Mid North Coast Rural Palliative Care Project –
Link Nurse Education 2004

Palliative Approach to the Person with Advanced Dementia

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To care for the dying is a very human opportunity for pure giving because the dying person can never repay what is received.

Communication

Sub cortical Communication

- feeling another's mood
- absorbing the atmosphere
- the environment
- skill of staff members
- expression
- touch
- sound of voice
- listening for key words
- closed communication
- flow of feelings

Team approach to communication.

“Who’s on the team?”

- family
- staff
- other residents
- doctors

Team approach to care.

“Who’s on the team?”

- Family dynamics
- Other residents

Spiritual / Religious Issues

- Beliefs
- Practices

Cultural Issues

- Multicultural society
- Observance of religious laws
- Beliefs
- traditions

Loss & Grief

"When goodbye is not a set moment in time – it's a continuing experience"

- Protracted grief
- How many years
- Emotional distance
- Turbulent relationship
- Guilt

Assistance

- Relaxed atmosphere
- Opportunity to vent emotions
- Approachable
- Non-judgmental
- Identify and explore anxieties
- Involve in the care

Last impressions remain with relatives for the rest of their lives

Closing contact

- Mouth Care
- Changing Positions
- Constipation

Palliative Care in Advanced Dementia

Adapted from presentation by Bronwyn Magnam

- Dementia is a syndrome characterised by confusion, behavioural and functional changes.
- Dementia is a broad term to describe loss of memory, intellect, social skills and normative emotive reactions.
- Dementia is NOT a normal part of ageing.

Dementia: Symptoms

- Memory loss: recall, short and long term.
- Disorientation: time, place, person.
- Mood changes
- Difficulties with language
- Loss of independence with ADLs
- Delusions and Hallucinations
- Failure to recognise people, objects.

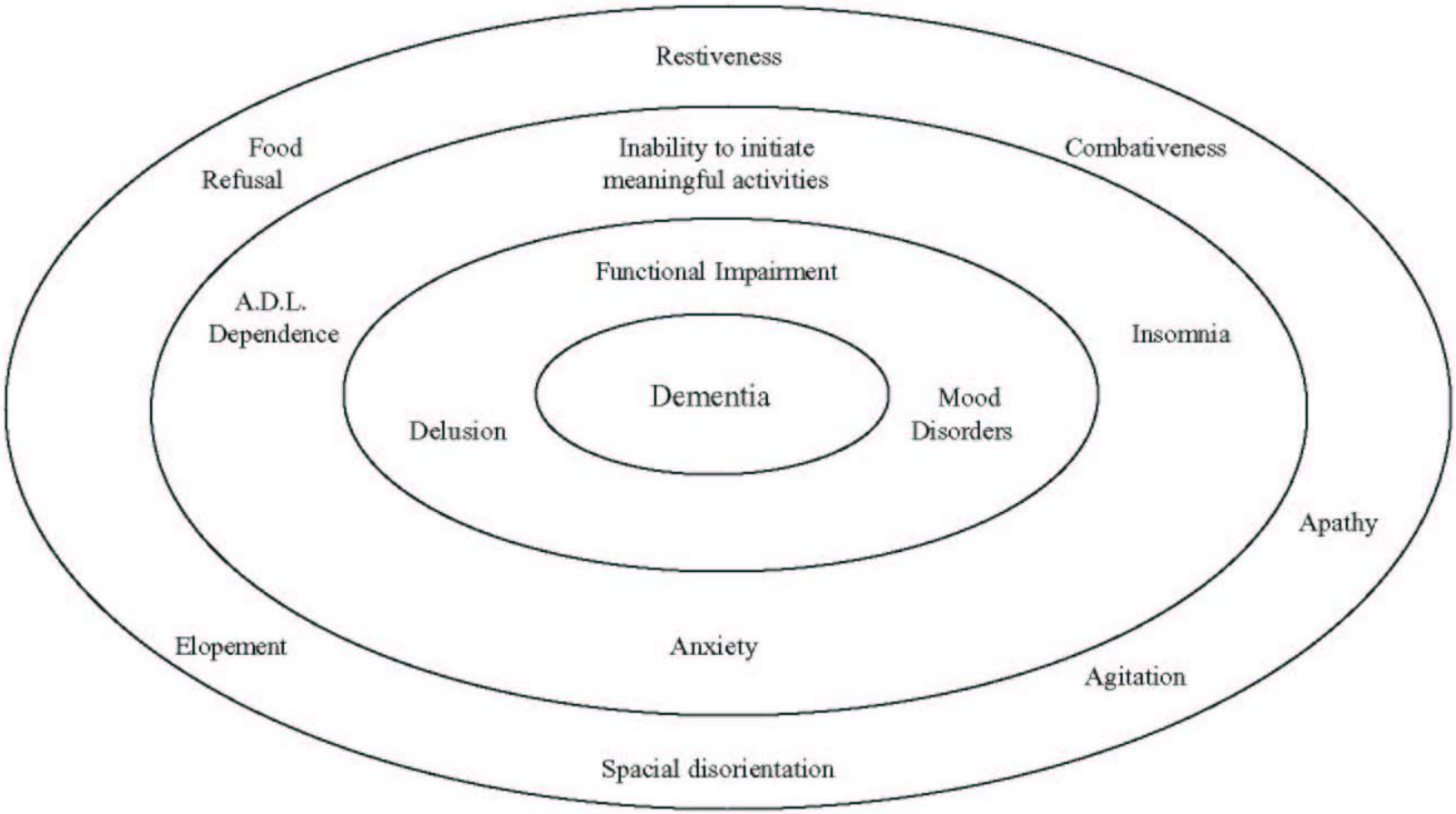
Dementia Types

There are many different diseases which cause dementia including;

- Alzheimer's disease which is the most common.
- Vascular Dementia
- Lewy Body
- Other - Picks, Alcohol, Parkinson's, CJD, AIDS, Huntington's

Dementia "Ripple"

Adapted from Professor Ladislav Volicier



The six most common forms of dementia are:

- Alzheimer's Disease,
- Vascular Dementia,
- Mixed Alzheimer's and Vascular
- Diffuse Lewey Bodies Dementia
- Frontotemporal Dementia
- Alcohol Related Dementia

Alzheimer's Disease

The most common form of dementia. The onset and decline is gradual with predominantly short-term memory loss initially. The usual four components are:

- Aphasia – searching for words. The person's ability to communicate is severely restricted as the disease progresses.
- Apraxia – initially the person may have difficulty reproducing a picture. As the disease progresses the ability to attend to activities such as dressing, feeding is no longer possible.
- Agnosia – difficulty recognising objects eventually unable to recognise family or their own body parts.
- Memory – initially recent and short-term memory is lost and eventually memory loss is profound.

Death usually results from an infection, malnutrition and dehydration.

Vascular Dementia

Unlike Alzheimer's Disease, it usually presents as abrupt, episodic with multiple remissions. The most likely scenario is that there is a history of hypertension.

- Abrupt onset.
- Stepwise decline.
- Gait disorder.
- Emotional lability.
- Memory may not be impaired initially.

MIXED ALZHEIMER'S
&
VASCULAR

Diffuse Lewey Bodies Dementia

Second most common form of dementia. Widespread lewey bodies diffusely distributed throughout the subcortical and cortical regions of the brain. There is progressive cognitive decline with fluctuating symptoms.

- Visual hallucinations.
- Auditory hallucinations.
- Delusions.
- Repeated falls.

Frontotemporal Dementia

Insidious onset with slow progression.

- Inappropriate behaviour.
- Loss of social awareness.
- Disinhibition.
- Mental rigidity.
- Inflexibility.
- Preservative behaviour.
- Loss of insight.
- Decline in hygiene.
- Difficulty communicating.

Alcohol Related Dementia

Alcohol can affect the brain directly or indirectly via vitamin B deficiency. There's shrinking and damage throughout the brain and quite often the damage is in the frontal area. The sufferers are usually younger and if they abstain they may even improve mentally. There is:

- Reduced attention span.
- Delusions and hallucinations.
- Poor nutrition and hydration.
- Loss of bladder and bowel control.
- Breakdown in family relationships.

The Brain

Incredibly complex system. It recognises all our physical, psychological and emotional needs and acts to control them.

- Storing and recalling memory.
- Coordinating / controlling movement.
- Protective mechanism such as pain reaction.
- Interpreting sensory impressions from the eyes and ears.
- Cognitive function such as thought, reasoning, recognition and control of emotions, problem solving.

The Dementias

- **Alzheimer's Disease**: Destruction of brain tissue affecting the cortex as a whole.
- **Multi infarct Dementia**: Multiple small lesions throughout the brain.
- **Huntington's Chorea**: Destruction of the basal ganglia and cerebral cortex.
- **Pick's Disease**: Frontal and temporal lobe atrophy.
- **Korsakoff's Psychosis**: Degeneration of the cerebrum as a whole.

It's not surprising that behavioural complications occur in up to 90% of people with dementia.

CONSISTENCY

THE KEY PRINCIPAL TO ANY TOOL IS CONSISTENCY.

EVERYONE NEEDS TO AGREE TO A CONSISTENT APPROACH.

Problem Solving

Step 1. Define the problem
(specific, accurate & agreed)

- What exactly is happening?
- Who is it worrying?
- When does it occur?
- Where?
- With whom?
- For how long?
- What impact is it having?

Concise statements.

Problem Solving

Step 2. Analyse the problem

- Listen to everyone involved.
- Build on information.

Step 3. Set Goals
(keep goals specific, realistic & achievable)

- Short term
- Long term.

Problem Solving

Step 4. Develop Strategies / Interventions

- Think creatively.
- Avoid premature judgement.
- Avoid quick solutions.
- Consistency, consistency, consistency.
- Agree on a time frame for implementation.
- Decide on how it will be monitored.
- Remember all the resources at your disposal.

Step 5. Evaluation

- An effective evaluation requires documentation of the problem, interventions, what worked, how it worked, what didn't and for what reason if possible.

OPEN YOUR MIND TO NEW WAYS OF LOOKING

DISMISS OUTDATED AND DISABLING MYTHS

ACQUIRE NEW IDEAS

TAKE ADVANTAGE OF YOUR EXPERIENCES AND INSIGHTS WITH CONFIDENCE

THE OUTCOMES FOR PEOPLE WHO RELY ON YOU WILL BE WORTH EVERY BIT OF EFFORT YOU HAVE EXPENDED

A FEW HINTS

- Organise your day around the individual not the tasks.
- Communicate clearly and calmly. Simple sentences and visual clues.
- Strive for consistency.
- Maintain a connection with the past.
- Avoid clutter: Furniture, Noise, Activity
- Limit distraction: Control noise, one noise source at a time.
- Use labels but don't "over label"
- Solve problems creatively.
- Know what resources are available and use them.
- Adapt the environment, not the person.
- Create a sense of importance, use compliments.
- Structure activities that help the person feel useful.
- Avoid communicating failure. Instead of "that's wrong", "try another way"
- Constantly reassess. As the dementia progresses, different problems may arise while others vanish or lose their intensity.