prevent Con's aggression to them and others, and meet his needs?

1. Continue to keep others away from his "office" area?
2. Employ a consultant to teach selected staff how to care for him in a safe way?
3. Develop policies and procedures that staff must adhere to in all interactions with Con?
4. Ask Con's wife, or only a few staff. to undertake his shower and other aspects of personal care each day?

While some of these approaches might help for a while, they will not stop Con from being aggressive to anyone he believes is encroaching on his territory, or insulting him.

Different approaches to managing behaviour



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How can we use Person-Centred Care to avoid/reduce need-driven behaviour

1. Get to know all about the person and habits, preferences, usual behaviours
2. Listen to/consider what they are trying to tell you through their actions
3. Learn and use active, attentive listening in every encounter with the person
4. Set realistic goals with them and their family
5. Allow & encourage choices in all activities
6. Use praise, compliments and acknowledgement for who they are, their past achievements and every attempt made to assist/cooperate
7. Avoid your own negative behaviours
8. Avoid negative reactions to behaviour
9. Avoid distressing the person

1. Set realistic goals

Having unrealistic goals can lead to:

- Belief that nothing works & nothing will change, eg. memory
- Giving up on effective ways of dealing with difficulties, eg behaviour
- Feeling helpless, angry, frustrated, burned out

Setting realistic goals can:

- Help to say focused on effective ways of caring
- Help the resident to achieve the things that are meaningful for them

2. Learn and use Active Listening

1. Show the person that you are listening-stop anything else you are doing, make eye contact, use words, head nods, smiles to show you are listening & understanding- Be attentive
2. Listen to what the person is saying verbally and communicating non-verbally, accept their point of view and their feelings- Listen for feelings
3. Restate in your own words what they are telling you, or seem to be expressing- Paraphrase
4. Make suggestions, give advice, reassure, or offer a different way of thinking about the concern- Guide and comfort

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3. Allow & encourage choices

1. Use open-ended questions for ***capable*** residents, eg. “ when would you like to get out of bed today?” “ what would you like to wear today?” “ Would you like a sandwich?”
2. Use limited choice questions for ***less able*** residents, eg. “may I help you with your lunch tray?” “ which dress would you like to wear- the blue one or the green one?”
3. Use simple step by step explanation of what you would like to do for/with ***confused/stressed*** residents, eg. “ I will help you to put your shirt on. Here we go. Now put your arm through this sleeve. Very good. Thank you for helping me”

4. Use praise, compliments and acknowledgement

1. Using praise for positive behaviour will reinforce that behaviour, eg sitting to eat
2. Praising, reinforcing and acknowledging positive behaviour is a social reinforcement, eg.sitting quietly in church
3. Make as many positive comments to the person as possible-praise, compliments
4. Use non-verbal reinforcers, eg smiles, hugs, nods, pats on the back, winks
5. Praise the resident's efforts to assist, to cooperate, to be kind, to be thoughtful-acknowledge these positive behaviours often

5. Avoid your own negative behaviours

- Nagging, arguing
- Repeatedly demanding that the resident do or not do something
- Making threats
- Giving the resident a ‘dose of their own medicine’ eg, insulting a resident who insults you
- Withholding privileges
- Scolding or reprimanding
- Using punishment
- Laughing at the resident/making the butt of jokes
- Engaging in power struggles with the resident
- Showing annoyance, frustration, or anger

6. Avoid negative reactions

1. Hold on: do not react out in feelings of anger, frustration, disgust, hopelessness
2. Think about what the resident is feeling
3. Think of the behaviour you would like to see in the resident, eg helpful,cooperative
4. Behave in the way you would like the resident to behave
5. Look for ways that your behaviour might be triggering negative behaviour in the resident
6. Consider changing negative riggers/reinforcers

7. Avoid distressing the resident

1. Be alert to signs of agitation/distress
2. Use active listening and a clam, low, quiet voice to find out what is causing the distress, ask resident what they need, provide reassurance you will meet that need when they calm down
3. Firmly but quietly ask resident to be calm, wait quietly with them till they calm down, provide praise when calmer and if they like it, a hug
4. If aggression escalates withdraw if & when appropriate. Follow facility policy for uncontrolled escalation of aggression and self-harm
5. Get other staff to assist the resident if you are the cause of the outburst/agitation
6. Have two staff provide care-one to comfort and distract and one to carry out care-use calm, soothing voice

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How did we help Olive Beach to overcome her apathy?

1. Listened to Olive and showed empathy towards what she was feeling-sad at life losses
2. Asked Olive what she would like to do before she died-to have her poetry bound
3. Worked with all staff and family to assist Olive achieve her goal of publishing her poetry
4. Encouraged and supported willing staff to make binding of the poetry collection a reality
5. Held a poetry book launch morning tea with all able residents, staff and family
6. Held regular morning teas with all interested residents and staff for Olive to present her poems
7. Supported Olive to help other residents write and read their poetry

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How did we help Edna Nabokov to be less agitated?

1. Asking Edna to tell us what she was rubbing-she was trying to get her paintings finished for the art exhibition
2. Asking Edna what she was touching on the other residents walls-she was checking that her paintings were hung ready for the exhibition
3. Reassured Edna that all her paintings were ready and hung by showing her the artwork that were hung along the corridors and in lounge and dining rooms
4. Giving Edna large sheets of paper and art materials to do her own paintings each day
5. Hanging her artwork and showing other residents and visitors her art, in Edna's presence
6. Providing Edna with praise and having her discuss her art to others at planned art discussion activities

How did we stop Sunny Matsanaga from wanting to leave the ward?

1. Listening to what Sunny was trying to convey and showing acknowledgement by making eye contact, head nods and smiling
2. Showing interest in Sunny each time staff passed by or attended to him
3. Assisting Sunny to walk to the toilet each time he needed to go without any negative reaction
4. Meeting with Sunny's family to explain what staff are trying to do to assist him and find out how he is best able to convey his needs to them
5. Ensuring all staff, permanent and casual, adhere to agreed communication and care approaches in meeting Sunny's needs

How did we reduce Con Soulos' aggression towards staff?

1. Meeting with Con's wife to find out how best to approach him for personal care, room cleaning and returning linen
2. Always greeting Con by his surname and title and requesting his permission to enter his 'office" for care-giving and housekeeping activities
3. Explaining on each occasion of care that staff wanted to help him get ready for his business meeting and/or his wife's visit to his office and requesting he accept their help to bathe and dress for these activities
4. Asking Con to choose the clothes he preferred to wear for his "meetings", with limited choice options
5. Using active listening and smiles, warmth and showing respect in all encounters with Con
6. Thanking Com for his permission and cooperation each time he was provided with care
7. Inviting Con and his wife to join with others for meals
8. Inviting Con to join/chair business meetings each day once bathed and dressed

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The ultimate aim of dementia care is to do all that we can to promote well-being and reduce ill-being

Well-being behaviour

- Making wishes known (non destructively)
- Initiating social contact
- Showing warmth and affection
- Showing signs of self respect
- Being helpful
- Showing bodily relaxation
- Creative self-expression
- Showing pleasure, enjoyment or humour
- Responding appropriately to others
- Holding one's own socially
- Being alert and responsive
- Being purposeful

Ill-Being behaviour

- Distress expressed
- Depression or despair
- Intense anger
- Anxiety
- Fear
- Physical discomfort/pain
- Bodily tension
- Agitation
- Apathy and withdrawal
- Cultural isolation
- Difficulty withstanding powerful others
- Repeated calls for attention

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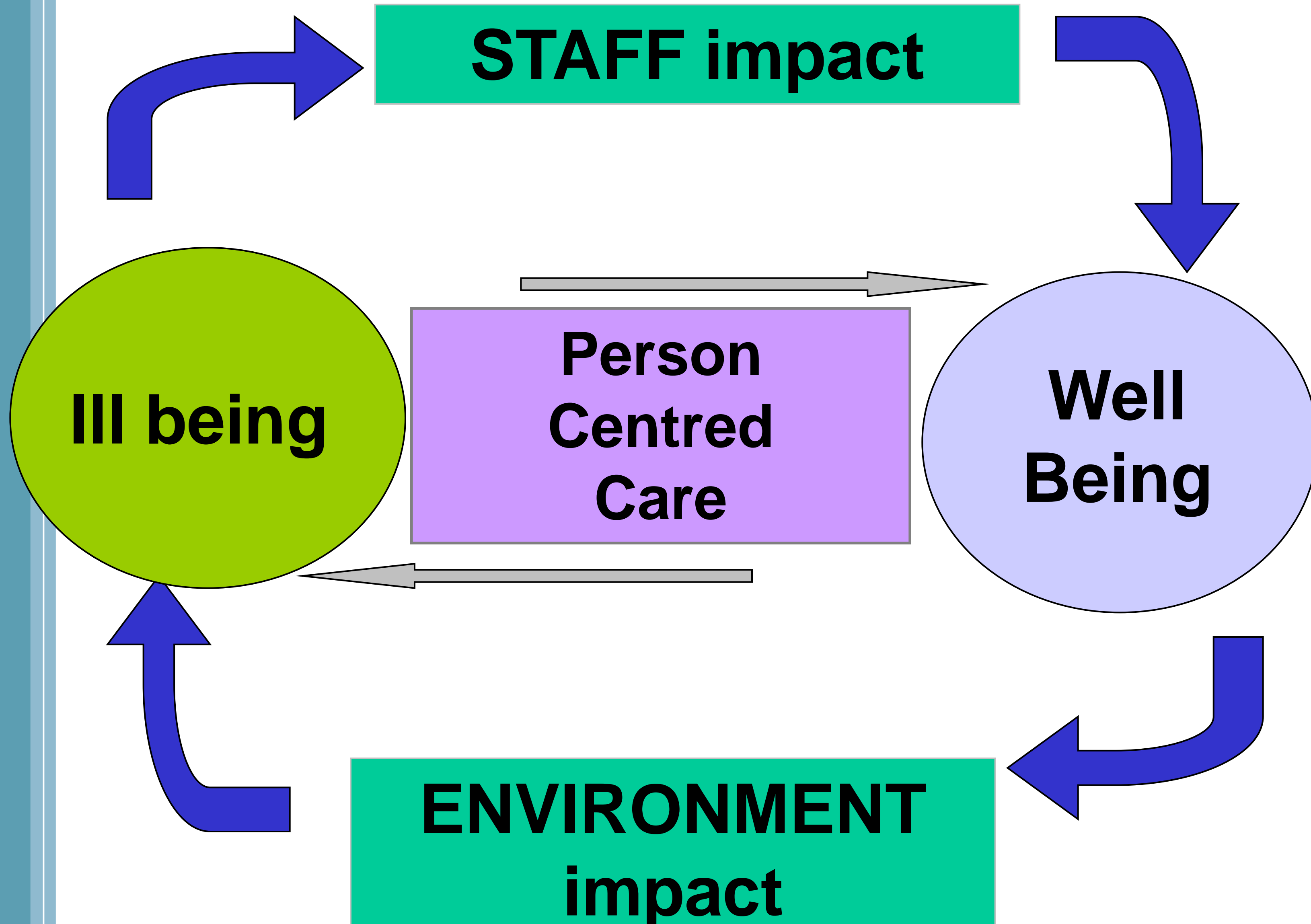

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Conclusion:
Best practice dementia care requires:

1. Ongoing review of the best evidence available to guide our practice

2. Employing Need-driven Dementia-compromised Behaviour (NDB) Model (Algase et.al. 1996) to understand dementia behaviour

3. Applying Socio-psychological Theory of Personhood in Dementia (Kitwood, 1997a) to guide care/therapy planning and evaluation

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