TRACS Community of Interdisciplinary Practice for People with Dementia

# Behavioural and psychological symptoms of dementia

*Definition, prevalence and manifestations*

*(Weeks 3 and 4)*

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## Learning Objectives

- Define the term behavioural and psychological symptoms of dementia (BPSD)
- Describe the average trajectory of BPSD across time
- Describe a range of different types of BPSD
- Understand which BPSD's tend to be more common than others
- Describe potential causes of BPSD's
- Demonstrate an understanding of how you might respond (i.e., what behaviours of psychological symptoms you might display) if you found yourself with reduced communication, memory or problem solving abilities

# Review Weeks 1 & 2

- As outlined in Week 1, the world's population is ageing
- Given that the prevalence of dementia increases with age, there will be an increase in the number of people needing dementia care
- A deeper understanding of the neurophysiological changes causing dementia helps to create a better understanding of the disease that is dementia. This creates an appreciation that such changes result in cognitive problems that may then lead to behavioural and/or psychological symptoms (collectively known as behavioural and psychological symptoms of dementia or BPSD)
- With an increase in the prevalence of dementia comes an associated increase in the number of people who may display BPSD.



# What are Behavioural and Psychological Symptoms of Dementia (BPSD)

- Behavioural and psychological symptoms of dementia (BPSD) are defined as:

*"symptoms of disturbed perception, thought content, mood, or behaviour frequently occurring in patients with dementia"*

- So BPSD is a term used to describe a variety of symptoms: cognitive, emotional, and behavioural, which can occur at any point during the dementia process.
- BPSD occur because the person with dementia continues to experience their world, but due to associated cognitive changes, is unable to function as well within, or have as good an understanding of, their environment.

## What are Behavioural and Psychological Symptoms of Dementia (BPSD)

- BPSD include any behaviour or mood that is distressing to the person with dementia, their family and/or care staff.
- These are behaviours and moods that arise from a range of factors, including such things as changes in cognition and/or changes to the environment.
- They are sometimes also referred to as distressing behaviours or behaviours of concern.
- It is important to be aware of other terminology, however it is also important to appreciate that using a single and consistent term aids communication among care staff, family members, and the treating team.



## BPSD Symptom Breakdown

- *Behavioural symptoms*
  - Usually identified via observation of the patient. Such symptoms can include physical aggression, screaming, restlessness, agitation, wandering, culturally inappropriate behaviors, sexually inappropriate behaviours, hoarding, swearing, and shadowing other people.
- *Psychological symptoms*
  - Usually assessed via interviews with patients and relatives. Such symptoms can include anxiety, depressive mood, hallucinations, and delusions.

# BPSD

- BPSD should be understood as being common (although not necessarily inevitable) symptoms associated with dementia.
- As discussed in week 1, viewing dementia primarily as a memory problem (or more broadly as a pure cognitive problem) is an inaccurate approach given the complex nature of dementia in general.
- BPSD are understandable
- BPSD are recognisable and treatable
- Undiagnosed BPSD or poorly managed BPSD has a tendency to increase the degree of suffering of the person with dementia and increases the degree of stress experienced by family caregivers, aged care facility staff, and other residents within the facility.



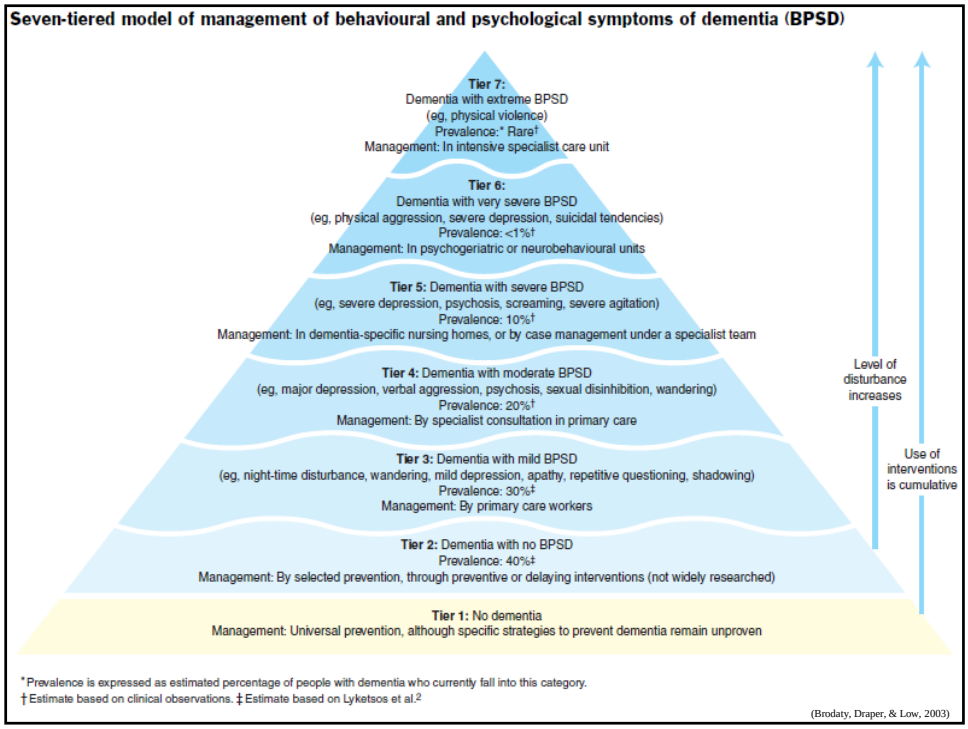
# Why is BPSD a Problem?

- Untreated or unrecognised BPSD tends to decrease the quality of life for the person with dementia
- BPSD can be distressing for the person with dementia
- BPSD can result in increased impairment and disability in the person with dementia
- BPSD increases stress for carers of persons with dementia
- BPSD can therefore result in premature institutionalisation of persons with dementia and can therefore increase the cost of health care and the level of distress in the person with dementia and their family

# Classification of Severity of BPSD

- Brodaty and his research team developed a seven tier model that summarises the prevalence and severity of BPSD
- It also describes interventions appropriate for each tier
- Have a look at the model as detailed on the next slide and familiarise yourself with the relative prevalence of different severities of BPSD, as well as the types of interventions that have been considered as useful forms of treatment
- Use the Forum on the website to share your own experiences, categorising BPSD that you might have seen within one of the 7 tiers and discussing the interventions you used and how they worked





## Progression and Development of BPSD

- BPSD symptoms tend to be stable and enduring symptoms unless they are appropriately identified and treated.
- However, it is also important to understand that BPSD can self-remit. Recall from earlier weeks that cognitive changes continue to occur and that such changes can make some BPSD 'disappear' and others 'appear'.
- Therefore, even within the context of successful treatment, BPSD can re-emerge throughout the dementia process – as neurological deterioration occurs and as cognitive function deteriorates.



## Progression and Development of BPSD

- Alternatively, the same BPSD may occur frequently but the cause may differ on each occasion
- Similarly, more than one BPSD can exist at the same time with potentially different causes
- A good understanding of BPSD therefore helps to manage and understand the complexity of such dynamic underlying processes

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## Progression and Development of BPSD

- As an illustration, early on in the dementia process, a person with dementia might display one form of BPSD (e.g., depressed mood because the person feels as if their memory is not as good as it once was). This may subsequently resolve with an appropriate intervention by staff at the aged care facility.
- As cognitive changes continue to occur, the person with dementia becomes less aware of their memory issues and therefore no longer feels depressed about their continuing poor memory.



## Progression and Development of BPSD

- Now as the dementia progresses, a new BPSD may arise (e.g., agitation as the person may be struggling to orient themselves in their environment, they cannot remember where the toilet is and may be in desperate need to pee).
- Each person is different and not everyone will experience the same progression of the disease, nor will they display the same pattern of BPSD. It is therefore important that an individualised approach is taken with regards the treatment of BPSD

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# Common Types of BPSD

- Aggression
- Depression
- Wandering
- Agitation
  - Verbal
  - Physical
- Psychotic symptoms
  - Delusions
  - Hallucinations
- Anxiety
- Disinhibited behaviours
- Nocturnal disruption
- Sundowning
- Inappropriate sexual behaviours
- Apathy
- Vocally disruptive behaviours
- Refusal of cares

Based on the earlier definition of what constitutes behavioural symptoms and what constitutes psychological symptoms, classify each of these types of BPSD as either behavioural or psychological



# Incidence and Prevalence of BPSD

- The rates of BPSD in dementia range from between 56% and 90%.
- According to some studies, more than 90% of people with dementia will experience at least one BPSD during their journey with dementia
- BPSD can occur whether the person with dementia is living at home or in an aged care facility. However, they are more likely to occur in aged care facilities. Why? Because the level of dementia tends to be more severe, which means more issues with cognitive function (refer back to the "Brodaty 7 tier model" on Slide 10)

## Incidence and Prevalence of BPSD

- Increased incidence of BPSD in aged care facilities has also been linked with:
  - more residents per room,
  - reduced resident functionality,
  - lower staff to resident ratios,
  - inadequate training,
  - fewer activities to engage residents, and
  - facility management less geared toward managing behaviours.



## Aggression

- Aggression is defined as behaviour (either physical and/or verbal) that is viewed as threatening and is directed towards the self, objects or other people
- Aggression can place the person with dementia, other residents and/or staff in danger of physical or verbally inappropriate behaviours
- Aggressive behaviours should always be followed up with a risk assessment focused on determining any immediate risk of harm and if needed, removal of triggers or persons from the environment to help maintain safety. It is also relevant to consider immediate medical review if immediate risk is indicated.

# Aggression

- Aggressive behaviours may include:
  - Shouting or screaming with/without abusive content (e.g., swearing)
  - Physically punching, hitting or kicking
  - Throwing objects
  - Sexual aggression



# Aggression

- Possible causes:
  - Environmental factors (commonly during personal cares, when the person with dementia may not understand that they are being helped to be washed or dressed and respond aggressively to what they perceive is a threat)
  - Changes in frontal lobe function (remember back to when we discussed brain function and what changes can occur as a result of damage to the frontal lobes)
  - Changes in neurotransmitter function
  - Side effects of certain medication(s) and/or combinations of medication
  - Secondary to depressive, anxious or psychotic symptoms
  - Infection

# Agitation

- Aggression and agitation are often confused. There are similarities between these types of behaviour, however there are also some very specific differences.
- Agitation is viewed as observable, non specific, restless behaviours that are excessive, inappropriate and repetitive
- Agitation may include such things as:
  - Irritability
  - Restlessness, fidgeting
  - Pacing
  - Vocalisations
  - Going into someone else's room and handling their belongings



# Agitation

- Neurophysiological changes associated with dementia (e.g., co-morbid medical factors, psychological, social, and environmental factors interacting with premorbid personality) can influence the development of agitation.

# Agitation

- Potential causes:
  - Environment factors
  - Changes in frontal lobe function
  - Changes in temporal lobe function
  - Increases in neurofibrillary tangles
  - Changes in neurotransmitter function
  - Medication side effects/interactions
  - Infection
- Substance intoxication
- Substance withdrawal
- Changes in sensory function

You will notice that a number of these potential causes are similar to those listed for aggressive behaviours. While external factors can cause behaviours of concern, so can changes in the brain and other physiological issues.



# Aggression vs Agitation

- Aggression and agitation can occur independently of each other, but they can also occur together or aggression can occur following a period of agitation
- To help distinguish between the two, aggressive behaviours tend to be:
  - Intentional
  - Violent
  - Intense
  - Harmful
  - Specific
  - Lack repetitiveness

## Inappropriate Sexual Behaviours

- Inappropriate verbal and physical sexual behaviors (also referred to as sexual disinhibition or hypersexuality) involve persistent, uninhibited sexual behaviors directed at oneself or at others.
  - This can include talking about sex, inappropriate sexual requests during the administration of cares, or sexual acts including exposure of genitals, exhibitionism, masturbation, and direct attempts to have sex
- Inappropriate sexual behaviours frequently occur within the context of dementia



## Inappropriate Sexual Behaviours

- They can be confronting for care staff, family members, and other residents
- Potential causes:
  - Environmental factors (e.g., changes in the social context of the person, such as reduced contact with their lifelong sexual partner)
  - Changes in frontal lobe function and circuits connecting the frontal lobe to other brain regions
  - Isolated brain damage (e.g., resulting from a stroke)
  - Changes to temporal lobe function
  - Medication side effects
  - Substance use

## Inappropriate Sexual Behaviours

- A good review of this topic appears in the "Inappropriate sexual behaviours in dementia" article on the *Learning Modules* page.

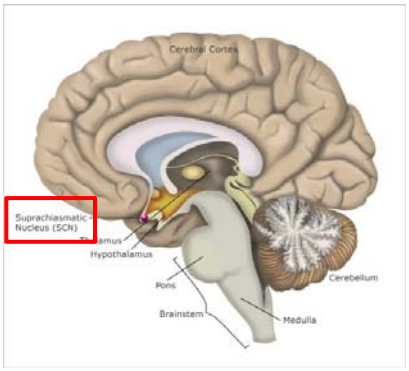


## Sundowning

- Sundowning refers to the occurrence or exacerbation of behavioural disturbance (any BPSD) in the afternoon or evening.
- Sundowning tends to occur at times where carer resources are limited due to low staffing levels and feeding residents
- Like all BPSD the potential causes of this behaviour will vary, however changes in circadian rhythm (sleep wake cycles and body temperature) are considered to play a role in prompting the expression of this behaviour

# Sundowning

- Potential causes:
  - Environment (e.g., poor exposure to day light during the day)
  - Biological changes resulting in changes in circadian rhythm
    - Changes to the Suprachiasmatic nucleus (SCN) - which plays a role in regulating sleep/wake
  - Fatigue
  - Hormonal changes

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# Sundowning

- The "Sundowning" article provides an excellent overview of this particular BPSD.
- One of the points this particular article looks at is the difficulty defining sundowning, and therefore the "plausibility" of the issue. You might find it useful to discuss your experience of this issue via the Forum to help you establish a more concrete definition and explanation of sundowning.

## Delusions and Hallucinations

- Delusions and hallucinations fall under the broad area of psychotic symptoms, which refers to a perceptual disturbance



## Delusions and Hallucinations

**Delusions**

- Refers to a fixed false belief that is not culturally relevant
- Common delusions include:
  - Theft
  - Suspicion
  - Abandonment
  - Misidentification
  - Danger
  - Infidelity

## Delusions and Hallucinations

- The frequency of delusions in people with dementia is cited as being between 10% and 73% depending on the study population and the definition of dementia (Wragg & Jeste, 1989). The most common delusions in demented people are persecutory or paranoid (Morris et al., 1990).
- According to an analysis of several studies (Tariot & Blazina, 1994), the most frequent single delusion is that 'people are stealing things,' experienced by 18% to 43% of patients.



## Delusions and Hallucinations

**Hallucinations**

- Refers to a sensory experience (e.g., visual, tactile, auditory or olfactory) in the absence of actual sensory stimulation
- Estimates of the frequency of hallucinations in people with dementia range from 12% to 49% (Swearer, 1994). Visual hallucinations are the most common (occurring in up to 30% of patients with dementia)
- They most frequently occur in dementia with Lewy Bodies and dementia in Parkinson's disease

## Delusions and Hallucinations

- While beyond the scope of this particular course, it is important to note that psychotic symptoms need to be differentiated from a diagnosis of schizophrenia.
- Some examples of criteria that are more indicative of Schizophrenia include:
  - Past history of psychosis
  - Family history of psychosis
- It can be difficult at times to establish a past history, but it is nonetheless relevant to identify such patterns of psychotic symptomatology



## Depression

- Depressive symptoms can occur within the context of dementia. These symptoms decrease the quality of life for the person with dementia, increase carer burden, and increase mortality
- Studies indicate that depressed mood occurs in approximately 50% of patients with a diagnosis of Alzheimers disease (Wragg & Jeste, 1989) and relapse of symptoms across the course of the dementia process is common (Levy et al., 1996).

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# Depression

- The primary symptoms experienced by persons with dementia who have co-morbid depression may include any of the following:
  - Low mood
  - Activity/social withdrawal
  - Fatigue
  - Tearfulness
  - Anhedonia (do not get pleasure from activities they usually gained pleasure from)



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# Depression

- Other symptoms of concern may include:
  - Changes in sleep (too much or too little sleep)
  - Changes in appetite
  - Thought content including themes of hopelessness or suicidal ideation*
  - Negativity – towards others or themselves

*Note: If suicidal ideation is present an immediate assessment of risk is needed along with a referral to a mental health service for review

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# Depression

- As cognitive function becomes compromised, deficits in language can make it difficult to obtain reliable self report data on the residents view of their mood (e.g., it is plausible they may inaccurately deny depressed mood due to a lack of insight or poor communication abilities)
- Key factors important to observe when determining if depression needs further investigation include a rapid decline in cognition, a life history of depression, a familial history of depression, suicidal ideation, loss of interest or pleasure in activity, withdrawal from activities, or a change in behaviour



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# Depression

- Identifying depression in persons with dementia can be difficult.
- Symptoms for the diagnosis of depression overlap with symptoms resulting from dementia (e.g., both conditions can share weight loss and sleep disturbance).

# Depression

- Potential causes:
  - Environmental factors (e.g., change of life role, moving to an aged care facility)
  - General neurological changes
    - Degeneration of cortical structures (brain cells on the outside of the brain)
    - Changes in the structure of subcortical networks (structures underneath the cortex)
    - Changes in neurotransmitter function
  - Genetic factors



# Apathy

- Apathy and related symptoms are among the most common of the BPSD (Lyketsos et al., 2000).
- Primary symptoms of concern include:
  - Loss of interest/inaction, in terms of engaging in activities or engaging in personal cares
  - Decreased spontaneity of emotion or restricted emotion
  - Fatigue
  - Activity/social withdrawal
  - Poor motivation
- Apathy is often confused with depression due to overlap in symptoms

## Apathy

- Potential causes:
  - Environmental factors
  - Changes in frontal lobe function
  - Changes in subcortical integrity
  - Changes in sensory function



## Depression vs Apathy in Dementia

- Given the overlap of symptoms between depression and apathy it is important to accurately determine which disorder is driving these symptoms, since the indicated treatment for each of these conditions is different.

# Depression vs Apathy in Dementia

- Shared symptoms include:
  - Loss of interest in activities
  - Fatigue
  - Activity and social withdrawal
  - Low levels of motivation
- Divergent symptoms tend to be:
  - Depression tends to have as part of its primary presentation a pervasive low mood whereas apathy tends to be a flat emotionless state
  - Feelings of sadness hopelessness dominate in depression vs apathy
  - Insomnia is more common in depression vs apathy



# Depression vs Apathy in Dementia

- The terms depression and apathy are unfortunately often used interchangeably despite being very different forms of emotional dysfunction that actually need to be differentiated between.
- The following table from the work of Landes et al. (2005) provides a summary of the differences and the overlaps:

| Symptoms of apathy | Common symptoms | Symptoms of depression |
|---|---|---|
| • Blunted emotional response<br>• Diminished interest<br>• Suicidal ideation<br>• Indifference<br>• Psychomotor retardation | • Dysphoria<br>• Low social engagement<br>• Fatigue/hypersomnia<br>• Hopelessness<br>• Diminished initiation | • Lack of insight<br>• Self-criticism<br>• Poor persistence<br>• Pessimism<br>• Guilt feelings |

# Anxiety

- Symptoms of anxiety in persons with dementia include:
  - Worry (e.g., "what if I fall over")
  - Thought content with fear-related themes (e.g., being left alone)
  - Irritability
  - Physiological symptoms of anxiety (e.g., shaking, increased heart rate, shortness of breath, tightness in the chest, or feelings of being flushed)
  - General restlessness – hyperactivity in motor movements
  - Avoidant behaviours associated with the fear triggers
  - Pacing
  - Facial expressions of worry/fear



# Anxiety

- Potential causes:
  - Environmental factors
    - Social needs
    - Psychological needs
    - Spiritual needs
  - For example
    - Changes to routine
    - Separation from a life carer
    - Concern about their health
    - Concerns about their finances
- For example (cont'd)
  - Concern about a pet that was not allowed at the RACF (this is a common anxiety trigger and needs to be treated with the same empathy as separation that would occur within the context of separation from a life carer)

## Anxiety

- The "Anxiety in dementia" article provides a good overview of anxiety in the context of dementia.



## Wandering

- Wandering is generally defined as:
  - A syndrome of dementia-related locomotion behavior having a frequent, repetitive, temporally-disordered, and/or spatially-disoriented nature that is manifested in lapping, random, and/or pacing patterns, some of which are associated with eloping, eloping attempts, or getting lost unless accompanied (Algase et al., 2006)

# Wandering

- Wandering can result in:
  - Getting lost, which can result in fear and anxiety
  - Change of residence (e.g., moved to an aged care facility)
  - Carer stress
  - Falls and mortality rate
  - Increased health care costs
  - Increased risk of falls
  - Weight loss in excess of that caused by the dementia disease process alone



# Wandering

- Longitudinal evidence for wandering starting an average of 10 months before diagnosis in 40% of individuals (Hope et al., 2001).
- Cross sectional studies show prevalence range 15-28% (Keily, Morris, & Algase, 2000; Klein et al., 1999; Rolland et al., 2006) and similarity between different care settings (Beattie, Song, & LaGore, 2006).
- A dynamic phenomenon fluctuating over time and change in cognitive and functional status (Devenand et al., 1997; Holtzer et al., 2003).

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# Wandering

- Possible factors related to the behaviour of wandering include:
  - Demography
  - Type of dementia
  - Type of cognitive impairment
  - Psychopathology and medication
  - Circadian changes



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# Wandering

- Neuropsychological factors related to wandering include:
  - Global decline
  - Visuo-spatial impairment
  - Attentional and executive impairment
  - Memory and language

Algase, D.L., Beattie, E., & Son, G.R. (2006) A model of risky wandering. In Nelson & Algase (Eds) *Evidence-based Protocols for Wandering Behaviour* (2006), Springer:NY.

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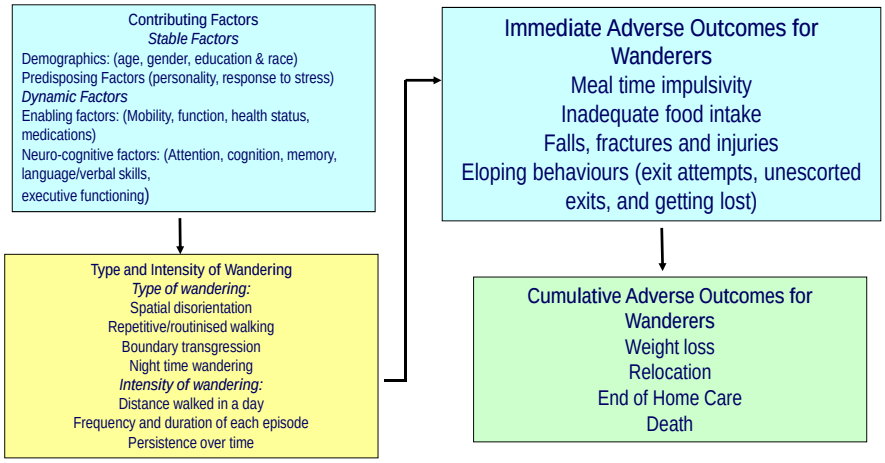
# Wandering

- Risky outcomes and adverse outcomes



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# Causes of BPSD - Overview

- Having considered individual types of BPSD, it is apparent that the best model in terms of the causes of BPSD is potentially one that incorporates genetic, neurophysiological, psychological (e.g., premorbid personality, response to stress), and social aspects (e.g., environmental change and caregiver factors)

## Link Between Cognition and BPSD

- BPSD are not behaviours and symptoms that occur because the person with dementia is trying to make life difficult for the carer or aged care facility staff
- The behaviours are therefore more appropriately seen as being expressions of the dementia process rather than the expressions of the person



## BPSD Within Context of Dementia vs Delirium

- Another consideration important in the context of dementia is that of delirium as in some cases it can be confused with dementia. It can also be difficult to recognise in a person with dementia.
- Delirium can be identified by an abrupt onset of behaviour, out of character for the person, which develops over hours to days. It is important for clinicians to distinguish between delirium and BPSD in order for appropriate treatment options to be implemented.
- Serious risk of harm to the person with dementia can arise from underlying, untreated physical or medical precipitants of BPSD. This most commonly manifests as delirium superimposed on the dementia.

## BPSD Within Context of Dementia vs Delirium

- Aggression, restlessness, hallucinations, clouding of consciousness, misinterpretation of events, disorganised thinking, and sleep disturbance may be evident. Delirium subtypes include hyperactive, hypoactive (quiet), and mixed.
- It is in the best interests of all concerned for potential causes of the delirium to be identified and treated as quickly as possible.
- We will look at delirium in more detail in later modules. At this point, it is important to just be aware that delirium may be a potential cause of BPSD and that it is something that can be treated.



## BPSD – Impact on Carers

- The presence of BPSD can lead to exclusion from much needed support services or aged care facilities:
  - The management of BPSD can present as a significant challenge to family carers, community care workers, and aged care staff alike, resulting in considerable stress and/or distress.
  - Factors affecting the family member's ability to respond to behaviours are universally and collectively referred to as carer burden. This burden is often willingly accepted due to the relationship between the carer and the care recipient, but this does not negate the difficulty of managing BPSD.
  - BPSD is associated with increased burden of care and carer depression.
  - Carers social and psychological resources, as well as their perception of the behaviours, have been identified as predictors of institutionalisation.

## BPSD – Impact on Carers

- Some of the most stressful BPSD for carers and the most common reasons for institutionalisation include screaming, physical aggression, wandering, depression, and insomnia.
- However, less frequent and severe BPSD, such as agitation and irritability, have also been shown to cause significant stress to carers.
- An awareness of the relationships in the home, the knowledge and experience of the family carers, and resources available is essential when developing a management plan.
- BPSD contribute to high stress levels and burn-out in aged care staff, however, support from management and the potential to relate to residents as individuals predict staff members perception of the behaviours.



## The Impact of BPSD

- The previous couple of slides highlighted the importance of identifying and treating BPSD.
- In the next module, we move on to looking at how we can assess BPSD within the context of models and frameworks aimed at helping to tease out what might be causing the particular BPSD(s) in question.

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