Advancing practice in the care of people with dementia

4th Edition

Module 7:

Behaviours and psychological symptoms associated with dementia

Dementia Training Australia

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Introduction

Alzheimer's disease and other subtypes of dementia are neurodegenerative conditions that over time affect the persons physical and cognitive abilities. From a clinical perspective they tend to be categorised in terms of symptoms and stages. From the individual's perspective "dementia is a shift in the way a person experiences the world around her/him" (Power, 2016. p.19). The person's experiences through the lens of dementia may be communicated by behavioural responses rather than the spoken word to express a need, an emotion, their reaction to illness or other social and physical environmental factors. The challenge for those who provide support is trying to identify and understand the factors that may be contributing to the changed behaviour.

Objectives

On completion of this module you will be able to:

- Debate why it is important to use contemporary terminology relating to responsive behaviours in people with dementia
- Describe the prevalence of responsive behaviours
- Understand how behaviour models and frameworks can aid the identification of factors contributing to the behaviour change
- Understand that a comprehensive assessment includes a risk assessment, ruling out reversible causes, and a thorough examination of contributing factors for the behaviour
- Advocate for non-pharmacological interventions as a first line approach to reducing or resolving the underlying trigger or cause of the behaviour
- Describe three different approaches to planning non-pharmacological interventions
- Identify the key considerations when initiating psychotropic drug therapy

Module topics

The current terminology

An overview of responsive behaviours associated with dementia

The prevalence of responsive behaviours associated with dementia

The impact of poorly addressed responsive behaviours on the person with dementia

Models and frameworks that support our understanding of responsive behaviours

A comprehensive approach to understanding responsive behaviours

The current evidence for pharmacological and non-pharmacological interventions

Considerations for cultural and special needs groups

Suggested readings for this module

James, I. & Jackman, L. (2017). Understanding behaviour in dementia that challenges. A guide to assessment and treatment (2nd ed.). London: Jessica Kingsley Publishers.

Power, G.A. (2016) Dementia beyond disease. Enhancing wellbeing, Revised Edition. Baltimore: Health Professions Press

Stokes, G., and Goudie, F. (2017) The essential dementia care handbook, Oxon: Routledge.

Responsive Behaviours Standardised Care Process

Access through the Victorian Department of Health website:

https://www2.health.vic.gov.au/ageing-and-aged-care/residential-aged-care/safety-and-quality/improving-resident-care/standardised-care-processes

Dementia Support Australia resource library

Access through the DSA website: https://dementia.com.au/resources/library

What's in a name: current terminology

There have been concerns regarding the stigmatising nature of the terminology used to describe behaviour change in people living with dementia. The Dementia Language Guidelines published by Dementia Australia (access via https://www.dementia.org.au/resources/dementia-language-guidelines) recommend that we do not use language to define the person by their symptoms; rather we see the person first and attempt to understand the biopsychosocial context in which the behaviour is occurring. Phrases such as 'problem behaviours', and 'challenging behaviours', seem to apportion blame and a sense of control to the person exhibiting the behaviour and are not recommended for use (Dementia Australia, 2014). The preference is for 'changed behaviours' and 'expressions of unmet need' (Dementia Australia, 2014). There are two other terms that need to be examined here as they promote a deeper exploration of why behaviour change occurs.

'Responsive behaviour' is a recent addition to the terminology relating to changed behaviours. The term originated from, and is preferred by, people living with dementia. This term was created by people with dementia in the Murray Alzheimer Research and Education Programme (MAREP).

The term represents how people with dementia may use words, gestures, or actions to express something important about their personal, social or physical environment. There are three principles on which the term 'responsive behaviours' rests:

1. These personal expressions have meaning
2. They are an important means of communication for the person living with dementia
3. Those providing care and support require a multidimensional approach to understand these personal expressions. (Murray Alzheimer Research and Education, 2018).

Rather than the current focus on disease and pathology as the root cause of all actions, words, or gestures, a multidimensional approach helps those who provide care to develop

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a broader and more comprehensive understanding of what the person with dementia is subjectively experiencing, which personal expressions they are communicating, and how best to offer compassionate support (MAREP Incorporating the philosophy of responsive behaviour into long term care, 2012).

The term BPSD or Behavioural and Psychological Symptoms of Dementia was introduced by the International Psychogeriatric Association (IPA) in 1996 to provide a standardised definition (Cunningham, Macfarlane, & Brodaty, 2019). BPSD have been defined as: "symptoms of disturbed perception, thought content, mood or behaviour that frequently occur in patients with dementia" (Finkel & Burns, 1999). The term BPSD has been identified as preferred terminology when used in a clinical context (Dementia Australia, 2014). The #BanBPSD campaign c. 2018, led by dementia advocates, raised concerns that the original BPSD definition failed to acknowledge the lived experience of dementia or use a biopsychosocial approach to understand the underlying cause of the behaviour (Cunningham et al., 2019). It has been suggested that the term 'BPSD' be reframed as 'behaviours and psychological symptoms associated with dementia', qualified by a vital difference in its original application: "*to understand the person and their behaviour*" (Cunningham et al., 2019, p.14) through a non-judgemental, holistic and comprehensive approach.

Dementia Training Australia (DTA) adopted the term 'responsive behaviours' in 2016 and this term will be used throughout this module. However DTA is currently reviewing it's position regarding the use of language about behaviour change in all its offerings.

ACTIVITY

Access and read Dementia Australia's Dementia Language Guidelines.

https://www.dementia.org.au/resources/dementia-language-guidelines

Defining behaviour and psychological symptoms associated with dementia

As the term implies, BPSD are often grouped into behaviours and psychological symptoms which are further categorised into mood and psychotic symptoms, as seen in Table 1.

Table 1

Behaviour symptoms	Psychological symptoms	
	Mood symptoms	Psychotic symptoms
Aggression	**Depression**	**Delusions**
Irritability	**Anxiety**	**Hallucinations**
Disinhibition	**Apathy**	**Misidentification**
Restlessness	**Euphoria**	
Agitation		
Wandering		
Sleep-wake disturbances		
Resistance to care		
Vocalisation		

(Ames, Chiu, Lindsey, & Shulman, 2010)

Responsive behaviours are often only seen as an issue if they are repetitive and have an impact on others (James & Jackman, 2017). It is therefore overt behaviours such as aggression, screaming, restlessness, agitation, sexual dis-inhibition, constant questioning, shadowing and wandering (an aberrant motor behaviour) that cause concern amongst clinicians. It must be remembered that less obvious behaviours such as withdrawal, ruminating, hoarding, hallucinations, and anxiety can also be expressions of need and an attempt to communicate..

The consequences of BPSD are associated with:

- Accelerated progression of cognitive decline (Zahodne, Ornstein, Cosentino, Devanand, & Stern, 2015)
- A change in the quality of the relationship between carer and the person living with dementia (Shin, Carter, Masterman, Fairbanks, & Cummings, 2005)
- Lower quality of life for the person living with dementia and their care partners (Corbett, Nunez, & Thomas, 2013; Gitlin, Hodgson, Piersol, Hess, & Hauck, 2014)
- Care giver stress and depression (Brodaty et al., 2001; Kales, Gitlin, & Lyketsos, 2014)
- Increased risk of early institutionalisation (Bakker et al., 2013; Corbett et al., 2013)
- Isolation for those living in residential aged care (Brodaty et al., 2001)
- Hospitalisation
- Increased use of psychotropic medications (Rosenberg et al., 2012)
- Excess morbidity and mortality (Kales et al., 2014; Peters et al., 2015)
- Increased cost of care (Black & Almeida, 2004)

Prevalence of responsive behaviours

Studies that have examined the prevalence of responsive behaviours have found between 76%-98% people living with dementia will exhibit at least one behaviour or psychological symptom during the course of the disease (Bauhuis, Mulders, & Koopmans, 2020; Borsje, Wetzels, Lucassen, Pot, & Koopmans, 2015; Brodaty et al., 2001; Hessler et al., 2018; Rozum, Cooley, Vernon, Matyi, & Tschanz, 2019; Selbaek, Engedal, Benth, & Bergh, 2014; Vik-Mo, Giil, Ballard, & Aarsland, 2018). In addition, responsive behaviours fluctuate in their occurrence, severity and presentation (Rozum et al., 2019) and this may vary according to the care setting, the dementia stage and subtype, as well as characteristics of the individual. It has been suggested that if we can understand the course of responsive behaviours and recognise the people at risk of persistent symptoms, then this will aid the development of approaches for the different stages of dementia (Borsje et al., 2015). Whilst there are a wide range of behaviours and psychological symptoms, some are similar and can be clustered into symptom groups (van der Linde, Dening, Matthews, & Brayne, 2014). For example, depression and anxiety are often coexistent with each other. A common symptom grouping is affective symptoms, psychosis, hyperactivity and apathy (Ames, O'Brien, & Burns, 2017). Table 2 provides a more detailed description of each symptom grouping.

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Table 2: Symptom grouping

Affective symptoms	Psychosis	Hyperactivity	Apathy
Depression **Anxiety**	**Delusions** **Hallucinations**	**Agitation** **Aggression** **Euphoria** **Disinhibition** **Irritability** **Aberrant motor behaviour**	**Apathy** **Eating disorders**

(Aalten et al., 2007)

The frequency and profile of responsive behaviours can also differ between dementia subtypes (Vik-Mo, Giil, Ballard, Aarsland, 2018) and care settings. There have been a number of studies that have identified the prevalence of responsive behaviours in different care environments. In the acute hospital setting in Germany prevalence was found to be 76% in patients with a diagnosis of dementia (Hessler et al., 2018). In Australian residential homes it is 92% (Brodaty et al., 2001) and in Norway it is 97% (Selbaek et al., 2014). In the BEYOND study conducted in the Netherlands, 96% of people living with younger onset dementia within residential homes had one or more responsive behaviours (Bauhuis et al., 2020). In a systematic review it was found that up to 95% of people living at home with dementia had at least one responsive behaviours (Borsje et al., 2015).

Table 3 compares the most frequently occurring responsive behaviours by subtype and table 4 compares those most frequently occurring responsive behaviours by care setting.

Table 3: Responsive behaviours by dementia subtype

Younger onset dementia *(Bauhuis et al., 2020)*	Alzheimer's Disease and Dementia with Lewy Bodies *(DLB) (Vik-Mo et al., 2018)*	Vascular dementia *(Borsje et al., 2015)*
Irritability **Agitation** **Eating change** **Disinhibition** **Apathy**	**Apathy** **Depression** **Appetite change** **Aberrant motor behaviour** **DLB** **Sleep disturbances** **Hallucinations**	**Depression** **Anxiety**

Table 4: Responsive behaviours by care setting

Living at home *(Borsje et al., 2015)*	Residential aged care *(Brodaty et al., 2001)*	Hospital *(Hessler et al., 2018)*
Delusions **Wandering/ agitation** **Aberrant motor behaviour** **Apathy**	**Activity disturbance** **Aggression** **Psychosis** **Depressed mood**	**Night time disturbance** **Depression** **Aberrant motor behaviour** **Anxiety**

Severity and persistence

The severity of responsive behaviours can be high even in the early stage of dementia and worsen as the disease progresses (Vik Mo 2018). Longitudinal studies help us to understand how responsive behaviours present over time. Some symptoms come and go (episodic), some may persist over time whereas other symptoms decline over time. Agitation, irritability and apathy have been found to be persistent over time, particularly in people with younger onset dementia (Bauhuis et al., 2020; Selbaek et al., 2014; van Der Linde et al., 2016).

Impact of responsive behaviours on others

Responsive behaviours have an impact on others. Those that have been reported as causing the most distress for family carers are sleep disturbance, agitation, aggression and depression (Craig, Mirakhur, Hart, McIlroy, & Passmore, 2005). For nursing staff in the hospital setting it is the delusions and aggression that cause the greatest distress (Hessler et al., 2018).

Impact of responsive behaviours on service delivery

The presence and severity of responsive behaviours often has an impact on the provision of optimal care. The Brodaty, Draper, and Low (2003) seven-tiered model of service delivery is useful for describing responsive behaviour symptoms, severity and recommended service delivery response. The following diagram is an adaptation of the model showing severity and symptom examples only

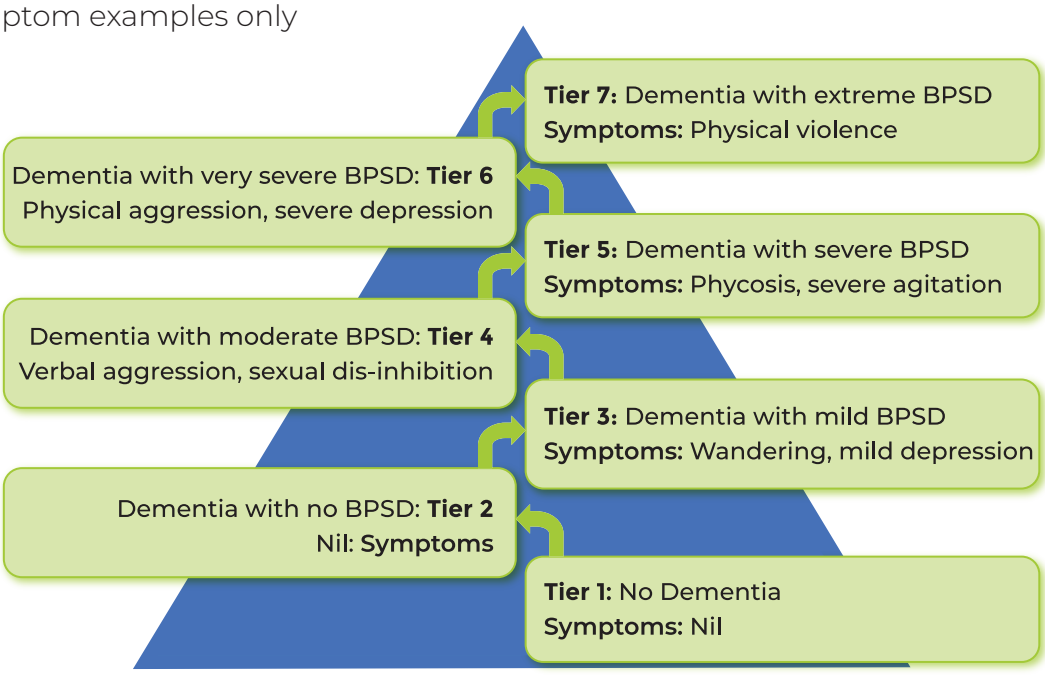

Figure 1: The seven-tiered model of service delivery

ACTIVITY

Read the article: Brodaty, H.; Draper, B.; Low, L-F. (2003). Behavioural and Psychological Symptoms of Dementia: a seven-tiered model of service delivery. Medical Journal of Australia, 178(5), 231–234.

The article is available on open access:

https://www.mja.com.au/journal/2003/178/5/behavioural-and-psychological-symptoms-dementia-seven-tiered-model-service

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Principles for understanding behaviour

Responsive behaviours require an early, considered and co-ordinated response. Behaviour models and frameworks can provide guidance and structure to comprehensively and systematically collect and analyse information about the person, their environment, the behaviours and the potential triggers. They also assist with the selection of the most appropriate treatment or intervention aimed at resolving, minimising or preventing the target behaviour. Stress, distress and 'need driven' behaviour unmet needs are important factors to consider.

The progressively lowered stress threshold model

The progressively lowered stress threshold model is built on stress theory (Smith, Gerdner, Hall, & Buckwalter, 2004). Dementia lowers a person's ability to deal with daily stress and increases their susceptibility to environmental stressors. In the image, the dotted grey line indicates the stress threshold of a person with dementia. Accumulated stressors such as noise, hunger, thirst, pain tiredness and confusion push the person past their stress threshold, and this will result in a behavioural response.

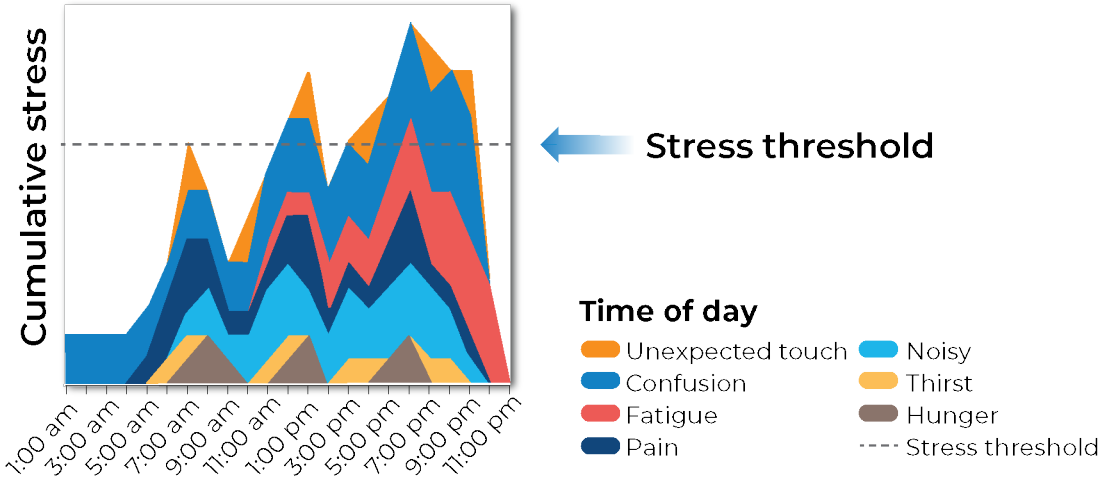

Figure 2: Graphic is from: ReBOC Reducing behaviours of concern. DBMAS. Published by Alzheimer's Australia South Australia

Behaviour changes that might be explained by this model are: agitation, night waking, late day confusion/sundowning, and combative behaviour. A useful strategy is to identify and remove cumulative stressors from the environment to reduce the likelihood of stress related behaviours. Scheduling rest breaks in the day will allow the person to cope with daily stress more effectively.

Need-Driven Dementia Compromised Behaviour Model

The need driven dementia compromised behaviour model (Algase et al., 1996) proposes that behaviours are an indication of unmet needs. Many people with dementia become progressively less able to meet their own needs. They also experience a loss of language ability which leads to difficulty expressing their needs to the nursing staff.

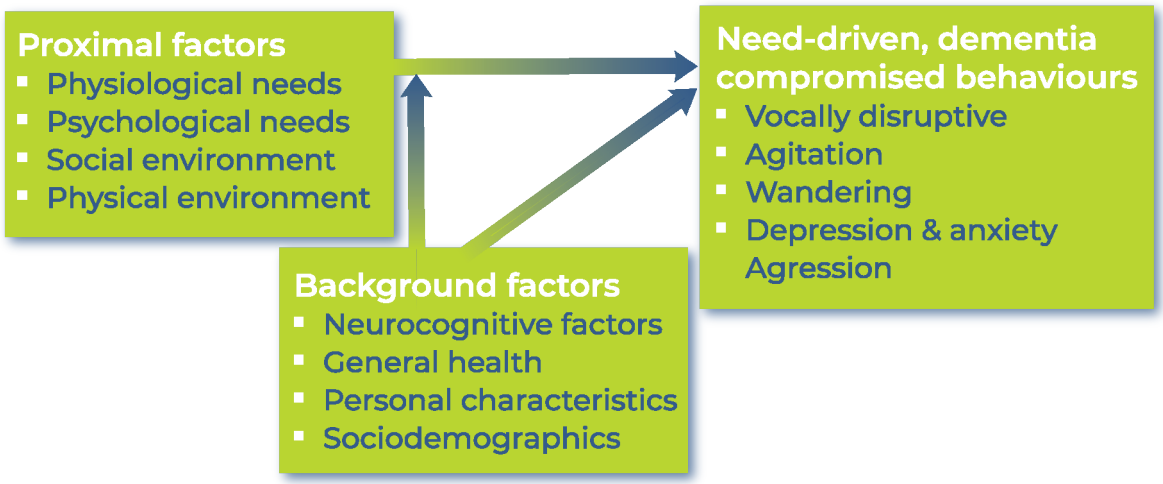

Figure 3: Need-Driven Dementia Compromised Behaviour Model (Algase et al., 1996, p. 12)

The model takes into account the influence of background factors.

These include neurological, cognitive, health, and psychosocial characteristics of the person, and Proximal factors such as the needs of the person with dementia and the impact of the social and physical environment on behaviour. Background factors are the more enduring features of the person that are less able to be modified while Proximal factors are those that staff and families can readily modify to make the person living with dementia more comfortable.

ABC behavioural model

The ABC mnemonic is often used as the basis of behaviour charts commonly used in residential aged care setting. This mnemonic aid the assessment and analysis of behaviour over three important points.

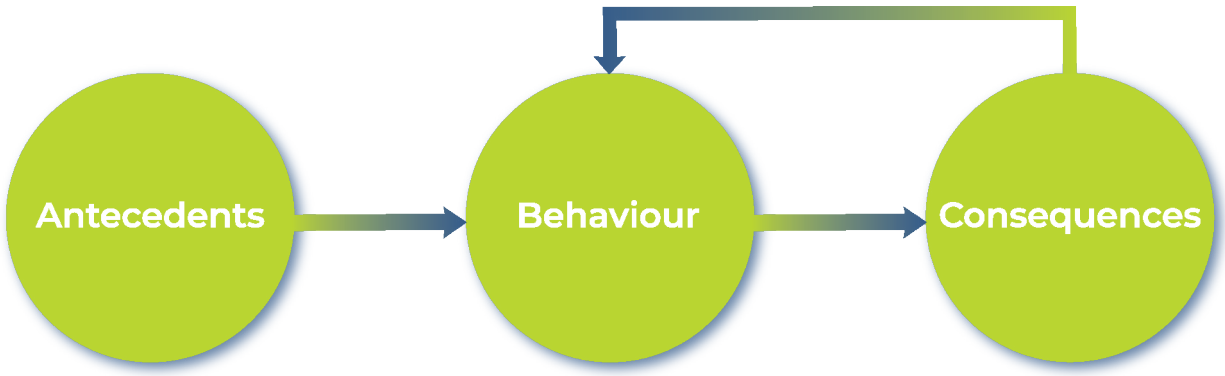

Figure 4: ABC mnemonic

Antecedent or triggering event that precedes the behaviour. Record what was happening immediately before the behaviour occurred:

- Describe the environment where the behaviour occurred
- What had the person been doing and how did they present?
- What else was happening at the time?
- Who else was present?

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Behaviour description. Describe as clearly as possible what happened:

- What exactly was said and done?
- How long did the behaviour last?
- How severe was the behaviour?

Consequence of the behaviour. Record how people responded:

- What was the response of others to the behaviour?
- What was said to the person?
- What was the persons reaction to the intervention by others?
- What else happened?

The ABCs can either be recorded each time a behaviour is observed (momentary time sampling) or during a specified period or periods within a day (Stokes, 2017a).

Concept mapping

Concept mapping is a visual aid and representation of thinking and problem solving (Aberdeen, Leggat, & Barraclough, 2010). This model offers a person-centred and team problem solving approach for understanding responsive behaviours. A spider map is used which places the person and their wellbeing as the central concept to thinking rather than focussing on the behaviour to be resolved. The concept mapping session is led by a facilitator; it takes 30 - 60 minutes with a group of 5 – 12 staff, health professionals (GP, pharmacist) and family. With the person as the central concept, the group members brainstorm using the assessment components in the image below as the starting point for the process (Aberdeen, 2015).

Figure 5: Concept mapping assessment components

It uses a five-step process

1. The emerging, persistent or complex responsive behaviour is the trigger for initiating the concept map
2. The concept map is implemented with the team by an experienced facilitator
3. The mapping data is evaluated. Strategies and care outcomes are identified and added to the care plan
4. The team implement the new care plan
5. The results are evaluated.

This process enables the care staff, no matter their level of experience or dementia training, to draw on their personal knowledge of the person; critically review and reflect on care practices, learn to look for pattern recognition and problem solve within a team environment.

The DICE approach

The DICE approach was developed through a systematic review of the literature and a multidisciplinary panel of experts in the US (Kales et al., 2014). The approach has four steps:

1. Describe the responsive behaviour and what triggers it
2. Investigate underlying and modifiable causes
3. Create and implement interventions to reduce the target symptoms
4. Evaluate the efficacy of the interventions

A comprehensive approach to understanding responsive behaviours

Identifying factors behind the behaviour change is the guiding principle to addressing responsive behaviours. The process by which this is achieved is through a detailed assessment by the interdisciplinary team in collaboration with the person living with dementia and including information about the behaviour from family and carers (Burns, Jayasinha, Tsang, & Brodaty, 2012; Registered Nurses' Association of Ontario, 2016). The key steps include:

- Assessing the risks
- Describing the behaviour
- Rule out reversible causes
- Gathering information to identify the cause of the behaviour
- Analysis of the behaviour
- Individualizing interventions
- Monitoring effectiveness and reviewing the intervention plan

Assess the risks

Risks can present themselves in a number of different ways. They may be caused by medical issues such as delirium, mental health issues such as Post Traumatic Stress Disorder (PTSD), or an unsafe environment which could range from hazards to allowing strangers into the domestic home (Burns et al., 2012). There may be a potential for physical harms to the person with dementia caused by impulsive behaviours, falls, or abuse; or potential harms to others from aggression or disinhibition (Burns et al., 2012).

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The aim of the risk assessment is to establish what level of response needs to be made to ensure no harm comes to the person with dementia or to others (Burns et al., 2012). Actual and potential risks relating to the behaviour should be considered. This will include severity of the behaviour, immediacy of any danger, the level of distress that it causes, the context in which it occurs, and what skills and resources are available for a considered response (Australia and New Zealand Society for Geriatric Medicine, 2016; Burns et al., 2012). Immediate action is recommended if it is determined that the risks or behaviour severity are high. Whereas moderate to low risk determinations enable the interdisciplinary team to conduct a comprehensive assessment and develop non-pharmacological interventions as the first line approach (Australia and New Zealand Society for Geriatric Medicine, 2016).

Remember that any risk management approach needs to balance the person's right to takes risks with achieving an acceptable level of risk using the least restrictive options. See the module on risk.

ACTIVITY

Go to the Dementia Support Australia website https://dementia.com.au/ ***and explore what services they provide***

Describe the behaviour

It is important to establish a clear description of the behaviour (Burns, Jayasinha, & Brodaty, 2014). This description is the target behaviour that will be the focus of analysis (Stokes, 2017a). The behaviour chart is a useful tool for collecting information, particularly if it is based on the ABC model described earlier. The aim is to collect accurate information about when the behaviour began and the

- frequency;
- duration;
- severity; and
- consequences of the behaviour

as well as the factors that trigger, aggravate or improve the behaviour. There are also a number of readily available standardised assessment tools that will provide this data. Tools that evaluate the presence of several behaviours include the Neuropsychiatric inventory (NPI) and Behavioural Pathology in Alzheimer's Disease (BEHAVE-AD). Those measuring targeted behaviour include the Cohen-Mansfield Agitation Inventory (CMAI), the Revised Algase Wandering Scale (RAWS) _ Community or RACF version, and the Apathy Evaluation Scale (AES).

ACTIVITY

Go to the Dementia Outcomes Measurement Suite on the Dementia Centre for Research Collaboration using this link

https://dementiaresearch.org.au/resources/doms/ ***and explore the assessment tools in the Behaviour domain.***

Recommendations for the length of time that observation and recording of the behaviour should be conducted for varies. Burns et al. (2012) state a minimum of three days. However, the argument for a longer period of one to two weeks is made by Stokes (2017a) as it helps to identify consistent patterns in the behaviour as well as which are low frequency and high frequency behaviours. The information collected in this baseline period will also aid in identifying if interventions have made a significant reduction in the frequency of the behaviour. For some behaviour, e.g. excessive walking without resting, some simple techniques can help in working out what is going on, e.g. using a pedometer to count steps.

Having a clear definition of a behaviour that is understood across the care team will support the assessment of the behaviour, improve the use of appropriate interventions and reduce the use of stigmatising labels (Stokes, 2017a). Stokes (2000) offers an approach that supports a shared understanding by working through the following:

- Behavioural definition
- Behavioural characteristics
- Explanations for the behaviour.

Table 5 provides an example using aggression as the behaviour.

Table 5: Aggression

Behavioural definition	**Aggressive behaviour associated with dementia is characterised by physical or verbal threats aimed at people or objects**	
Behavioural characteristics	**Verbal** **Swearing** **Insults** **Sarcasm or derogatory remarks** **Yelling** **Blaming and accusing**	**Physical** **Hitting** **Spitting** **Biting** **Slapping** **Pinching** **Punching** **Kicking** **Pushing** **Physical resistance to care** **Throwing of objects** **Damaging or destroying property**
Explanations for the behaviour.	**Delirium, pain, discomfort, infection** **Depression, anxiety or psychosis** **History of trauma or abuse** **A defensive behaviour when feeling threatened, e.g. during care delivery** **Frustration** **Misunderstanding the situation** **Unable to control emotional responses due to frontal-lobe brain damage** **Staff approach or communication style** **Task orientated style of care**	

(Stokes, 2017b, p. 141)

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ACTIVITY

Work with a small group of colleagues to develop your own shared understanding of a particular behaviour. The example below is wandering behaviour, but you may prefer to attempt another such as agitation or vocally disruptive behaviour.

You can use the DTA Behaviours App in the Google Play Store or Apple store to assist you with this activity.

Download the free Responsive Behaviours App

App Store – for iPhone and iPad devices

Google Play – for Android devices

Behavioural definition	**Wandering is a frequent, repetitive, temporally-disordered and/or spatially-disoriented ambulation 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, Moore, Vandeweerd, & Gavin-Dreschnack, 2007)**
Behavioural characteristics	
Explanations for the behaviour.	

Rule out reversible causes

There is a higher risk of physical and mental health problems in older people and those living with dementia. There are a number of conditions that can cause a presentation similar to dementia or exacerbate an existing dementia (James & Jackman, 2017). It is important to carry out comprehensive screening to identify or exclude physical, medical and psychological causes for the behaviour (Burns et al., 2014; Therapeutic Guidelines Limited, 2018). These include but are not limited to:

- Delirium
- Pain and discomfort
- Dehydration and malnutrition
- Severe constipation
- Endocrine disorders
- Side effects and interactions of medicines
- Sleep disturbances
- Depression and anxiety
- Hallucinations and delusions
- Terminal restlessness

Gather information

If the behaviours remain despite physical and mental illness having been ruled out or treated, then more assessment is required to identify the underlying causes or triggers for the behaviour. The goal is to establish relationships between the behaviour, the person and their environment. The behaviour models and frameworks listed earlier are useful to employ when gathering information during the comprehensive assessment

ACTIVITY

There are useful guidelines that support the comprehensive assessment of responsive behaviour. For this activity locate the Standardised Care Process (SCP) Responsive behaviours on the Victorian Department of Health website

https://www2.health.vic.gov.au/ageing-and-aged-care/residential-aged-care/safety-and-quality/improving-resident-care/standardised-care-processes

Planning and implementing strategies

Analysis of the behaviour

An important step that should not be rushed is the careful analysis of the data that has been gathered in the assessment. The aim is to identify the underlying causes of the target responsive behaviours as this supports the development of individualised interventions (Dementia Training Australia, 2017). It is important that this step is led by an experienced and skilled person in partnership with the resident, family and the interdisciplinary team (Therapeutic Guidelines Limited, 2018). The behavioural analysis is then used to support the development of the persons intervention plan.

Planning interventions

Selection of interventions should aim to reduce or resolve the underlying trigger or cause of the behaviour rather than modify the behaviour itself (Dementia Training Australia, 2017). When planning interventions aim to:

- modify, reduce or eliminate the underlying cause or trigger for the behaviour
- set realistic outcomes or goals
- work collaboratively with family and other members of the interdisciplinary team
- develop strategies that are based on the persons preferences, abilities and needs
- build on strategies that are known to be effective
- use evidence-based interventions where possible, and
- establish a plan to monitor and evaluate the effectiveness of the care

(Dementia Training Australia, 2017)

There are two management routes, pharmacological and non-pharmacological. The first and recommended approach is non-pharmacological in nature, unless the behaviour presents a high risk to the person and to others (Australia and New Zealand Society for Geriatric Medicine, 2016; Therapeutic Guidelines Limited, 2018). These interventions are often described as psychosocial.

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Non-pharmacological management of responsive behaviours

The advantages of a non-pharmacological approach are that they:

- Recognise rather than mask the underlying needs being communicated by the behaviour
- Have fewer limitations than pharmacological management; that is, side effects, drug interactions
- Are practical and relatively in-expensive
- Enhance carer attitudes towards care recipients with responsive behaviours compared to pharmacological approach
- Meet the Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019 for using alternatives to restraint

There are different approaches that can be used for planning interventions that may help reduce the presenting responsive behaviours. A general approach (Gitlin, Kales, & Lyketsos, 2012), protocol led interventions that are tailored to the presenting behaviour rather than the person (Brechen, Murphy, James, & Codner, 2013) and individualised interventions that are based on the careful analysis of the target behaviour (Brechen et al., 2013; Burns et al., 2012; James & Jackman, 2017).

Generalised approach

Generalised approaches are not specific to any one type of behaviour or individualised to the person but focused more on the context in which the care is being provided. They could be regarded as good practice and include:

- Good dementia knowledge
- Quality interaction
- Communication skills training
- Dementia friendly environments and environmental modification
- Life story work
- Opportunities for meaningful engagement, activities and social interaction
- Person centred care and approaches such as Montessori
- Sensory focused strategies for people with advanced stage dementia
- Simple behavioural techniques such as distraction, redirection, reassurance and reorientation

(Brechen et al., 2013; Gitlin et al., 2012; Macfarlane & O'Connor, 2016)

Protocol led or behaviour specific interventions

This an approach where specific strategies are used for a particular behaviour. Gitlin et al. (2012) describe it as "problem-solving to identify precipitating and modifiable causes and consequences of the identified behavior, followed by efforts to modify these conditions" (p. 10). Agitation during bathing (Sloane et al., 2004), the Treatment Route to Exploring Agitation (TREA) (Cohen-Mansfield, 2000), the Serial Trial Intervention (Kovach, Noonan, Schlidt, Reynolds, & Wells, 2006) and the Needs Hierarchy (James & Jackman, 2017) are

good examples of protocol led interventions. Equally, research evidence is indicating that there are specific strategies that have a positive effect on mood and behaviour. Examples of this include:

- Person's preferred music for agitation, depression and anxiety (Travers et al., 2016)
- Reminiscence therapy for mood and cognitive functioning (Travers et al., 2016)
- Exercise for mood and sleep (Brechen et al., 2013).

Individualised interventions

Individualised interventions are formulated once the underlying causes and triggers of the behaviour have been established following a comprehensive assessment. The interventions also need to consider the person's life story, social history, preferences and the resources available within the care environment to support the plan of care. These interventions will draw on a wide range of strategies, some which have strong evidence for their efficacy and others less so. The standardised care process for responsive behaviours list these as follows:

- life review / life story work
- modifications to the physical environment
- social inclusion
  - one-to-one interaction
  - meaningful occupation and roles
  - meaningful hobbies and past times
- validation therapy
- sensory therapies
  - aromatherapy
  - sensory stimulation
  - music therapy / preferred music
  - massage (and therapeutic touch)
  - animal-assisted therapy (pet therapy)
- reminiscence therapy
- simulated presence therapy
- physical exercise and dancing
- assistive technology
- psychological therapies.

The clinicians approach

It is important to note that clinicians' approach and behaviour impacts on the person with whom they are interacting. Be cognisant that staff may inadvertently be the trigger. Health and care facility work routines and care delivery systems can also trigger responsive behaviours. Remember it is much easier to change our own behaviour than it is to alter the behaviour of the person with dementia.

Some very simple behaviour and communication strategies that can minimise the risk of behavioural symptoms presenting include:

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- Identify yourself
- Respect personal space
- Sit down – standing over a person can be perceived as intimidating and threatening. Being at the same height reduces this threat
- Stand at an angle of 45 degrees – standing directly face-to-face can appear threatening whereas standing with your shoulder facing the person and turning your head towards them is much less intimidating
- Move slowly – do not rush movements as any sense of urgency or perceived sudden movement can invoke fear
- Voice tone should be calm and convey reassurance
- Explain what is happening as it occurs
- Closed questions should be used wherever possible as the person may more easily be able to respond, allowing them a sense of control
- Offer simple choices – as this enables the person with dementia to make choices within the limitations of their impairment
- Ask one thing at a time - Short, one-step instructions are more easily understood and followed and cause less frustration and anxiety
- Allow the person time to consider, reply and respond to your question or instructions
- Use active listening skills
- Generally, it is better not to contradict, argue, or attempt to reason with the person with dementia. It is extremely difficult and often unproductive to try to convince someone with dementia that they are incorrect
- Never talk over the person as though they were not present. It is very easy for clinicians to fall into the trap of excluding the person with dementia from their conversation with each other or with the person's family members. This can cause fear and frustration and trigger behavioural symptoms, such as aggression
- As with the statement above it is very easy in care situations for two or more clinicians to ask questions or give instructions to the person with dementia at the same time. This only promotes confusion and frustration. It is therefore important that only one person speaks at a time.

  (The above information is based on expert opinion)

Pharmacological management of responsive behaviours

Pharmacological management is the second line approach and indicated when behaviour causes severe distress or harm; or when first line non-pharmacological interventions have been trialled with little success.

There is concern that the use of psychotropic medications is higher than it should be for the for the management of responsive behaviours (McMaster, Fielding, Lim, Moyle, & Beattie, 2018). Psychotropic medications include:

- Antipsychotic agents
- Benzodiazepines
- Antidepressants (Guideline Adaptation Committee, 2016).

The prevalence of regular antipsychotic use and benzodiazepines for people living with dementia in Australian residential aged care can be as high as 53% for both drug types

(McMaster et al., 2018). It has been found that the average length of time that people with responsive behaviours remain on antipsychotic drugs is 2.1 years (Brodaty et al., 2018). The recommendation is that antipsychotic medications should not be continued for more than three months when used to treat responsive behaviours and benzodiazepines for no longer than two weeks (Therapeutic Guidelines Limited, 2018).

Antipsychotic medications are associated with potential harm when used for the treatment of responsive behaviours Adverse effects include sedation, postural hypotension, extrapyramidal symptoms and anticholinergic effects (e.g. dry mouth, constipation, urinary hesitancy, delirium) as well as cerebrovascular events and death (Therapeutic Guidelines Limited, 2018).

Prescribing an antipsychotic drug should always be made with the end in mind. Some key considerations when initiating psychotropic drug therapy:

- Have non-pharmacological approaches been trialled first?
- Are the behaviours intermittent, situation-specific (e.g., emerging on care interventions) or goal-directed (e.g., trying to leave the premises)?
- Do the benefits of a psychotropic drug outweigh the risks?
- The decision to commence a psychotropic drug should be discussed first with the person who is to receive the medication or from their nominated decision maker; informed consent should be obtained and documented (Australia and New Zealand Society for Geriatric Medicine, 2016)
- Target the right drug therapy to the right symptom (Macfarlane & O'Connor, 2016)
- Utilise one drug at a time, at the lowest dose for shortest duration (Macfarlane & O'Connor, 2016)
- Start low go slow (Macfarlane & O'Connor, 2016)
- Maintain regular monitoring for adverse effects and effectiveness (Macfarlane & O'Connor, 2016)
- Antipsychotic medications should be tapered and stopped if they have stabilised the symptom within a three month period or if there has been no response to the drug trial (Bjerre et al., 2018)

ACTIVITY ***Consider whether the use of pharmacological interventions in your workplace is a first or second-line approach?***

Monitor effectiveness and review at regular intervals

Ongoing monitoring and review are vital for identifying how effective the interventions have been in reducing the underlying causes and triggers of the behaviour (Burns 2012; DTA 2017). When medications have been commenced, they need to be monitored for adverse events or side-effects over a twelve-week period (ANZSGM, 2016).

Cultural considerations for responsive behaviours assessment and management

Although assessing and addressing responsive behaviours remain constant, there are particular issues to consider with people from culturally and linguistically diverse (CALD) and Aboriginal and Torres Strait Islander populations. These are summarised from the Behaviour Management – a guide to good practice (Burns et al., 2012). Considerations include:

- English may not be the first language of the person with dementia
- There may be cultural differences in communication styles; either verbal or non-verbal communication
- The person's current or past lifestyle and habits may be very different from that commonly found in a westernised society
- People from CALD and Aboriginal and Torres Strait Islander populations may have a complex past life history
- People from CALD and Aboriginal and Torres Strait Islander populations may have lived in home environments away from that typical of westernised culture
- There is still a stigma associated with dementia within cultural groups, with negative words used to describe dementia
- Dementia is not well-understood. Many cultural groups still regard memory loss as a normal part of ageing
- Access to dementia education and services will vary according on how well-established the CALD community is and their geographical location.

Difficulties for clinicians include:

- Lack of cross-cultural assessment tools
- Assessment takes more time
- Communication barriers; interpreters need to be trained in how to work with people who have dementia
- The need to consider experiences of war, trauma, migration, family separation and disappearance of relatives.

Responsive behaviours resources

Behaviour Management – a guide to good practice. Managing Behavioural and Psychological Symptoms of Dementia (2012).

Access through the Dementia support Australia website: https://dementia.com.au/resources/library/understanding-and-responding-to-behaviour-resources/behaviour-management-a-guide-to-good-practice.html

Clinician's Field Guide to Good Practice (BPSD) Managing Behavioural and Psychological Symptoms of Dementia (2014)

Access through the Dementia Support Australia Website: https://dementia.com.au/resources/library/understanding-and-responding-to-behaviour-resources/a-clinicians-field-guide-to-good-practice-managing-bpsd.html

ReBOC Guide – Reducing Behaviours of Concern
Access through Dementia Support Australia website:
https://dementia.com.au/resources/library/understanding-and-responding-to-behaviour-resources/reboc-guide-reducing-behaviours-of-concern.html

Dementia Outcomes Measurement Suite
Access through the DCRC website: https://dementiaresearch.org.au/resources/doms/

Responsive Behaviours Standardised Care Process
Access through the Victorian Department of Health website:
https://www2.health.vic.gov.au/ageing-and-aged-care/residential-aged-care/safety-and-quality/improving-resident-care/standardised-care-processes

Responsive Behaviours App
Access through the Dementia Training Australia website:
https://dta.com.au/resources/responsive-behaviours-app/

Dementia Support Australia
- Dementia Behaviour Management Service
- Severe Behaviour Response Teams
- Needs Based Assessment Programs

Access through https://dementia.com.au/
24-hour helpline: **1800 699 799**

Dementia Training Australia
Free online courses, webinars, downloadable resources and tailored training packages
Access through https://www.dta.com.au/

Guidelines for diagnosis and care of Aboriginal people with dementia in remote communities (2012)
Accessed through the Dementia research website: https://www.dementiaresearch.org.au/wp-content/uploads/2020/01/364-rr3_guidelines.pdf

Clinical Practice Guidelines for Dementia in Australia (2016)
Access through the Cognitive decline partnership centre website: https://cdpc.sydney.edu.au/research/clinical-guidelines-for-dementia/

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