Enhancing quality of life in dementia
Sue Austin 27/10/16

Objectives

- Recognise and respond to clients changing needs
- Useful strategies to assist staff and family
What do you see?

The elephant in the room

Dementia – What does it mean to you?
Dementia

- Dementia describes a collection of symptoms that are caused by disorders affecting the brain. It is not one specific disease.
- Dementia affects thinking, behaviour and the ability to perform everyday tasks. Brain function is affected enough to interfere with the person’s normal social or working life. (Alzheimer’s Australia, 2016)
- The perception of dementia as a terminal disease has been associated with greater comfort in patients dying with dementia.  
  (van der Steen et al, 2013)

What observations are seen in advanced dementia?

- Start to withdraw even further into the past and become so preoccupied with their memories that they ‘live’ almost entirely in that time and reality.
- The person may also start expressing needs, wants and feelings increasingly through body language – using gestures and actions. Speech is limited.
- Wander
- Incontinence /becomes dependent in all ADL’s
- They may not respond when someone walks into the room or speaks to them.
- Weight loss/pressure ulcers  
  (DCA,2016)
Dementia is one part of the PWD

- Intrinsic aging—Physiologic changes: cognitive deficits, skin changes due to aging, muscular skeletal changes. Compounded by fall in cardiac output, arteriosclerosis, decrease in Langerhans cells: affects the immune function—increases risk of infection, reduces healing (Benbow, 2010).
- Extrinsic aging—chronic illness, environmental pollutants, decreased mobility, medication (Benbow, 2010).
- Ageist attitude—can portray older people as frail, "past their sell-by date", unable to work, physically weak, mentally slow, disabled or helpless (WHO, 2016).

COMMON SYMPTOMS

Below are examples of the most common symptoms experienced by people who have dementia:

1. 65% experience pain
2. 60% experience confusion
3. 80% experience fatigue
4. 60% experience depression
5. 70% experience incontinence
Pain

- Identify the best type of pain scale to use to express pain with PWD e.g. Pain-ad scale, Abbey pain scale, Wong-Baker faces or colour scales
- Does the analgesic offer any relief? How long does pain relief last after it has been administered, look at non-pharmacological as well as pharmacological ways to support the client.
- Ensure the carer is aware of how to access help when/if they require it in the community

Challenges for Health Professionals

- Communication/behaviours
- Understanding Cultural/Religious/Social beliefs (attitudes towards aging and dementia) Persons with dementia (PWD) are speaking in their first language
- Time constraint/Staff issues (gender)
- Lack of confidence/education or knowing how to comfort a PWD (Carmody & Forster, 2003)
Labelling a patent as 'non-compliant' can have disastrous effects, as it can lead to exclusion or different treatment of the patient, resulting in only more personal and physical health problems (Gooda, pers. comm., 11 April 2013).

Miscommunication can be one reason for 'non-compliance', Factors impeding communication, as identified in Cass et al.'s study (2002), can include lack of control by the patient, lack of staff training in intercultural communication and failure to call on trained interpreters.
Culture

- Differing perceptions surrounding health do influence health outcomes. Cultural differences demand a holistic approach towards health and healing, in order to account for miscommunication and to close the gap in poor health outcomes.
- An association with spiritual causes of illness that can be seen to provide answers to the questions of 'why me?' and 'why now?' that Western biomedicine cannot explain (Maher, 1999; Neumayer 2013.)

Ageism - sexuality remains a sensitive & taboo topic
- Actual practice of sexual intercourse may change with age
- Fundamental need for expression of sexuality remains - even for older people & people with dementia (PWD)
Behaviours

Seven I’s
- Iatrogenic (consider anticholinergics, sedatives, opioids, etc.)
- Infection (pneumonia, UTI, Cellulitis etc.)
- Injury (falls, consider any source of pain)
- Illness (any acute illness or exacerbation of a chronic illness)
- Impaction (faecal)
- Inconsistency (major change in the environment, relocation, new people etc.)
- Is the pt. depressed? (Sekerak, Stewart, 2014)

P-LI-SS-IT Model of Care

P-LI-SS-IT Model of Care (White, 2011)
An useful model to guide discussion with primary carers of PWD to not only gain an understanding of the person with dementia’s history & behaviours but also proactively offers the family an opportunity to discuss their concerns
### P-LI-SS-IT Model of Care (White, 2011)

<table>
<thead>
<tr>
<th>Category</th>
<th>Suggestion</th>
</tr>
</thead>
<tbody>
<tr>
<td>PERMISSION</td>
<td>Gain family permission to discuss behaviour of their loved one.</td>
</tr>
<tr>
<td>LIMITED INFORMATION</td>
<td>Provide information on how the process of dementia may impact on a person’s behaviour</td>
</tr>
<tr>
<td>SPECIFIC SUGGESTIONS</td>
<td>Offer suggestions on caring for the needs of PWD: sensory therapies (remedial massage, aromatherapy, music); inviting spouse or partner to stay overnight or to take the person living with dementia home for occasional overnight stays (if they are in residential care); &amp; asking family to ensemble an autobiographical account of the person’s life with photos &amp; reminders of good times to be used in later reminiscence-distraction programmes.</td>
</tr>
<tr>
<td>INTENSIVE THERAPY</td>
<td>Advise family on options and help family work through their own feelings &amp; obtain support.</td>
</tr>
</tbody>
</table>

---

### Case study

- Mr B has dementia of the vascular type. Mr B’s wife died 2 years ago and survived by 2 devoted daughters; he returned to a RACF from hospital where he was admitted; following a fall.
- He had low blood pressure, unsteady gait, an ulcer on his left heel. His behaviours were; varying levels of night time wakefulness and desire to walk about, so they had increased his night sedation hoping that this would help him to sleep. The sedation did make him very sleepy; however; it increased his disorientation and did nothing to reduce Mr B’s determination to get out of bed and look for his wife. Mr B did not understand where he was or why he was here.
- The daughters were anxious, as they could not care for Dad at their home.
Case Study

- He received assistance with medication and most ADL’s.
- Over time Mr B became agitated, he would repeatedly ask how he was going to pay for his care worrying about having no money.
- He was demanding with his daughters and became anxious at night.
- He would try and wander outside his room. A pressure mat was placed by his bed to alert staff when he got up; this was not so that we could prevent him getting up but be aware of him being out of bed and could monitor him discreetly.
- His mental capacity declined and needed assistance with all ADL’s.

Case Study

- Mr B’s health continued to deteriorate and he began experiencing more frequent falls and swallowing became increasingly difficult. He became incontinent.
- Care staff coordinated care with Allied Health Professionals to assist Mr B with mobility aids and some dietary changes.
Case Study

- Mr B’s care needs increased until he was confined to a wheelchair for mobility.
- Care staff organised a gel and foam combination pressure relief cushion, hospital bed, lifting hoists and a regency air chair so Mr. B could still attend lunch in the dining room. In his room, care staff provided two hourly turns when he was in bed to reduce pressure areas. As his health worsened, care staff provided extra and more frequent checks to make sure he was secure, safe and comfortable 24 hours a day.
- His GP visited Mr. B regularly in his room and Nursing Care staff took care of wound dressings, adhering to the directions of the GP.

Case Study

- Mr. B was sent via ambulance to Hospital after care staff noticed he was having had what appeared to be a seizure. His daughters met with Hospital staff regarding his condition and as Mr. B had an Advance Health Directive they clearly understood his wishes not to have medical intervention to keep him alive. A decision was made to keep Mr B as comfortable and pain free as possible and to return Mr. B to his home at RACF where he was familiar with the care staff.
Case Study

- He was discharged from Hospital and given medication for pain relief. A Syringe driver was organized by care staff and Palliative Care Nurses provided support.
- That night, the Registered Nurse stayed overnight with Mr B in his room so his daughters could get some sleep. His daughters returned early the next morning and they and the Registered Nurse stayed with Mr B until he passed away later that day.
- Mr B’s family were very involved in all decisions with the Hospital, GP, Allied Health, and the Palliative Nurses and were given as much support as possible by care staff.

Remember

- Offer hope for QOL
- Optimize function, emotional well-being, safety at every stage of dementia.
- Focus on remaining abilities, life story and engage family.
- Identify risks and prevention strategies
What do you see now?

The elephant in the room

Any Questions
References